

## CHAPTER ONE



# WHAT IS ALZHEIMER'S DISEASE?

ALZHEIMER'S DISEASE IS A FORM of dementia characterized by the loss of memory and other intellectual abilities to the point that the disease interferes with daily life. It is the most common form of dementia, accounting for 50 to 80 percent of all dementia cases.<sup>1</sup>

“Dementia” is a term used to describe a multitude of diseases or conditions that develop as a result of damage to the brain's nerve cells (neurons). The damage to or destruction of the neurons creates changes in an individual's memory and behavior and affects the person's ability to think clearly.

As Alzheimer's runs its course, it ultimately impairs basic bodily functions, like walking and swallowing, and finally results in death.<sup>2</sup>

A person can have dementia but not have Alzheimer's disease. However, a person cannot have Alzheimer's and not have dementia.

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1. *What Is Alzheimer's?*, ALZHEIMER'S ASS'N, [http://www.alz.org/alzheimers\\_disease\\_what\\_is\\_alzheimers.asp](http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp) (last visited May 27, 2012).
  2. *2012 Alzheimer's Disease Facts and Figures*, 8 ALZHEIMER'S & DEMENTIA: J. OF THE ALZHEIMER'S ASS'N 131 (2012), available at [http://www.alzheimersanddementia.com/article/S1552-5260\(12\)00032-5/fulltext](http://www.alzheimersanddementia.com/article/S1552-5260(12)00032-5/fulltext).

The term “Alzheimer’s disease” comes from German physician Dr. Alois Alzheimer. Dr. Alzheimer presented a case history of a 51-year-old woman suffering from a rare brain disorder at a medical meeting in 1906. An autopsy of the woman’s brain revealed the plaques and tangles that characterize Alzheimer’s disease.<sup>3</sup>

## THE ALZHEIMER’S JOURNEY

Lawyers need to be aware of the many questions that must be addressed when a client or a client’s loved one has Alzheimer’s disease. These questions should include the following:

- How do we get health care for the patient?
- What options are available for health care?
- How are these options going to affect the patient and the family/spouse?
- What is the long-term outlook for everyone?
- How can we protect the family assets?

(Foremost on lawyers’ minds may also be the ethics of working with clients with Alzheimer’s and how to protect themselves; this is discussed in detail in chapter 2.)

Most lawyers are not accustomed to dealing with a client with Alzheimer’s and probably are not prepared to answer these types of questions. This book is designed to educate lawyers so that they will have the knowledge needed to answer these questions and guide their client through the arduous journey of dealing with Alzheimer’s disease.

Before the questions can be answered, lawyers have to be able to identify the signs signifying the onset of Alzheimer’s or dementia. Unfortunately, the initial signs of Alzheimer’s or dementia are usually the most difficult to spot. It may be months or longer before family members realize that a loved one is forgetting a few too many things or is confused too frequently. Often, these first signs are dismissed as “natural aging.” However, neither Alzheimer’s nor dementia is a natural part of growing old.

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3. WILLIAM G. HAMMOND, RICK L. LAW, KAREN HAYS WEBER & MARY HELEN GAUTREUX, *THE ALZHEIMER’S LEGAL SURVIVAL GUIDE: ACTION GUIDE 10* (2009).

One of the first signs of dementia is also one of the most dangerous—a growing inability to understand and control financial matters. In the oldest American generation, those who saw World War II and the Korean War, most couples' finances have been controlled by the husband; it is not unusual for the wife to have no idea of the family's financial situation. That can be particularly problematic since men, on average, decline and die earlier than their wives.

It is very important that the healthy spouse and their children be alert for signs of memory loss, which can lead to both financial vulnerability and folly. The sooner these signs are identified and reported to the family doctor and lawyer to be dealt with, the better off everyone will be. Once a lawyer suspects that a client has some form of dementia, he or she should take extra care to protect the financial assets.

There is no legal standard for “vulnerability,” but vulnerable individuals are more likely to make poor financial decisions and are prime targets for scam artists and criminals. Many so-called charities send direct mailings to senior citizens that are actually solicitations for donations but, to the untrained eye, appear to be bills. Some of the less scrupulous charities are hoping that these solicitations will result in donations from recipients who are confused and think that they must owe this amount since they are receiving a “bill” from a charity. Other organizations prey on the fears of senior citizens and send out mailings promising a dire future or political upheaval that is unavoidable without contributions from good people like the recipient.

The lawyer needs to make the client's family aware of these dangers and to warn the client's relatives of the possibilities that their loved one could become the victim of financial foul play.

Criminal enterprises and scam artists are not the only financial threat to clients with dementia. Online shopping, infomercials, and the lottery can be just as dangerous to a person with Alzheimer's.

Senior citizens afflicted with Alzheimer's on a fixed income may choose to spend thousands of dollars buying gifts for their relatives on their computer, or they may buy what they see on an infomercial because the commercial convinces them that they need something that they do not really need and quite possibly cannot afford.

Who does not enjoy playing the lottery occasionally? Legitimate lotteries are incredibly popular and, when the jackpots grow, the television and radio news coverage can be very exciting. Most people are able to play

the lottery without going overboard and spending more on tickets than they can afford. However, one of the effects of dementia is the lessening of healthy cynicism. Most people “know” they are not really going to win the lottery and may buy a ticket here and there and daydream about winning, but deep down they do not expect to really win. Individuals with dementia may not understand that they are not going to win or that they are spending more money on tickets than they can afford. Individuals with dementia lose their capacity to understand financial meaning and to appreciate the consequences of their own actions.

People on the Alzheimer's journey often progress through this trajectory:

- memory loss ignored
- memory loss masked/denied
- unsafe alone
- aid needed
- assisted living required
- nursing home required
- hospice care required/death

The family of a loved one with Alzheimer's often progresses through a complementary trajectory that may have some of these components:

- memory loss ignored
- memory loss masked/denied/facilitated
- memory loss assistance needed by loved one, but hidden from “outsiders”

Family members need to be extremely proactive in carefully investigating a loved one's change in behavior. It is equally important for lawyers to be aware of these stages so that they may identify the stages themselves or assist the family in identifying or coming to terms with the symptoms of Alzheimer's disease.

### *Memory Loss Ignored*

It is difficult to determine when memory loss is the first step of Alzheimer's or just normal aging. As people age, they forget things. However, forgetting what they had for lunch last Saturday is different from forgetting that they do not have unlimited financial assets.

Lawyers often need to rely on the client's family members when dealing with a client with Alzheimer's disease. Lawyers must be able to determine which relatives the client believes are honest and reliable, and who may be able to safeguard family finances and provide ongoing care and attention to the situation. Familiarity with multiple family members gives more options if signs of dementia do start to appear, and an atmosphere of open communication can go a long way toward preventing suspicion, family fights, and claims against the lawyer by disgruntled family members later on.

Once a lawyer has discussed options for the future with the client's family members and determined who might be the best person to take control of the client's finances in the event that the client is unable, the lawyer can assist the family with the development of appropriate legal documents and power of attorney for financial decision making. These documents give a nominated agent the power to make financial decisions for the affected loved one. The time to work on these plans is while the client with Alzheimer's still has sufficient capacity to make a will, trust, power of attorney for health care, power of attorney for property, and any other estate protection plans. Lawyers trained in this area of planning work to make sure that the healthy spouse is not excessively impoverished by long-term care expenses. (More on estate planning in chapter 4.)

There is no single factor that can provide a clear sign that an adult is functioning with diminished capacity, but there are clues that, when taken together, may indicate that professional medical tests should be conducted. For a lawyer, the potential signs of incapacity focus on decisional abilities rather than a person's cooperativeness or friendliness. Therefore, the lawyer will have to rely on the client's family to provide much of the information. Knowing the factors to look for allows the lawyer to ask the client's family the correct questions.

Some of the factors include

- change in the client's typical manner of behavior (these changes may take place over a long period of time and may not be instantly recognizable);
- unusually poor grooming or hygiene;
- short-term memory loss;
- comprehension problems;

- lack of mental flexibility;
- calculation problems;
- emotional signs of incapacity, such as emotional distress or emotional inappropriateness; and
- behavior incapacity, such as delusions or disorientation.

Do not assume that the normal aging process is the same as diminished capacity.

### *Memory Loss Masked/Denied*

One good way to help determine if a client has diminished mental capacity is to observe the “15-minute reset.” Look at a watch to note the beginning of a conversation with a person suspected of being affected by Alzheimer’s or a related disorder. Often, people with excellent social skills (still common in women in their 80s and 90s) are able to hold a conversation that includes all the correct words and head nods. They are so adept at making conversation that it seems certain that there is nothing wrong with them. However, after about 13 or 14 minutes, they will start the conversation over again, almost as if they were playing a tape. Once again, they are so masterful with the skill that it makes people question their own memory of the conversation—as if they might have misremembered—or at the very least it makes people look around to see if someone else has entered the room to create the “reset.”

In addition to the “15-minute reset,” even when the client has excellent “small talk” skills and what seem to be appropriate interactive skills, the client may neither understand nor remember anything that the lawyer has said, either then or during any subsequent conversations. Seemingly appropriate questions and head nodding may imply understanding, but do not expect actual understanding on the part of people with disability or impairment. They often do not understand, and even if they do, they do not remember what was said. In reality, they have difficulty remembering new information and/or retrieving that information later. Lawyers should test for understanding by asking individuals to summarize their understanding of what the lawyers have told them.



## Case Study

### Peter and Helen

“Peter” and his wife “Helen” came to their lawyer to deal with Helen’s failing physical and mental health. They were very fortunate to have a loving and healthy adult caregiver daughter (something lawyers may encounter quite often). This daughter was sacrificially serving in a way that allowed Peter and Helen to continue living in their home. She was reaching the end of her ability to care for Helen, so they needed a lawyer’s advice. Peter was a successful businessman in the community and had a reputation for frugality and integrity. He was in the role of the caregiver spouse and the focus of concern was about Helen and her need for long-term care.

Over the next two years, their lawyer received a number of calls from their daughter, who was distressed at Peter’s financial decision making. One day, she called after she learned that her father had called a private ambulance service to take Helen to her hairdresser. Peter was deeply devoted to Helen, but he could not afford to spend \$800 to have Helen transported to and from her hairdresser.

Peter and his daughter saw their lawyer the next week. At that appointment, the lawyer met with Peter alone and reviewed his finances with him. Peter seemed capable and intelligent at the meeting. He was able to add and subtract and respond appropriately to the questions. Nonetheless, one week later, Peter called another ambulance to take Helen to her hair appointment. The lawyer was dumbfounded—he did not realize at the time that Peter was suffering from his own rising level of dementia.

A person with dementia may be able to answer questions correctly, but completely fail to appreciate the consequences of the answer that he or she has given. In other words, Peter was able to say what his income was and what his assets were, but he no longer understood the difference in the effect upon him of spending \$8 or \$800.

If family members live far away, some of the first people likely to notice these signs of dementia are the person’s own advisors—their doctor, lawyer, or financial planner. Unfortunately, these advisors often do not always have the ability to take action. Doctors and lawyers are bound by patient or client privilege, and even if they want to inform the family of their suspicions, they may not be able to do so. Recent changes to Illinois State Bar Association code of ethics do allow a lawyer to take

action to protect a client when there is a reasonable belief that the client has become incapacitated and is in danger—check the state's code for similar allowances.<sup>4</sup> The American Medical Association is also sensitive to this issue, and has guidelines for dealing with patients who show signs of incapacity.<sup>5</sup>

Unfortunately, doctors are under pressure to spend minimal amounts of time with patients. Many people are able to “fake it” during a short interview by doctors, lawyers, or financial advisors.

Lawyers will sometimes need to step in and help provide guidance when there is memory loss and assistance is required but is being refused. Alzheimer's is a progressive disease, and the memory loss will eventually rise to the level that the afflicted individual is no longer safe living alone.

### *Unsafe Alone*

#### **People with Alzheimer's living alone—quick facts:**

**An estimated 800,000 individuals with Alzheimer's (or one in seven) live alone.** People with Alzheimer's and other dementias who live alone are exposed to higher risks, including inadequate self-care, malnutrition, untreated medical conditions, falls, wandering from home unattended, and accidental deaths, compared with those who do not live alone.<sup>6</sup> Of those who have Alzheimer's and live alone, up to half of them do not have an identifiable caregiver.<sup>7</sup>

One of the signs of early-onset Alzheimer's is the tendency to wander off or to become lost.<sup>8</sup> This is especially dangerous because people with Alzheimer's do not act, or react, in the manner that a typical lost person would. Wanderers with dementia typically will not cry out for help or respond to calls to them, nor will they leave many physical clues to lead

4. MODEL RULES OF PROF'L CONDUCT R. 1.14 (2002).

5. AMA CODE OF MEDICAL ETHICS: OPINION 2.191 (2011), *available at* <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2191.page?>

6. *2012 Alzheimer's Disease Facts and Figures*, *supra* note 2, n.198.

7. *Id.*

8. *Id.* at n.178.



people to them. More than likely, a wanderer will go to an old place of residence or a favorite location from the past.

Advise clients to register their loved ones in the Safe Return program run by the Alzheimer's Association. Members of the Safe Return program are issued a bracelet or other form of jewelry with the association's logo on one side and the individual's identification number on the other side to aid in identification.<sup>9</sup>

Lawyers can also suggest that adult children living with a parent suffering from dementia put a baby monitor in the parent's bedroom so that they can hear them get up in the middle of the night. It is also a good idea to put safety devices in the home and warn the neighbors of the possibility of wandering and ask them to keep an eye out.<sup>10</sup>

Another danger is falling. Many elderly adults suffer falls as they age, but falls are more likely and can be more dangerous when the individual has Alzheimer's disease.<sup>11</sup> Because clients with Alzheimer's or other dementias commonly suffer from impaired judgment and disorientation, and a decrease in problem-solving abilities, visual perception, and spatial perception, the risk of falls is significantly increased.<sup>12</sup>

People caring for a loved one with Alzheimer's should also be warned about hallucinations or delusions. It is hard to tell if these are brought on by the disease or if they are side effects from a medication, but individuals with Alzheimer's have been known to suffer from one or both. Of course, some people will never suffer from either.<sup>13</sup>

If the client suspects that the hallucinations or delusions are being caused by a drug the patient is taking to treat a condition, it is advisable to contact the patient's doctor. If the hallucinations do not upset or frighten the patient, it may be best for the caregiver to just go along with the hallucination. In fact, validating the hallucinations is important and even healthy.<sup>14</sup> However, if the hallucinations upset the patient, advise clients to consult the patient's doctor.<sup>15</sup>

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9. RICK L. LAW, EVERYTHING YOU ALWAYS WANTED TO KNOW ABOUT ALZHEIMER'S BUT WERE AFRAID TO ASK 5 (2009).

10. *Id.*

11. 2012 Alzheimer's Disease Facts and Figures, *supra* note 2, nn.196–97.

12. *Id.* at nn.194, 195.

13. LAW, *supra* note 9, at 6.

14. *Id.*

15. *Id.*

### *Aid Needed, But Fights Back*

When an individual with Alzheimer's needs aid but is fighting back, it can be very hard on that person's family. Caring for a loved one with Alzheimer's can be draining, and at a certain point additional help is needed.

Lawyers who know their elder law can make a couple of helpful suggestions to their clients at this point of the journey. One option is to take advantage of a respite care program. These programs offer substitute caregivers and are designed to provide temporary relief for the primary caregiver from day-to-day responsibilities. Some respite programs are offered by paid health aides, while others involve volunteers from churches or other groups.<sup>16</sup>

If more intensive help is required, the lawyer can suggest home-based care. This involves having a health aide provide custodial care in the home of the patient. This can be a good option when the primary caregiver is also elderly.<sup>17</sup> This type of care allows patients to keep their independence for as long as possible and continue to live in their home.

Unfortunately, Medicare does not cover home health aides who provide custodial care, which is the type of care an individual with Alzheimer's needs. Custodial care involves bathing, dressing, help with the housekeeping and grocery shopping, and occasionally staying overnight when needed.<sup>18</sup>

Medicaid may cover portions of custodial services through a waiver program. Because the services available through the waiver program vary greatly state by state, lawyers should advise interested clients to contact their state office on aging to schedule a medical assessment to determine the level of service necessary to keep their loved one at home.

Another option lawyers should be aware of is adult day care. This option is great for situations in which the primary caregiver (perhaps an adult child) still works, but wants to keep the individual suffering from Alzheimer's in the home. Adult day care programs provide socialization and therapeutic activities that may slow the mental decline brought on by Alzheimer's.<sup>19</sup> Often these programs offer different levels of care

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16. HAMMOND ET AL., *supra* note 3, at 34.

17. *Id.* at 35.

18. *Id.*

19. *Id.* at 36.

ranging from one half day per week to full-time care Monday through Friday.<sup>20</sup>

Adult day care is considered to be a stage between independent living and living in a nursing home. Lawyers should suggest that clients and their family decision makers visit a few facilities prior to picking one to ensure the program offered is what their loved one requires at this stage of the Alzheimer's journey. Clients' family members and/or decision makers should look for the following:

- Is the program licensed? State regulations vary, so lawyers should be aware of state regulations so that they can educate their clients.
- Is the atmosphere friendly? They will want their loved one to be as comfortable as possible.
- What medical care is available?
- Are the activities aimed at socialization and mental stimulation?
- What is the staffing level? Generally, it's good to aim for one staff member per four adults in adult day care.
- Is the program exclusively for people suffering from dementia?
- Is a contract necessary? Alzheimer's progresses at unpredictable rates, so avoid contracts longer than 30 days in case they need to switch to a nursing home sooner.<sup>21</sup>

### *Assisted Living*

There comes a point in time when the client will need to be placed in an assisted-living facility. The lawyer can play an important role in this very personal decision by identifying the signs when a client has reached this stage of the Alzheimer's journey and by counseling the family members and advising them of the many available options.

As mentioned earlier in this chapter, individuals in the beginning stages of Alzheimer's disease often wander off and can become lost. When a client has begun to wander off, it is time for the lawyer to suggest that the family consider assisted-living options.

Lawyers need to be aware that older people with dementia who live alone are more likely to need emergency medical services because

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20. *Id.*

21. *Id.* at 38.

of self-neglect.<sup>22</sup> Overall, people with dementia who live alone are at a greater risk of accidental death than those living with others. This increased risk may be due to lack of recognition of harm and delays in seeking medical help.<sup>23</sup>

When lawyers are aware of these facts, they are in a position to counsel the family of the afflicted client and ultimately help both the client and the family. Assisted-living facilities can be the right choice for people suffering from Alzheimer's when skilled nursing is not yet needed—a step before a nursing home.<sup>24</sup> Moving a loved one into one of these facilities often allows the healthy spouse to better cope with the difficulties of caretaking for the spouse with the disease.

Lawyers with clients considering moving a loved one to an assisted-living facility should ask their clients the following questions about the facility to ensure they are making an informed choice:

- Is the facility licensed? Check with the state's guidelines to see what kind of licensing is required.
- What is the environment like? What are the common areas like? Is there an enclosed yard or patio that is a safe area that an Alzheimer's patient could not wander away from?
- What kinds of activities are offered? Ask to see the activities calendar. Is there a full-time activities director? It is important to find a place that offers a wide variety of activities to provide social interaction and mental stimulation.
- What is the staff to patient ratio? Generally, look for one certified nurse's aide (CNA) per five residents during the day, and a ratio of 1:10 at night.
- How well trained are the staff? Look for a facility where staff instruction includes interaction with an instructor, group discussions, and role-playing activities to ensure a quality staff that is ready to help a loved one.
- Does the facility have a special Alzheimer's unit? Some facilities have residents with a variety of needs, while others have a unit for people with dementia, and others are completely dedicated to residents with dementia. The best choice may be a facility with a special care unit devoted to residents suffering from dementia.

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22. 2012 *Alzheimer's Disease Facts and Figures*, *supra* note 2, at nn.189, 192.

23. *Id.* at n.197.

24. HAMMOND ET AL., *supra* note 3, at 40.

In these facilities, the staff is more experienced in handling people with dementia and more extensive care can be provided. Integrated units that have residents with dementia mixed in with otherwise healthy residents can cause problems for the residents with dementia because they may be excluded from group activities due to disruptions just when they need socialization and mental stimulation the most.<sup>25</sup>

By helping clients work their way through this list of questions, lawyers can help the clients make the best choice for their loved one.

Assisted-living facility contracts are very similar to apartment leases. However, lawyers need to be aware that the common yearlong contract can be problematic for someone with Alzheimer's disease. As previously mentioned, the progression of dementia is different for everyone and can be incredibly fast. A client could be in the early stages of Alzheimer's at the beginning of the contract term but need more extensive care, such as a nursing home, well before the year is over.

Ensure there is an escape clause in the contract allowing the resident to move out with reasonable notice in the event a higher level of care is needed.<sup>26</sup> By doing this, lawyers can save clients a lot of money and heartache.

### ***Nursing Home***

When clients reach the point where they have to put a loved one in a nursing home, it can be one of the hardest decisions they ever have to make. When Alzheimer's disease has progressed to the point where the afflicted person can no longer live alone or when the primary caregiver cannot provide the needed level or expertise of care, a move to a nursing home becomes necessary.

There are ways lawyers can help their clients through this difficult time. As always, having a plan and knowing the right questions to ask beforehand will allow lawyers to provide invaluable help to their clients.

Counsel clients to visit several different nursing homes before narrowing down their choices. Once they have found a few facilities that stand out, they should visit each one several times, preferably at different

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25. *Id.* at 41.

26. *Id.* at 42.

times in the day and at least once during a meal.<sup>27</sup> It is important to find a nursing home with an Alzheimer's special care unit.<sup>28</sup>

As discussed earlier, people with Alzheimer's disease have a tendency to wander off and can easily get lost, confused, and scared. Some special care units accommodate this behavior by providing a safe area to wander in, in the form of a walled-in garden or yard.<sup>29</sup>

Just like when a client is looking at an assisted-living facility, staff training is an important area to examine. Staff in special care units should take specialized training courses in order to be able to encourage the residents' independence and help them realize the maximum potential of their mental and physical abilities as their dementia progresses.<sup>30</sup> Lawyers need to advise their clients that the special units often come at an added price. Some states have established guidelines for these units, but there are no federal guidelines. Lawyers wishing to practice elder law should become familiar with their state's guidelines.

Advise clients to look for the following qualities from a nursing home with a special unit before agreeing to pay the higher rate:

- Does the facility confirm all incoming residents' Alzheimer's diagnosis?
- Is the staff aware of the progressive nature of Alzheimer's disease, and how do they address the expected changes in the mental and physical abilities of the residents?
- Are all of the employees in the special unit (the housekeepers, maintenance workers, etc.) given some training regarding Alzheimer's?
- Are the buildings and grounds designed for people suffering from Alzheimer's disease?
- Are the resident activities appropriate for people with Alzheimer's?<sup>31</sup>

It is important to advise clients early on in the nursing home search that this type of care is expensive. Fees average around \$45,000 a year nationwide, and can be as expensive as \$100,000 or more. Most insurance plans do not cover this type of long-term care and neither does Medicare.

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27. *Id.*

28. *Id.*

29. *Id.* at 43.

30. *Id.*

31. *Id.*

Fortunately, Medicaid is available for qualified individuals. Medicaid is a federally funded, state-administered medical assistance program that is explained in detail in chapter 5.

### ***Hospice/Death***

Hospice care is a team approach to caring for an individual in the final stages of a terminal illness, such as Alzheimer's. The goal of hospice care is to provide comfort, reassurance, and support for dying patients and their families and friends.<sup>32</sup>

Qualifications for hospice care require a physician's prognosis that the patient only has a life expectancy of six months. The point of hospice care is not to attempt to cure the illness, but to comfort the patient, lessen the pain, and help all involved deal with the inevitable death. Hospice care focuses on "dying well."<sup>33</sup> Medicare usually covers charges for hospice services for qualified patients, and most hospice program requirements conform to Medicare and National Hospice Association Guidelines.<sup>34</sup>

Because the lawyer does not have the emotional attachment that the family members have, it may be easier for the lawyer to identify (or admit) when it is time for hospice care. It is a good idea for lawyers to counsel clients to explore the possibility of hospice care before it is needed so that the clients do not have to deal with this at the most emotional point of the journey. The client should be advised to discuss hospice criteria with the patient's doctor to see how willing the doctor is to certify a patient for a hospice program. If the doctor seems unwilling, lawyers should advise their clients to consider finding another doctor.<sup>35</sup> Alzheimer's is terminal, and all sufferers reach the point where the only thing left to do is to comfort and prepare them as best as possible for death.

Jo Huey, the owner of the Alzheimer's Caregiver Institute, warns us that the symptoms that signify that a patient is in the final stages of Alzheimer's disease can be as varied as the individuals and their personalities and may be affected by other unrelated health conditions.

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32. *Id.* at 38.

33. *Id.*

34. *Id.* at 39.

35. *Id.*

With that fact in mind, Huey notes that there have to be some guidelines to follow.

According to Huey, only about 6 percent of people with Alzheimer's (and related disorders) actually make it to the end stage of the disease. The most easily identifiable sign that someone is dying from Alzheimer's and related disorders is when he or she can no longer swallow safely (without aspiration) and has chosen not to use a feeding tube (often a legal issue, discussed further in chapter 3). If clients are not allowed to take oral nutrition or hydration safely, they are unlikely to survive for a long period of time. Lawyers should be aware that it is advisable, at the very least, to have a speech therapist make this determination.

Huey says the second most common qualifier for hospice is when there is a significant weight loss even though the person is eating meals regularly. She notes that the majority of people with Alzheimer's and related disorders actually die from infection. Common examples are

1. sepsis from undiagnosed urinary tract infection or other infection (abscessed tooth, etc.) that creates an infection in the blood and can't be stopped if it has progressed too far; and
2. pneumonia, sometimes from aspiration or an illness or virus; because the clients cannot communicate their illness, it goes undetected until it has progressed too far.



### Case Study

#### **Jo Huey, Owner of the Alzheimer's Caregiver Institute**

Jo Huey's mother was 84 years old and had vascular dementia. She hated going to the hospital ER, which was the legal procedure required if she became ill in the assisted-living community where she lived. When she went to the ER, Jo would hurry there from out of state, and, in the meantime, one of the relatives (sometimes Jo's sister who also had medical POA) would accompany her. They would have the "doctor/attending ER physician/medical residency student" call and talk to Jo because the family did not want her mother to have an MRI, CAT scan, and any extensive diagnostic procedures that terrified her.

An angry physician in August 2006 told Jo that he was trained to "treat" people in the ER and if Jo wanted to decline treatment for her mother, then she should put her mother in hospice and stop bringing her to the ER. Jo called hospice and learned that her mother qualified for the service. Her doctor was willing to sign for it and she was recertified again in six



months. She happened to be doing quite well in August of 2007 when the recertification came up again. Although she still qualified, a physician's signature was required for recertification. The physician declined to recertify her because "she could live another 10 years."

Jo called her physician, who just happened to be someone with whom Jo had grown up, and asked him why he wouldn't recertify, and he gave her the same answer. Jo asked what to do about ER and extensive diagnostic procedures and he said something to the effect of, "You can just come here and stop those things or tell the community not to send her to the ER (he was unfamiliar with the community's regulations or didn't care). When Jo told him her mother qualified for hospice and that Jo wanted her recertified, he angrily accused Jo of "using the system" (Jo's mother was in a private pay community and had insurance that supplemented her Medicare). Jo retorted, "Even if we were using the system, it was none of his business that I wanted her to have hospice." He asked Jo how she was going to do that without his signature and Jo told him that she would call another physician in the same town "whom we both knew" and change doctors. He said, "You wouldn't really do that." Jo said, "Without a signature you will be getting a fax to transfer records in the next 15 minutes." He was furious and signed the hospice certification.

Just 19 days later, Jo's mother died in her sleep following a massive stroke and four days of being comatose. She died in her own bed in the assisted-living community where she had been dancing and smiling less than a week prior.

Huey stresses the importance of making certain that lawyers individualize situations to meet the specific needs and desires of the person with Alzheimer's disease and the loved ones who are responsible for the decisions when the person can no longer make them alone.

**Alzheimer's Association—quick facts:**

Alzheimer's is the sixth-leading cause of death in the United States and the only cause of death among the top 10 that cannot be prevented, cured, or even slowed. Based on final mortality data from 2000 to 2008, death rates have declined for most major diseases—heart disease (-13 percent), breast cancer (-3 percent), prostate cancer (-8 percent), stroke (-20 percent), and HIV/AIDS (-29 percent)—while deaths from Alzheimer's disease have risen 66 percent during the same period.<sup>36</sup>

36. 2012 *Alzheimer's Disease Facts and Figures*, *supra* note 2.

It is not uncommon for people in the final stages of Alzheimer's to reach the point where they do not want to go to the hospital again—they're ready, and hospice can help them achieve a "wonderful death." According to one hospice nurse: "The three essential elements to providing a wonderful death are the collaborative efforts of the family, the assisted-living staff, and the hospice personnel—which then allows our residents to stay in their home environment with friends and familiar caregivers and peacefully live out the end of their lives. I have been part of several end-of-life decisions with our residents. I am richer for it and tremendously grateful to have shared with the resident and his or her family some wonderful deaths."

## STATISTICAL PROJECTIONS

The Alzheimer's Association estimates 5.4 million people are currently afflicted with the disease.<sup>37</sup> Because Alzheimer's disease is underdiagnosed and many people with Alzheimer's may think that they are just experiencing the normal issues associated with growing older, many of the afflicted are unaware that they have the disease. Current estimates are that one in eight Americans 65 or older has Alzheimer's.<sup>38</sup>

As our population ages and people live longer, it is only natural to assume that the numbers of Americans with Alzheimer's disease will grow. In fact, the Alzheimer's Association predicts that the annual incidence of Alzheimer's disease and other dementias will double by the year 2050.<sup>39</sup>

The baby boomers, who make up a large part of our population, are entering the age brackets where they will be in greater danger of Alzheimer's and other forms of dementia. The first baby boomers turned 65 in 2011. It is estimated that the population of those 65 years old and older will double to 71 million by 2030. Those senior citizens will make up 20 percent of the total population at that time.<sup>40</sup> When the first baby boomers turn 85 years old in 2031, the number of people 85 years old and older is expected to reach 3.5 million, up from 2.5 million in 2012.<sup>41</sup>

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37. *Id.*

38. *Id.* at nn.A2, A3.

39. *Id.* at n.76.

40. *Id.* at n.81.

41. *Id.* at n.47.

Alzheimer's breakdown by age:

under 65 years old = 4 percent  
65 to 74 years old = 6 percent  
75 to 84 years old = 44 percent  
85 years old and older = 46 percent<sup>42</sup>

Every 68 seconds a new case of Alzheimer's develops in America.<sup>43</sup> However, that rate is estimated to double by mid-century, with a new case developing every 33 seconds.<sup>44</sup> The time to become educated about Alzheimer's is now. If the Alzheimer's Association's future projections are even close to accurate, we are about to witness an explosion of new cases of the disease. The number of Alzheimer's sufferers will soon be too high for the current elder law practitioners, and more expertise will be needed.

There were an estimated 411,000 new cases of Alzheimer's disease in 2000. That number was estimated to increase by 10 percent to 454,000 by 2010. By 2030, it is projected that there will be 615,000 new cases, a 50 percent increase from 2000. By 2050, it is believed that there will be 959,000 new cases, a 130 percent increase from 2000.<sup>45</sup>

By 2025, the number of people 65 years old and older with Alzheimer's is estimated to reach 6.7 million, nearly a 30 percent increase in just 15 years.<sup>46</sup> By 2050, the number of people 65 years old and older with Alzheimer's may double or triple to a projected 11 million to 16 million, unless a medical breakthrough is developed to prevent, slow, or stop the disease.<sup>47</sup>

By 2050, it is estimated that the number of Americans 85 years old and older will nearly quadruple to 21 million.<sup>48</sup> In fact, between 2010 and 2050, Americans 85 years old and up are expected to increase from 15 percent of all older people in the United States to 24 percent.<sup>49</sup>

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42. *Id.*

43. *Id.* at n.A7.

44. *Id.*

45. *Id.* at n.76.

46. *Id.* at n.47.

47. *Id.*

48. *Id.* at n.80.

49. *Id.*

With all of these new victims of Alzheimer's disease, more lawyers will need to be versed in elder law.

The more educated a lawyer is in elder law issues, the quicker the lawyer can act. Acting early allows those afflicted a better opportunity to have their wishes honored and puts the lawyer in the best position to help the client and the family, and decreases the chances of claims arising that the client's best interests were not followed.<sup>50</sup> Getting the appropriate legal documents in place early, while the client is still able to take part in the decision-making process, is a crucial step.<sup>51</sup>

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50. HAMMOND ET AL., *supra* note 3.

51. *Id.*



### Client Confabulation: The Attorney's Consternation

Dr. Nishad “Nick” Nadkarni is a licensed physician and surgeon in Wisconsin and Illinois. In addition, he is certified as a general and forensic psychiatrist. His professional experience includes working in private practice and, starting in 2004, working full time for the Circuit Court of Cook County, Forensic Clinical Services. The Forensic Clinical Services are primarily charged with determining clinical competencies, like fitness to stand trial and fitness for medications, for people indicted or charged with criminal offenses. Part of the training is learning to understand the different levels of capacity from the standpoint of legal definitions of capacity; for example, testamentary capacity, contractual capacity, donative capacity, and other criminal and civil competencies.

**Q:** Would you say based on your experience that it’s common for someone to admit to their dementia or their memory issues?

**A:** I would say it is *not* common, and almost always it is outright denied, even in the face of tremendous contradictory evidence.

**Q:** Despite short-term memory issues, can people develop a masking technique?

**A:** Yes. One of the techniques is confabulation—the insertion of details to fill in holes in the memory. For example, if I really couldn’t remember what happened this morning, I might give you what sounds like a reasonable explanation. You could ask me, “Dr. Nick, what did you do this morning?” and I could say, very convincingly, “I ate breakfast—I had two eggs, bacon, and toast,” and even with that I may be confabulating. I really can’t remember what I did—but I’m going to fill in the detail and not even be aware that I’m telling you something that is confabulated or made up. It’s very possible that someone can give you a complete rundown of what they did even though they have absolutely no actual remembrance. People will tell you what meets social expectations and what you would expect to hear.

Whatever that person may be consulting you about, it may have absolutely no basis in truth. Without reliable collateral information, you, the attorney, would not know that. So when you hear about a person’s activities of daily living and independence, it’s important to receive collateral information to back up what

someone who is confabulating is telling you. The only way that you would know that there were problems is by doing some formal testing, some mini mental status exam testing, which would not be appropriate for your role as an attorney.

With all due respect, I don't believe that attorneys are trained or competent in doing those kinds of tests. I think it brings about a bigger issue philosophically, ethically, about the responsibility you take on. If an attorney decides to try to do these kinds of workups, you'd better be competent and you'd better do it right, because if you make a mistake, you're going to be held liable for that.

**Q:** Over the years as a forensic psychiatrist, have you had the opportunity to observe a large number of lawyers?

**A:** Yes, several hundred.

**Q:** You have had the opportunity to observe attorneys in the civil and criminal arenas. What do you wish lawyers knew about dementia?

**A:** There is an old saying in medicine: get consultation, get consultation, and then get consultation. Whenever there is a question about mental capacity, to protect everyone's interests—primarily the client's—I wish more attorneys would seek consultation from mental health professionals before drafting and filing complaints.

The other thing that concerns me is attorneys' basic understanding of dementia, even attorneys who focus in elder law. It can be very difficult to assess. For example, early-onset Parkinson's disease has a dementia component. These types of dementias will present themselves very atypically and might affect a 58-year-old man who is having a bizarre complex of symptoms that may not be understood unless professionally evaluated. They are not necessarily affecting the short-term memory of the individual.

Also, there are certain things that cause *reversible* memory impairment, like major depressive disorder—what's called the pseudodementia of depression. If the depression is bad enough, the thinking can be so slow that they're unable to take in and retain information, and in a sense it dissipates. But antidepressants can reverse that. This is a very common phenomenon in the elderly. In addition, many older people are affected by hypothyroidism, which can increase the appearance of dementia.

Attorneys need to be aware of more than just memory impairment. An attorney should look for clusters of problems with cog-

nitive processing, memory processing, behavioral processing and control, emotional problems, emotional control, impulsivity, activities of daily living, sequencing and arranging, what we call executive functioning, ability to communicate, ability to feel secure with familiar people. All of these things may deteriorate in dementia and some may be subtle. If an attorney has a bona fide doubt about a person's capacity, they should make a referral to an appropriate healthcare professional for an evaluation.

On the other hand, just because a person is on a certain medication doesn't mean that they have incapacity. A person may be taking Aricept, Namenda, or some other medicine often prescribed for dementia—but they may still have testamentary or contractual or donative capacity. A medicine doesn't equate a diagnosis, and a diagnosis does not equate a capacity issue.

**Q:** Describe a typical evaluation.

**A:** When I do an examination I break it up into three phases. First I like to see the person in their own home. I am able to look at safety issues. I then spend 30–45 minutes asking people what they think is important. I then go through a formal evaluation of psychiatric history, any history of psychiatric symptoms, memory problems, history of substance abuse, current medications, allergies, medical problems, and their understanding of why they're taking their medications. We'll often go through a brief legal history as well.

Secondly, I would make an examination called a Mini Mental Status Exam, or MMSE, which is a screening tool for the grossest levels of dementia. At that point I have a quantitative number that may or may not mean something, but courts seem to appreciate an ability to quantify. I personally think that the mental status observations on the person's thought flow are more significant, but I do a Mini Mental Status Exam.

The third phase involves understanding of one's finances. I go through a series of questions to ascertain someone's general knowledge about how much they make in a year, how much their home costs, how much their car costs, etc. Then I address areas of insight, judgment, and impulse control regarding safety issues. What should you do if the house smells like gas? When is it appropriate to call emergency services? When should you go to an emergency room?

I'm interested in looking at whether they're jumping from one time frame to another without any logical connection. That tells

me whether the person is confused regarding significant key events in their life and whether or not they're able to identify or tag certain areas and build a story around those areas.

So I do much more than just asking somebody to add two plus two. It is a comprehensive evaluation that allows me to see *how* people are thinking, in addition to *what* they're thinking.