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Dealing with Dementia: Part 1

"Once-revered South Carolina lawmaker freezes to death." The article was buried on the back page of my Sunday newspaper. Juanita Goggins at age 75 froze to death in her home. She had been dead for over a week before a concerned neighbor contacted the landlord who then called authorities. She had dementia.

This trailblazing African-American woman was a teacher with a

Masters degree. She was a delegate to the Democratic National Convention, the first black woman appointed to the U.S. Civil Rights Commission, and she beat an incumbent white man to be the first African-American woman elected to the South Carolina legislature. She helped pass a 1977 law that was the basis for education funding in South Carolina.

How did this vibrant, bright, educated woman end up alone and frozen to death? We can only speculate as to why her life ended this way. People who cared about Ms. Goggins did try to intervene. Perhaps they visited an attorney seeking advice and were discouraged that the legal solutions were inadequate, expensive and often protracted.

As advocates, what can we do to help clients like Juanita Goggins? We need to become educated about dementia and other disabilities that impact thinking, mood and behavior. Some intelligent educated dementia patients compensate so effectively that it is difficult to recognize that they are impaired. Many of those same clients easily demonstrate testamentary capacity, yet lack the clarity of judgment and insight to make sound financial and legal decisions.

For example, an intelligent and investment savvy client with undiagnosed frontal lobe dementia began "investing" in sweepstakes. He arranged secret meetings at the local five-and-dime with telephone solicitors. Then barricaded his home for fear someone knew his winnings would be delivered any day. This information was not revealed during the discussion of

"the natural object of his bounty" or the "nature and extent of his estate." He gave accurate and detailed answers to those questions. Instead, his "new investment strategy" came to light when family members expressed concern about the volume of checks being sent to the sweep-stakes and the strangers calling around the clock to discuss his "winnings."

A person suffering diminished capacity may be "alert," know what he ate for breakfast, the president's name, or the date. Yet, his diminished capacity may manifest as hoarding, mismanaging money, wearing dirty clothes, not bathing, missing medicines, combativeness, disinhibition or other destructive behavior.

As the family lawyer, we are often the trusted advisor when Momma or Daddy (or both) start to have trouble balancing the checkbook or shows signs of forgetfulness. Perhaps Dad has been diagnosed with dementia, and the family asks you to draft a deed, will or power of attorney. Family is worried that Daddy may one day need long-term care. Then again, there are times we notice our client suddenly has a marked change in appearance, behavior or conversation.

You wonder: "If my client has a diagnosis of dementia, what does that mean? Does he have capacity to sign a deed, power of attorney, will or retainer agreement? Is a conservatorship required once the doctor has diagnosed my client's dementia or is a power of attorney sufficient? Do I have a duty to intervene if my client suffers from self-neglect? If my client is over a certain age, should I

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presume he suffers diminished capacity?"

Knowing basic facts about dementia will help the family attorney sort through these issues. How common is dementia in older adults? Dementia occurs in about 13 percent of Americans over the age of 65. The number of people with dementia increases with age. By the time we reach our early to mid 80s, half of us will have dementia.

Dementia is not a disease. The term refers to a group of symptoms caused by disease or other conditions. Those symptoms may include one or more of the following: short-term memory loss, changes in personality and behavior, impaired judgment, inability to problem-solve, language or "word finding" problems (a watch is a "hand clock") and visual spatial relations (think: driving issues). In other words, dementia isn't just about memory.

Only 10 percent of dementia patients suffer from a treatable dementia, sometimes called a "pseudo-dementia." That is dementia caused by hormonal or metabolic problems, such as a B12 or thyroid deficiency, depression or toxins. Organic and incurable causes of dementia include: Alzheimer's disease, vascular disease, Lewy bodies, Parkinson's disease, Creutzfeldt-Jakob disease, Huntington's disease and Wernicke-Korsakoff disease, and normal pressure hydrocephalus.

Alzheimer's disease is the most common cause of dementia occurring in 60 to 80 percent of patients who have a dementia diagnosis. It is a progressive illness, and staging systems provide useful frames of reference for understanding how the disease may unfold. While not everyone will experience the same symptoms or progress at the same rate, Alzheimer's patients die an average of four to six years after diagnosis. However, the duration of the disease can vary from three to 20 years.

A diagnosis of "dementia" or Alzheimer's disease does not automatically mean the client lacks capacity to make legal or financial decisions. A client's decision- making capacity depends on his level of impairment and functionality. Clients who are diagnosed and treated early show higher levels of functionality and capacity than those who are diagnosed late in the disease process, refuse to take the medicines, and lack physical and mental stimulation, care and support.

Family participation is an essential part of the medical provider's assessment of capacity and functionality. Like physicians, attorneys may need to consider family input in order to adequately represent a client or intervene when a client is at risk of neglect, harm or exploitation. As we counsel our clients and their families, we must understand that a client's capacity to make legal, financial and health care decisions may not be self-evident.

As the general practitioner tries to get a handle on her client's legal capacity, she may begin a meeting by chatting with the client and her family. Often, the older adult, especially one with some impairment, is anxious about meeting with the lawyer and will want family members to attend. As long as the family plays a supportive role, as opposed to a dominant role, meetings with the family present help us assess the client's capacity. Open-

ended questions such as "tell me about you" and then, "tell me what I can do for you today," often lead to answers like: "I don't know why I'm here," or "I don't want the nursing home to get all I've worked so hard for."

This is the first in a series of articles about intervening with clients who have diminished capacity due to dementia or mental illness. In the next article, we will consider tools for intervention including involuntary and voluntary psychiatric hospitalizations. We will also examine trends in the law related to conservatorship, capacity and self-determination. These topics will spark questions about who we represent, our duty of confidentiality, and our moral and ethical duty to get involved when our client, like Juanita Goggins, refuses help.

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