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# Promoting Good Principles of Dementia Care

by Karen Knutson, MSN, MBA, RN

It's insidious, it's frightful, it's demanding and it's complex. It raises many questions and has few answers. It's dementia. It comes in many forms and etiologies. It represents one of the greatest and growing challenges to our aging population and to the care managers responsible for clients' care.

Everywhere we go we see family caregivers dealing with issues of aging relatives and dementia such as Alzheimer's disease. Why is it then that the common experience of developing dementia late in life is still invisible in our society?

Is it myths about aging? Myths that keep this vulnerable population invisible? How often as a care manager are you faced with the attitude "of course she has memory impairment, she's in her 80's?" Such myths make dementia seem inevitable to happen. Or do you talk to professionals who say "there is nothing we can do and send potential clients off to facilities without a dementia work up or thoughtful consideration of preferences, needs or financial resources?" "Turning a blind eye prevents better solutions" you say to yourself. "If only I had been given a chance to work with this family!"

Is it hard to distinguish the diseases of dementia from normal aging, and harder yet to get a dementia work up? Or is it that we want our relationships to continue as normally as possible and so we assign the cause to something for which we do not feel responsible, thus leading to a delay in seeking help? Family caregivers report "all of the above" and to an overwhelming lack of support and understanding available to them at this time.

Is there more? The answer is a resounding YES! The articles in this issue of the *Geriatric Care Management Journal* will offer new insights and approaches as to why dementia is still invisible in our society. Selected issues have been chosen to provide more understanding of the complexities of client functioning and how dementia interrupts relationships with family, friends and providers. Hopefully you will find suggestions as to how you

*It's insidious, it's frightful, it's demanding and it's complex. It raises many questions and has few answers. It's dementia.*

can better identify these invisible clients early on and help families, friends, and other professionals in the process.

The first article "Anosognosia

or Denial of Deficit in Dementia: A Challenge for the Geriatric Care Manager" by **Patricia Gross** describes case studies of clients who deny dementia and are unaware of their deficits. Dr. Gross explains changes in brain functioning that lead

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# Anosognosia or Denial of Deficit in Dementia: A Challenge for the Geriatric Care Manager

Patricia Gross, Ph.D., ABPP-CN

**ABSTRACT:** Anosognosia refers to denial of illness or of deficit in neurological disorders. The prevalence of the condition in dementia, and particularly in those with Alzheimer's disease (AD), frequently presents challenges for family members as well as the geriatric care manager attempting to help client and family. Definitions, common issues related to the disorder, and proposed interventions will be addressed in this review.

**CASE #1:** Maisy's family knew she had memory problems for a year when she was diagnosed with lymphoma at age 78. Nevertheless, her son was at a

loss when she refused treatment after 2 sessions of chemotherapy for the mass on her left jaw, belligerently stating, "I don't have cancer." Three years later, she was admitted to the hospital with apparent chest pain. Her son saw her clutch her chest twice, but after admission she denied any pain. By this time at age 81, she was obviously in the moderate stage of AD, oriented only to herself. She did not know she was in a hospital, saying it was "a camp ground", could not give the number of her children, and the last president she could name was Truman. When asked what the lump on her jaw was, Maisy told the doctor,

"Cancer," but denied having chemotherapy.

**INTRODUCTION:** Was the patient in Case #1 in psychological denial about having cancer initially, and about the later chest pain? Was it merely a memory problem caused by progression of the AD? Or was it a larger issue of her awareness of any illness or deficit, including the memory problem?

Psychological denial is a normal defense mechanism used by individuals to help them handle unacceptable or challenging new information. The person is capable of understanding and remembering the information presented, but is not yet ready to accept or adapt to it. Denial in psychological terms is rarely involved in denial of deficit shown by those with dementia. People with dementia frequently lack the cognitive capacity to fully incorporate the new information or to remember it.

As a clinical neuropsychologist with close to 20 years of practice, I have helped diagnose thousands of

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## Guest Editor's Message

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to decreased self awareness and lack of insight into behavior. As a clinical neuropsychologist with 20 years of practice she differentiates denial in psychological terms which she says is rarely involved in denial of deficit shown by her patients with dementia. She explains how individuals with dementia lack cognitive capacity and the impact of this loss. Common issues related to anosognosia are discussed as well as interventions to improve care and make care management easier.

The second article "Better Outcomes for Clients with Dementia in a Retirement Community Setting" reports results from a descriptive study of clients with dementia in a retirement community setting. A for-profit care management company

collaborates with a non-profit CCRC to implement a model designed to improve services for clients in independent living, for their families, as well as the retirement community. The typical client with dementia is portrayed as undiagnosed with four co-existing chronic illnesses to manage, unaware of deficits and resisting help! The client resists services in the apartment and resists moving out to a different level of care. Specific barriers, functional limitations and services/interventions are highlighted.

Elderlaw attorney, **Jan Warner**, has written a thought-provoking article on how to legally have the best quality of life during incapacity. "Health Care Planning for Married Couples in the 21<sup>st</sup> Century in the Face of Terri Schindler-Schiavo" describes a tragic scenerio when a woman with dementia remains invisible, her spouse has conflicts of interest and breaches

his fiduciary obligations, and professionals turn a blind eye. Challenging us all to learn from this case, Mr. Warner recommends a team approach to health care planning with back up strategies that include protections such as written directives retaining geriatric care managers. Examples of clear language for documents are given.

It's a wonder we can do what we do! In spite of the obstacles and challenges we face every day I still find this work in dementia care the most rewarding. So much advocacy is required. So much more education is needed. As care managers we are in a unique position to promote good principles of dementia care. I hope you can apply the authors' specific insights and interventions to your practice as you assist clients and their families through this difficult, complex and still largely invisible transition.

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patients with dementia. The majority had probable AD. Of those with AD, only a handful could say that they had the disorder and were able to explain what Alzheimer's disease was. That handful of patients was able to say it was a brain disorder that affected thinking and memory. Yet, when asked about their memory, they invariably said it was fine, or no worse than anyone of their age. This denial of memory deficit sometimes occurred within seconds of failing badly on a memory test.

Denial of deficit presents a difficult challenge to the geriatric care manager (GCM). To arrive at a client's door for a previously arranged doctor's appointment, only to be told, "But I'm not sick," or "My memory is fine, I don't need to see a doctor," is frustrating, to say the least. The client may get upset or hostile if the point is pursued. For most GCM's and the families they help, it is a daily challenge that requires walking a fine line between providing enough information to reassure and persuade the client without setting off a catastrophic reaction.

**Anosognosia (ANOS)** was first described by Babinski (1914) as denial of illness seen in patients with neurological disorders, particularly in stroke victims with hemiparesis (paralysis of one side of the body) or blindness. The term has been expanded to refer to a patient's inability to fully appreciate the nature and extent of his illness (Critchley, 1966). In stroke patients with hemiplegia, ANOS is generally transient during the initial part of the acute hospitalization (Heilman, Watson, & Valenstein, 1993), but can be permanent in some patients. In fact, in patients with right hemisphere strokes, ANOS contributes to poorer functional outcome and decreased improvement compared with those with left hemisphere strokes

(Gialanella & Mattioli, 1992).

ANOS in dementia is common (Frederiks, 1985), but patients with other disorders than dementia can show evidence of ANOS. For example, alcoholics frequently underestimate and deny their memory problems (Ryan & Lewis, 1988), and patients with right-sided seizure focus tend to have more denial of deficit (Bear & Fedio, 1977). Traumatic brain injury often compromises awareness of cognitive and functional deficits (Damasio & Anderson, 1993; Prigatano & Schacter, 1991; Togliola & Kirk, 2000). The severity of ANOS can range from a "critical underestimation" of a specific deficit to "explicit, intractable denial of phenomena" (Bisiach, Villar, Perani, Papagno, & Berti, 1986).

**CASE #2:** Derek was a 26 year-old-man seen 1 year following a severe brain injury from a motor vehicle accident. He appeared to have recovered well, but his father reported marked judgement problems. For example, Derek bought a \$13,000 pick-up truck, but did minor damage to it by running through a ditch. Rather than repairing the truck, which would not have cost very much, he sold it for \$3,700 just 5 months after purchasing it. He admitted he lost a lot of money, but acted unconcerned about it, saying he needed the cash to move in with his girlfriend. When asked if he would make the same decision again, he blandly said, "Yeah, it's not the best decision, but I needed the money."

Critchley (1966) described anosodiaphoria, in which the patient will admit neurological deficit without any show of concern. This condition is also known as an **indifference reaction**. Case #2 represents an indifference reaction, which is

typically associated with traumatic injury or stroke damage to the nondominant (usually the right) hemisphere of the brain (Gainotti, 1972, 1989). Patients with indifference reactions may either deny or make light of their disability. Gainotti felt the indifference reaction was an abnormal mood associated with ANOS, because

the expected mood would express some level of attached concern, anxiety, or dysphoria.

An individual's sense of self is highly vulnerable to damage to the frontal lobes of the brain (Schacter, 1991; Stuss, 1991). Deficient

self-awareness leads to an inability to perceive errors in performance, to acknowledge the impact of such errors on others, or to assess a social situation appropriately (Prigatano & Schacter, 1991). For example, of those patients with frontal lobe tumors, 67 percent act indifferent to their deficits or are unrealistically optimistic (Hecaen, 1964).

**ANOSOGNOSIA IN DEMENTIA:** Patients with many forms of dementia show evidence of ANOS. For example, it is common with Huntington's disease (e.g., Cummings & Benson, 1983; Deckel & Morrison, 1996), in vascular dementia (formerly multi-infarct dementia), and in Parkinson's disease patients who have vascular changes (Danielczyk, 1983). However, those with cortical dementia such as AD and Pick's disease show the greatest lack of awareness (Benson, 1983; Danielczyk, 1983; Neary, et al., 1986; Wagner, Spangenberg, Bachman, & O'Connell, 1997).

During the first year or so, many AD patients are aware of their initial symptoms, especially their memory problems (Neundorfer, 1997; Zec, 1993). Zec makes the point that loss of insight in those with dementia can vary over

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*To arrive at a client's door for a previously arranged doctor's appointment, only to be told, "But I'm not sick," or "My memory is fine..."*

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time and across symptoms. It is rarely an "all or nothing" event. Some studies have reported on the variability of insight shown by patients with dementia (Neary, et al., 1986).

Early in the progression of AD, there is extensive loss of cholinergic neurons in the nucleus basalis of Meynert, or basal forebrain nucleus (Coyle, Price, & DeLong, 1983). Acetylcholine is a neurotransmitter, or brain chemical compound, that is essential in cognitive functions, including memory. Cholinergic neurons innervate wide areas of frontal cortex, as well as other brain areas. This change in frontal lobe functioning may lead to early decreased self-awareness in AD patients that eventually becomes full-fledged ANOS. Moreover, in AD patients with ANOS, SPECT scans reveal decreased regional cerebral blood flow in the right frontal lobe compared to AD patients without ANOS (Reed, Jagust & Coulter, 1993; Starkstein, Vasquez, Migliorelli, Teson, et al., 1995). Thus frontal lobe compromise, particularly right frontal lobe, may be necessary for ANOS in AD.

Insight into their own behavior is rapidly compromised in the early stages of AD (Lezak, 1995). Awareness declines with disease progression (Anderson & Tranel, 1989; Gil, Arroyo-Anllo, Ingrand, Gil, Neau, Ornon, & Bonnaud, 2001; Starkstein, Chemerinsky, Sabe, Kuzis, Petracca, Teson, & Leiguarda, 1997). The patient may in fact report improved memory as he loses awareness of his memory deficits (McGlynn & Kaszniak, 1991b).

**CASE #3:** Delores, a 73-year-old woman with a 3-year AD course, told the doctor she did all of the cooking at her house without help. She said she did all the cleaning as well, because "who else would?" When asked where she lived, Delores claimed that she lived by herself in

her own house. The daughter and son-in-law sitting in the interview with her said that, in fact, she had moved in with them 2 1/2 years before and had done no cooking or cleaning in that time.

As shown by Case #3 above, AD patients have impaired judgment of their ability to perform everyday tasks (Duke, Seltzer, Seltzer, & Vasterling, 2002; McGlynn & Kaszniak, 1991a). Patients with mild to moderate dementia are less aware of errors in daily actions such as grooming or meal preparation, and much less likely to correct their errors (Giovannetti, Libon, & Hart, 2002). They were aware of 20% of their errors compared to 73% awareness in healthy older controls. Omission errors are more common than commission errors, and tend to increase with dementia severity (Buxbaum, Schwartz & Montgomery, 1998; Giovannetti, Libon, Buxbaum, & Schwartz, 2001). Omission errors are much more difficult to monitor for the client, and thus less likely to be corrected.

Studies have shown that AD patients greatly overestimate their memory abilities (Schacter, McLachlan, Moscovitch, & Tulving, 1986) and greatly underestimate their daily cognitive problems compared with relatives' ratings (McGlynn & Kaszniak, 1991a, 1991b). The latter discrepancy increases with disease severity.

ANOS also leads to patients' failure to take appropriate precautions, particularly with driving (Cotrell & Wild, 1999). The client's lack of awareness can be quite dangerous to themselves and others, as families sometimes learn too late. A client with dementia and severely limited awareness of his deficits needs a referral to an occupational therapy driving evaluator. O.T. driver's screening and on-the-road tests are available at most major medical centers with a physician referral.

ANOS probably consists of more than a single factor or construct. For instance, a cognitive unawareness (CA) factor was

associated with illness duration while a behavioral awareness (BA) factor was not (Starkstein, Sabe, Chemerinski, Jason & Leiguarda, 1996). The CA factor included memory, calculation, praxis, time and spatial orientation, and abstract reasoning. The BA factor consisted of irritability, selfishness, emotional lability, and instinctive disinhibition. The CA factor was correlated with delusions.

In mild to moderate AD, awareness of cognitive deficits, moral judgements, and prospective memory were most disturbed, while the awareness of personal identity and mental body representation was relatively intact (Gil, et al., 2001). Gil and his colleagues concluded that AD patients may have difficulty maintaining both sequential and simultaneous "attention to life." In other words, those with ANOS miss the big picture. They not only can't see the forest for the trees, but they eventually focus only on individual pine needles, to stretch an analogy. The case below illustrates this.

**CASE #4:** Roger, a 69-year-old retired airline pilot, had shown 2 years of AD changes. He was fixated on an event that occurred 2 years earlier when he began to display symptoms of AD. While waiting to board a plane as a passenger, he was given a routine search at the airport. He expressed deep outrage at the search: "They took off my shoes, my belt, and ran a wand over me. They searched my bags without my presence." On questioning, he easily explained the events of 9/11, knew the Office of Homeland Security was "to prevent terrorism," and knew refusing the search would have meant not flying. He clearly had the memory and comprehension of each item in the sequence, but failed to integrate them. He furiously insisted, "I shouldn't have let them search me." His wife added that he frequently ranted about the event.

Another term for attention to life is **reality monitoring**, or the ability to discriminate one's own intentions

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from one's actions, or internal from external events (Johnson, 1991; Johnson & Raye, 1981). There may be confusion between an internal thought and the external reality. For example, a person may think about paying his bills and then assume they were paid because he remembers having thought about it. This can lead to a disassociation between error recognition and error correction.

In my evaluations, I typically have patients perform clock drawings. The patient is asked to place numbers and hands on a large circle. Even with less than a year of cognitive decline, a patient will often remark, "That's wrong," after placing numbers or hands incorrectly, but almost invariably fail to correct the mistake. He may spontaneously state what should be done to correct it, but still not attempt a correction. When asked if he wishes to change the drawing, the response is often, "Well, it's good enough."

### TREATMENT ISSUES:

The patient or client who is unaware of his own deficits is unlikely to attempt to compensate for them (Crosson, 2000). He will fail to utilize strategies or compensatory devices if he cannot accurately evaluate his own abilities (Zec, 1993). For example, stroke patients with ANOS during the acute stage frequently refuse physical therapy and other hospital treatment, and may become hostile and belligerent (Kaufman, 1995). Similarly, the woman with AD cited in Case #1 above refused treatment for cancer.

ANOS can coexist with depression (Kaufman, 1995). In those cases, treating depression can help treatment, as the patient may not have as negative an outlook and may be more amenable to attempting other treatments or interventions. The GCM should advocate for treatment of the depression through pharmacotherapy. Clients with ANOS and depression are unlikely to benefit from psychotherapy

as their cognitive deficits are generally too severe by the time the limited awareness becomes marked. Similarly, treatment for anxiety or other psychiatric conditions can help improve a client's awareness level.

The medications that were developed to slow the progression of AD are acetylcholinesterase inhibitors. They allow more acetylcholine to remain present, particularly in the frontal lobes of the brain. Within the first to second year of symptom onset, some AD patients can show a marked improvement in cognitive function and some functional improvement. Since the neurotransmitter involved may benefit frontal lobe function, awareness of deficit and general awareness may show some improvement.

GCM's should make sure the client has had an adequate evaluation to determine the type of dementia, and that the client is on the appropriate dose of one of the three commonly used medications. The four medications are Cognex, Aricept, Exelon, and Reminyl, though Cognex is rarely used now because of its more severe side effect profile that can include liver toxicity. The dose should be taken up to the highest recommended level. For example, sometimes a client is started on the 5 mg. dose of Aricept, which is never increased to the higher 10 mg dose, which led to the best outcome.

Naturally, anything that adversely affects the client's thinking and reasoning abilities is likely to impact his or her awareness level. The GCM should help the client to eliminate alcohol and caffeine use. The client's family needs to understand the reasons, as they often feel that the professional is trying to "take away" one of their loved one's few pleasures. Since alcohol is metabolized more slowly in older people and affects those with dementia more severely, even small amounts can lead to greater cognitive and awareness problems. Caffeine constricts blood vessels in the brain, leading to less oxygen and glucose availability and a higher risk for blockage and subsequent stroke.

Although tobacco use is equally an issue in those with limited awareness, it is a much harder habit to break

and may need physician intervention. Ensure the safety of the client with dementia and ANOS who still smokes by guaranteeing that smoking occurs under direct supervision. Lighting materials (lighter, matches) need to be under the caregiver's control. Some clients will agree to smoke outside, which reduces the risk of fire.

ANOS has been associated with increased caregiver burden (DeBettignies, Mahurin, & Pirozzollo, 1990; Seltzer, et al., 1997). Thus, the GCM's effort to increase the client's awareness can decrease the caregiver's burden and potentially allow the patient to remain at home longer. The reduction of ANOS can thus lead to greater client and family satisfaction, since most clients and families find staying in the home an important issue and resist placement efforts.

The GCM learns many techniques for managing care of the client with ANOS. If the client is on good terms with family members, the family should introduce the GCM and be present at a few meetings to familiarize the client with the new person in his or her life. On the other hand, if family relations are strained to begin with or have become so because of the client's low awareness of deficits, family may wish the GCM to make contact without an introduction. In that case, the GCM may be able to say he or she was "sent by your doctor" or "recommended by your friend, Mrs. X."

The creative GCM may need to come up with strategies to get in the house of a resistant client. A GCM I know has found that bringing flowers, lemonade, or a small gift helps her get her foot in the door (Knutson, 2004). Once in the door, distraction may be necessary each time the client questions, "What are you doing here?" Usually keeping a steady but not-too-rapid pace through the interview helps to avoid such questions.

Most care managers learn early to avoid directly confronting a client with his or her lack of awareness. Even gentle confrontation tends to lead to disbelief and hostile reactions from the

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client. The GCM can help family members and other professionals involved in client care become aware of the client's decreased awareness of deficit. If the client insists he or she has never seen the care manager before, the GCM would do well to act as if it is the first contact until later in the visit or until the client refers to "the last time you were here."

Avoid using words that trigger hostile reactions, and teach family members to avoid them. Ask family members if they know of any such triggers. For example, if "doctor" is a trigger word, use "appointment" or "specialist" instead. Circular reasoning can be used for patients in moderate disease stage. For example: "We have an appointment." "What for? I don't have any problems." "It's just a follow-up appointment."

Sometimes distraction from the point of the visit is necessary. A client who is very resistant to doctor visits may need to be told he or she is being taken to a more acceptable destination. The GCM can tell the client they are going to a bank, the library, or out to lunch. On the way to the doctor, a casual reference can be made to "your appointment" and, if questioned, elaborate that it is an appointment "for your eyes", or whatever body part the client acknowledges as a problem. Most clients will not express overt anger once they are in the doctor's waiting room or in the exam itself.

A client may vent anger after the

visit. Again, distraction may help. Once the visit to the physician is over, then the GCM can take the client to the bank, library, or out to lunch as promised, discussing the anticipated destination. The negative emotion engendered by the unwanted doctor visit is then replaced by the more pleasant emotions of the outing that was planned. Since emotional memory is more deeply processed than memory for new facts, the client is more likely to remember the pleasant affect attached to the outing than the initial more negative emotional state.

For very difficult clients, advance planning may help. Processing all paper work in advance of the visit, contacting the doctor's nurse, P.A., or social worker, and requesting an immediate room to minimize the client's agitation may help. Geriatricians are more likely to respond to such requests

because of their familiarity with dementia behavior. Make sure the doctor's office or other healthcare provider has a written release from the client authorizing the GCM to be present during office visits and to communicate directly with treatment professionals.

**CONCLUSION:** Most patients with dementia show some lack of

awareness for their illness or deficits, or agnosognosia, with the most profound lack of awareness often seen in patients with Alzheimer's disease. Though lack of awareness can be a difficult block to providing client care, some potential interventions can make care management easier. Helping the client's family and other healthcare providers to understand the limited awareness will lead to the elimination of roadblocks that can further assist in your ability to provide good care.

**Sometimes distraction from the point of the visit is necessary. A client who is very resistant to doctor visits may need to be told he or she is being taken to a more acceptable destination.**

## REFERENCES

- Anderson, S. & Tranel, D. (1989). Awareness of disease states following cerebral infarction, dementia, and head trauma: Standardized assessment. The Clinical Neuropsychologist, *3*, 327-339.
- Babinski, J. (1914). Contribution a l'etude des troubles mentaux dans l'hémiplégie organique cérébrale (anosognosie). Review de Neurologie (Paris), *27*, 845-847.
- Bear, D.M. & Fedio, P. (1977). Quantitative analysis of interictal behavior in temporal lobe epilepsy. Archives of Neurology, *34*, 454-467.
- Benson, D.F. (1983). Subcortical dementia: A clinical approach. In R. Mayeux & W.G. Rosen (Eds.), The Dementias (pp. 185-193). New York: Raven Press.
- Bisiach, E., Villar, G., Perani, D., Papagno, C. & Berti, A. (1986). Unawareness of disease following lesion of the right hemisphere: Anosognosia for hemiplegia and anosognosia for hemianopia. Neuropsychologia, *24*, 471-481.
- Buxbaum, L.J., Schwartz, M.F. & Montgomery, M.W. (1998). Ideational apraxia and naturalistic action. Cognitive Neuropsychology, *15*, 617-643.
- Cotrell, V. & Wild, K. (1999). Longitudinal study of self-imposed driving restrictions and deficit awareness in patients with Alzheimer's disease. Alzheimer's Disease and Related Disorders, *13*, 151-156.
- Coyle, J.T., Price, D.L. & DeLong, M.R. (1983). Alzheimer's disease: A disorder of cortical cholinergic innervation. Science, *219*, 1184-1190.
- Critchley, M. (1966). The Parietal Lobes. New York: Hafner Publishing Co.
- Crosson, B. (2000). Application of neuropsychological assessment results. In R. Vanderploeg (Ed.), Clinician's guide to neuropsychological assessment (pp. 95-244). Mahwah, NJ: Lawrence Erlbaum Associates.
- Cummings, J.L. & Benson, D.F. (1983). Dementia: A Clinical Approach. Boston: Butterworth's.
- Damasio, A.R. & Anderson, S.W. (1993). The frontal lobes. In K.M. Heilman & E. Valenstein (Eds.), Clinical Neuropsychology, (3<sup>rd</sup> edition, pp. 409-460). New York, Oxford: Oxford University Press.
- Danielczyk, W. (1983). Various mental behavioral disorders in Parkinson's disease, primary degenerative senile dementia, and multi-infarct dementia. Journal of Neural Transmission, *56*, 161-176.

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DeBettignes, B.H., Mahurin, R.K., & Pirozzolo, F.J. (1990). Insight for impairment in independent living skills in Alzheimer's disease and multi-infarct dementia. *Journal of Clinical and Experimental Neuropsychology*, *12*, 355-363.

Deckel, A.W. & Morrison, D. (1996). Evidence of a neurologically based "denial of illness" in patients with Huntington's disease. *Archives of Clinical Neuropsychology*, *11*, 295-302.

Duke, L.M., Seltzer, B., Seltzer, J.E., & Vasterling, J.J. (2002). Cognitive components of deficit awareness in Alzheimer's disease. *Neuropsychology*, *16*, 359-369.

Frederiks, J.A.M. (1985). The neurology of aging and dementia. In J.A.M. Frederiks (Ed.), *Handbook of Clinical Neurology* (pp. 199-219). Amsterdam: Elsevier.

Gainotti, G. (1972). Emotional behavior and hemispheric side of brain lesion. *Cortex*, *8*, 41-55.

Gainotti, G. (1989). The meaning of emotional disturbances resulting from unilateral brain injury. In G. Gainotti & C. Cattagione (Eds.), *Emotions and the dual brain*. Berlin/Heidelberg: Springer-Verlag.

Gialanella, B. & Mattioli, F. (1992). Agnosognosia and extrapersonal neglect as prediction of functional recovery following right hemisphere stroke. *Neuropsychological Rehabilitation*, *2*, 169-178.

Gil, R., Arroyo-Anllo, E.M., Ingrand, P., Gil, M., Neau, J.P., Ornon, C., & Bonnaud, V. (2001). Self-consciousness and Alzheimer's disease. *Acta Neurologica Scandinavica*, *104*, 296-300.

Giovanetti, T., Libon, D.J., Buxbaum, L.J., & Schwartz, M.F. (2001). Naturalistic action impairments in dementia. *Neuropsychologia*, *40*, 1220-1232.

Giovannetti, T., Libon, D.J. & Hart, T. (2002). Awareness of naturalistic action errors in dementia. *Journal of the International Neuropsychological Society*, *8*, 633-644.

Hecaen, H. (1964). Mental symptoms associated with tumors of the frontal lobe. In J.M. Warren & K. Akert (Eds.), *The frontal granular cortex and behavior*. New York: McGraw Hill.

Heilman, K.M., Watson, R.T. &

Valenstein, E. (1993). Neglect and related disorders. In K.M. Heilman & E. Valenstein (Eds.), *Clinical Neuropsychology* (3<sup>rd</sup> edition). New York, Oxford: Oxford University Press.

Johnson, M.K. (1991). Reality monitoring: Evidence from confabulation in organic brain disease patients. In Prigatano, G.P. & Schacter, D.L. (Eds.) (1991). *Awareness of deficit after brain injury: Clinical and theoretical issues* (pp. 176-197). New York: Oxford University Press.

Johnson, M.K. & Raye, C.L. (1981). Reality monitoring. *Psychological Review*, *88*, 67-85.

Kaufman, D. (1995). *Clinical Neurology for Psychiatrists*, p. 183. Philadelphia: W.B. Saunders Co.

Knutson, K. (2004). Personal communication.

Lezak, M.D. (1995). *Neuropsychological Assessment*, 3<sup>rd</sup> edition. New York: Oxford University Press.

McGlynn, S.M. & Kaszniak, A.W. (1991a). Unawareness of deficits in dementia and schizophrenia. In G.P. Prigatano & D.L. Schacter (Eds.), *Awareness of deficit after brain injury: Clinical and theoretical issues* (pp. 84-110). New York: Oxford University Press.

McGlynn, S.M. & Kaszniak, A.W. (1991b). When metacognition fails: Impaired awareness of deficit in Alzheimer's disease. *Journal of Cognitive Neuroscience*, *3*, 183-189.

Neary, D., Snowden, J.S., Bowen, D.M., Sims, N.R., Mann, D.M.A., Benton, J.S., Northen, B., Yates, P.O. & Davison, A.N. (1986). Neuropsychological syndromes in presenile dementia due to cerebral atrophy. *Journal of Neurology, Neurosurgery, and Psychiatry*, *49*, 163-174.

Neundorfer, M.M. (1997). Awareness of variability in awareness. *Alzheimer's Disease and Related Disorders*, *11*, 121-122.

Prigatano, G.P. & Schacter, D.L. (Eds.) (1991). *Awareness of deficit after brain injury: Clinical and theoretical issues*. New York: Oxford University Press.

Reed, B.R., Jagust, W.J. & Coulter, L. (1993). Anosognosia in Alzheimer's disease: Relationships to depression, cognitive function, and cerebral perfusion. *Journal of Clinical and Experimental Neuropsychology*, *15*, 231-244.

Ryan, J.J. & Lewis, C.V. (1988). Comparison of normal controls and recently detoxified alcoholics on the WMS-R. *The Clinical Neuropsychologist*, *2*, 173-180.

Schacter, D.L. (1991). Unawareness of deficit and unawareness of knowledge in patients with memory disorders. In Prigatano, G.P. & Schacter, D.L. (Eds.) (1991). *Awareness of deficit after brain injury: Clinical and theoretical issues* (pp. 127-151). New York: Oxford University Press.

Schacter, D.L., McLachlan, D.R., Moscovitch, M. & Tulving, E. (1986). Monitoring of recall performance by memory disordered patient. *Journal of Clinical and Experimental Neuropsychology*, *8*, 130.

Seltzer, B., Vasterling, J.J., Yoder, J. & Thompson, K.A. (1997). Awareness of deficit in Alzheimer's disease: Relation to caregiver burden. *Gerontologist*, *37*, 20-24.

Starkstein, S.E., Chemerinski, E., Sabe, L., Kuzis, G., Petracca, G., Teson, A. & Leiguarda, R. (1997). Prospective longitudinal study of depression and anosognosia in Alzheimer's disease. *British Journal of Psychiatry*, *171*, 47-52.

Starkstein, S.E., Sabe, L., Chemerinski, E., Jason L. & Leiguarda, R. (1996). Two domains of anosognosia in Alzheimer's disease. *Journal of Neurology, Neurosurgery, and Psychiatry*, *61*, 485-490.

Starkstein, S.E., Vasquez, S., Migiorelli, R., Teson, A. et al. (1995). A single-photon emission computed tomographic study of anosognosia in Alzheimer's disease. *Archives of Neurology*, *52*, 415-420.

Stuss, D.T. (1991). Self-awareness and the frontal lobes. In G.R. Goethals & J. Strauss (Eds.), *The Self: An Interdisciplinary Approach*. New York: Springer-Verlag.

Toglia, J. & Kirk, V. (2000). Understanding awareness deficits following brain injury. *Neurorehabilitation*, *15*, 57-70.

Wagner, M.T., Spangenberg, K.B., Bachman, D.L. & O'Connell, P. (1997). Unawareness of cognitive deficit in Alzheimer's disease and related dementias. *Alzheimer's Disease and Related Disorders*, *11*, 125-131.

Zec, R.F. (1993). Neuropsychological function in Alzheimer's disease. In R.W. Parks, R.F. Zec & R.S. Wilson (Eds.), *Neuropsychology of Alzheimer's Disease and Other Dementias* (pp. 3-80). New York: Oxford University Press.

# Better Outcomes for Clients with Dementia in a Retirement Community Setting

*Karen Knutson, MSN, MBA, Dana Bradley, PhD, Suzanne Langner, PhD and Mary Cooper, RN, NHA*

## Introduction

Studies of care management as a means of promoting quality of life for older adults and their families have focused primarily on institution based models: hospital and health maintenance organization; or community based models: area agency on aging, home health care and public health/visiting nurse association. Few studies evaluate the role of the private geriatric care manager in assisting home and community based older adults. While research efforts have focused on conceptualizing individual quality of life, the notion of family quality of life is receiving more attention.

Investigation of a new geriatric care model was conducted in two stages at a non-profit CCRC in the southeastern region of the United States. A for-profit geriatric care management company joined in partnership with a non-profit CCRC to implement a geriatric care model designed to improve services for senior residents in independent living, for their families as well as the larger retirement community.

The purpose of the overall project was to describe how geriatric care management results in a coordinated system of fluid and progressive care responsive to changes in residents needs. The CCRC and geriatric care management company utilized the GCM process to address the chronic long term care needs of residents who wanted to continue living independently but were no longer able to do so without additional services (See

Figure 1: The GCM Process). Stage 1 consisted of reviewing care manager records of a group of retirement community residents who were in transition, but not ready to move to assisted living or skilled care. Stage 2, which is in progress, consists of responses of the family caregiver of the retirement community residents from Stage 1. The focus of this article is to describe the results of Stage 1. By creating a coordinated system of progressive care as residents needs changed, the authors were hoping to see improved care during the transition as well as reduced family caregiver burden.

## Method

The sample for this descriptive study represented every retirement

community resident referred for a geriatric care management assessment and services from the period of June 1997 through January 2004. The retirement community residents in independent living accessed the geriatric care management services through referral. Referrals were made to the care manager by a retirement community professional or community service professional working with a resident or family member. The study focused primarily on residents who were willing to pay for care management and other home and community-based services while remaining in their apartment. All residents received as part of their contract with the retirement community prepared meals, housekeeping, apartment repairs and maintenance.

Subjective and objective data was obtained by a master's level care manager in nursing, social work or gerontology. Subjective data included experiences of the client and family as well as demographic and financial information. Objective data included observations made by the care manager as well as data from the functional assessment instruments conducted in the resident's apartment. The functional assessment included physical, cognitive, emotional and social functioning as well as the physical and social environment.

Early in 2004 the family caregivers  
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FIGURE 1: THE GCM PROCESS

### INTERVIEW

- Client
- Family Members/Caregivers
- Client Environment

### FAMILY DECISION MAKING

- Review written plan of care
- Select alternative recommendations
- Determine who will organize, coordinate, monitor and evaluate

### OBSERVE

Assess and Screen

Synthesize and Analyze

Develop Written Plan of Care

Facilitate and Empower Family Decision Making

### SUPPORT THE PROCESS

Develop Knowledge, Models, Tools and Services  
Communicate with Other Professionals  
Continue to Improve Practice, Research, and Education

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of residents who had received services from June of 1997 through January of 2004 were contacted by phone. The initial phone call briefly described the importance of the study, the sampling process and the amount of time needed to participate in a telephone interview. Family caregivers who agreed to participate were sent a consent form and a self-addressed return envelope. Thirteen out of fifteen retirement community residents participated in the project.

Stage one consisted of reviewing care manager records of the retirement community residents. The sample characteristics were age, gender, medical diagnoses, number of chronic illnesses, functional limitations, mental status and depression, previous dementia work up, anosognosia (unawareness of the cognitive deficit) resistance to help, and services/interventions implemented by the care manager. Twenty services/interventions were reviewed:

caregiver/companion care, medication supervision, transportation, assistance with social events, exercise program, fall prevention, equipment/assistive devices, nutrition intervention, pharmacologic intervention, ongoing care management, care management reassessment, referral to primary care provider, referral to neurologist, referral to psychiatrist, referral to ophthalmologist, referral to

pain management specialist, referral to podiatrist, referral for physical therapy, referral for driving evaluation, referral for financial management. Data were analyzed descriptively using frequency distributions.

The Mini-Mental State Examination (MMSE) instrument was designed as a brief objective assessment of cognitive functioning and as a measure of change in cognitive status. The MMSE has moderate to high reliability and sensitivity in detecting dementia. Criticism of the MMSE includes its failure to discriminate between people with mild dementia and those who do not have dementia. The Geriatric Depression Scale (GDS) designed specifically for rating depression in the elderly represents a reliable and valid screening scale

tions were an important indicator of services needed.

To evaluate caregiver burden/stress the second stage of the study consisted of a telephone interview conducted with family caregivers. The instrument was a self report questionnaire that measured the meaning of caregiver stress. The instrument was adapted from the Appraisal of Caregiving Scale (ACS), a self-report instrument that measured dimensions of caregiver stress. A 36-item version of the ACS was validated by seven family caregivers caring for a family member with Alzheimer's disease. A five-point Likert-type response format was used with choices ranging from very true to very untrue. Caregiving demand was measured by asking family members to quantify the time and type of caregiving activities that required their greatest time and effort. Results of the second stage of the study are being reported elsewhere.

## Results

Figure 2 summarizes the information for the thirteen retirement community respondents. Respondents studied were 69% female with an average age of 86.7. The typical respondent had cognitive impair-

ment with a mean MMSE score of 22, was unaware of the cognitive deficit, resisted help, had not had a dementia work up, had vision and hearing impairment, difficulty with balance and mobility and four co-existing chronic illnesses. Eleven respondents (85%) had Mini Mental State Examination (MMSE) scores of less than 28 out of 30 suggesting cognitive impairment

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**FIGURE 2: RESPONDENT INFORMATION**

Variable .....	%
<b>Gender</b>	
Female .....	69
Male .....	31
<b>Age Range</b>	
70s .....	15
80s .....	46
90s .....	39
<b>MMSE Scores</b>	
Less than 28 .....	85
<b>Anosognosia</b>	
Unaware of cognitive deficit.....	92
Acknowledged some memory impairment.....	8
<b>No previous dementia work up .....</b>	<b>62</b>
<b>Geriatric Depression Scores</b>	
Greater than 6 out of 15 .....	15
<b>Co-existing medical illnesses .....</b>	<b>92</b>
Four chronic illnesses .....	31

within this population. As part of the assessment of anosognosia the authors reviewed the chart for documentation of awareness of cognitive deficit and resistance to help by the respondents self assessment and reports by the family caregiver in narrative form. Respondents were classified by functional limitations based on the care managers' assessment as functional limita-

## Better Outcomes for Clients with Dementia in a Retirement Community Setting

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and further evaluation. One respondent had an MMSE of 28 out of 30 but by history was having difficulty with recall. One respondent had an MMSE of 30 out of 30 but by history was having difficulty with executive function tasks. Twelve respondents (92%) were unaware of their cognitive deficit and stated that they did not think they were having memory problems; they resisted help from family and professionals. One respondent (8%) acknowledged some memory impairment. Eight respondents (62%) had not previously had a dementia work up. Two respondents (15%) had geriatric depression scores of greater than 6 out of 15 suggesting depression and the need for further evaluation. Twelve respondents (92%) had co-existing chronic medical illnesses with four (31%) chronic illnesses as the mean. After dementia (diagnosed and undiagnosed), the most frequently listed chronic illnesses were depression, hypertension, hypothyroidism, osteoarthritis and stroke.

Respondents were classified by functional limitations based on the care managers assessment. Figure 3 summarizes the functional limitations of the thirteen respondents. Thirteen respondents (100%) had cognitive impairment, ten respondents (77%) had difficulty with

balance and mobility; eight respondents (62%) had vision impairment; eight respondents (62%) had hearing impairment; five (38%) in addition to having difficulty with balance and mobility had experienced recent falls and walked with a walker. Two respondents (15%) experienced depression. Specific barriers were identified by chart review of the care manager's assessment. These barriers included lack of knowledge by residents and their families about available services, resistance by the resident to accept formal services in the apartment and resistance to moving out of the apartment to a different level of care.

After a plan of care was developed with the care manager, services/interventions were imple-

tion supervision, transportation and assistance with social events, referral to the primary care provider and ongoing care management. Ninety-two percent of the respondent records reviewed implemented these services/interventions. Fifty percent of the respondents receiving caregiver/companion care needed standby assistance and supervision only. Forty-two percent needed hands on assistance with bathing and dressing in addition to standby assistance and supervision. Eight percent needed additional hands on assistance with walking and toileting as well as bathing and dressing and standby assistance and supervision. Sixteen percent of the respondents receiving caregiver/companion care received care for their spouses as well.

*Referral to primary care provider came next with 76% of respondents. Forty percent of the respondents referred to the primary care provider by the care manager were reconnected with the primary care provider they had stopped seeing. Forty percent were referred to new primary care physicians. Twenty percent of the referrals were referred to the primary care provider specifically for a dementia work-up. Ongoing care management was sixth provided by 69% of respondents. Seventh was referral to*

*neurologist. Eighty-three percent of the respondents who were referred to the neurologist were referred for a dementia work up and 17% were referred for follow up evaluation.*

(continued on page 12)

FIGURE 3: FUNCTIONAL LIMITATIONS

VARIABLE	%
Cognitive Impairment .....	100
Difficulty with Balance and Mobility .....	77
Vision Impairment .....	62
Hearing Impairment .....	62
Recent Falls, Walked with Walker .....	38
Depression .....	15

FIGURE 4: THE TOP 10 SERVICES / INTERVENTIONS IMPLEMENTED

SERVICES/INTERVENTIONS IMPLEMENTED	%
1. Caregiver/Companion Care .....	92
2. Medication Supervision .....	92
3. Transportation .....	92
4. Assistance With Social Events .....	92
5. Referral to Primary Care Provider .....	76
6. Ongoing Care Management .....	69
7. Referral to Neurologist .....	46
8. Pharmacologic Interventions .....	46
9. Exercise Program .....	46
10. Fall Prevention .....	46

mented by the client and family. Of the 20 services/interventions implemented the ten most common are noted in Figure 4. The most common services/interventions cited were caregiver/companion care, medica-

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After dementia work-ups for clients identified with mild to moderate dementia 46% of the respondents referred received *pharmacologic interventions*. Sixty-seven percent of the respondents receiving pharmacology interventions were started on a cholinesterase inhibitor. Other pharmacologic interventions initiated included anti-depressants, anxiolytics, anti-psychotics and hypnotics. Finally, 46% of respondents received exercise programs and 46% received fall prevention programs.

### Conclusion/Discussion

The study describes how geriatric care management results in a coordinated system of progressive care as residents needs change. The study reported is subject to a number of limitations. Because of the small sample size, it is not possible to generalize to a larger population. The results of the current study serve as a guide for further study.

The typical client respondent was female, age 86.7. had cognitive impairment, was unaware of the deficit and resisted help, had not had a dementia work up, had vision and hearing impairment, difficulty with balance and mobility and four co-existing chronic illnesses. While all 13 respondents had cognitive impairment, the MMSE was not sensitive enough in detecting mild dementia with two respondents. The instrument was not intended to substitute for the benefits of working with an experienced care manager. Each new care manager must develop experience as to the instrument's appropriate use and additional information that must be gathered.

The typical services and interventions implemented included caregiver/companion care, medication supervision, transportation, assistance with social events, referral to the primary care provider and ongoing care management. The study identified that

62 percent of respondents had not previously had a dementia work up or treatment. This result is consistent with the literature reporting slightly over one-third of patients with Alzheimer's disease receive treatment for their dementia.

Dementia interrupts relationships with family, friends and providers and impairs client functioning.

Often clients lack awareness of changes or loss of functioning.

Anosognosia, or unawareness of deficit, interferes with the client accepting help and is associated with higher levels of caregiver distress. Ninety two percent of study respondents were unaware of their cognitive deficit and resisted help. Clients who are unaware of memory and other intellectual deficits may engage in activities that might cause physical or financial harm to themselves and others.

Geriatric care managers need to have a greater understanding and skill in dealing with the client with anosognosia and understand how it affects both client and caregiver. A variety of strategies are needed to help family caregivers. For example, finding ways to involve the client while working through the resistance; helping family members attribute resistance to the "disease process" and not purposefully creating stress; and helping family caregivers appreciate the clients strengths despite the resistance.

Dementia prevents the client and

family caregiver from seeking help early. This delay in diagnosis and care can result in additional disabilities and difficulty managing other chronic medical illnesses. Geriatric care managers are in a unique position to access and maintain medical care as well as help the client get the services they need in the retirement community.

Ninety-two of the study respondents had co-existing chronic medical illnesses with four chronic illnesses as the mean. The literature reports increased acute exacerbations of common chronic conditions such as diabetes and congestive heart failure among individuals with dementia increasing the likelihood of hospitalization even in the early stages of the disease. Disease management strategies are more difficult to implement successfully in clients with known dementia. Seventy-six of the respondents in

**Geriatric care managers need to have a greater understanding and skill in dealing with the client with anosognosia and understand how it affects both client and caregiver. A variety of strategies are needed to help family caregivers.**

our study were referred to a primary care provider. Forty percent were reconnected by the care manager with the primary care provider they had stopped seeing. After dementia work ups for clients identified with mild to moderate dementia 46% referred received pharmacological interventions.

Our findings help identify next steps to move this research forward. Questions for further research include the following:

1. How can geriatric care managers better identify clients who may be at risk for cognitive impair-

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## Better Outcomes for Clients with Dementia in a Retirement Community Setting

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- ment and encourage earlier assessment and treatment?
2. What care management skills and interventions work best with clients who do not recognize their cognitive deficits and resist help?
3. What specific care management interventions optimize client function, reduce caregiver burden and improve the quality of life for everyone involved with the client?
4. What interventions minimize or eliminate potential hazards in the client's life-style and/or environment?
5. What medications have the greatest benefit in prolonging function when implemented in the early stages of the disease?
6. What are the most effective strategies in communicating client functioning to primary care providers?
7. What specific strategies help the care manager with the management of other medical conditions?

In conclusion, increased referral to geriatric care management services may allow for improved health and functional status, earlier intervention and treatment, improved care and reduced family caregiver burden among frail senior residents. Clients choose retirement communities to allow for more freedom to maintain independence, quality of life and quality care. Progressive retirement communities celebrate the day-to-day successes at overcoming the stereotypes and society's perceptions of aging by allowing residents to have more choice and control in managing their lives and their well being. Geriatric care management is a valuable option for clients considering retirement living.

As residents age in place geriatric care managers working with complex clients can improve care and reduce family caregiver burden by arranging appropriate services, referring to primary care physicians, reconnecting residents with primary care physicians who have stopped seeing their physicians and referring to other health care specialists. Geriatric care managers play an invaluable role in advocating for dementia work ups, appropriate pharmacologic interventions, treatment of other acute and chronic illnesses and educating and supporting family caregivers to maximize client functioning and improve their lives.

### References

- Browdie R. Area agencies on aging and home health agencies. *Caring*. 1992, 11:3; 70-72.
- Emlet C, and Hall A. Integrating the community into geriatric case management: public health interventions. *Gerontologist*. 1991, 31: 4; 556-60.
- Folstein MF, Folstein, SE and McHugh, PR. Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-198.
- Haworth M. Hospital-based community outreach to medically isolated elders. *Geriatric Nursing*. 1993, 14: 1; 23-25.
- Hill J, Futterman R, Duttagupta S, et al. Alzheimer's disease and related dementias increase costs of comorbidities in managed Medicare. *Neurology*. 2002, 58:1; 62-70.
- Knutson K. Dementia and the Older Adult: The Role of the Geriatric Care Manager. In: Cress, K, ed. *Handbook of Geriatric Care Management*. Maryland: Aspen Publishers Inc; 2001: 207-254.
- Knutson K. Family Caregiving and Memory-Impairment: why decision-making is so difficult. *GCM Journal*. 1995, 5:4; 2-8.
- Knutson K, and Langner, S. Geriatric Care Managers: A Survey in Long-Term Chronic Care. *GCM Journal*. 1998, 8:3; 9-13.
- Oberst M, Thomas S, Gass K, et al. Caregiving demands and appraisal of stress among family caregivers. *Cancer Nursing*. 1989; 12: 209-215
- Parker m. Private Geriatric Care Management: How Families Are Served. *Journal of Case Management: New Developments in Case Management Practice*. 1992, 1:4; 108-112.

Small G, Rabins P, Barry P, et al. Diagnosis and treatment of Alzheimer's disease and related disorders. *JAMA*. 1997; 278: 1363-1370.

Seltzer B, Vasterling J, Yoder J et al. Awareness of Deficit in Alzheimer's Disease: Relation to Caregiver Burden. *The Gerontologist*. 1997; 37: 1; 20-24.

Tombaugh TN, Hubley AM, McDowell I, et al. Mini-Mental State Examination (MMSE) and the Modified MMSE (3MS): A Psychometric Comparison and Normative Data. *Psychological Assessment*. 1996, 8: 1; 48-59.

Yesavage J, Brink T, Rose T, et al. Development and Validation of A Geriatric Depression Screening Scale: A Preliminary Report. *Journal of Psychiatric Research*. 1983, 17: 1; 37-49.

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# Health Care Planning For Married Couples In The 21st Century In The Face Of Terri Schindler-Schiavo—An Ever Broadening Role For Geriatric Care Managers Through Appropriately Prepared Advance Directives

*By Jan L. Warner*

Given the debacle playing out in the Florida courts surrounding Terri Schindler-Schiavo, husbands and wives throughout the United States would be well-advised to take a hard look at who will make their health care decisions should they become incapacitated and their partner become involved with another person or develop another conflict of interest.

For those of you who have not heard or read about it, Terri Schindler-Schiavo collapsed in 1990 from as yet unknown reasons, suffered brain damage, and is cognitively disabled. Because she had not signed a health directive to the contrary, her husband, Michael, had priority under Florida law to make her health care decisions and be appointed as her guardian. She can breathe on her own, move, and, according to her family, react to stimuli. But she has been kept alive thanks to a feeding tube because she is not able to eat or drink. Her family contends that even though she has brain damage, Terri would be able to eat and drink had her husband spent the necessary resources for rehabilitation such as swallow therapy. But I am getting ahead of myself.

After being appointed as her guardian, Husband Michael sued every medical professional in sight, blaming them for Terri's condition. After espousing his undying love and swearing to a malpractice jury in 1993 that he would take care of Terri for the

rest of her life and make sure she received needed medical care and therapy, approximately \$800,000 went to her trust for her rehabilitation, and \$300,000 went directly to him for lost consortium.

But no sooner had the ink dried on the deposit slips, than Michael changed his tune. After putting Terri's cats to sleep, Michael took up with another woman, had two illegitimate children by a woman with whom he now lives, and went to court seeking to have Terri's feeding tube removed. As the beneficiary of Terri's trust, Husband Michael now says that Terri would not have wanted to live in this condition were she able to express her wishes.

So, instead of using Terri's trust funds for rehabilitation, to fight infections that sometimes ravish her body, and to give her proper dental care, Michael hired lawyers to take out her feeding tube and, with court approval, used Terri's trust fund to his campaign to take her life. Although Terri's parents wanted to take her home, care for her there, and let Michael keep the money, Michael wanted Terri dead and refused to back down. So, for years, her parents have had to seek permission from the philandering Michael to even visit their daughter.

Meanwhile, Husband Michael has refused to follow mandatory Florida law that requires guardians to file

annual care plans for three years – and the judge has given Michael extension after extension even though Florida law limits a guardian's authority to the terms of court-approved health plans. The upshot: many infections because Michael would not allow doctors to treat her or give her antibiotics, and, most recently, the removal of five teeth due to utter lack of cleaning and dental hygiene. And Terri's parents have no say.

So, even though Michael Schiavo has irreconcilable conflicts of interest and has violated Florida law by not filing mandated care plans and reports for more than three (3) years, Florida Judge George Greer not only allowed Michael to continue to serve a guardian, but also ordered on October 15, 2003 that Terri's feeding tube be removed. And so the feeding tube was disconnected for six days — until Governor Jeb Bush ordered it reinserted pending the outcome of even more litigation and legislative efforts.

So what do we have here? We have a husband-guardian breaching his fiduciary obligations to his wife that are required by law. We have a judge who has turned deaf ears – and blind eyes — to these transgressions and has allowed the husband to continue to serve even though the Florida law clearly limits a guardian's authority to the terms of court-approved health plans that have not been filed for more than three years. We have a judge who ordered that a wife to die a slow, agonizing death by dehydration and starvation in proceedings where funds earmarked for rehabilitation have been used for assassination.

What can we, as professionals, learn from the Schiavo fiasco to help our clients? First of all, each state has adult health care consent laws for those who do not choose to sign advance directives. These laws list, in order of legislative priority, the relationships of those who will make health care decisions. Generally, if there is no guardian or health care proxy, spouses are first in line (unless they are separated) and then parents, adult children, adult siblings, and so on. This, of course, technically means that a spouse or second spouse of five minutes has priority to serve as health care proxy

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## Health Care Planning For Married Couples In The 21st Century

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under the law unless “good cause” to the contrary is determined by a court order after an expensive proceeding.

Therefore, should there are two or more candidates available to make decisions at any priority level who don’t agree – say three adult children or a second spouse of a few years and adult children who don’t agree — a decision in a guardianship action in the probate or surrogate court will be necessary at great economic and emotional expense.

Since none of us – or our clients – can predict the future, none of us know which unlucky spouse could find himself or herself in a situation like Terri Schiavo. For that reason alone, quality time and effort should be put into planning for incapacity while we are able to do so.

For these and many other reasons, and from my experience, health care planning – and the implementation of that plan when necessary – must be accomplished through a coordinated, team approach that includes “back up” strategies. I don’t believe it is enough to advise a client to pick an agent and an alternate, sign a health care directive, and leave the future to chance because there are too many unpredictable events that can occur.

Therefore, I believe that as much protection as possible should be built into written health care directives in order to protect married individuals who later become incapacitated from a fate similar to Terri’s.

While I understand that most husbands and wives want their spouses to make their health decisions should they become incapacitated and appoint them as health care agents, I believe that reasons for removal of a health care agent should be included in all health care documents so as to express the clear intent of the signator. In this way, should the unthinkable occur, there will be clear guidance for alternate agents and a judge who may have to make the

ultimate decision.

To avoid and/or deal with conflicts of interest like Terri Schiavo’s family is now facing, there should be clear language in the documents to guide those who will could be making decisions in the future. For example:

Believing at this time that my spouse shall have my best interests at heart should I become incapacitated and be unable to make my health care decisions, I name, nominate, and appoint my spouse \_\_\_\_\_ as my health care agent to make my health care decisions for me; provided, however, should my spouse be at any time romantically involved with another person, such a relationship shall constitute an absolute conflict of interest in which event my spouse’s appointment hereunder shall be irrevocably revoked and, in that event, I name, nominate, and appoint \_\_\_\_\_ as first alternate agent and \_\_\_\_\_ as second alternate agent.

In addition, language to the following effect could create a priority in the judicial appointment of a guardian:

Unless my appointed health care agent is not following my specific health care instructions as outlined in writing in my health care documents, there should be no reason for the appointment of a guardian to make my health care decisions.

However, should my appointed agent not follow my specific written instructions regarding my health care during my incapacity, I name, nominate, and appoint \_\_\_\_\_, \_\_\_\_\_, and \_\_\_\_\_, in that order, to be appointed as my guardian.

In that event, I direct and mandate that the powers and authority provided to my attorney-in-fact hereunder shall survive and shall not be altered or terminated by the appointment of a guardian who shall be mandated to follow my written directions whether contained in this document or any document written in my hand or signed by me before two witnesses. Since I have placed in writing all of my health care directions, any oral statements to the contrary that any person may

attribute to me shall carry no force or effect, and shall not be considered by any Court.

Because hospital and nursing home visits with incapacitated persons is often withheld because of control and financial issues, language to the following effect to establish visitation policies may solve a potential future issue:

During any period of my incapacity, it is my express desire that my health care proxy allow me visits with [my children (my spouse), etc.] unless my attending physician and the administrator of the facility where I am a patient or resident determines in writing that said visits are contrary to my best medical interests.

Similarly, because some individuals wish to give one or more persons other than their agent access to speak to physicians and other health care providers, I may include language, coupled with a HIPAA release, that authorizes this interaction.

And because the services of geriatric care managers are essential in many situations, I often include requirements in documents prepared for my clients that include a directive that a geriatric care manager be retained:

During any period of my incapacity, I direct that my health care agent use such of my funds as are necessary to hire a geriatric care manager to regularly review my medical records, assess and examine me, communicate with my physicians, and report on my condition to my agent and to [my children, spouse, etc.].

This provision is mandatory because I want to assure that I have the best quality of life available to me during my incapacity and that I receive, if it is in my medical best interests and will help me to recover or have a better quality of life, such rehabilitation and therapy as my medical professionals deem appropriate.

And lastly, I sometimes suggest to my clients language requiring the health proxy to establish and act on an appropriate health care plan with the assistance of the geriatric care manager, the physician, and the facility includ-

*(continued on page 16)*



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## Health Care Planning For Married Couples In The 21st Century

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ing, but not limited to, the following:

1. Confirmation that the current residential setting is best suited for the current needs of the incapacitated person; and
2. A Plan for assuring that during the following quarter of a year that the incapacitated person is in the best residential setting to meet his or her care needs; and
3. Reports from the attending physician and care manager who examined the incapacitated person not less frequently than quarterly that contain an evaluation of the incapacitated person's condition and a current statement of the level of capacity; and
4. A plan for providing medical, mental health, dental, and rehabilitative services in the quarter year; and
5. The social and personal services currently utilized by the incapacitated person; and
6. The social skills of the incapacitated person, including a statement of how well her or she maintains interpersonal relationships with others; and
7. A description of the incapacitated person's activities at communication and visitation; and
8. The social needs of the incapacitated person; and

9. A summary of activities during the preceding quarter that were designed to increase the capacity of the incapacitated person; and
10. An opinion each quarter by the physician and care manager as to whether the incapacitated person can have any rights restored and, if so, which ones; and

A failure to discharge these responsibilities will result in the health care proxy being removed.

Of course, in some situations, there are simply not sufficient funds to pay for this type of care; however, where there is, or where there are children who may agree to pitch in, I believe that better results will be attained for the incapacitated person.

Remember: A person can make his/her own health care decisions unless or until he or she is incapacitated and can't express his/her desires. For that reason, health care proxies should be drafted to include the express intentions and desires of us who have capacity today. None of us would like to find ourselves or a loved on in the Terri Schiavo situation. And we can help prevent it by 1) making sure that individuals sign advance directives after being fully informed, and 2) where possible, drafting documents to fit the needs of the individual. If we all liked vanilla ice cream, there would be no reason for all of the other flavors.

*For 17 of his more than 36 years' experience as a matrimonial, tax, and elder law attorney, JAN L. WARNER has provided valuable information to those who read his weekly newspaper columns. He conceived and has co-authored Flying Solo®, a weekly newspaper column about divorce that is distributed by Knight-Ridder Tribune News Service, for 17 years. He conceived and has co-authored NextSteps®, a weekly newspaper column about matters affecting the elderly and disabled that is syndicated by United Features Syndicate, for eight years. Both have established Internet presences ([www.flyingsolo.com](http://www.flyingsolo.com) and [www.nextsteps.net](http://www.nextsteps.net)). He hosts NextSteps® Senior Talk™, a weekly call-in radio program on WISNews Radio (AM 1320). He received his A.B. and J.D. degrees from the University of South Carolina and earned a Master of Legal Letters (L.L.M.) in Taxation from the Emory University School of Law in Atlanta, Georgia. He is a frequent lecturer at legal education and public information programs throughout the United States. His articles have been published in national and state legal publications. He and his programs have been featured in articles appearing in **Kiplinger's**, **The Wall Street Journal**, and many other publications. He is based in Columbia, South Carolina. He is a Certified Fellow of the American Academy of Matrimonial Lawyers and a member of the National Academy of Elder Law Attorneys, and many other legal organizations. He founded and is a principal of ElderLaw Services of South Carolina, a state-wide practice of elder law ([www.elderlaw-sc.com](http://www.elderlaw-sc.com)). He can be reached at [janwarner@janwarner.us](mailto:janwarner@janwarner.us).*