

A PROBLEM CLIENT: HOW TO HELP THE CAREGIVER SPOUSE WHO MAY NOT EASILY ADJUST TO A SPOUSE BEING PLACED IN A NURSING HOME

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The Problem Client

Ginny came to me for help preparing a Medicaid application for her husband, John. John was a large man for his 82 years and was now in a nursing home unable to walk or transfer himself from his bed to his wheelchair. John and Ginny had maintained an active social life until seven years ago. John started to refuse to participate in events, so Ginny left him at home while she played tennis or met with friends. Five years ago, John began to have such severe memory and judgment problems that he could not be left alone and had to be watched at all times. Ginny found part-time respite care allowing her to continue some activities without John and so that he could interact with others. But from that point forward, Ginny's energies became focused on John's care. Her sense of self worth became connected to her ability to enable John to go to church and dancing at the Senior Center with her. Then, one year before she came to my office, John was hospitalized due to a fall. With much encouragement and effort by Ginny, he went through rehabilitation in a nursing home and was able to use a walker. He went home. Soon he was hospitalized after falling again. This time, the hospital social worker refused to allow John to return home, stated that he needed nursing home care and placed him in a nursing home, and told Ginny she could not care for him at home anymore. Ginny was a frail but determined 80. She told the social worker that John would walk again. By this time, John could not follow

instructions, in fact could not stay awake long enough to try, and finally refused to get out of bed for long.

Ginny told me that she was terrified of the \$4,500.00 a month nursing home bill . I told her that there would be a lot to do to gain Medicaid eligibility for her John, but we had a good chance of success once we gathered their current asset information. Ginny came with three large boxes of financial records which were remarkably devoid of any current information. She said she had rarely bothered to open statements since the first hospitalization began and she was not sure where they were. We met several more times, but were still missing the majority of her recent statements. She said she was so preoccupied with her battles at the nursing home with her husband's new doctor that she would "forget" to look for the necessary documents. She was spending at least twelve hours a day with her husband, having taken over much of his hands-on care from the staff. That left her with little time and no energy to respond to my requests for financial statements . She told me that she had received calls from the insurance company representatives who had sold her husband many of their deferred annuity assets. They had told her to put all her financial concerns in their hands and she'd have no more financial worries. I sent them a letter to communicate with my client only through me. Ginny herself now became sick with one infection after another. Her children had tried to help her gather the needed Medicaid application information but she quickly alienated them by her constant fury at the doctors, nurses and nursing home staff . Her children saw their father's care as better than it had been at home after his first fall. They stated to me when they came in with their mother that they felt John's care was reasonably good. Finally, Ginny told the nursing

home that she was removing John and placing him in a six bed board and care even though he was not ambulatory nor awake much of the day. John really did not know where he was. Again Ginny started to fight with John's new caregivers. Frantic to keep their Dad in some care outside the home, their children forbade Ginny to spend more than 30 minutes a day with him. They told her that because she had chosen the facility and she was now very ill herself, she had better accept it. She did. John's systems, which had been failing slowly, continued to fail. John was transported back to the hospital from the board and care after a few weeks and remained hospitalized until he died. Ginny was devastated, and claimed that John was not that sick before he was placed "in that horrible nursing home".

Ginny's example illustrates many of the problems caregivers face when their loved one is moved from the home care into institutional care: caregiver stress caused by the guilt and uncertainty of the new role after placement, caregiver dissatisfaction with the particular nursing home, an elderly caregiver who can not transition from being the full time caregiver to the organizer of care, the caregiver who feels the care is so poor that they feel they must be a vigilant "watcher" or attempt to provide most of the hands-on care themselves, and the caregiver who is so physically and cognitively weakened that it is very difficult to determine whether the care is that bad, the judgement of the client is so impaired that they see bad care even when the care is adequate or both. (Family Caregiver Satisfaction with Nursing Home After Placement of a Relative with Dementia, by Jane B. Tornatore, PhD and Leslie A. Grant, PhD, Department of Health Care Management, University of Minnesota, Minneapolis; prepublication at the Journal of Gerontology, page 5). Ginny also presented the problem of a client who is very vulnerable to undue influence in her case an annuity salesman, who would promise her a way to eliminate her problems

and thereby take away her anger, anxiety and guilt. (“When Does Interference Become Undue Influence” by Martin Binder, M.D. and Marita K. Marshall, Esq., California Trusts and Estate Quarterly, Vol. 4, No.2 Summer 1998, pgs 13-16,15)

Although I will be examining the point of view of the female caregiver spouse, these problems are not limited to female spouses but frequently also occur with the male spouses, with the children and with other relatives who are the caregivers of someone placed in a facility (Family

Caregiver Satisfaction with Nursing Home After Placement of a Relative with Dementia, by Jane B. Tornatore, PhD and Leslie A. Grant, PhD, Department of Health Care Management, University of Minnesota, Minneapolis; prepublication at the Journal of Gerontology page 5). Whether spouse, child or other relative, the caregiver has felt as if the caregiving work was one of the most important things that the giver has done. The sense of loss and guilt after the placement of the person dear to you in an institution is an emotionally wrenching experience. Although my analysis of this problem is primarily centered around the female caregiver spouse, the solution proposed are equally useful for the male spouse, the child or other relative caregiver. Nevertheless, I will refer to the caregiver spouse, who in the Medicaid application process known as the community spouse, also as the “spectator or watcher” spouse. as “she” and with the possessive “her”.

As elder law attorneys we often see clients who have gone from being a full-time hands-on caregivers at home to “spectator or watcher” caregiver in a very short period of time. The caregiver spouse may have been unable to provide effective care for some time. Often this type of client can not see her own caregiving limitations and the gradual changes and failing health of her spouse. Yet her children and friends may have been

pointing it out for months. The children and friends may have seen an exhausted caregiver with increasing problems of her own and assumed that once the sick spouse was institutionalized, the caregiver spouse would feel relief from the burdens and feel more freedom to take care of her own illnesses. Instead they find the “well” spouse in despair, having lost the role as full-time primary caregiver. Angry, guilty and anxious, she wants her old job back. Unable to give up the primary caregiver role that has directed her life for a long time, the community spouse may spend most of the day in the institution with the sick spouse. The only job the caregiver spouse may see available is that of the vigilant “watcher.” She may see her new job as requiring her to demand that the facility caregivers respond immediately to the sick spouse’s needs, as she believed she did.

Surrounded with all the germs found in the nursing home, the exhausted and depressed “well” community spouse often gets sick. Many caregiver spouses will not go home to care for themselves. As the “watcher” they are afraid to leave their post. The “well” spouse just gets sicker. Exhausted by the new role as the “watcher”, many caregiver spouses are also unable to participate effectively in taking care of business including Medicaid applications. The caregiver spouse may not even pay bills anymore. In this struggle to remain the primary caregiver of the institutionalized spouse, she often becomes angry at everyone. Ginny said of her children and her husband’s doctor: “they are robbing me of my job.” The caregiver spouse may isolate herself from family and friends. At this point, the community spouse may be desperate to find someone to turn back the clock. Exhausted, focused on being the “watcher” of the caregiver to her institutionalized spouse, her judgment of other people’s motives often becomes impaired. She may now be very open to the undue influence of people who prey on the elderly. She is looking for a savior. (When

Does Interference Become Undue by Martin Binder, M.D. and Marita K. Marshall, Esq., at page 15).

The elder law community has seen many versions of Ginny, before or after they become the prey of a “savior”. They may come to us expecting us to be their savior. An elder law practice is not in the business of saving people. It is in the business of facing the fears and limitations of the elderly and recognizing that these must be creatively approached so that we can do the attorney work we are being hired to do.

How can we help our clients stop that initial sense of losing their job as caregiver and their sense of identity? How can we help to create a situation where they will work with us to accomplish necessary legal business and work with the new caregivers to improve care rather than trying to take over the hands-on care? Why are the caregivers in Ginny’s shoes so unhappy with nursing homes placement when the care actually is not substandard? What can we do to help them tolerate a nursing home placement that is actually necessary?

Caregiver Satisfaction with Nursing Home Care

If a primary caregiver is going to be able to be satisfied and accept nursing home care for the person placed in the nursing home, that caregiver has to have a sense of positive involvement and influence over the care that their sick relative receives and the facility in which their spouse is placed. (Family Caregiver Satisfaction with Nursing Home After Placement of a Relative with Dementia, by Jane B. Tornatore, PhD and Leslie A. Grant, PhD, at page 5) The Tornatore and Grant study, done in Minnesota nursing homes, indicated that the more advanced the dementia of the family member in the nursing home, the lower the caregiver satisfaction with the care received. Caregivers who continued to be

more involved with hands-on care at the nursing home were also likely to have lower satisfaction with the care provided. On the other had, the more the caregivers visited, if they were not doing hands-on care, the higher their satisfaction. Finally, caregivers with a high expectation of the facility generally had a higher satisfaction rate. (Ibid, page 6).

The investigators in this study believed that when the caregivers choose the facility they had higher expectations in it. By choosing where to place the sick spouse, a caregiver would feel connected to the new caregiving situation and more able to control what happened.

In an earlier study of the same group of Minnesota family caregivers, Tornatore and Grant, investigated the “burden”, i.e. the stress, on family caregivers of person with Alzheimer disease when that person is placed in a nursing home. These investigators found that when a facility has specialized care units for dementia the caregivers were significantly less likely to feel burdened by stress. These units provided dementia related services and some outreach to the caregiver. Standard custodial care, that is really set up for those who are not demented, created a substantially greater burden for the caregiver. Custodial units provide fewer dementia related services. (Burden Among Family Caregivers of Persons with Alzheimer Disease in Nursing Homes, Jane B. Tornatore, PhD and Leslie A. Grant, PhD, *The Gerontologist* Vol. 42, No. 4, 497-506, 504).

This authors of the study stated that the data were consistent with previous research showing that caregiver perceptions are integral in the patient’s process of adaption to a nursing home. The researchers hypothesized that the burden created by hands-on care at the facility by the caregiver may be because some caregivers provide direct care to the sick spouse to compensate for perceived inadequate care by the nursing home staff. This study

further suggested that nursing homes need to provide opportunities for caregiver involvement in ways that facilitate caregiver adaptation to the placement of the spouse but which do not create ambiguity between what are considered the nursing home functions versus what are the family caregivers functions. (Ibid 505). The implications of this study are that a caregiver will adapt to nursing home placement better and with less burden when services are available to the caregiver that help a caregiver understand the various stages of family caregiving over time and the caregivers new role. The two most “burdened” groups they found were the caregiver who had never had the role of caregiver decision makers before and the elderly caregiver who had difficulty adapting to changes. For these they recommended direct help by the nursing home for these two groups of caregivers to be able to adopt to the new role. (Ibid 505).

What to Do?

As elder law attorneys we cannot single handedly fix the American medical system. It is designed mainly to prevent illness and to rescue younger healthier people from the effects of injury and stop death (Living Well at the End of Life, Adapting Health Care to Serious Chronic Illness in Old Age, Joanne Lynn, David M. Adamson, Rand Health, page 2 at www.raud.or/publications/wp/wp137/index.html). What we can do is acknowledge that our client and Medicaid applicant spouse now in a nursing home have had a lot to adapt to already. The chronically ill spouse has usually had to undergo multiple changes of setting as to how their care is directed (from the doctor’s and home, from the hospital, from a nursing home, possibly back to a doctor’s office and a board and care or assisted living, etc.). (Ibid, page 3). It will help a client accept the situation, if we start by helping our client see that their spouse is chronically ill and probably fatally chronically ill.

Elder law attorneys often have to explain medical information never explicitly told to their client. It is likely that no one has ever explained to the caregiver spouse that their spouse most likely has a fatal chronic illness. Nine of ten elderly people who die have one of the fatal chronic illness in their final year of life (cancers, organ system failure of the liver, heart or kidney or respiratory system, dementia or strokes) and most are sick with one of these conditions three years before death. Most do not know that 25% of that population are actually ill or disabled by one of these fatal chronic conditions at any given time. (Ibid, pg. 2). The community spouse may never have been told that their spouse is likely to eventually die from the effects of this kind of condition. Most chronically ill people have an ambiguous medical prognosis that is really based on their fragility, not their life expectancy in terms of time. (Ibid, page3) The caregiver may have not really considered that their spouse's care needs will continue to change after placement and become progressively more demanding. A community spouse needs to be told that her new job is to locate the best care that other people can provide for her spouse to respond to the progressively greater care that her spouse will need in the time left to her spouse. The community spouse needs to understand that the care needs will change continually and because she knows her sick spouse so well she is the best person to supervise that care.

To determine the best care, the caregiver should first determine whether full time in-home care, assisted living care, board and care type care or nursing home care will provide the best setting for their spouse to function and be as comfortable as possible and what it will cost. If nursing home custodial care is the best solution to the care needs of their spouse, then while we are doing Medicaid application preparatory work, the

community spouse should be looking for a nursing home that is the community spouse's choice, even if it is the best of the worst. Our Medicaid applicant spouse may never have been told that she had a choice of facilities. Helping that spouse to learn how to look for the best local nursing home, if that is appropriate, and to find out what type of caregiver support is provided may be a greater value to the caregiver spouse than an extra month of Medicaid eligibility. Therefore, finding the placement that community spouse can accept may need to take precedence over submitting an earlier Medicaid application.

Nationally, the Center for Medicare and Medicaid Services (CMS) now publishes benchmarks on nursing home performance (www.medicare.gov/NHCompare/home.asp?) This service provides a starting place for the search for the nursing home closer by the community spouse. Under this website's section entitled "About Nursing Homes" it includes the number of beds and the type of ownership of the facility. In its "Quality Measure", it provides data on aspects of care including percent of residents with pressure sores and physical restraints. The "Inspection" portion provides information on deficiencies found during the most recent state nursing home survey and recent complaint investigations. Finally its "Nursing Home Staff" information includes the average number of hours worked by registered nurse, LVN vs. NS and CNAs per resident per day. If your client has no family to help them review this information through the website, print out the CMS information for the caregiver spouse or have a staff member do so.

The National Citizens Coalition for Nursing Home Reform has a consumer guide to choosing a nursing home which can be printed out and given to the client. (www.nursinghomeaction.org/public/50156455.cfm). It explains how to use the CMS Nursing Home website. This guide has other listed websites to get further information .

This guide is practical and direct. It tells a visitor to a facility to use your senses - sight, hearing, smell and touch- to evaluate a facility.

A shorter, simpler guide is put out by the California Advocate for Nursing home reform at the CANHR consumer website at www.canhr.org . It can be found within the CANHR website at an internal website at www.nursinghomeguide.org/ccis_guide_how_to_ch. The guide has a short printable checklist to take to a facility during a visit(www.nursinghomeguide.org/pub_eval_checklist.) This checklist helps a caregiver to remember what she saw and provides a means to compare what she saw at various facilities. Although created by a California nonprofit, this guide and the checklist could be used in any state. This website also has information on facilities in California listed by county along with violations by facility. Other state organizations may also have this type of specific violation information which may be more comprehensive than the CMS violations list.

Once the community caregiver spouse has chosen a facility, encourage her to do short regular visits and to vary the time of day visited so that they still have a sense of knowing what care is being provided every day. The Tornatore and Grant research indicates that this type of reassurance is very helpful for the caregiver to adapt to turning over the hands-on care to the facility. Tell your client to personally get to know the caregivers, all of them. Have the community spouse put out photos of the couple as a young couple and as an older person with their extended family, to remind the facility caregivers that the institutionalized spouse was once young, active, and is now someone's grandparent or great-grandparent, just like the staff's family members. Encourage the community

spouse to be part of the plan of care meetings and to join in the family counsel. Explain the ombudsman system and help them get the ombudsman phone number before there is a problem. This way they know there is an official patient's rights advocate responsible for each facility and someone to appeal to about problems. Finally ,regularly remind the community spouse of the value of the caregiver who takes care of business to make sure the greatest amount of assets are available to supplement care or to create more time for the caregiver spouse to supervise care by freeing her from household or gardening work.

As you go forward with the Medicaid eligibility work, remember that an overwhelmed elderly caregiver spouse who controls the family assets needs to be surrounded by a circle of elder safe professionals who can counter any undue influences of others. Refer your clients to the "elder friendly" CPAs and to a few trustworthy investment advisors (who you have seen in operation over the years). Sometimes a caregiver also needs to be referred to support groups or to a psychologist who has experience with caregiver's and the depression that is normal for this type of placement. Provide the community spouse with a variety of trustworthy people to consult with so that she will feel comfortable talking to her safety net before acting on proposals made by the "savior" who has suggested ways to eliminate all her problems such as to invest in annuities that are not elderly friendly.

In retrospect, Ginny would have functioned much better if she had been directed (not just encouraged) to go to other nursing homes, compare them and chose one to care for her husband. Ginny did agree to limit the hours of her visits and stop her hands-on care after family insistence, after she had placed her husband in the marginally appropriate board and care. No doubt we would have still had a struggle to get the documents together

to do the necessary Medicaid work. Nevertheless, it is likely that Ginny would have focused better on her financial issues, if Ginny had connected better with a facility staff. If she had felt that she did not have to remain at a facility and be vigilant to get proper care for her husband, she would have been less exhausted and vulnerable to illness and more likely to fulfill her part of what was required to complete a Medicaid application. Ginny's family's satisfaction and ability to make the best of the situation would have improved