

THE NEED FOR LAWYER INVOLVEMENT

Published in the April 2002 Issue of *The NAELA News*

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Federal law provides:

"A nursing facility must provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care which..." 42 USCA § 1396r(b)(2).

Unfortunately for many dying persons and their families, technology for keeping people alive enables care givers to extend the dying process for months or years. Life support has gone beyond our ability to provide for mental and physical well-being. In many cases the highest practicable "well-being" is interpreted by the nursing home to mean to keep the resident physically alive even when that necessitates ignoring the other aspects of well-being.

Often, without any input from the family of an incapacitated resident, the care plan meetings are planned by the nursing home staff. Each member of the staff makes his presentation of what he or she thinks is best for the resident. Present at the meetings are usually the Care Plan Coordinator, the Director of Nursing (DON) or the nurse on duty, Activities Director, Social Services Director, Nutritionist/Dietary Manager, and others. The resident, if able to attend, and resident's family and/or agent, should also be at the meeting. A family member(s) of the resident is told about the meeting and asked to attend. Some nursing homes strongly encourage attendance.

However, my experience is that all the planning and discussions by the nursing home staff are made before the resident or family member is asked about the long term goals. See Exhibit "A" which is from a nursing home's Resident Handbook.

If the family knows what their options are before the meeting, they are better able to express their goals. After counseling my clients about financial arrangements for nursing home residency, I lead them into a discussion to help equip them to make wise decisions concerning life support. I will say something like: "Let's change the subject. Tell me about your husband. What is his condition?"

A common scenario is that the husband (or wife or mother or father or aunt or...) has Alzheimers (I use Alzheimers in this article for convenience, the illness or condition could be anything). "He is confused. He has gotten so bad he often does not know me. He doesn't know his children. He is incontinent. He just doesn't remember anything. We have had to do nearly everything for him for years. We just could not take care of him at home anymore."

I then say something to the effect of, "Have you ever been to a funeral or with family after a death, where comments are made, such as, 'It is a blessing he died.'?" A common reply, "Oh yes,"

and then frequently the client will relate a family incident where death was a blessing. I comment that with medical technology we can now keep people alive even though death is a blessing. A wife may comment, "I know my husband would not want to be kept alive. He has told me to never put him on any machines." My reply would be, "Your husband is slowly dying. Someday when your husband dies you will think or say, 'It is a blessing he died.' My definition of 'blessing' is 'a gift from God.' The opposite of being blessed is to be cursed. If death is a blessing then why do we want to keep your husband from dying?"

At that point, I have the family openly discussing, often for the first time, their feelings about the death of their relative. I engage the family in discussions about medical technology, etc.

There are many medical technologies that keep people alive. Prior to thirty years ago when someone could not eat, they died. Today we have a twenty minute medical procedure which results in a feeding tube. We have pace makers for the heart. If you were born before 1950 you probably remember that when someone broke a hip it was a death sentence. We knew they would stay in bed, get pneumonia, and die, usually within a few months. Today we send a person with a broken hip to the hospital, the doctors replace the hip bone, they go through therapy, and they are soon walking. This is great for people who can look forward to an enjoyable life. But if death would be a blessing, we may not have blessed them.

What is life support -

A hip operation?

Antibiotics?

A feeding tube?

Blood pressure medicine?

Insulin?

An operation to remove a cancerous colon or a blocked colon?

An operation to stop a stroke?

I usually tell the clients one to three stories in which my clients or others had allowed medical technology to be used keeping a family member from dying. The wife may comment: "He has a living will. He has told us...." "When he was better he talked about suicide. We had to get all the guns out of the house." I also tell the clients one to three stories in which medical technology could have been used to keep someone alive but instead they were allowed to die. By picturing others in these situations, it is easier for clients to picture themselves in the same scenario.

This leads up to helping the clients see themselves at the care plan meeting. The normal focus of the care plan meeting is: "How can we keep this person alive as long as possible?" I encourage the family to be in control. "Your husband/father is commander-in-chief of his body. You are his Five Star General, but you may need someone to represent the family's views." I tell the family, "When death is a blessing, you need to hire us to go to the care plan meeting with you. An attorney at the care plan meeting helps the family to express their decisions and enforce their decisions. We help the nursing home to understand the importance of the family's decisions."

At the care plan meeting, after the nursing home staff has gone through their presentations,

they will ask the family for comments and suggestions. When I am present, I compliment the staff on their plans. They really do have concern, and they do focus on trying to help the resident stay alive. I will then tell the staff that the family has concluded that it will be a blessing if the resident dies; that he would not want to be kept alive in his present condition; that death would be a blessing. I will usually then ask each staff member, "If you were in the condition of the resident would you want everything done to keep you from dying?" Often each of them say something like: "For me, I would rather die than be like he is." Finally, I refocus the meeting discussions to implement the family's decision to let their loved one die. I frequently say something such as, "Let's make sure decisions are made for him that he would want."

Every care plan meeting must result in a written plan.

After the nursing home staff is in agreement with the family that death is a blessing, we have several objectives:

1. Give the nursing home protection from state inspectors. If Hospice is appropriate, it provides the easiest solution. But there may be conflict because the nursing home is to provide most of the hands-on care which Hospice is also paid to provide. This needs to be resolved at the meeting. Document in the care plan meeting that weight loss and other declining symptoms are acceptable to the resident and the family. Written documentation protects the nursing home when it is signed by the resident's family.
2. Advise the physician, or have the nurse advise the physician, of the decisions. Get physician orders changed to stop life-extending prescriptions. No prescriptions should be continued, or started, which help the person live longer unless needed for long term comfort, unless the family agrees.
3. Be certain that the DNR (Do Not Resuscitate) order is known and will be followed. It needs to be charted and may require specific signatures.
4. Get prescriptions for pain relief as needed or alert the physician to order when needed. If the patient is on Hospice, pain relief will be supplied by Hospice.
5. Be sure the nursing home does not transport the resident to a hospital without a family member's approval. Hospice usually eliminates this problem. When someone is taken to a hospital, the hospital staff concludes that they must see that everything is done to get the patient better.
6. Write the care plan meeting notes to conform to the decisions. The nursing home care plan form usually does not fit the situation. Change the form. Write in the necessary directions.

See Exhibit "B" for an example of how I filled in the Plan of Care form provided by a nursing home. If the resident does not have a durable health care power of attorney, then we prepare and have all the immediate family sign a document which states the resident's wishes as known by them. They agree that nothing should be done to keep the resident alive. See Exhibit "C" for an example.

I have been accused by a long-term care insurance promoter of helping my clients take advantage of the Medicaid laws to pay for nursing home expenses. That is true. I help the spouses of nursing home residents to retain assets and income for their next ten, twenty or thirty years. I give them peace of mind. But, because of my counseling, millions of taxpayer dollars are not spent on paying for nursing home expenses or on Medicare paid health care treatments that are not wanted. Medicare is wonderful but not when it is used to keep someone from being blessed by death.

When "death is a blessing" be sure the client is in control and not kept "in hell" here on earth. Strong statement? Yes, but I believe we are morally obligated to help our clients make wise decisions concerning the use of medical technology.

Why the attorney at the care plan meeting? Because we can speak objectively for our clients. The nursing home feels secure in following the instructions. The attorney fees paid to me are a great investment by the client. Our fees are usually equivalent to one week of care in a nursing home. The clients are saving weeks, months, and sometimes years of emotional concern. The state and federal government saves tens of thousands, even hundreds of thousands of dollars not paying for additional nursing home care and expensive medical care that is really not wanted.

How to get paid: During a planning session about either financial or health care decisions, I will discuss the Care Plan Meeting. I tell the clients they need to have me go with them to the Care Plan Meeting, and I tell them what my fee will be. It is usually the equivalent of two (2) or three (3) hours, but never quoted as an hourly fee. If the nursing home is not within 15 minutes of my office, then my fee will be more to cover my travel time.

Conclusion: The benefits to the family and their loved one are worth much more than the investment in attorney fees.

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