

Choosing an American Nursing Home for Families Touched by Huntington's Disease

By Francis J. Gilooley, Jr.

Supervising Service Consultant of the Advisory Coalition to the Regulatory Board of Overseers, *ex officio*

Preface:

I am grateful for my experience in American nursing homes to my late aunt, Dorothy "Dolly" Guilfoyle, who owned and ran The Dineen Home in Lower Mills for many years before her untimely passing. I'm grateful for this opportunity to share these contemplations with you and I do pray that you may find one or two of them to be helpful.

-Frannie Gilooley

By way of introduction...

Placing a husband, wife, son, daughter, mother, father, brother or sister in a nursing home is a most difficult task. It's made even more difficult when he is relatively young. And it's still even more difficult when he has Huntington's Disease. Together the family has ruefully anticipated the day it may have to do it. A friend once called it "breaking the hardest promise of my life" when he placed the love of his life in a nursing home. Does he regret it? "Every day." Was it the best thing to do? "Without a doubt." Hopefully, these tips and personal reflections will be helpful if you face the same challenge. Remember, for all the problems families have locating nursing homes to care for their family member, most across the United States are satisfied with the care that their nursing homes provide for them.

Preparing: You Can't Start Too Early

- Ask your doctor which are the better nursing homes in your area. Doctors are often overlooked as sources of information about nursing homes. If they are general practitioners or have a family practice, most physicians have caseloads in one or more local nursing homes. With the exception of the resident, no other person is in a better position to judge the quality of care in a nursing home. Have your close friends and relatives ask their own doctors for their evaluations, too. You might ask your local pharmacist too.
- If possible visit a friend, neighbor or relative in any nursing home. This is simply to get "the lay of the land." Or go with a friend, neighbor or relative when they visit a nursing home resident. If you don't know someone who lives in a nursing home, ask the folks at your church, fraternal, or ethnic group if they know of someone who might enjoy a visit from you. Even though you anticipate reluctantly having to place your family member in a nursing home, you may be surprised that this is a very positive experience.
- Keep an open mind about nursing homes. Unfortunately, today in the United States nursing homes still labor under a negative stereotype. Many families believe that they have failed if they cannot care for their parents, children, spouses and siblings at home. However, most families of nursing home residents are satisfied with the care that they receive. Many, many families touched by HD are pleased with their nursing homes. A nursing home plays a vital role in its community. It's an employer or both professional

and paraprofessional staff. It has links to hospitals, churches other businesses and many, many families in the community. Although there's no place like home, people live rewarding lives and have rewarding careers in them. The residents who live there require a level of care that most families are unable to provide for them, especially in the more advanced stages of HD. For all the problems that nursing homes face, you may be pleasantly surprised!

- Trust your own wisdom and judgment. Even thinking about placing a family member can be a daunting, fearful and overwhelming task. Most people who do it will do it for the first and only time in their life. As you go through this whole process many folks you trust will give you their opinions on one aspect or another. In the end though, many people find that they have to set aside much of the information that they have gathered and simply trust their instincts.

Preparing: Knowing When

People who care for their person with HD at home wonder, worry and pray that they will know "when it's time" to give the care for their family member over to a nursing home. That is, that point in time when they can be sure that they've made every effort to provide care in their home and that, everyone and all things considered, these many complex nursing needs can be better met by round-the-clock professional caregivers. However, another difficult aspect of this process is that there is no sure-fire way to tell "when it's time."

There are as many different stories of how families came to know that "it was time" as there are people with HD in nursing homes! Many times unforeseen events make it the right time. It might be a change in your health, a rapid change in his condition, the unexpected departure of someone who was helping you, the physical demands this type of care puts on you, sheer exhaustion, children in the home or some other reason beyond your control. For all the sleepless nights wondering "when," the time may come suddenly and unexpectedly. Hopefully, this may make your decision an easier one and assure you that it was the right time to do it.

HD has many aspects and any one of them may signal "when." There are the physical changes that impair walking, eating, swallowing and speaking. Changes in mood may bring depression and problems with sleep, appetite and energy. And, in some cases, the changes in thinking may present behavior that you cannot manage or tolerate in your home. These events, often unanticipated, can range from a choking episode to significant weight loss, from falling down a flight of stairs to outbursts or rage; from cigarette burns to frightening the children. It's impossible to accurately predict the hastening circumstances.

Some folks with HD need hospitalization to treat psychiatric or behavioral problems. This may hasten your decision to seek long-term professional care for him but shorten the amount of time you have to find it.

Touring: What To Look For

Cleanliness is always important! Is there a shine on the floor of residents' rooms? "How are the corners?" Is there a wax build-up? Is there a lingering musty odor or, Heaven forbid, an odor of urine? Please do remember that, just as in your home, transient odors are expected when residents move their bowels.

Dignity is more important! Does staff knock on residents' doors when they enter the room? Can you see a resident in various states of undress as you walk the hallway?

Ask about Air Conditioning. You don't want to be in a nursing home without air conditioning in most states, provinces or counties in July and August.

Activities Calendar. Monthly activities calendars are prominently posted in homes. As you take the tour look to see if the activity scheduled for that day at that time is actually in progress. If you don't see it, then ask about it.

Avoiding Common Mistakes

Don't refer HD to the nursing home! Remember that you're referring this person to a nursing home; you're not teaching HD 101. When you meet with the nursing home staff typically people begin by saying, "I'm interested in placing my husband with HD in your home. Are your staff familiar with Huntington's?"

"No, I don't believe so. Tell me about it," says the social worker or admissions coordinator.

"Well, it's a progressive, neurologic disorder. Each of my children..."

Twenty minutes later the introduction to HD is over, the social worker knows all about it and may ask, "Now, tell me about your husband."

Since families are often more expert in HD, it's common for them to have to educate healthcare professionals. But a large amount of information in this setting may serve to unintentionally exaggerate the complexity of the care that he needs and discourage the home from admitting him. Remember, most typical nursing homes can meet the needs of most folks with HD. Give them a chance by introducing them to your husband. There's plenty more to say about this wonderful guy than this godawful disease! We're not suggesting that you downplay or sugarcoat Huntington's; rather, we're suggesting that you spend more time talking about him than his diagnosis.

Don't make surprise visits! Some healthcare professionals and published guides to selecting nursing homes suggest that families make off-hours surprise visits to nursing homes. We suspect that they suspect that, if the home doesn't know you're coming, then they can't conceal "what really goes on!" We suspect that they suspect that when you tour a nursing home, staff are giving you a show! What a terrible way to begin a partnership! What are they thinking you'll find?

Every day many, many people "visit" nursing homes off-hours and unannounced. They are families who visit throughout the day and evening; doctors checking on patients; ambulance and van drivers transporting residents to hospitals and appointments; laboratory and mobile x-ray technicians, delivery staff from pharmacies, volunteers, letter carriers and suppliers of all sorts. They do their work in each and every area of the home. You will find nothing different than the scores of people who pass through the home 24 hours of each and every day.

The residents and staff of the home are not unlike you. Most people prefer to be prepared when they meet someone for the first time. Naturally, they want to put their best

foot forward. They want to make sure that you are greeted by the proper person and given accurate information. Suggesting "surprise" visits is bad advice. Caring for your family member is a partnership between the family and the nursing home. It's best not to begin by basing it on mistrust and suspicion. It's certainly not adversarial in nature.

Call Lights! Call lights are required to be within reach of every resident for them to ring for immediate assistance. If the light is flashing outside a room it means the resident is waiting for assistance. If you don't see a staff member responding, you might want to stop walking beneath the flashing light and say to your tour host, "Let's wait until the poor soul gets some help. Bejeezus, what if she's bleeding to death in there?" You pretty much can bet that if they don't jump then that there won't be a lot of running to answer the light on the 11-7 shift...and if they still don't answer, turn to your guide and say, "God have mercy that the woman's last mortal act wasn't pressing that light for help. Let us pray. Together."

Don't study too much! Many states put out brochures with questions to ask about the home. They include staff ratios and many other things. By the time you get through with them you feel like you need a doctoral degree or an army of friends and acquaintances to assist you. Just make your visit and trust your instincts. Tour the home and simply ask yourself, "Do I believe that this home can adequately and safely care for my loved one?"

Be Reasonable In Your Expectations

It's unreasonable to expect any nursing home to provide perfect care. In fact, it's unreasonable to expect them to match anything near your tender loving care provided in your own home. It is very reasonable, though to expect very good care consistently provided.

It's unreasonable to expect absolutely no odors. It is reasonable to encounter an occasional passing bathroom odor just as you would in your own home. Certainly there should be no tolerance for lingering odors, especially urine.

Your expectations may be unreasonable if you find yourself saying, "They should understand HD." However, given the chance to learn about HD in a reasonable amount of time, the staff should gain expertise in the care of their resident with HD.

It may be unreasonable to expect the home to have special equipment as soon as the person arrives. However, it's very reasonable to expect that they will provide it in a short period of time. You get the drift.

Banking Goodwill: Family Council

Federal regulations require nursing homes to sponsor a "Family Council" of the residents' family members. It meets quarterly or monthly with the home's professional staff to discuss issues and common concerns. Frequently, there will be a guest speaker from another agency in your community. Despite a home's best efforts to have a vital active Family Council, meetings are often sparsely attended. Fortunately, most homes can count on a few faithful family members to consistently attend and participate in the meeting. Make every effort to participate in Family Council. Strong partnerships can be informally forged between you and the professional staff as you discuss his care over a cup of coffee after the meeting...especially if you're among the few in attendance.

Communicate with Management

Comment on the quality of care to senior management on every visit. The two senior managers in a nursing home are the Administrator and the Director of Nursing. They are directly responsible to the ownership of the home for its operation and quality of its care. They are accountable to state agencies for compliance with all regulations. They both care a great deal about their home, the care that it provides and your satisfaction. Give them some feedback every time you visit. They are never too busy to hear from a family about their satisfaction.

Here's how to do it so that you don't have to be intrusive or interrupt them. If there's a secretary or receptionist positioned outside the administrator's office, stop and wait for attention. Ask them directly, "Would you kindly pass on a message to the administrator? I'm Mrs. Beauregard. I was just in to see my husband Ed. I wanted him to know that everything was fine and I'm pleased with his care. Thanks! He'll get the message, right? Thank you." Do this each and every time you're in to visit. Jotting it on a scrap of paper and leaving it, dated and with staff names you want to single out for praise is even better.

Visit as Often As You Can

Remember that nothing can substitute for family. Perhaps nothing conveys to the staff whom the person in their care really is more effectively than meeting and seeing him with his family. Knowing that someone who cares about him enough to visit, that someone cares about how he looks, that someone is concerned about his care and that they're grateful to his professional caregivers are often motivating factors to nursing home staff. It certainly gives the resident and his caregivers something to look forward to and then to discuss at length. As many people look ahead to having HD in their lives they say they fear being abandoned by their families. Is there a more concrete way to reassure them than visiting as often as you can?

Visit as Soon as You Can

Moving to a nursing home is a difficult event for the entire family, especially when it's a relatively young person doing it. What better time to stick together than during those first few hours and days? Remember, unless he was in the military or a hospital, this very well could be the first night of his life that he shares a bedroom with a stranger. There is a myth that families should refrain from visiting for an initial period after admission, for example, for the first thirty days. Please know that there is no published clinical evidence that nursing home residents adjust any easier or more quickly to their new home when their family waits a period of time to begin visiting them.

Visit Routinely

Many caregivers find that folks with HD do very well with a predictable routine in their lives. They do as well in nursing homes when they can establish a new or similar routine. It's so difficult for them to organize information that having a regular interval and a consistent day of the week makes it easier to anticipate your visit. Whether it's once a month, once a week or once a year, it gives your resident predictability, something to look ahead to. But remember, never break a promise; be sure to visit when you say you will.