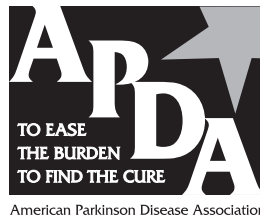


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THE CHALLENGE OF PARKINSON'S DISEASE: ADAPTING TO A NURSING HOME

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Even in the best of circumstances, residing in a nursing home can bring overwhelming challenges, and when you add a chronic progressive neurological disease, such as Parkinson's disease (PD), the challenges add up and may seem insurmountable. The word "challenge" can be defined as: to take a stand against or to confront boldly and courageously. The challenges that come with being a resident with PD in a nursing home are surmountable when appropriately confronted. To accomplish this, one must be educated about the issues, willing to educate others, take a stand when needed, and be patient, creative and adaptable. One must also be willing to look at the changing family roles and at the issues that come to the forefront when adapting to these changes. The number of people living to an older age continues to increase: 43% of Americans age 65 or older will spend some time in a long term facility and 50% of the stays in a long term facility will average 2.6 years. Even if you don't end up needing nursing home care, it is likely you will be involved with someone who does. Nursing homes are staffed with a minimal number of professional people and many of the staff members may not have experience with chronic diseases. The nursing assistants are often transient individuals within the nursing home industry, and even with training be-

ing done by the nursing home administration, it is an uphill battle to provide skilled care. Those in administration have dealt with the problem by making nursing homes more institutional: a classic example is medications given only at set times.

Individualized Care: How important is individualized care to the person with PD? Parkinson's disease manifests itself differently among those affected. The goal in its treatment is: decrease symptoms, increase mobility and improve quality of living. The uniqueness of the symptoms of the disease in each person leads to the need for care tailored to that person. Fine tuning can take a while and be challenging and/or frustrating to all involved. A former APDA I & R Center Coordinator, Glenda Whitsett, gave the following scenario: Bob has PD and is a nursing home resident. He has an order for Sinemet 25/100 T.I.D. (T. I. D. means three times a day, dividing the patient's waking hours). Bob gets his medications at 7 a.m. (with breakfast), 2 p.m. and 9 p.m. Bob wakes up stiff and rigid and is unable to feed himself. The aide cheerfully places a bib on Bob and feeds him. He feels humiliated, but is unable to express himself clearly because his speech is also affected by PD. Bob pushes the food away after only a few bites and motions the

aide out of the room. Confused and offended by his seemingly rude behavior, the aide leaves the room. A few minutes later, the nurse comes and gives Bob his medication. Since his breakfast is over, it is time to bathe and change linens. The medication is taking a while to “kick in,” especially on top of a fat and protein laden meal of bacon and eggs. Bob is still stiff and cannot get out of bed to shower, so he is given a sponge bath. He is cross and barely cooperative. After his bath, it takes two aides on either side of him to safely move Bob into a chair next to his bed. By now, Bob is beginning to loosen up and can dress himself with assistance. Within another 30 minutes, he can walk down the hall. Physically, he is now able to interact with others and participate in activities, but emotionally Bob is angry, frustrated and depressed, so he chooses to isolate himself. By noon his medication is wearing off.

In an effort to maintain some dignity, he insists on feeding himself lunch, but because of the tremor and rigidity, he manages little more than a few bites. By 2 p.m. he is once again very stiff and rigid. His speech is also impaired again so he avoids talking to others. He sits alone in his room and waits for his Sinemet. The evening meal is easier since he has had Sinemet on board for about three hours. By 7 p.m. though, it is wearing off, movements are quite difficult, speech is barely audible. Once again he goes to his room alone. At 8 p.m., it is time to get ready for bed, but Bob’s tremor and stiffness make it impossible to unbutton his shirt, wash his face, or even brush his teeth without assistance. It is 9 p.m. and his last dose of Sinemet comes and he goes to bed. However, his sleep is fitful (a common side effect of Sinemet). Restraints are used to prevent him from falling from his bed due to his thrashing. Bob is tired and depressed.

What would happen with a few changes? At 6 a.m. the nurse brings Bob his morning dose of Sinemet. By 7 a.m. when breakfast arrives, he is able to move well enough to feed himself without assistance. At 8 a.m., he gets out of bed, and walks down the hall to shower. He is slow and asks for help with the buttons, but otherwise functions on his own. It is much easier to change the linens and tidy up with Bob out of the bed. By 9 a.m., he is feeling well enough to join others in the recreation room for stretching exercises. Afterwards, he plays cards for a while. At 11 a.m., his symptoms are creeping back. The nurse brings

him his Sinemet. By noon, when lunch is served, his tremor and rigidity are fairly well controlled so he eats lunch in the dining room. It takes a good 30 to 45 minutes, but he finishes his meal without assistance. In the afternoon, Bob takes a slow stroll in the courtyard, enjoying the fresh air and sunshine. He might play cards or join others in an organized activity. By 5 p.m. his Sinemet is wearing off again, and the nurse brings his medication. When dinner is served at 8 p.m., he can eat without assistance. In the evening, he enjoys the company of visitors or others in the nursing home. At 9 p.m., he is fatigued and moving slower. Since the main reason for taking Sinemet is to help him move, he doesn’t really need to take it before going to bed. He sleeps better without it anyway, no more nightmares and thrashing about. Occasionally, he may need to urinate in the middle of the night, in which case he has to use a nearby urinal or ask for assistance.

Overall, his quality of life has greatly improved and he needs much less assistance from the nursing staff. The employees of the nursing home are required to take care of patients with a variety of acute, chronic and often complicated illnesses. Unless they know someone with PD, they may not know anything about the disease or the patient’s needs. The employees are concerned with accomplishing their assigned tasks and are usually kept on the run.

Often, the Parkinson’s patient is thought to be malingering or just trying to get his own way. The family can take an active role and help the employees become knowledgeable about Parkinson’s.

The Ability To Partner With The Nursing Home Staff: The ability of the nurses in charge to think critically can benefit to the PD patient. Critical thinking is the ability to look at a situation and be able to come up with options, evaluate them and understand why something is occurring. A nurse with this ability strives to find a solution that is a win/win for all involved and results into a better quality of life for the patient. The ability of problem solving should be a desired quality of the charge nurse. This quality gives the patient and family an increased chance of partnering with nursing home employees to provide the care that encourages a loved one to function at the highest level possible of his or her capabilities.

The Nursing Home Decision: The decision to enter a nursing home facility is usually made after all parties have agreed that care in the home is no longer manageable or safe. Making the decision is often heart wrenching, a difficult process in the best of circumstances and even more difficult when made during a crisis. Our society puts emphasis on taking care of people in their own home. However, caregiving can be exhausting and difficult. Many times when a family member is placed in a nursing home a sense of failure is felt or projected upon the caregiver. Recognizing when one is physically and emotionally spent, and then taking steps to remedy the situation is healthy for all involved.

Where do you start? Begin by assessing your support system. For example, what is your relationship with others in the family? If there has not been a close relationship for years, you can probably assume that there won't be much help or support. On the other hand, if there has been positive relationships that have remained close, include them in the decision making process. Do you have close friends? Are you involved with a church? Seek their input. Ask your physician for advice regarding the situation. Make a list of the people in your support system and a list of suggested nursing homes. What location is most convenient for them to make frequent visits?

Next, you'll need to make a decision about the level of care your loved one need, and your physician can definitely help you with it:

- **Custodial care** - is suitable for a person who does not need the care of a practical nurse but needs help with meals, personal hygiene and getting dressed.
- **Intermediate care** - is suitable for a person who does not require 24-hour nursing and is not able to live alone.
- **Skilled care** - is for a person who needs intensive 24-hour supervision by a registered nurse.

Now you are ready to make an assessment of the financial situation. Does the individual have any financial assets to pay for his / her care? Is there any long-term care insurance? Can the family contribute any financial help? Is there any provision with the medical insurance for care in a nursing home and if

so, what does the insurance require for the patient to qualify for this assistance? How do you choose? Visit each of the homes being considered. Make sure you have a list of questions you want to ask. Plan on a scheduled and an unscheduled visit. There shouldn't be any difference. If the unscheduled visit is first, do they offer to give you a tour? Before the final decision is made, drive by the home in the evening and on a weekend. If possible, make a visit during one of these times. Check out the lighting outside. Is there a security system? Is there any difference seen in the care provided during these times and that of during the day? You will also want to eat a meal at the facility to evaluate food quality. Also think about the loved one's personality and lifestyle. Where will they be happiest and have their needs met? What quality of life does the person have and what environment would encourage the highest quality possible for this person? Take a friend or pastor along on these visits if possible. Having an objective perspective can help make the decision clearer.

Changing Roles: Prior to nursing home admission the patient and family have most likely already dealt with some changing roles, for example, the patient now being dependent on the caregiver for assistance. A spouse or child may be providing financially where previously the Parkinson's patient has been the provider. The degree of adaption to these changing roles affects the transition to nursing home placement.

Good communication and cooperation of all parties involved will go a long way to encourage the highest quality of life possible for the situation. How the individual or family faces the challenge of nursing home placement depends on how healthy the relationships are prior to the move. Also, one must realize that dealing with a chronic illness such as PD stresses family relationships. This can overshadow the initial transition.

Another important fact to remember is that the first couple of weeks in a nursing home can be overwhelming for all involved. At home the resident lives with a spouse or other family members. In the nursing home they are suddenly in the midst of a large number of unfamiliar people. The employees assigned to the resident will also be responsible for a number of other patients, whereas at home, the caregiver was available much quicker.

One must remember that each person involved is unique and each person will exhibit his/her own individual coping style. How a person previously adapted and accepted change plays a large role in how he / she reacts to nursing home placement. Feelings such as denial, anger, resentment, guilt and depression are normal in such transitions. Acceptance and adaptation to nursing home placement is important for optimum functioning and quality of life providing there is proper support for the nursing home resident.

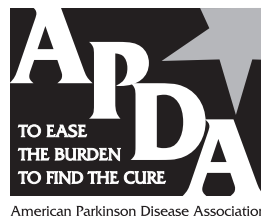
Adequate Care: How do you know if a loved one is receiving adequate care? Even when you made careful assessments of needs and evaluated the options available you may find yourself uncomfortable with the results. First, remember that a lot of emotional energy will be spent during this transition. Initially, be careful making a judgment that may be emotionally based. Ask the following questions:

1. How is the individual functioning compared to prior to nursing home admission?
2. Is the resident clean and dry?
3. Is the individual being encouraged to be as active as possible?
4. Is your loved one receiving individualized care that is fostering mobility, functioning and dignity?

The caregiver or family is encouraged to maintain an active role in the resident's life. Make frequent visits at varying times to the nursing home. Upon admission you should receive a copy of "Resident's Rights". Know these! When a question or problem arises, confront the issues at the beginning. Small problems allowed to fester become volcanoes just waiting to erupt. When confronting an issue follow the chain of command in the facility and the grievance policy they have in place. After trying all these avenues, if you still are not satisfied contact your "Area Agency on Aging" and ask for consultation with an ombudsman. Sometimes, having an objective outside person involved can have a profound effect on solving a problem. Remember when confronting a problem, no one likes or wants to be attacked. Approach the subject with the fact and the determination to work together to solve the problem.

Conclusion: Moving someone into a nursing home is never easy. Do your homework, educate yourself, and plan ahead. These steps will provide a smooth transition when the time arrives. Living in a nursing home can be a challenge. When families, caregivers, patients, and nursing home employees confront and understand the issues involved with PD and work as a team to coordinate the care of individual PD patients, the move is successful. Parkinson's patients are courageous and able to face the challenge of long term care.

The information contained in this supplement is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's own physician.



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