

The Peter Rabins Alzheimer's Family Support Center

funded by the Jane Shapiro Family Education Program
at the Johns Hopkins Memory and Alzheimer's Treatment Center
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TIPS FOR FAMILY CAREGIVERS

The Nursing Home Decision

Video Script - to view video go to www.hopkinsmedicine.org/rabins_alzheimers

Rabins: Family members often ask “What’s the trigger for placing someone in a nursing home?”. In fact, there is not one. It varies a great deal from person to person and family to family. My experience is that families usually wait too long to put someone in a nursing home, that it would have been better for the person to have gone in sooner. But that too varies a great deal.

Caregiver: My children came home at Christmas time and, see, they weren’t with him. They saw him, but they did not live with him anymore. Judy said “Mother, you’ve got to put him in a nursing home”. She said, “We lost Daddy and we don’t want to lose you.”

► The Most Frequent Reasons for Nursing Home Placement

Rabins: Nursing home placement is often the result of an accumulation of a number of different things that happen. But the development of a physical impairment, of physical needs that the caregiver can no longer meet, becomes a common trigger for the family to finally decide that it’s really best for the person to be in long-term care.

Caregiver: Physically, it took two people to handle him. And I wasn’t strong enough to be the one person. I mean, if I kept him home, it would have been somebody around the clock and me. It just wouldn’t make sense because we wouldn’t give him the care that he could get in a good nursing home.

Rabins: For both of you that was the right decision.

Caregiver: Oh, yes.

Rabins: Family members shouldn’t feel that they have to make this decision on their own. They can talk with their physician, their priest, minister, or social worker. There are a lot of agencies that can help people think through this issue. Feeling that you’re facing it all alone puts more of a burden on you as a caregiver and more of a burden on the family than there needs to be.

Caregiver: I was relying on people at day care also to keep me clear. I thought I was too close to the situation to be able to make that decision. And I was in touch with her caregivers at the daycare center to try to keep me informed about when they thought our current situation, living situation with her going to day care wasn’t working out anymore. I was getting to a breaking point there. But also relying on other people to tell me that I had enough, that I had done enough.

► The Advantages of Nursing Home Care

Rabins: One of the surprises that many families find is that the ill person may do a little bit better when they go into a nursing home or other long-term care facility. I think one of the reasons that happens is because the person is able to get the physical care that they need from the staff. The family members are then able to provide the loving care, the interaction that they have not been able to do because of the overwhelming physical nature of the care they were providing at home.

Caregiver: I didn’t have to cut fingernails. I didn’t have to shave. I didn’t have to brush teeth. I didn’t have to get him dressed.

Rabins: So things got better after?

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Caregiver: Yes. He's still the most important person in my life. I see him every day and I know that he misses me when I am not there. This is the dearest man who ever lived, I love him so much.

► The Benefits of Daycare

Rabins: Daycare is one of the resources that can help families delay long-term care placement. I often recommend daycare earlier in the course of the disease than many families might think that they need it, but it gives families a break from the day-to-day, 24-hour care that the person needs and that they become overwhelmed by.

Caregiver: Daycare was also a tremendous help. And that took a lot of convincing. My father thought she'd hate it, and he didn't want to put her in daycare, and really resisted. And the group kept saying, this poor group kept suggesting, you know, "You got to try it. You got to try it." And he said, "No, no, no, no." And finally-- after about a year of real prodding, he decided reluctantly he'd allow her to go two days a week. And within two or three weeks, he had her signed up for five days a week.

► When Nursing Home Care is Necessary

Rabins: Most families and most people would rather never go into a nursing home. I see my job as a professional and helping people stay home as long as possible. On the other hand when the care becomes overwhelming for the family or the caregivers, it's often in the ill per-

son's best interest to move into a long-term care facility, and I see it as part of my job, and I think it's the job of the professional to help families see that sometimes it really is the right thing to do for the ill person. It's not a failure on the family's part. It's the disease that's necessitated somebody moving to a higher level of care.

Caregiver: I hope that we are able to keep my mother at home for the duration of the illness. That is something I would like to do, if that will be possible, only time will tell.

Rabins: Do you think it would be a failure if it came to that?

Caregiver: No. No. I mean I'm realistic where if I see my father's health declining and my own health declining at that point then we would have to make that decision. But when it comes to a physical need that's not being met, for either my father or my mother, then I know that it's time to step in.

Rabins: The majority of people who advance in Alzheimer's disease to a later stage condition require nursing home placement. That's disappointing to many families and to many patients, but the positive is that it allows the love, the care and the relationship actually to blossom more because the physical care that the family was providing is no longer the focus of care.

Caregiver: I mean this was my best friend, my lover, my husband; the man who could solve any problem, who knew everything. I didn't need an encyclopedia if John was around. This man was so much of my life. And he still is.