

When the Person With Dementia Rejects the Care

Families often think their family member who has dementia would never go to day care or accept a home visitor. People who have dementia often surprise everyone by enjoying the day care or a home visitor. Avoid asking the person if she would like to go to day care. She is likely to answer "No," because she does not understand what you are suggesting. Some people continue to say they don't want to go even when they are clearly enjoying themselves. This usually means that they do not understand or do not remember their enjoyment. Continue to take the person to day care cheerfully.

When a family is able to arrange for someone to stay at home with the person, the person who has dementia may fire the sitter or housekeeper, may get angry or suspicious, may insult her, may refuse to let her in, or may accuse her of stealing. People who have dementia may refuse to go to day care or put up such a fuss getting ready that the caregiver gives up.

To the person who has dementia, the new person in the house may seem like an intruder. The person entering day care may feel lost or abandoned. What she/he says may reflect those feelings more than fact.

Be prepared for a period of adjustment. People with dementia adjust to change slowly: it may take a month for such a person to accept a new program. When you are already exhausted, arguments over respite care may seem overwhelming. You may feel guilty about forcing your relative to do this so that you can get a break. Make a commitment to yourself to give the program a good trial. Often the person who has dementia will accept the new plan if you can weather the initial storm.

What you say will make a difference. Refer to the respite plan as an adult activity

the person will like. Present the home care provider as a friend who has come to visit. Find things the person with dementia likes to do that the two can do together: take a walk, groom the dog, play a game of checkers (even if not by the rules), or make brownies. Call day care anything the person will accept, for example, "the club." Often people with mild impairment prefer to "volunteer" at center. Most day care programs will support this. "Helping" people who are more impaired allows the person to feel more successful while reducing the pressure on her/him to perform.

Write the person who has dementia a note – explain why she/he is there (or why the day care home provider is there), when you will return, and that she is to stay and wait for you. Sign the note and give it to her or to the provider. If this does not work, have your doctor write and sign such a note. The provider can read it to her each time she becomes restless.

Some families make a short videotape of the care of the person. This is particularly helpful when the provider will be assisting in personal care such as dressing or eating. You can show the order in which you do things, like which arm goes into its sleeve first. You might leave written instructions as well.

(From The 36—Hour Day by Nancy L. Mace, MA, and Peter V. Rabins, MD, MPH)