

# What I Want If I Get Alzheimer's Disease

**D**EAR FRANCES: Since I treat a lot of patients with Alzheimer's disease, I've had a chance to see what's wrong with our system of health care (if you can even call it a system).

The problem is too much emphasis on the extremes: the caregiver either going it alone at home or finally resorting to a nursing home after getting worn out. Now there is a middle ground, and I want you to know about it just in case I have bad luck and get Alzheimer's disease myself.

The middle ground is an adult day center and that's where I want to go. Enroll me for 2 or 3 days a week so that I can have some fun while you play tennis and go shopping. (Yes, fun. It's a bad disease, but life doesn't have to end with a diagnosis.) If I want to think of it as going to school or to work, humor me.

Don't try to take care of me full-time on your own. You'll wear out quicker and I couldn't afford for you to run out of gas, because I don't want a nursing home unless I'm bedridden or a total nuisance or if you're not around and the only alternative would be to stick one of our children with me. Nursing homes aren't so bad, but they don't lend themselves to eating snacks while watching a golf tournament on television.

Our current system is poorly designed to help you do what I'm asking. Because it's so heavily weighted toward nursing homes, it's the exact opposite of the way it

should be. Nationally, we have close to 2 million nursing home beds but less than 100 000 places in adult day centers, and I think that the numbers should be reversed.

Here's why I want to go to an adult day center instead of a nursing home (I never could resist making a list):

1. It's cheaper. Nursing homes can easily run up to \$100 a day and day centers are usually less than half of that. Nursing homes are 7 days a week, while day centers are only the number of days you want. You'd have enough money left over to hire someone to come in and keep an eye on me on the days I'm not enrolled in the center.

2. You won't have to wait until you're desperate to put me there. Enroll me while I'm still relatively okay, and I might be able to keep going there for years.

3. It's more like a normal life. You go in the morning and come home at the end of the day.

4. You—not some physician—will have control over what happens to me. I don't want tubes and machines, so if I get pneumonia you can just give me chicken soup and aspirin.

Whether or not you will have an adult day center in which to enroll me depends on which direction we take over the rest of this decade: more nursing homes or more day centers. At least we're off to a good start. The National Institute of Adult Daycare had 20 members in 1969; now there are over 3000, but we need around 10 000 centers to have a real

impact on the "system." (Let me know if you want me to explain how I came up with 10 000. The calculations are sound, they just tend to put people to sleep.)

There have been some wonderful success stories showing that people want the services enough that they're willing to pay for them. The St Elizabeth Adult Day-care Center in St Louis, Mo, and the Parker Jewish Geriatric Institute's center in New Hyde Park, NY, have done so well financially that they've used the surplus revenues to expand.

Some centers have become famous for their programs, like one in Logan, Utah, that relies totally on music therapy and that made the front page of the *New York Times*. I hope more people get a chance to see their participants put on one of their performances, including a woman who has little language ability left but has the nicest smile when she plays her violin.

Unfortunately, a lot of centers are struggling to break even, and the big problem there is awareness. People don't realize how good they are.

Child day centers went through three stages to get to where they are today. At first mothers were looked down on for using them, then the centers were okay for working mothers who didn't have a relative handy, and now they're well accepted as good for the child even if the mother is at home. With adult day centers, the United States is somewhere between stages 1 and 2 (just substitute "families" for "mothers"),

but with older people being the fastest growing segment of the population, we need to get to the well-accepted stage quickly or go broke paying for nursing homes.

Two pieces that appeared by coincidence the same day in our local newspaper explain why I think everyone should know about adult day centers. The first was an article about a tragedy in Pittsburgh, Pa, in which a man who felt he was alone in caring for his wife with Alzheimer's disease shot her and then killed himself. The second was a short letter to the editor by a thankful husband whose wife was enrolled in an adult day center, and he described how much it meant to both of them. A day center can't transform total despair into contentment,

but I can't help wondering whether the first man had access to one.

If you think I need a day center, please enroll me. If I object, look at it the same way you did when you left Jason and Dana at child day care the first time. Like them, I might make a fuss, but by the time you're playing your first set of tennis, I'll be too busy to notice you're gone. At night I can have some pasta while watching a tape of an old golf tournament I've seen a hundred times before and still be in suspense at the outcome. What nursing home can match that?

Love,  
Burton

PS. It's easy to find the nearest adult day center. You can call

our local senior citizen center, the local area agency on aging, the state Department of Aging Services, or the National Institute on Adult Daycare in Washington, DC, at (202) 479-1200.

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