

The following is a letter written by Dr. Burton V. Reifer to his wife, Frances, about his wishes should he ever get Alzheimer's disease. Dr. Reifer is Director of Partners in Care-giving, the Dementia Services Program.

What I Want If I Get Alzheimer's Disease

Dear 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 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'd want to go. Enroll me for two or three days a week so I can have some fun while you play tennis and going 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 and 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, 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 I watch a golf tournament on TV.

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. I think 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 over \$120 a day and day centers are usually less than half of that. And nursing homes are seven 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 keep an eye on me on the days I'm not at the center.
2. You won't have to wait until you're desperate to put me there. Enroll me while I'm still relatively OK and I might be able to keep going there for years.
3. It's more like a normal life. I'd go in the morning and come home at the end of the day.
4. You—not some doctor- 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 to enroll me in depends on the 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 organization of day centers had 20 members in 1969; now there are over 3,000. 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. An adult day center in St. Louis and another in New York have done so well financially that they've used surplus revenue to expand.

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

Unfortunately, lots of centers are struggling to break even, and the big problem there is awareness. People don't realize how good they are, or how important they are for the person with Alzheimer's and the caregiver.

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 they were OK for working mothers who didn't have a relative handy. Now they're accepted as good for the child even if the mother is home.

Adult day centers are somewhere between stages one and two (just substitute "families" for "mothers"). But with older people 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 which 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, where 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 short letter to the editor by a thankful husband whose wife enrolled in an adult day center. 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 a child care for the first time. Leave me! 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. And 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?