

Re-able Us to Use All Our Abilities

Richard Taylor, PhD

RICHARD TAYLOR, PhD, is a retired psychologist who lives with and writes about Alzheimer's disease (AD). Richard has agreed to maintain frequent E-mail contact with *ALC* to provide us with a diary of his impressions, struggles, and conquests. Richard Taylor's reflections on AD follow.

May 30, 2007

Note to Self May 21st Respite Care

Who actually cares about Respite Care...

People who attend it care the Most And are Generally consulted the Least

Three cheers for everyone who works hard in their countries, states, and communities for funding of respite care! It provides a necessary and useful pause for caregivers.

Now, what about the person who uses the service? What about the quality of the service? Is the person who uses the service—the actual customer of the service—involved in the evaluation of the service? Does the representative of the people (the government official who signs the check) evaluate the service? Licensing organizations most often ensure that everyone who works there has passed a test, gone to school, or sat through some in-service. In no way does it ensure the quality of the service, the usefulness of the service, or the enjoyment of the service.

Unfortunately, the need for these services far surpasses their availability. The marketplace does not work when it comes to respite service.



Richard Taylor, PhD, provides reflections on his battle with Dr. Alzheimer.

Open your door and in come the customers! Most caregivers are happy simply to find an opening!

As a person living with the diagnosis of dementia, probably of the Alzheimer's type, I want advocates of government-supported respite services to first identify what are quality respite services, as determined jointly by people with dementia and their caregivers, and then crusade for payment for these services. Too little attention has and is paid to first determining what constitutes excellent respite care for any one person living with a diagnosis of dementia. There seems to be a rush for respite service to benefit those who drop us off and too little attention paid to what happens to, with, and for us after we have been dropped off. I am not suggesting we are necessarily abused, (how about bored, confused, bewildered, withdrawn, or disinterested) but we need to be more than just entertained. We need to be challenged to be all we can be. We need to be treated as whole human beings, not defective ones who are stored here while our caregivers take a much-

needed break. We need to be involved to the extent we can in planning and evaluating these services.

There is a surge of support with dollars from state legislatures to fund respite care. The need is so great and growing so fast, it will never be fully met.

Where is the surge of support with dollars from state legislatures to fund inspecting these services?

Where are the considered standards that ensure everyone who uses this service will be provided with an individualized plan of activities?

Hello—isn't the "new" approach to assisted living to develop individualized plans of care, patient-centered care? Why shouldn't the same requirement be instituted with respite care?

Some nursing homes seem quick to convert a lunchroom or unused space to a respite care center. It is another source of income. Another pathway to their door.

I have visited and spoken with the users of many, many respite services. Many of the participants know what is good and bad for them about the services. Most of them are not asked for their opinion, and if they are asked, when their opinion is negative, it is ignored. It is time for the users to speak up, and it's time for their caregivers to speak out for standards of care, for appropriate activities. Don't waste a day of our lives watching TV, listening to people speak in whom we aren't interested, participating in child-like activities—when we can and should be treated as adults. Enable us to act like adults. Re-able us to use all our abilities. *ALC*