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Forgiving Forgetting and Building a Circle of Friends

I've been living with dementia for the past six years. I've met dozens of others over the Internet who live with dementia as well. People with dementia not only need help with the activities of daily living, but they need help in reconstructing a social life for themselves.

When our colleagues are no longer available; when our driving is restricted; when our families and friends look at us and see only loss -- then it is time to make new friends!

This I know: we live only in the moment. The past falls away as our memories fade, and the future for us requires planning (which we then forget). All we have is this moment, so our social needs are always in the forefront. We need each other now, in this very minute, and then in the next minute and the next and the next.

Our culture simply cannot provide the full-time social support we need, so we must provide it for each other. We certainly have the time nobody else has. We have empathy for others struggling with a "world turned upside down by Alzheimer's," as our friend, Jeanne Lee, says.

People with dementia offer very special gifts to each other when they are introduced to each other. While his family may grieve the loss of their father the reconstructive surgeon, I meet the man and discover a multitude of strengths he has right now. He is a new person to me, and I can reflect back to him the "new person" he has become.

We with dementia change so rapidly that we are always on a quest to understand who we are now. The love and support of others with dementia show us the mirror through which we can understand our new selves. In a peculiar way, we are very much like young adolescents. We become very self-preoccupied in our quest for self-discovery. This isn't a very flattering trait in young adolescents, and it is even less flattering in "mature" adults. Maturation implies knowing oneself and being aware of and accommodating the needs of others in addition to ourselves. We have difficulty with that.

If our disability were a broken leg, others would see the cast on our leg and make special allowance for us that we don't climb stairs and hop fences. Our disability is invisible because it is internal and cerebral. Thus, people with dementia are judged much more harshly than the physically impaired.

When I first discovered others struggling with memory loss, I was struck by the differences in the way they treated me. I thought that they were forgiving my forgetting and not counting it against me. Because I cannot remember your name or your face, it does not mean I discount your significance. Tell me your name and relate to me as a real human being. I WILL remember the feelings associated with the relationship!

In claiming our own disabled status, we acquired a new, group identity. It served us well.

I look for the time when people with dementia are introduced to others with dementia in the knowledge that our sharing with one another is validation of our existence and of our importance in the world!