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Record
239
File Number
10212

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Title: Our relationship to her has bonded us together

Original source: Families and Disability Newsletter Volume 1 Number 2

Resource type: Written **Publication Date:** 01/01/89

Publisher info: -

Abstract

This brief story about a woman who has Alzeimer's Disease describes how a family was enriched by her continuing inclusion as a family member and a contributing citizen. **Keywords: Aging, Families**

Our Relationship to Her Has Bonded Us Together

Eleanor Kharasch celebrated her 87th birthday this summer. Her three children, many of her grandchildren and several great grandchildren gathered from around the world to commemorate this day with her. They ate cake, shared old memories, and sang "Happy Birthday."

Eleanor may not have known it was her birthday or understood that she was attending a party in her honor. Alzheimer's Disease, which she has had for at least 18 years, has left her unable to speak, care for herself, or even leave her bed. Why did her family members gather at her bedside for this special occasion, knowing that Eleanor probably could not even recognize them?

Shirley Behr, Eleanor's daughter and Beach Center researcher, explains: "Our family has learned that we grow and change through our relationship to Mother. Keeping her as a central part of our family has given us an opportunity to bond together in a special way. We have changed ourselves by moving beyond seeing her disability as a depressing event."

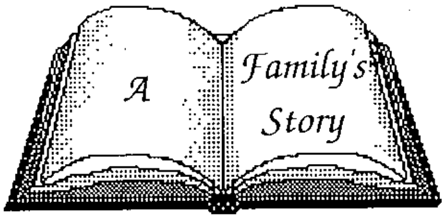
The process has not been easy. "It has taken years for our family to get here, and we have gone through tremendous family stress," Shirley reports. When Eleanor's problem was finally diagnosed, family members found themselves in a new and often difficult relationship with each other, trying to decide how to handle this "family problem."

Family members were scattered across the United States and even as far away as Israel. Eleanor lived with Shirley and Ben for a time until they found a nursing home that had a special program for persons with Alzheimer's Disease, but that turned out to be unsatisfactory. Shirley and Ben determined that it was important to have Eleanor live with them for as long as possible. They wanted the family to perceive that, despite her problems, Eleanor was still a "member of the family" and a vital force in their lives.

Contemplating a move to Kansas from the east coast, they resolved to base their decision on two criteria: were appropriate services available for Eleanor, and was a house available where Eleanor could have her own living suite? Professionals urged them not to take Eleanor out of the nursing home, and family members became concerned that Shirley and Ben might be taking on too much of a burden. But Shirley and Ben followed their own beliefs, based on past experience and what they had come to value as important in family life. On December 26, 1984, Eleanor moved into her own suite in their home in Lawrence.

It was a joyous day. The grandchildren came to help welcome Eleanor. Shirley's daughter, Jill, looking for a way to continue the sense of meaning the event had in bringing the family together, decided to establish a monthly family newsletter. That was the beginning of *Grandma's Family Gazette*, in which Jill still keeps family members up-to-date on Eleanor's health and care, and on the comings and goings of other family members.

Although Eleanor now lives in a nursing home, the three years that she lived in Shirley and Ben's home gave family members and close friends an opportunity to feel good about their relationship to Eleanor. The grandchildren contribute to the "Grandma Fund," and the proceeds are used to fund the *Eleanor Kharasch Staff-Family Interaction Award* for the nursing home staff member who does the most to reach out to families.



Seeing Families in Different Ways

Shirley interprets Eleanor's story as a "full citizenship" parable. "We kept Mother as part of our family. That was recognizing her right to a family and our right to her presence in it. It was our way of saying to her that she is a full citizen in our family."

For Shirley and her family, life is all about moving beyond Eleanor's rights to family and appropriate care. "When we established the newsletter, we began to contribute to each other in ways that we had not done for quite a while. We basically said that Mother, though she cannot speak to us and may not understand us, still contributes to us. The newsletter links us to each other; it is a means for our common good."

And the birthday party? "I see the party on two levels. On one, there is the matter of what we would have done if she did not have Alzheimer's. We would have celebrated her birthday. That would have been her right—to a celebration. And it would have been her choice— to have everyone together at her side. On another level, however, the party was symbolic. "It represented the fact that each of us has been changed by Mother's disability. Here we all were, talking to Mother as though she could hear us and understand what we are saying. Perhaps she can. Perhaps not. It doesn't matter.

"What matters is that we have been changed. We found ways—through the newsletter, through birthday parties—to say to each other and to her that we are a family, a small but very important community. And we also found that, although Mother has a severe disability, she still makes her gifts known to us. How else can you explain what we have done?

"Somehow, we have achieved a fuller family than we could have imagined possible. Somehow, we have achieved a different kind of family. And somehow, each of us is a different kind of person, a different kind of citizen. We always knew about rights and preferences, but we have just learned something new about community, contributions, and reciprocity. We have a new appreciation for the meaning of 'commonwealth' and it's because of Mother. We see the world differently now. We understand citizenship in a richer sense."

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