



NATIONAL FAMILY CAREGIVERS ASSOCIATION

“It Doesn’t Have to Be This Hard”

How One Family Caregiver Answered the Call

An NFCA Commentary 4/07

Bonnie Danowski is a member of NFCA’s Caregiver Community Action Network. She volunteers her time to help make life better for family caregivers. Bonnie’s passion is advocacy, so we asked her to share her thoughts on what that means to her; what she’s accomplished; and what you can do, even if you can’t or aren’t willing to make the same level of commitment that Bonnie has made. Here are her answers:

What does advocacy mean to you?

For many, the words “being an advocate” may bring to mind a picture of someone talking with politicians. That is advocacy, but you’re also an advocate in any situation where you recognize an injustice. For me, being an advocate means that I have spoken up for people who, for whatever reason, can’t speak for themselves. I’ve also been an advocate for causes, like peace in our world, pretty much my whole life. And of course I am my own advocate.

Specifically, I speak up for my husband when his medical attention isn’t up to par: in a restaurant, store, school, office building, etc. if there is a step, the door is too narrow, or the aisles are inaccessible. That’s an injustice to the people with disabilities who can’t go there, and it’s an injustice to those who care for and about them as well. That affects quality of life and deprives people of full participation in life. Anytime someone speaks out against an injustice, that’s advocacy.

Why did you choose to become an advocate for family caregivers?

In the last six years I have been focused at the political level on advocacy for family caregivers. I made this decision after my husband, Jim, who has had multiple sclerosis (MS) for 35 years, went through the most serious exacerbation he’d ever had. I had to give up my work and any outside involvements to stay at home to care for him and manage the house. This went on for 18 months, after which time he stabilized and I could resume my outside interests. Well, I had a lot of time to think during those homebound months (after I’d painted the house, took up some new hobbies, and did whatever I could to maintain my sanity). I knew if I was able to get out into the world again, I had no choice but to devote my time to improving the lives of family caregivers. That’s why I say “advocacy chose me; not the other way around.” Given my experience, I just felt I had to become an advocate so that neither I nor other family caregivers would have such a hard time of things.

How did you get started?

It began in the broad-based organization that my church is a member of — the Valley Interfaith Project. I've had a leadership role there for many years and so I brought to the table the idea of taking on family caregiving as one of our issues. I shared statistics and stories. It just so happened that others were raising the same concerns. It wasn't hard for everyone to see the relevance and the need.

We began by finding many other family caregivers who, like me, found the long-term care system less than desirable — that's the understatement of the year! As we gathered our energy together, we knew things had to change. It did no good just to sit around and cry on one another's shoulders. We decided to focus on the staffing problems, the lack of state-based training standards for aides, and the lack of a career ladder for them to climb. We knew we had to go to the heart of the problem: the laws that regulated the system. This took us to the state Capitol; to the governor's office; to the legislative offices; and to the state agencies that regulated, monitored, and funded much of the long-term care system, which included home and community based care, assisted living, and skilled-nursing facilities. I can proudly announce that our advocacy efforts on behalf of caregiving families over the past six years are making a difference. *It's amazing what one person can do when working with other like-minded allies!*

This is what happened: Because of the work I was doing, I was appointed to a seat on the Arizona Senate's Committee on Caregiver Wages. The Senate president recognized the value of having a family caregiver like me who could talk about the reality of what it's like to have an ill spouse. The committee made recommendations to address the low wages and lack of benefits and career path for those folks we so depend on to come into our homes to give good care to our family members or friends — the very issues that Valley Interfaith Project had identified as being key to better meeting the needs of caregiving families.

Rather than stop there, I continued the dialogue with the governor's office to create a mechanism for addressing these issues. The governor-appointed Citizens' Workgroup on the Long-Term Care Workforce began its work with 25 members. I once again served in a leadership role and brought the authenticity of the family caregiver's experiences to the table.

We are now in the beginning stages of standardizing training statewide. We brought together a professor at Phoenix Community College and three of the county's long-term care agencies that were known for their quality service. A pilot project was developed rather quickly and within four months, we had a course. The professor said she'd been trying to make this happen for 10 years!

The direct-support paraprofessionals who go through the program will have portable credentials they can take with them to new employers. Those who have already gone through the pilot are getting college credit and encouragement to pursue further education and to climb the career ladder to better jobs. Many who have never stepped onto a college campus before now dream of becoming Licensed Practical Nurses (LPN) and Registered Nurses (RN). Those receiving care will no longer have to worry about being dropped or being treated poorly by inadequately trained aides. One of the workers who completed the first course said, "I know I'll be a better caregiver after this."

While a member of this last work group, I had a heated discussion with a couple of long-term care employers when I made the statement that spouses who have had to cut their full-time work back to part time or even to leave their jobs completely (as I had) should be paid for the care they give to their ill partners. I was told it would “break the bank.” I said: “I don’t care; it’s the right thing to do.” I am happy to report that Arizona has just received a spousal waiver from the Centers for Medicare & Medicaid Services (CMS) that will go into effect in 2007, allowing spouses of community-dwelling Medicaid recipients to be paid. We will be working out the details in early 2007. It really wasn’t as easy as I’ve made it sound, but it does prove that one person can make a difference; and I get goose bumps when I think of the difference this will make in the lives of many caregiving families. I know it will change lives!

My latest “mission” has been to strategize with other leaders in our organization to get a bill to the state Legislature in January that would provide respite care for all caregiving families. Working with the National Lifespan Respite Coalition, state agencies, the governor’s office, long-term care businesses, and legislators has helped us to understand and articulate what needs to be in this legislation. What an exciting adventure to be called to do this work! I’m so grateful that advocacy knocked on my heart and I was able to answer the call.

What advice do you have for other family caregivers who want to make a difference but may not have the time or inclination to take this on as a cause, as you have done?

When you see something wrong in a business, restaurant, store or school, talk to the managers. Tell them how unjust it is that people with disabilities can’t take full advantage of life in their buildings. Oftentimes, they are grateful. And if you’re rejected, so what? You’ve done the right thing. In the political arena where public policy is made, just making a phone call or sending an e-mail to your representatives (state or federal) and your governor can be enough. Tell them your story, what your life is like, and what you need. Share what you know. We elected them. They represent us! How can they do that if they don’t know what we think? Remember, they work for us! You have the right and, I believe, the responsibility to say what’s on your mind. If we all do that, we cannot be denied.

What have you gained from your experience?

The greatest benefit, I think, is the growth that I have experienced, the wonderful people with whom I’ve been privileged to work, and the deep satisfaction that both Jim and I feel having answered advocacy’s knock and doing what we can. Our conversations are often about this or that meeting and are peppered with wonderful insights, clarifying questions, salty anger, silly laughter, deep frustrations, and, finally, genuine joy.

One person can move a rock; many persons, when pushing together, can move a boulder! What a difference we could make if the more than 50 million family caregivers in our country united on the common goal to make our lives better! Think about it and please do what you can.

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