Until there’s a cure . . .

By Debbie Selsavage, CDP

My primary training is in The Positive Approach to Care, developed by Teepa Snow. Teepa’s slogan is, “Until there’s a cure, there’s care.” This trips nicely off the tongue and seems too obvious to be profound, but there is so much more meaning in this statement than we might see at first glance.

I had this brought home to me recently when I had the opportunity to attend a two-day conference in Orlando organized by the Alzheimer’s Association, the Florida Department of Health, and others. This event brought together some of the top people in the field, including cutting-edge scientists who are conducting research for a cure.

I was overwhelmed with the amount of knowledge imparted, but came away feeling quite unsettled, for two reasons. First, we heard nothing very optimistic about the state of research for a cure. The more research we conduct, the more questions – not answers – we seem to uncover. Fundamental theories about the cause of the disease that have directed research for two decades are now being abandoned as dead ends! I did not see even a glimmer of that hoped-for cure at the end of the tunnel.

The second reason was that I heard so little about care. The Alzheimer’s Association and the Florida Department of Elder Affairs offered some really good workshops about care techniques and resources available to caregivers, and this is good. But there seems to be so little attention, and money, directed toward the development of an art or science of better care. By this I mean, how do we better deploy to caregivers what we already know, and what shall we do to research and develop new techniques of care to improve the quality of life for both the caregiver and those living with dementia?

It is true that the U.S. Congress has recently approved historic increases for support of Alzheimer’s cure and care programs, and this is wonderful evidence that our public education and awareness programs are working. But when I speak of better funding for “care,” I am talking about money for innovative care research in addition to the increased funding that is going to the training, education, and respite programs that are already intact.

Don’t misunderstand me. I am all for the research for a cure, and I hope one day soon it will succeed. One person at the conference expressed his enthusiasm for cure research by excitedly predicting, “There is a person living on Earth today who will be cured of Alzheimer's!" Indeed, we hope, but I thought sadly to myself, "Okay, but with greater longevity, this could be another 90 years!"

In addition to a continuation of heavy spending toward a cure, here is how I would like to see us allocate more funding toward care:

I would like to see more research into the behavioral psychology of individuals living with dementia. Can we learn more about what motivates their behaviors and thereby learn ways to serve and communicate with them more effectively, compassionately, and less disruptively?

I would like to see money spent on evidence-based research into compassionate techniques of care such as hug therapy and humor therapy. We know they work. How can we better understand and develop them so more caregivers – both family and professional – know how to apply them?

I would like to see research into kinder and gentler non-pharmaceutical, wholistic methods of mood management. After all, none of the psychotropic drugs used on people with dementia were ever intended for dementia, and sometimes they bring more problems than solutions.

I would like to see publicly-funded dementia hotlines, manned by volunteers who have received extensive training in understanding the personality and behavioral changes that people with dementia experience. These skilled facilitators would be on hand to de-escalate difficult situations so that deputies do not have to be called to Baker Act people who have no control over their behaviors.

[NOTE: "Baker Act" is a reference to the Florida Mental Health Act of 1971, so named in honor of Representative Maxine Baker, an advocate for better mental health services. It provides for the involuntary institutionalization of individuals who appear to be a danger to themselves and others. When this procedure was established nearly 50 years ago, less was known about dementia and little distinction was made between the behavior of psychotics and individuals living with dementia. In recent years it has been recognized that "Baker Acting" can be disruptive and inhumane process for individuals living with dementia, often leaving them worse off than when they were admitted. Most States – if not all – have similar laws.]

And speaking of the Baker Act; this is a whole topic unto itself. Significant resources should be allocated to updating and reforming this process so that people with dementia are not treated like drunks, criminals, and drug addicts, or thrown into chaotic and sometimes violent populations that only escalate their confusion and anxiety to a level worse than when they arrived.

I would like to see state legislatures and regulating agencies raise the minimum standards of care required for professional providers. These have not been updated in 15 years, which I believe is quite unacceptable.

I would like to see more funding for public and private-sector agencies to provide workshops for family caregivers since many of us will never be able to afford professional care.

Finally, I would like to see well-planned and funded research and learning institutes devoted entirely to the topic of better care. Through these, we can produce a whole new generation of young, compassionate medical professionals who understand they are dealing with people, not just a disease.

By all means, let’s keep chasing that cure. But let us not forget that until there is a cure, there is care. No, let me rephrase that: “Until there is a cure, there is ONLY care!”

Debbie Selsavage is an independent certified trainer in the Positive Approach to Care, a Certified Dementia Practitioner, and President of the Alzheimer’s Family Organization. Her company, Coping with Dementia LLC, is dedicated to making life better for individuals and their caregivers who are living with dementia. Contact Debbie at deb@coping.today.