

WE ARE NOT STUPID

Geri Taylor

9/13/19

For the Empowering Partnerships Workshop

Good morning! I chose my provocative title this morning not out of rudeness but in case the coffee was not strong enough!! I am deeply appreciative of anyone who embraces the **reality** of people living with Alzheimer's.

Who are we – now? We are slow to put our thoughts together, but we are not stupid. Our language may be broken, but we are well-intentioned people with patience who know what we are saying.

At 65, with a few symptoms showing and my parents' history haunting me, I knew I was boarding the Alzheimer's train. Boldly carrying my kit bag of strategies with confidence and determination. Ten years later my kit bag is frayed and tattered. My speech is halting and often void of critical words. People often fill in and I appreciate the help—even when I am offered the second-best word.

The conversation goes on and I am still in the game. Harder to deal with today is the rapid talking style adopted by the younger generation.

I believe that simple, strong approaches can be powerful game changers in how people think and act. In 1972, my boss, a physician, and I, a nurse and statistician, changed how people and the medical community thought. With straight-forward research findings published in the *New England Journal of Medicine*, empowerment for “second opinion” surgery became a household word in a few years. Today “second opinion” is a powerful common expression.

I am bringing up this experience to illustrate the ability to change the common wisdom to better outcomes.

We are here today to challenge and find new ways for the person living with the disease and care partner to function better and longer.

So I will leave you with this challenge: find what needs to be done to better the functionality of persons living with the disease and care partners.

POEM—MY BEAUTIFUL SOUL

She travelled light; carrying only what she needed to survive

There was no beauty, no grace; survival was all.

And in that survival, the effort, the foregone

pampering and diarizing, she looked up and

saw real beauty.

Her soul: strong—grasping to be and to

Become.

BEING THE BEST CARE PARTNERS WE CAN BE

Jim Taylor & Geri Taylor

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Well, at first I thought maybe I should call my talk “**but I am stupid!**” but decided that this would not be getting off on the right foot. I had the **great fortune** more than 25 years ago to **marry Geri Taylor**. Besides being a **wonderful partner**, her background in **public health and as a senior health-care EXECUTIVE** has enabled her to be an **inspiring model** for people living the dementia. But **what about me? I had no health care background and was totally unprepared and reluctant** to become a care partner. **** I had married a nurse** to take care of me!! Fortunately, Geri has been **patient** and is helping me to **develop appropriate skills**, and I am **still learning** every day. And **every day I make mistakes**, but the good thing about AD is that the next day Geri doesn’t remember my errors; she only remembers **my good intentions**.

I know that we here **want to be the best possible** care partners. **Our job** is to help **maximize our partner’s quality of life**. Likewise, many of us have also striven to be the **best possible parent**. **** To do this, as my children grew, as a single parent I had to learn to strengthen their ability to manage for themselves as much they could handle, to encourage their independence, and to allow them to fail**. This was often a **painful process** for me to learn. It was much **easier to rush in and “help,”** but what this often re-enforced was **my child’s inability to stand alone, to gain and maintain their confidence and self-worth**. Finding the right balance was a challenge, and I often made mistakes. Unlike Geri, my kids remember all my mistakes and remind me whenever possible! But I remind them of the golden rule of relationships: He who holds the gold makes the rules

As a **new CP filled with good intentions**, I **failed to apply these same principles** to my interactions with Geri. Obviously, my relationship with **Geri is very different from my relationship** with my children, but **I failed to fall back on my only other experience in helping a loved one to be fully actualized**. I too frequently was **too helpful**, assisting **too quickly and frequently**. Slowly **declining cognition creates many challenges** for the person living with the disease: what Geri helped me realize is **that she maintains much greater self-worth, confidence, and independence when I am not a HELICOPTER partner**. We have an **agreement** that I will not help her with something until she asks for help or she fails. When we are asked questions, I **try to remember** to allow her to speak first, lest I inhibit her ability to express her own views clearly.

These are **hard guidelines** to follow, **especially when they contradict an established way of relating/the established give and take** of a relationship. It’s very **hard for me not to speak first**, or to watch Geri do something slowly what I could do in a flash. It takes **patience** and that has never been my forte. I make mistakes every day.

So Geri, how does it make you feel when I do something for you that?
you are trying to do for yourself?

It makes me feel that I’m not fast enough. It makes me feel inadequate and insufficient.

Why does it cause you a problem if I answer a question or express my opinion before you speak?

GERI: Given my halting and deteriorating speech, it is often challenging to express the important things I have to say. It's even harder if I must be concerned about what you have said. If you speak for me or us, people will value me less, not look at me, turn away from me. This discounts my opinion and thoughts in the situation. I am **diminished**.

So, is this totally my problem, or can you help me learn to handle these situations better?

GERI: We need to work on this together, and I can say to others: "Oh, I can answer that."

So how can we put these ideas into practice during these two days of training?

Geri: I think that the care partners need to make a big effort to allow their partners to speak first. But also, we living with the disease must gently assert Ourselves and remind our partners to **wait their turn**.

We're all in training! **Good luck**