

Change is HARD

*What Would Help, If Anything, When You Were Told
You Had Dementia?*

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I recently had the amazing opportunity of providing an interactive webinar for [Dementia Alliance International](#). The topic I was asked to present on was, “When Getting a Diagnosis of Dementia, What are Some Strategies to Control Your Reactions so that You Can Maintain Your Self Control and Others Don’t See You as *Losing It/Outrageous/Uncontrolled/Less/Irrational....*” What I found myself considering is, whether it is even possible to ask this of yourself in the moment when you hear that a core piece of you has been labelled as unstable and even disappearing?

All the members of the group that I spent time with are living with some form or type of dementia. Some individuals may have only one form of the condition while others are living with more than one variation. Additionally, multiple participants noted that there are other health challenges to be dealt with and that having the *dementia* label can make getting effective, supportive, and best-quality care even more difficult to obtain.

So, what typically happens when a person hears that they have dementia?

If the person has any awareness of what that word means, has had family or life experiences related to dementia, or has watched any of the ads with traditional versions of people living with dementia in them, then the brain’s primitive survival system should kick into gear! Its goal is to protect the individual from danger and to help that person find what is needed to survive, if survival is desired and possible. The amygdala takes over, it shuts down intellectual abilities for the moment, *it’s all about survival!* Heart rate changes, respiration shifts, blood pressure alters, there is routinely a blood sugar surge, muscle tension increases, visual awareness tunnels, and body pain awareness is lost. The primitive instinct to freeze and become invisible, to flee and escape the threat, or to fight back with all that is possible to eliminate the threat is *front* and *center!*

(Note: If the person does not experience or exhibit any of these reactions, our concern should be heightened. It will require an entirely different approach and type of support being offered. We will cover that scenario at another time.)

The person will **not** be able to comprehend language at their normal level, they will not be able to produce speech in their routine pattern, and their ability to find the words they are looking for will dry up. Additionally, their pre-frontal executive control center has been effectively *shut down* for the time being! Skills like being logical, reasonable, and rational are not possible in those moments, and the ability to control whatever impulse you have will greatly diminish and may disappear entirely. Ability to make choices or to accept what has been chosen for them may not be possible, right then.

At this moment the potential to start a *new* life, to initiate new action plans to sequence through what to do next, to even know then the discussion is ended, and the ability to move onward has been eliminated, at that time. Perhaps, most importantly, two additional skill sets are turned off right now. The ability to see myself clearly in this new situation and be able to know whether I am okay or that I need help, combined with the ability to see another person's point of view.

I'm sorry, but in that moment of devastation, it is simply not possible for me to be the *me* you have always known, because I have just been told that person has been kidnapped and they will not be ransomed back, because we currently have a **no negotiation** policy when it comes to dementia!

Given this situation, what can help? After much very helpful input from the people in the group, and years of experience with situations that went well and ones that did not, I have a few ideas to explore. I think we, as a culture, need to change things! I know this is a surprise to you all 😊.

Here is what I propose to try to help:

1. We need to create a simple Provider's Guide for ***Talking with Someone Who is Being Diagnosed with Dementia BEFORE You Start the Conversation! What Every Health Care Provider Working in the Field Needs to Know to be Helpful, NOT Harmful!***
2. All potential providers would *need* to read and follow the Guidelines BEFORE they are given the right and privilege of providing a person the news of a dementia-type diagnosis.
3. All people who are going to be receiving this type of news, "It does look like you are going to be living with dementia in your life" will be provided with:
 - a. an ***After the Diagnosis Follow-Up Protocol*** that supports that individual through the crisis and into their new life
 - b. the creation of an individualized support system that works for the person, based on *who* they are, combined with what is needed to help them work through the conversion of life with undiagnosed dementia to living with dementia.
 - c. A *cue card* for all future health care providers that provides supportive strategies to be consistently used when working with *that* person living with dementia and their support system
 - d. A *cue card* for the person living with the diagnosis that offers options for taking a *pause*, seeking a *time out*, during interactions to recover or adjust.

What's the first step? I already took it, I listened to what people living with dementia shared with me about what did and did not work for them when they got their diagnosis. I absorbed their emotional and spiritual feelings of rejection, isolation, despair, hopelessness, and anger. We problem solved through some ideas and different experiences to explore alternatives that would work better and what is critical. After we talked, I was able to put together my thoughts and came up the four items listed above.

The follow up is that I am beginning to work on these resources for people living with dementia to review and comment on.

Thanks to all of you who are living with dementia and are willing and very able to share what those of us not living with dementia NEED to know in order to support you better.