

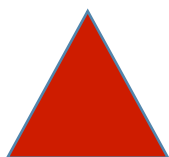
## How Will Dementia Change Everything?

*YES, that is the question.*

*by Teepa Snow, MS, OTR/L, FAOTA*

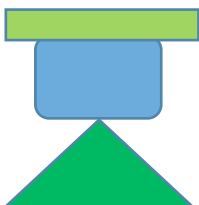
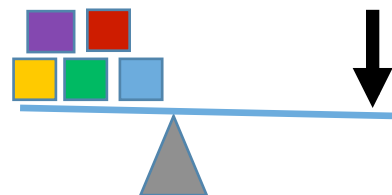
March is considered the month of change. “In like a lion, out like a lamb” is the phrase oft used for this month. If only we could see the changes that come with the onset of dementia in that way. Dementia certainly provides change; it comes into our lives and frightens us with its roars and fierceness. What we thought was a cute and fluffy kitten or a sleek and self-contained cat is now a fully enraged lion, on the prowl and seeking to rule. It is hard to find a lamb, in this situation.

So for me, the question is not: Will dementia change everything? It is: How will dementia change everything? AND more importantly: How will I change to find the new place and life of calm that may be possible, once these changes are accepted.



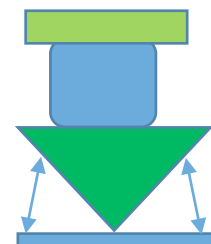
The symbol for change in science is the Greek symbol delta. It is a triangle. What is fascinating about a triangle is that there are three points and when used as a fulcrum it can enable us to lift or move much more than we can using just our own bodies or strength. Just as in dementia we are much more

powerful and effective when we are trying to adapt to the changes if we reach out and form a team to create a new dynamic rather than continuing to try to do what we have always done, just doing it ourselves. It is a time when we can get used to having the different and appreciate what it can offer, not just what it took away.



It also interesting that a triangle is stable in a way that allows for more stress application without crushing the structure because pressing on one point distributes the force out to the other two points. However, that single point of contact also makes the structure inherently unstable when trying to balance a load. The very nature of a triangle distributes the weight differently and makes use of the underlying supportive structure. In

dementia, as we reach out and create new partnerships and relationships that will help us learn to cope with the changes that simply ARE, we would do well to keep in mind that many of these new balance points will not be stable. They help us carry the load for a while, but then they too will need to be adjusted as the load shifts. Additionally, thinking one of us is the ONLY one, the only point of contact really makes the whole system and plan unstable! At least two of the three are the foundation that creates some stability.



One of the first possible planned changes that we can choose to make when dementia comes calling is to move into partnership with another person. It may be that there was an existing relationship, one that is long-standing, deep, and valued. Don't let go of that, but consider making it the underlying structure and then form the new above it, connected but different. This new structure allows for time outs, shared experiences, reconnects, and a different way of being with one another. It can be used to cope with medical advisors and medical or health issues, with lawyers and legal concerns, as well as day-to-day life and engagement.



A second change is to realize that life is no longer simple. The person living with dementia will not be able to fill their day and life with meaning and value AND move from one activity to the next without support, structure, and guidance of some sort. Each task must be explored for continued safety, ability, and interest. Each change from one to another must be appreciated and sometimes fostered. There are four major categories or groupings for activities for all human beings. Work offers opportunities to feel productive and valued. Leisure provides the fun in life and joy in the moment. Self-care allows us to take care of our body, brain, and environment. Rest and restoration fosters recharging of batteries – physical, emotional, mental, and spiritual. The interesting thing we find in dementia is that as the condition takes its toll, an added time use is present. It is called **waiting**. It exists because each time a person does something there is a complex series of brain activities that must engage and function to allow for the performance of one activity and the movement to the next. The pre-frontal skills involve sending complex commands to the other lobes of the brain to perform! Here is the series of commands initiate, sequence through the task, finish or complete the task, then transition to a new task and repeat with a variation.

Loss in any skill area will change the pattern that fills the day. Therefore, another monitor is needed to insure that what the person intends to do and wants to do, is happening. If the primary care partner takes this additional responsibility on without seeking additional support or partners, there is a high risk of system failure. Trying to plan and execute life for two people tends to result in multiple negative emotions and interactions for both parties. Accepting the value and importance of sharing the load, spreading the responsibility, can begin the shift from *me* and *you*, to at least a *trio* and *us*. This offers opportunities for new connections and hope for all. *It is a time for change...rough and rocky at first, but smoothing out over time as the new becomes the normal and different is accepted as the same. For the moment, there is a lamb! Change is happening – embrace it. Breathe deep and LET GO of what you cannot hold on to.*