

Loving Seems Different When Relationships Change

by Teepa Snow, MS, OTR/L, FAOTA

As many dementias progress, changes of roles and responsibilities for each person in the relationship can cause stress and distress for both. A statement that people are encouraged to make in counseling is “I love you, but I don’t like this behavior” does not seem to help the feelings of frustration, anger, longing, isolation, and loss. Unfortunately, for many forms of dementia, the behaviors are what I am experiencing 24/7 and I lose sight of the person. Here is a short list of things I am not **LIKING**. This list may ring true, whether I am the person living with dementia inside my brain, or I am the person living with the person living with dementia.

I don’t like your behaviors

I don’t like how you act when I try to talk about your behaviors

I don’t like how I am spending my time

I don’t like how I am behaving

I don’t like what is happening for us

I don’t like how others are treating me, you, or us

I don’t understand why you are doing this

I don’t know how to get things back on track

I don’t like the new responsibilities I am having to take on or that you are taking away from me

I don’t like giving up or letting go of what it used to be like

I don’t like... the new me OR the new you!

The brain changes that one partner experiences create inconsistent and unpredictable behavioral changes that can and will often trigger the other person into a more powerful and unexpected reaction; this can cause both parties to use more primitive brain functions rather than integrated processing. The result is that it gets harder and harder to sustain or maintain valued relationships when the other can’t be *trusted to be* the way they have before.

What can help? Awareness, knowledge, skill AND SUPPORT for **both** parties. This new relationship will be *different*. Any new relationship has to be explored, nurtured, and developed. The tricky part with dementia is that it is ever-changing; and in addition to changing relationships there is a change in **ROLES** and responsibilities for living life together. Who did what, what skills each person has, how tasks got done, when things got done, even how one person’s interests and abilities affected the other are all up for grabs.

For the Person Living with Dementia (PLWD), having a support person available and involved with you can promote your sense of wholeness and self. The person or people who take on this role will do best if they can:

- see things from your perspective and offer appreciation and understanding of your perspective
- help you express through words and actions what you mean, how you feel, what you are trying to do, why you are doing what you are (when your abilities to use the strategies and techniques to communicate these things are no longer working well)
- help you appreciate the other person's reasons and perspectives in ways that you can get
- help you fill your day and find new roles and responsibilities you can take on when those you used to do are no longer possible (giving both you and your primary partner time, space, and roles away from one another)

For the person trying to support and love the PLWD through the duration of the condition, having a support person who is available and involved can make a tremendous difference. It is vital however, that that person can:

- see your perspective and listen to your concerns and reactions without judgment
- help you in coping with the grief and loss you are experiencing
- help you develop and practice more effective responses to the changing behaviors and abilities to reduce your distress and change the dynamics between partners
- guide you seeking other supports and resources as roles and relationships are being further modified (legal, financial, health care, social, spiritual, home maintenance, etc.)
- provide you with a time and place to focus on your own needs and well-being
- possibly help you sustain other relationships that are being fractured or broken by this thing called dementia that has entered your life

Who might these supporters be? Great question! There is no one answer that fits for everyone. One thing that is vital in creating these new relationships is that there is a good match between what each person needs and what the new partner(s) can provide. Personality traits, learning preferences, availability, life experiences, and understanding of dementia are all factors to be considered and appreciated. Finding good matches is critical to success for all involved. For all new relationships, it is typically a good idea to seek out confirmation of authenticity, skill, and intent. Doing a little homework to determine that the *helper* is indeed there to help *you and your partner*, and not themselves, can save both heartache and financial or legal problems later.

For some, support groups play a vital and very pivotal role in helping to change what is not working well into success. Others might use a 1:1 friendship or counseling service to get what is most needed. While still others might find internet support better serves their situation and status. For almost everyone the hardest part is taking the first step, initiating the NEW, trying something out, getting both people to give it a try, and even if it wasn't everything you hoped for, try it again, maybe with a little variation. There are many resources that can be tapped, finding out about them can be time consuming and tricky when you are not functioning at 100%, so consider getting help for that part if it is blocking change. LET GO of the idea that you have to do it all yourself and build that TEAM! It is part of the changing relationship you have in front of you.

One final note. Each form of dementia will be similar and yet very different in how it changes the relationship and the feelings of love versus like. Intellectually, I can explain that that is because each dementia affects different regions in the brain at different rates, different sequences, and to different degrees. That works, until you are confronted by a moment in life and the change you feel, see, hear, and experience with the person you love *overwhelms* you. Of all the things we tend to do in those moments, most are governed by our primitive brains. The part that says either:

- THIS IS A THREAT!
 - FRIGHT (you are scaring me – this is not right),
 - FLIGHT (I have to get away from this and you – it is dangerous to be with you)
 - FIGHT (this needs to stop, I will not allow this to happen, I need to get this threat stopped)
- I NEED SOMETHING – YOU NEED TO GIVE IT TO ME!!!
 - I need YOU to do something
 - I need YOU to say something
 - I need to MEET my NEED so I can find JOY and PLEASURE again!

For each situation and each type of dementia, the retained abilities of the PLWD combined with the missing pieces change what has been before. So the partner who does not have the condition will typically be unsuccessful if she or he demands that the person be like they were, do what they used to do, or act like they used to act in the relationship that was. The new skill is to PAUSE, take a deep breath and LET IT GO completely; REPEAT until you sense/feel your brain coming back to its full function, not its primitive, reactive self and respond. What is the unmet need being expressed or what is the sense of threat being experienced? How can I offer the support that lessens the threat or provides for the need in a way that does NOT trigger my own distress?

Learning a new way of responding will take awareness, practice, and support. Learning how to show love and be loved in different ways will take time and energy. Building new based on shifting sands is a tricky business, but it is what we have to work with, if we choose to love and spend time with those whose brains are changing without their willing it to be so. Finding the support for ourselves to do it well can change not only our relationship but the interactions of everyone around us. As Gandhi said, “Be the change you wish to see in the world”. My only change to the quote, I believe we must all choose to do so to create a new culture and community of friendship and acceptance.