

## Pleasurable Activities with One Other Person

*Sustaining Intimate Relationships*

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

When someone is living with dementia, the ability and interest in maintaining or engaging in intimate relationships may change, or they may actually become less pleasurable. It may become less pleasurable for one partner or for both people, but for different reasons.

What causes these changes? It could be the symptoms of the condition that are affecting the person's abilities or it could simply be that opportunities for, or scheduling of, these interactions become more challenging. It might be that those around the pair react and create situations of discomfort for the partner or the person living with dementia making the entire experience less comfortable and more frustrating. It is also possible that one of the partners no longer finds the degree or type of intimacy is pleasurable at all and actually becomes distressing or overwhelming.

So, what creates an intimate relationship? An intimate relationship can take on many forms. It could be intellectual, physical, or spiritual. It could involve productive or valued roles and responsibilities, fun or leisure-based activities, restful or spiritual restorative opportunities, or fitness and wellness activities for brains and/or bodies. Our best friends at work may not at all resemble our partner at home. My exercise buddy may or may not be my book club friend because our interests diverge or abilities are so different.

With various forms of dementias and the GEMS<sup>®</sup> states, each person will experience variation in intimacy needs, desires, and preferences, as will the potential partners or intimates of that person. Our perspectives, awareness, and sense of fulfillment or satisfaction will affect our desire to DO something, to PLAN to do something, FIND the TIME to do something, and to SEARCH out opportunities to do something with the other person. The same is true with the other person. If either of us is beginning to find the relationship less satisfying, less fulfilling, more annoying, or less comfortable, that person will tend to begin to dislike AND possibly avoid or limit the amount and intensity of contact.

SO, my question is: If you aren't getting what you like, want, or need from your previous partners, how are you getting these likes, wants, or needs met? When dementia comes to live at your house, you will **each** still have the need or want to find intimate pleasures at some level. What will be the substitution that is offered, how will it be offered for each person involved?

If not me, then who?

If not this activity, then what?

If not now, then when?

If not here, then where?

If not that long, then how long?

If not that much, then how much?

If I am the person living with Lewy Body dementia, and being in bed with my spouse is no longer comforting, it is annoying both in a sensory sense (I don't like a moving touch on my arms, legs, or trunk) and also in an emotional sense (I'm not sure that this person is actually my spouse at times). I don't want to mean to hurt my spouse's feelings, but it is so irritating that I just can't stand it. I either need to get up and get out of bed or I need them to sleep elsewhere. I still want to have them as my intimate partner in other ways and at other times, but **touch** is always *challenging for me* these days, *if I don't initiate and sustain it*.

If I am the partner of a person living with Lewy Body dementia, I miss the ability to show affection and intimacy through touch. I know my spouse doesn't mean to push me away, but I feel rejected and I miss our previous intimate relationship and can't find much satisfaction in only being able to touch when *you* want it. I feel like I shouldn't reject any touch you offer, since it is the one effort that you still make toward intimate contact. I am noticing your breath is bad because you don't like the sensation of mouth care or the taste of the mouth wash, and I understand that, but I really don't enjoy intimately kissing you or close talking with you anymore. I am missing touch, connection, trust, partnership in sleep time, and our partnership.

So, what can we do to help both of us cope with these changes, continue to find pleasure with each other in the places and time that are possible, and how and where will we get our unmet preferences and likes met?

- Is it possible that we could share a bed, if we have separate bedding?
- Is it possible someone else might be able to help the person living with dementia with mouth care in a way that feels more comfortable or in a way that is less distressing (using a mouth wash that has less alcohol and less flavor and a toothbrush with less texture)?
- Is it possible that hand massages might provide some sensory satisfaction for one or both of you?
- Could it help the care partner to get body massages so that intimate touch is being provided on a regular basis so that those continued needs are somewhat satisfied?

If I am a person living with Alzheimer's or vascular dementia and I can't hold on to the details of recent events the way I used to, and I used to and always liked to be involved in the daily lives of my grandchildren, I may seek intimate information in ways and places that make them or my children uncomfortable. I may ask the same questions over and over and then share what I hear with people that are not my grandchildren's intimates. I may be too intense, too close, or do too much touching.

As a daughter, I am feeling caught between two generations, both of whom would rather not spend time with the other, but feeling a need to try to preserve some sort of familial intimacy. I am feeling time pressured. I try to give my person living with dementia what she needs and also try to get my kids to better understand why grandma is doing what she is doing and meet their needs and preferences. What I am missing is, how much I am missing my relationship with my mother and her previous positive and intimate relationships with my kids. I am also having to pick up and manage some of the tasks she used to be able to do, leaving me with even less time to get my needs met in a one-on-one relationship.

How could this changing relationship be better navigated?

- Are there any activities my grandkids do that I could still enjoy watching them do or doing with them?
- Are there places or activities where I am still comfortable and competent. Can I still guide cooking, flower arranging, card playing, singing, or dancing? Could we use those opportunities to have intimate time with just us or to encourage time between the grandkids and myself?
- As a mom, could car rides be times for intimacy with the kids? It turns out that talking while traveling can provide moments of intimacy that otherwise seem to evade us. The article [“Kids in the Car: Talking to Teens”](#) in *Psychology Today* explores just that!
- How can conversations and moments of intimacy go beyond words? Are there places or spaces with visual cues or touch cues that can provide a shared experience of pleasure without the presence of words? Are there sounds or music that can connect us with joy or remembrance for one or both of us?
- Might there be value in adding in a new friend or confidante to listen and share our moments? Is it time to build a few new opportunities into each of our days to allow each of us to find other outlets for some levels of intimacy that are being lost?

As dementia changes abilities, it is vital to find that which each of us still likes about being with the other, in order to enjoy moments of our time together. If I can't find ways in which I like you, it is hard to spend long periods of intimate time with you without disliking you or resenting your presence. Taking short breaks from our time together by simply creating private moments for breathing, looking outward or inward, doing something special for me, or considering what is good in that moment is as important as what is done throughout the day for maintaining a healthy relationship with another whom you love. As much as we may want to care for another, we cannot BE that other person. We are ourselves. Each of us is unique and different, in some ways we compliment and complete each other, and in other ways we provide reflections of ourselves for each other. Creating moments of intimacy are those times when we find our place with each other and it is good.

In my experience, one of the most interesting things is that we may not realize how amazing the moment will be until it happens, or that we may not know how terrific it was until it is over, and that we may not understand it as a remarkable moment until much later in time. All we can do is strive to do our best, learn from our missteps, let go of the disabling feeling or belief that we could have done better or more, to be willing to try again with a wiser perspective and a hopeful heart, and to reach out to another if we are in need of help.

As I was researching this topic I ran across the article [\*\*“The Lesson of Every Conversation: Encouraging Teens to Have Meaningful Interactions”\*\*](#) from the website *We Are Teachers*.

For me it was certainly sad and yet seemed to offer some concrete ideas about creating opportunities for more personal communications between people who are not connecting. In the world of dementia care and support, it is not unusual for us to spend time with another person and yet not take the opportunity to reach out in some fashion to join, appreciate, understand, or accept them. Could we use something like this, even if not in a group, if we are trying to help care partners create intimate moments of connection when their life partner is changing and older relationships are no longer as strong or meaningful as they used to be? Could it help when we are seeking to support younger people in our lives and in the lives of people living with dementia? Could it help to offer more time, different support, more silence, or more willingness to see beyond the obvious and the actual words when we are trying to connect to the person living with dementia? Most importantly, will we allow ourselves to be curious and committed to finding ways to better understand the person who is living with something we can never experience as they are experiencing it.