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National Center on Caregiving



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Sexuality and Dementia

Coping with Changes in Your Intimate Relationship

How has your relationship with your partner changed as a result of disease? Physicians seem reluctant to address this question with caregivers dealing with a long-term chronic illness.

“No one asked me about my marriage or sexuality. Yet it plays a large part in our well being. No one asked me, ‘what’s the quality of your life?’ ... I’m a sexual individual. I’m 76 years old and I’m still alive,” said Jerry, who cared for his wife with dementia.

At a recent conference of the Caregiver Resource Centers of California, the keynote presentation was on sexuality and intimacy. At this presentation, there was a panel of caregivers who shared their experiences caring for their loved ones. As the audience of professionals listened, the moderator asked each one if anyone had ever asked them how the disease had affected their ability to be intimate. Each one, in turn, said that the subject had never come up with any professional, not even in a caregiver support group. Outside of the issue of disease, our society as a whole tends to deny the sexuality of sick and/or older people.

Dementia, diabetes, Parkinson’s, and stroke, to name a few diseases, can affect the ability of someone to perform sexually. Coupled with that, the medications that people are taking can also adversely effect sexual functioning. Although the incidence of a heart attack or stroke caused by sexual activity is extremely low, this is often a fear. One person shared that sex wasn’t gratifying; it was less frequent and more awkward. People may experience changes in arousal patterns and in the way in which sexual desires are manifested. There is often guilt and anger about not being able to meet the sexual needs of one’s partner and feelings of rejection if the caregiver doesn’t respond.

Being sexual in a relationship is part of how we have a sense of closeness and intimacy. “It was very comforting; there were periods when we were very anxious, devastated, scared... and being sexual with each other was real important. It became a time of connecting, a time of reassurance, a time of pleasure, it was a time when things felt normal when nothing else felt normal. Our life was unraveling and being sexual with each other was a time that felt good.”

The loss of the sexual relationship is a major part of the grief and sense of loss that caregivers experience while caring for a loved one. If the caregiver is tired and exhausted, frustrated and confused, it is hard to feel sexually attractive. “I became more of a caregiver and less of a romantic partner; it’s very hard to be sexual when you are acting like the mother,” said Ann. Anger and guilt can lead to not feeling good about one’s self, which can make it hard to feel sexual arousal.

The caregiver has another dilemma in wondering if he/she is taking advantage of a loved one when initiating sex, particularly when it is difficult to determine if this is a consensual act. Caregivers wonder if they are being selfish and irresponsible if they attend to their own sexual needs through masturbation or pursuing a sexual relationship outside the marriage. One caregiver shared that she sometimes has sex with her husband as a way to calm him down when he is agitated. But sex without passion or emotional connection can leave the caregiver feeling degraded.

Some people with dementia become hypersexual and need medication to decrease their sex drive. Inappropriate overtures to a nonspouse, verbal obscenities, and undressing in public are behaviors that may cause significant concern and challenges. When the spouse is exhibiting these behaviors, caregivers can find themselves even less willing sexual partners.

Each couple has to find ways that work for them to experience intimacy when disease changes the relationship. The history of how problems have been resolved in the past and how intimacy was expressed will affect how to cope under these circumstances. “...I realized how much I was losing, I realized how important it was, and I realized it didn’t have to be over for me. My husband at this point was still interested and it was me who was turning off.... Part of our lovemaking had always been being intimate and talking and sharing...and he would listen, but that part was going.... I had to do some real attitude shifts and I had to make a lot of adjustments....”

It may be possible to explore other ways to express intimacy and ways to enjoy nonverbal expressions of closeness. Acknowledging and mourning the loss is important. Joyce said, “Once the diagnosis came through, we had a period of great tenderness in our relationship—affection, holding, being able to look at each other deeply was very special. As time has gone on that has really shifted, my partner has become much more withdrawn.”

Caregivers have found support by talking with physicians, therapists, social workers, and clergy. “The doctor didn’t help me at all, except he listened...professionals don’t have to have answers or give advice, but just listen. He provided a safe space and he gave me permission to talk about this. What happened for me is that a light went on about an area of my life that I didn’t want to think about. I realized how much I was losing....”

Feel free to talk with your Family Consultant at FCA for support and guidance if you are struggling with this issue or others that are causing you stress. Call (800) 445-8106.