

Intimacy: A Casualty of Caregiving

There is a hidden cost to caregiving. It's not a financial expense, although you may be paying a pretty steep price. It's measured in emotional currency and there are no insurance policies to guarantee you protection. What is it? It's the price you pay when illness or disability deprives you of the intimacy you once enjoyed.

Families share multiple layers of intimacy. Between spouses, it has a sexual dimension; among the rest of the family intimacy becomes tangible in the caring and understanding acts that reassure family members that a safe and loving place exists for them. Caregiving changes roles, alters expectations and brings unwanted responsibilities. After a while, even the most resilient individuals may find that the burdens of caregiving have transformed their closest relationships in ways that leave them feeling frustrated and unhappy.

"The delicate balance of intimacy-difficult to achieve at best-suffers when expectations are derailed by disability," says Deborah Warren, a social worker for more than 20 years, now in private practice in Virginia. "It's normal to be angry when so much has to change, but society tells us we cannot be angry toward someone who is impaired; after all, it's not their fault. Caregivers are expected to pitch in and do the work; the impaired person gets the sympathy. Talking about the loss of intimacy is just not done-it's like the ghost at the party that no one mentions."

Changes in Intimacy

If your spouse must give up his dreams of the future because he's now bedridden, you, who shared the same dreams, must give them up too. If your mother's disease makes her belligerent and angry, you're the one who catches the brunt of her abuse. And if your child is no longer independent, you're the one on whom she is now depending. There's little wonder that in trying to adjust to a whole new life, intimacy can be lost. While everyone is different, there are some common experiences.

Altered Roles

For most people, work and independence equal self-esteem. When illness leaves someone unable to hold down a job, incapable of doing daily chores, or dependent on someone else for personal needs, their caregiver suffers greatly. Not only must you take on these roles, but you may find yourself with a troubling new view of your spouse or parent. When Ellen Burke's husband suffered a stroke her life turned upside down. "All of a sudden I became the primary breadwinner and had to take out the trash as well. I resented these added responsibilities. It seemed Tom was no longer the man I married."

Loss of Sexual Intimacy

It's hard enough to deal with sexual problems in the best of times; when illness or disability is added to the equation it can seem impossible. "It's not the sort of thing you just blurt out," notes Craig Roca, whose wife suffers from fibromyalgia, an illness that causes a great deal of pain. "Here she is living with constant pain, and I'm complaining about my sexual frustration. It just doesn't seem right, even though the problem is very real."

Sexual intimacy can suffer in many caregiving situations. Fatigue from caring for a parent can affect the relationship between spouses. The presence of a new person in the home changes the chemistry. Caregivers and care recipients alike need the emotional support that comes from hugging, touching, holding, and kissing. Experts agree this is one of the most difficult aspects of caregiving.

Loss of Balance

Families have their own internal mechanisms to keep life predictable and promote harmony. The added demands that caregiving makes on time and energy can shatter that equilibrium. Catherine Keane, a caregiver whose five-year-old daughter has acute leukemia, says, "Suddenly this illness, this outside force, has become the prime mover behind everything I do. There's no time to sit and talk with my husband about everyday things, or just go out for a walk. Everything is focused on the disease. I don't know who I am anymore."

No Right Answer

Take Care! spoke recently with several caregivers who have experienced enormous changes in relationships. Some feel extremely stuck and have become depressed. Some turn to other family members or friends to replace a connection that is simply lost. Some are able to redefine the relationship into something different but sustaining. Here are some real-life snapshots of people coming to terms with their new lives. (Names have been changed to respect the privacy of those interviewed.)

Anne Ford had been married just six months when her husband was diagnosed with secondary progressive multiple sclerosis. Over the past five years, he has experienced cognitive damage, significant right-side weakness, and is now unable to walk alone.

"I refer to MS as a very dark gift. I would never have volunteered for this. At first, there was a lot of misunderstanding and anger. He had so little control of things, I had no time to prepare, and we both had Scotch-Irish tempers to be proud of.

"At first we screamed a lot and then learned to fight fair. We agreed to stomp around the house and go to separate rooms if we had to. Eventually one of us would say, 'It's safe, you can come back into the house.

"The key to survival for us is to not look back at the dreams we had, but live in the present and maximize what we have now. By living in the present, I get unexpected gifts and miracles-such as sunsets. Last week we were arriving home just as thousands of fireflies lifted off the field. We go to the movies, or go someplace beautiful, and take time to talk."

Anne sometimes uses online support groups to explore grief and coping. She does Tai Chi and is going to school. "I have to look to the future. And my husband believes I can do anything; he supports my passion. That is unconditional love. And we have found things that we might not have found in our old life. This is certainly not the easy route, but life is so much what you make of it."

Sally Masterson's life changed totally when her first child was born with Down syndrome. "We went from starting a family in a new home with steady income and lots of dreams to a lifestyle I could never have imagined." Both Sally and her husband encountered difficult job situations for many years, due to a changing economy and the demands of caregiving; they were even forced to sell their house. Because their daughter was aggressive as well as disabled, school placement and care were hard to find. Both parents became passionate and effective advocates as

well as devoted parents, but the pressures took a substantial toll. Caring for ill and dying parents added to the burdens. There were few family members who could help. Sally and her husband are now divorcing, even as they struggle together to find the best placement and support for their daughter.

Looking back, Sally has some advice: "Be more selfish, whether that involves your employer, your faith community, or your family. Scream for help at the earliest point you see trouble coming. Start at the top with elected officials and work down the chain. And don't make things worse by doing a lot of volunteer work to 'help the cause.' You have enough to do, and working with the condition or disease you live with means you never get a chance to do something else. Try to do something for yourself."

Fred Hartford was unusually close to his mother, probably in part because his father was 23 years older than his mother. "I played games with her and did things most kids don't do with their mothers. Mom was completely independent until age 84 when cognitive loss began. She now requires 24-hour care, and over the past year, her decline has been rapid.

"It made me sad, but it also made me more useful in her life. Of course, there was the frustration of dealing with an impaired person; I had to learn patience and acceptance. And I had to change my own life and schedule.

"Anger and frustration are real," says Fred, a minister who has counseled others in his situation. "You have to deal with it. The worst thing you can do is stuff it-and this is what we do all the time because we feel guilty about the anger.

"In some ways, I am closer to her now, but we are on a different level. There are no more clashes over control. I have worked through a lot of old attitudes to understand and accept her and all that I mean to her. She now needs to be held, prayed for, and encouraged. It gives me satisfaction to do this. Nobody else can occupy the role I play in her life. For me, it's a precious time."

Natalie Imhoff advises, "Anger is not a productive use of energy when it comes to a loved one with Alzheimer's. In fact, it makes a difficult situation worse because the patient only becomes more bewildered or confused. It's best to flip the emotion from a negative to a positive, and focus on what needs to be done next.

"My friend and I have young husbands, both accomplished men, who developed early-onset Alzheimer's. We hang out together and call ourselves POAs-Prisoners of Alzheimer's. Practically speaking we are widows, yet we remain married, intimacy and companionship lost. We spend 24/7 attached to their care and then have to suffer friends who have the nerve to say we must feel guilty, or we would put them away and get on with our lives. Give us a break."

Celeste Schubert's husband had a brain disease. It meant her husband could no longer work and needed help organizing his thoughts and his days. Not long after he became disabled, a mouth lesion was found to be malignant, and over the next three years, Celeste and her daughter cared for him as head and neck cancer progressed. Caregiving required meeting all his personal needs and, eventually, complicated medical treatments.

"I was prepared for this by many years of spiritual practice. My daughter and I supported him long after the doctors and the hospice people wanted to give up. He needed total care, and the disease was so disfiguring that most people would not go near him. I would wake up at 5:00 am to do three hours of preparation each day-healing touch, forgiveness meditation, third eye exercises, and other practices. Many people came to help us. I consider 'staying in forgiveness' 100% of the time the crucial ingredient.

"Just before he died he said that this was the best time in his life because he felt so much love. And I got what I always wanted from him-he opened up. The cancer cracked him open and love flowed through him at the end. He was radiantly happy, and so were we."

What to do?

Each of us is unique, and our responses as a caregiver draw upon all the prior realities and nuances of our family relationships. Everyone has a different personality and set of coping mechanisms, and the change of roles can bring out the worst and the best in us, sometimes both in the space of a few hours. The professionals and family caregivers we spoke with suggest the following three approaches. Here are the basics:

- **Enhance independence** - It's important to encourage your loved one to carry as many roles as possible. Sharing responsibilities and activities is an essential

aspect of intimacy. Beware of any tendency to overprotect or swaddle your loved one. This will harm the relationship as well as both of you.

- **Communicate** - No avoiding this essential element of any relationship-what you say and how you say it is critical. Talking about your feelings will not only help you to remain positive, it will reduce misunderstandings and frustration. Don't assume what someone else needs or wants. Ask. And say what you need and want. This includes people who can help as well as your care recipient.
- **Strive for Balance** - Although caregiving can be pervasive, you can't let it be all-consuming. What you don't want is to let the disease dominate the entire family system. Remember to take breaks and maintain portions of your life outside the home no matter how hard it might be to do. The only way you can continue to do this work is by nurturing yourself. It is the only way you can stay healthy enough to provide good care for your loved one.

Intimacy requires trust, hard work, and faith. It is not automatic and never consistent. It is not like an unending merry-go-round but rather like a roller coaster with its highs and lows, swooping turns, and scary thrills. Caregiving causes changes in intimacy and the effort to maintain it or redefine it can be more strenuous than before, but the reward can also at times be sweeter.

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