

# The Surprising Erotic Life of the Elderly, Disabled and Chronically Ill

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In media, sexuality, sex and intimacy so often have as its subjects those who are young, strong and beautiful. They are the ones believed to be sexy, desirous, and desiring. In America we unabashedly use their image to sell products, health, success and influence. In so doing we inadvertently communicate that these are the people who are “sexiest” and thus having sex ... the “best sex”. But in my years as a clinician and qualitative researcher, I have had the privilege to hear stories of sexual passion, intimacy and celebration that have been silenced in the sexuality so often paraded in pop culture. In this paper, I will introduce you to four couples I interviewed over the last 10 years – names and identifiers have been changed. These couples have had at the center of their relationships an unwanted and uninvited visitor – progressive MS, cancer, spinal cord injury, and health complexities brought about by aging and chronic conditions. While each story primarily focuses on the specifics of one couple, I include in these stories the themes shared by other couples dealing with these particular illnesses and life states. One important variable to note is that each of these couples had in common a deep and unwavering devotion to each other and a ripened sense of the preciousness of time. Through these stories we not only learn about the effects of certain illnesses, but we also learn of the capacity of love and intimacy to penetrate significant hardship in order to touch the body and soul of their lover.

Though I will focus on one theme per story, you will hear all four recurring themes in each of the stories. The four themes are:

1. Great lovemaking is more than a set of behaviors
2. Illness must be put in its place so loving touch can be sanctified – or set apart

3. When sex doesn't fit the cultural construction you finally realize how varied and dynamic it can be
4. Life is short, loving is precious, and touch is more delicious as time goes on

### **Great lovemaking is more than a set of behaviors**

Bill and Carol have been married for 40 years. They have raised 3 kids and now enjoy being grandparents to 5 children. 15 years ago Bill was diagnosed with prostate cancer. He underwent surgery and radiation and has been cancer free since. 5 years ago Carol was diagnosed with inflammatory breast cancer and underwent a bi-lateral mastectomy, chemotherapy and radiation. Over the course of Carol's treatment, I got to know this couple. Carol and Bill described their sexual relationship as playful, fun and important to both of their sense of connection to each other. They agreed it was a primary way they pushed the intrusion of the world away and melted into each other. As we talked about the adjustments Carol and Bill would make as Carol prepared for her mastectomy, Carol was quick to say that they had been through this before and knew they would find new ways to love and touch each other. They both described how Bill's prostate surgery left him with significant erectile dysfunction. It had been a challenging adjustment, but in time they had found all kinds of new and surprising ways to pleasure each other and craft sexual touch that was in its own way playful, fun and restorative. They described a clearer awareness of the preciousness of life which gave them added determination to find new ways to be erotic and work with the erectile changes. In their time of discovery, Carol said they talked about how their previous sexual relationship had ignored so many other senses and other parts of their bodies. Smiling at Bill she said, "Though it was great then, it focused on body parts and orgasms". They loved what their bodies could do when they were young and healthy, but now they were more intentional to move the focus away from the genitals determining "good sex" and allowing fun, playfulness, and the vocabulary of their whole body to communicate love. As they did this they began to discover many new ways to give and receive touch. They were often surprised by the depth and freshness of their lovemaking. As they looked ahead to Carol's bi-lateral mastectomy and as we talked several times after her surgery, they had confidence that this new change would have its losses and challenges as Bill's experience had. But they had a deep confidence in their ability to find new discoveries of touch, love and mystery. Sex and

sexuality had been transformed from behaviors and genitals to discovering and expanding a repertoire of ways to express their gratitude for life, their relationship and more time to discover the mysteries in their naked space.

### **Illness must be put in its place so loving touch can be set apart**

I met Phil and Mary shortly after meeting a couple of their grown children. They had been married 34 years and described the first 14 years as filled with all that is good - a playful and strong marriage and the birth of a son and daughter. When their kids were just entering grade school, Mary gave birth to their youngest child. Less than a year later, she awoke with severe vertigo and blurred vision. Two weeks later she was diagnosed with MS. Now more than 20 years later, Phil and Mary describe the constant redefinition of life, roles, and their marriage. Another couple, Greg and Patricia, who have also lived with Greg's MS for over 20 years tell similar stories. As the illness progresses there is a time of redefinition of every aspect of life. Grief, anger, frustration, exhaustion, are sprinkled with mysterious moments of love and gratefulness. As time passes a "new normal" is found. The enduring challenge as the illness progresses is searching for a way to keep illness in its place as the roles of care-giver and care-receiver become more intrusive and expansive. Phil and Mary in our last conversation talked about how their roles can eclipse any awareness of their love for each other as life partners, and how they intentionally must set aside time to touch and connect to their love for each other. Greg and Patricia comment on this as well. Patricia said that intimacy and touch seems to evolve and change constantly. Now with the advance of Greg's cognitive challenges, Greg spends evenings as Patricia falls asleep gently stroking her body. Patricia says this gives Greg great joy and gives her a sense of being able to connect to the heart of Greg that has always loved her so. "Though this may not sound like much, and there is much that I miss about how we were able to share our bodies when Greg was more healthy", she says, "This is the sweetest part of my day. It helps me remember all the ways we have loved and touched each other over the years."

**When sex doesn't fit the cultural construction you finally realize how varied and dynamic it can be**

Life for David and Julie was irreversibly changed 8 years ago when David had a serious fall snowboarding and broke his neck. Prior to the accident, they were like so many young professional families I see. David was VP of an investment firm, Julie was a stay at home mom and together they had three children, 3, 6, and 8. Julie describes their life before the accident as harried with both of them completely absorbed in the many tasks of their life roles. David adds that they used to fight a lot and neither seemed to understand why the other was so stressed out. Their sex life was routine, stilted and failed to reconnect them. The accident turned everything upside down and learning to craft a life as a paraplegic took all of their attention and energy for more than a year. It was during this time however, that both of them realized how close they had come to losing each other and losing their family. As this realization crystallized, they began to see in each other the strength, wisdom, tenacity and love that had become buried by their middle class life and cultural definitions of success. They both talked about the enormity of adjusting to David's injury and the year of grief upon grief as they both realized the specifics of all that was and would be changed. But it was then in the conversation, that Julie began to talk about what they discovered in the wee hours of the night when it was finally just them behind closed doors. "I think a kind of desperate love was carved into our marriage though this. After David was settled in bed and it was just the 2 of us again, it was like we could not touch, taste, smell, see each other enough. We needed each other to get through this and we needed each other bad. Without even realizing it, we let this desperate need for each other craft a whole new way of loving and touching each other. David's injury immediately meant our touch would be different, but in those moments, our need to love each other with as much of us as we could, seemed somehow to eclipse this." These experiences of the first year in particular seemed to set the stage for dealing with the losses and changes that were evident in David's body. Somehow, it was this new found discovery of each other, the acuity of their senses and their visceral desire to feel each other that gave them confidence in their ability to craft over time a varied and dynamic sexual relationship. Now 8 years later, with kids 11, 14, and 16, life is still very busy. David has returned to a thriving career, Julie is as busy as ever with taxiing kids around to school and sports, but there is a determined intimacy that has been well tested and is regularly enjoyed. Though life has many challenges, they describe themselves as happier as a family and happier as

a couple then they were prior. “I sure would never have guessed that if I hadn’t experienced it”, David said. “You’d think from what you grow up learning that Julie and I would not have a sex life at all ... but that is so not true!”

### **Life is short, loving is precious, and touch is more delicious as time goes on**

John and Kathy have been married for 32 years, it was the second marriage for both. John is 77 and Kathy is 69 and both are delightfully affectionate with each other. John jokes that Kathy is still the apple of his eye and pretty much a saint now, having put up with him so long. They have come to talk to me after hearing about my research and desire to gather stories of those whose sexual expression is deeply satisfying in spite of illness, disability or aging. They remind me of my parents. John is the talker in this relationship. He says that he wishes he knew when he was young what he has learned as he has gotten older about sex, love and touch. When he was young it all had to do with erections and how his penis performed. Sexual satisfaction was determined by the number of times a week he had sex and not on how invested he was in the act of love making. “Sex, (intercourse), was something you were supposed to do several days a week or something was wrong with you as a man, or with your wife, and something was wrong with your marriage.” He said, life with Kathy has taught him that the best sex and best touch comes when he is overflowing with gratefulness for Kathy. She blushes. He goes on to say that 32 years have gone so fast and each day he is more and more grateful for her and for their life together. He says that it is this awareness of love and gratefulness that seems to fuel their passion, touch and energy for each other. He laughs as he says, “And those blue pills have helped a little too!” “Now I just chase her around the bed.” Kathy rolls her eyes. “Actually”, Kathy says, “It isn’t about how our bodies work or don’t work anymore, it is about using our bodies however we want to love each other. I love this man and I love to touch him, he loves me and he loves to touch me. It’s about using our bodies to speak what our hearts want to say.” She looks at him. “We both wish more people knew that and didn’t have to wait so long to discover it.”

Let me conclude with a final story of Jake and Cami. On one particular fall day, I was on my way to meet with Cami and Jake at their home. Jake had end stage cancer – a brain tumor

called glioblastoma multiform grade IV. He had already lived longer than any patient I had treated with this tumor, but after 2 years the tumor had taken its toll. In the last two months it had slowly taken Jake's left side, then his legs entirely and in this past month, Jake was primarily in his bed except for occasional "walks" outside in the wheelchair. Jake and Cami had demonstrated the strength and passion of their love in countless times over the 4 months I had been meeting with them. Jake would talk to me about his worry about Cami and then find a way to talk with Cami about life after he was gone. He called his closest friends and family members and recounted memories, asked for their continued care for Cami, and said his good-bye's. Cami and Jake had braved precious and courageous conversations of their deep love for each other, their most precious memories, their hopes and fears for each other, and all the difficult logistical conversations of life after the death of a spouse. When I arrived to the house, Cami greeted me and said that Jake was sleeping. We sat in the kitchen and had a cup of tea. She looked off over the view of the city .... "Jake slept most of yesterday and seems to be slipping further and further away. I had been so sad and down most of the day and had not wanted to leave his side. Though this stage is killing me, I am so acutely aware that when he is gone, he is gone." Then with fierce intention, she turned to look at me ... "But last night the most incredible thing happened. I was ready for bed and sitting in the chair by his bed reading. All of a sudden, he turned to me. His eyes were more aware and awake than I have seen in days. He said, "Sweetheart, come here and lie down with me." I was so surprised. I slid my body next to his and put my head in the crook of his neck like I had done so many times before. His arms cradled me. Tears were rolling down both of our cheeks. "I hope you never forget how much I love you", he whispered. "How could I", I said, "You are my kindred". I just laid there feeling every inch of where his body was touching mine, smelling his smell and listening to his breath. I soon fell asleep as well. There was something about those moments next to him, drinking him in as if it was the last time, which felt somehow sacred. Like the deepest lovemaking of our spirits. Words really don't describe it well – but I will never forget those moments for as long as I live."

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