



SILICON, SEX and POLIO SURVIVORS

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Last January I got a brand new Macintosh computer that came with a modem. Ever since I've been "surfing" the Internet, hardly stopping for food or sleep. You'd be amazed at what I'm finding on the disABILITIES bulletin boards: Sex. Yes, unbridled, undiluted and unimpeded discussions about sex among people with all kinds of disabilities, from high-level quads to quadruple amputees. However, there is one place where I've heard no discussion of sex: the Post-Polio bulletin board. There are lots of questions about PPS that you had the answers to years ago: Do I have ALS; does exercise make you weak; where can I get a scooter? But, not one question or comment about sex.

I guess I shouldn't be surprised. Many of our patients at Kessler don't mention sex, either. Some mention that spouses do not believe that PPS symptoms are "real." But, most often spouses are very supportive about the need for their post-polio mate to slow down and take care of themselves, even if that means a new brace, crutches or a scooter. So, if spouses are so supportive, why is there no mention of sex?

ALL'S TOO QUITE ON THE SOUTHERN FRONT

There are probably several reasons for the lack of talk about sex:

- Many polio survivors grew up in the 50's when discussing sex was the same as walking down Main Street without your pants. Also, 40 years ago, even more than today, people with disabilities were thought not to be fully human, let alone sexual beings;
- Also, it was vital back in the dark ages that anything not "normal" (that is anything not seen on Ozzie and Harriette) be hidden. So, if a polio survivor expected to have a relationship with someone the disability had to be hidden. Since the polio residuals were often hard to hide, the disability was often just ignored or denied. It amazes me still how many survivors tell me that they have never, ever discussed the fact they had polio with their spouse, let alone the experience of having had polio or - God forbid - their feelings about it.

The process of hiding, denying or ignoring the reality of what's happening in one's body caused problems. Many people just turned off any awareness of their bodies and any feelings they have below the neck. Others have turned off ALL feelings, both below and above the neck. Since you can't turn off pain without turning off pleasure as well, an inability to feel will make sensuality or sexuality nearly impossible - or as appealing as eating dry toast.

Also, walling off one's feelings also cuts off the ability to be intimate with oneself and with others. And,

intimacy is the gateway to sexuality.

- Having a visible disability at an early age can result in other barriers to intimacy and sexuality. There is a disturbingly high frequency of physical, emotional and sexual abuse among polio survivors. Nearly one third of the patients we treat have been physically or emotionally abused, and 25% of the women have been sexually abused. Not surprisingly, those who have been abused are much less likely to risk intimacy or be interested in sex.

Also not surprisingly, the more obvious the assistive device people used following polio the more likely it was that [they] had been abused. No wonder polio survivors discarded their braces and crutches and don't want them back - ever! Now, 40 years later when PPS symptoms start and braces, crutches and wheelchairs are appearing again, the painful memories of the past and the reality of disability can no longer be hidden. Old fears of unacceptability and new fears of rejection surface and cut self-esteem off at the pass. And, the old vicious Rules of Society also come screaming back:

Rule #1: If you're disabled, you're not attractive;

Rule #2: If you're not a attractive you can't be sexual;

Rule #3: If you can't be sexual, you shouldn't have sexual feelings;

Rule #4: Wear flannel pajamas and sleep on the couch.

"IF I THINK I'M SEXY AND I LIKE MY BODY..."

Well, sexy is a sexy thinks. One of the disABILITIES bulletin boards is actually called "Sex is 99% Mental." Sure you may not look like Cindy Crawford or Mel Gibson. But, how many non-disabled people do? What counts is how you feel about yourself, not how you look to others. If you're not acceptable to yourself, you won't be sexually available to or even intimate with others.

The first step to intimacy and sexuality is recognizing and dealing with the emotional reality of the original polio and any abuse you have experienced because of it. Next, you need to identify your own negative feelings about yourself and stop projecting them in to the heads of potential friends and lovers. Since a whopping 72% of polio survivors are married, it's your spouse's head that you're filling with your own negative thoughts about yourself and fears of rejection.

Finally, if you turned off your body to stop feeling physical pain, you need the experience of good physical feelings. You need to decrease your PPS fatigue, muscle weakness, and pain by decreasing physical and emotional stress. Then, you need to start sending pleasant physical sensation to your brain. Try long hot baths, a whirlpool or best of all a massage. When you make nice to your body and good feelings start traveling to your head, other good physical sensations (like the erotic ones) will follow that "stairway (or ramp) to heaven."

For those who are single, get a computer, a modem and start "surfing the net." It is actually possible to meet hundreds of people without leaving your living room. Whether you decide to let them into your life (or your bedroom), the safety of the computer gives you the freedom to be yourself and even practice being intimate with others, without worrying that everyone is looking ONLY at your brace.

When all is said and done, here's the Golden Rule for being an intimate and sexy polio survivor (with apologies to Nike):

Turn off your thoughts, turn on your body and JUST DO IT!

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