



## Sexy with a Disability

By Alessandra Djurklou, Sirens Magazine

Posted on May 14, 2007, Printed on November 5, 2008

<http://www.alternet.org/story/51775/>

I was 12, and I was standing at my school's snack bar, waiting to buy a sandwich. Next to me was Susan, who, like me, was on break from rehearsing the sixth grade play. Susan didn't like me. I knew this for a fact, since she once announced it publicly. I don't know why she disliked me. I didn't have any classes with her; I never really spoke to her. But it was middle school. She didn't need a reason.

"You're ugly."

She didn't say it in a mean way. It was kind of offhand, like she was talking about the weather.

"You're ugly, too."

I was just as casual, but that got her. She was flustered. I don't know what she expected from me. Maybe I was supposed to cry?

"Well," she mumbled at last, not looking at me. "At least I'm not deformed."

I pretended not to hear. I had won, and she knew it. And I knew it. But she was right. While beauty may be in the eye of the beholder, let's face it -- at 12, in sixth grade, I was deformed.

I am deformed. I was diagnosed with rheumatoid arthritis at age 5, and this was the picture the doctor painted of my future: hammer toes, "swan-necked" fingers. No movement in my wrists, ankles, eventual crippling of knees, elbows, hips. Much of it has now come to pass. And because of that, I've faced a lifelong struggle when it comes to sex -- not the physical act so much as the most crucial part of getting it on: feeling desirable. In this society, being sexy is required if you're a woman, and from Susan's hurtful comments onward, it's been made clear to me that my arthritis -- and, in fact, any physical shortcoming -- is not hot. What I can say, though, is that we can get past it, with a little defiance ("You're ugly, too"), a little denial, and a little patience until the right partner comes along (he has).

We are obsessed with being sexy -- so obsessed that we get implants, suck out fat, pump ourselves with Botox and even mess with areas best left unmessed with. But sadly, my condition is one thing plastic surgery can't fix. Finger joint replacement is still experimental, and usually not recommended unless you're over 40. Nor are cosmetic procedures. For a while, I considered getting a nose job. And a chin implant. The arthritis had impaired the development of my chin. (As for my nose -- gee, thanks, mom.)

When I mentioned this to my rheumatologist, she was horrified. "Do you have any idea what that would do to your immune system?" You see, rheumatoid arthritis is an immune system disease, where cells attack healthy tissue, particularly in the joints, and destroy it.

Boy, talk about self-hatred, huh?

My condition is most obvious in my hands, with the left worse than the right, my left middle finger frozen at the middle joint. It comes in useful when I need to make obscene hand gestures, but other than that, it's awkward and unsightly. The finger right next to it, the ring finger, is a bit more flexible, though equally twisted. But the sparkly new ring I have been sporting there for the past two months makes it easier to look at.

And to wonder over, because I never thought this would happen. I never thought I would get engaged, much less married. After all, being deformed isn't sexy. And neither is the disability that comes with it.

It's not like there are many role models out there in the media. The disabled are rarely portrayed as sexy. Brave, yes. Melancholy, sure. Angry about their lot, check. Objects of concern and pity (stop calling me "special!"). But sexy? No. The hot babe who gets the guy isn't limping toward him, gnarled fingers grasping his strong shoulders as they kiss. And if she is in a wheelchair, it is only temporary.

Because if you're disabled, you're pretty much unfuckable.

But I'm not about to ask you to strike up the violins for me. I started dating in ninth grade, which is perfectly respectable. I was, in fact, the first in my circle of perfectly abled friends to get a date. As a bonus, he was the guy I had been crushing on for months in French class.

I went to the Winter Formal, I went to the prom. College was an arid experience, but that's because I went to an all-female school. The few men around were either

terrified or had harems. If I'd had any sapphic leanings, I would surely have scored (something my fiance bemoans to this day).

After college, my luck improved. For a few tumultuous passionate months, I was sleeping with a man who can only be described as a hottie, and who told me, point-blank (after he'd already gotten some!), "You are really sexy." It was such a Harlequin moment, but I know he meant it.

One time, I was driving home from his place, listening to "Love Line." A woman was talking about being disabled. "I can't get laid to save my life!" she told Dr. Drew. I felt for her, thought about how much I could relate. And then I realized I was going home after getting laid.

Why wasn't I unfuckable then? I was in denial. About being disabled. I never thought of myself that way. Dry dating spells had nothing to do with the way my fingers or toes or elbows looked. I just needed to lose a few pounds, needed to get out and meet more guys. I am a decent conversationalist, I have led an interesting life, and I have an interesting job. And there was never much wrong with my legs, or my hair, or my skin. Woo them with the good things, I figured, and ignore the bad.

But even denial doesn't always work. Reality tends to slap you when you least expect it. For example, one New Year's Eve in my 20s, I was going to a club with friends. I was dressed up, with fuck-me shoes and a cute short skirt and just the right hair and makeup. The yummy bouncer was about to stamp my hand. I smiled at him flirtatiously.

"Oh my god, what is wrong with your hands?"

Denial doesn't work at the doctor's office, either, which is why I hate going there. (Not to mention that at 35, I'm by far the youngest there.) Denial is what kept me from getting a blue tag for my car for many years. I finally succumbed when I moved to a neighborhood with no parking. The thought of limping 2 miles home late at night in sketchy circumstances was just not appealing.

Accepting I am disabled would mean accepting society thinks I am unfuckable. Or to put it in a nicer way, that I am not sexy. And yet, my fiance thinks I am sexy. But what if he disappeared? What would I be up against without my denial?

Apparently I wouldn't be out of the game completely for many men, but I would be required to be extra-grateful for their attentions. On one well-known online men's mag site's message boards -- a ruthlessly honest place, where threads include rants against "fat chicks," "feminazis," and hotties with "entitlement issues" -- a guy posted a story

about finding a woman's profile on an online dating site. Whatever disability she had, it put her on crutches, and made her dependent on her parents. To this guy's credit, her disability didn't stop him from emailing her.

But his reaction to her rejection was interesting: "Now I thought handicapped people had this whole new perspective on things when it came to dealing with their disability," he wrote. "But apparently, they don't see their disability as a shortcoming, as, say, compared to a short guy or something. First, overweight women thinking they can land a GQ guy ... now we have handicapped people thinking they can do the same thing. Heck, might as well do away with handicapped parking lots, eh?"

A subsequent poster, who identified herself as a disabled woman, responded: "One of the things it took me too long to realize about my husband is that he married me in part because he thought he finally had a beautiful woman who couldn't leave him. He thought I would be so overwhelmed with gratitude that I'd put up with any crap he dealt out, and his anger when this turned out to be false still hasn't cooled."

So how do women with disabilities like mine deal with dating? Do they feel sexy?

"It does affect my appearance," wrote one poster on a rheumatoid arthritis site. "I've had both knees replaced, and I have these horrible, ugly 9-inch scars running vertically from just below to just above my knees. It looks like I have runs in my hose, so I have to keep my knees covered. It's hard to keep your hair properly when it hurts to raise your arms, and the crooked toes aren't too attractive in sandals either. I was 'lucky' in that I did not develop RA until my mid-50s, and I've been married to the same dear, sweet man for over 43 years." Another interesting note: She said her doctor told her most of his women patients who develop arthritis are divorced within a few years after diagnosis.

"It is just a reality now that I can't swing from the chandeliers, do flip-flops and summersaults, hand stands and seductive twists and twirls," wrote another. "But I can flutter my eyelashes and give a wink. I can say 'I love you.' I can give a hug and kiss."

So true. Still, I can't help but wish I were limber enough to actually strike some of the poses in the Kama Sutra. Or even pounce on my fiance in the morning, when his hormones are highest, instead of wincing in pain and reaching for drugs. But the one post that struck me most was one from a woman about my age, who had gotten arthritis as a teen: "My worry has always been that no man would ever want 'damaged goods,'" she wrote. "Why would someone marry me if I had a disease that would only get worse with time?"

But not every guy is like the one on the men's mag board: "My current boyfriend has

done wonders with my self esteem," she continued. "He loves me despite having RA. He actually helps me get through times where I am feeling useless and worthless. And I'm confident that if he and I don't end up together, that I will find someone just the same."

But some things are even more important than finding that special someone. As that first disabled poster (the one who responded to Mr. Disgruntled) wrote: "I have the rest of my life ahead of me to do whatever I want, because the worst has already happened and I have survived it. There is nothing more liberating than realizing that everything people have told you about what's important in life -- money, status, a man on one's arm -- is meaningless noise. The pursuit of them will drag you down a lot farther than a faulty immune system will."

She has reached a point I'm getting closer to, with a lot of help from my fiancé (and no help from the likes of Susan and Mr. Disgruntled): acceptance. Not of the idea that she is unfuckable, but that there are more important things than being fuckable. Which is really kind of sexy.

*Alessandra Djurklou is  
the food editor and  
theater critic at the  
Press-Telegram in  
Southern California.*

© 2008 Sirens Magazine All rights reserved.

View this story online at: <http://www.alternet.org/story/51775/>