

Sex, Women and SCI

BY STEPHANIE D. LOLLINO



FacingDisability.com features women with spinal cord injuries answering questions about sex, dating, pregnancy and more.

Try Googling “spinal cord injury and sex therapy.” The results may surprise you, especially if you’re a woman. Most of the links are to information about men — fertility, ejaculation, penile implants and the whole world of male enhancement drugs.

For women with SCI, finding trustworthy, reliable sex advice and information is a struggle. Mostly, they are on their own. “Most of the sex talk in rehab is more geared toward the men. They have sex dysfunction clinics, fertility support groups, devices to help collect semen and medication ... and the women tend to get bypassed,” says Kristine Cichowski, director of the Life Center at the Rehabilitation Institute of Chicago.

“It really bothers me that there’s not a lot of information about sex and sexual issues with women at all,” says Michelle, who was paralyzed in 2002 at age 21.

“If someone had just come to me and been like ‘you can still have sex,’ just blunt like that, that would have been great,” says Carrie, injured at age 20.

“I probably would’ve slept around a lot more in high school if I could have taken my pants off without help,” comments Tiffany, 36. She is the executive director of SpinalPedia.com, a website which contains many videos on SCI topics, including women and sex.

The three women, all quads, shared their thoughts on FacingDisability.com, a website where people with disabilities answer questions about their lives in video testimonials.

Internet Info on Women, SCI, and Sex
Increasingly, women with SCI are turning

to the Internet for information on sexuality. “Often there is not enough time in the hospital or in rehab to delve into sex and intimacy,” says Thea Flaum, founder of FacingDisability.com. “Typically people with SCI get 11 days in the hospital and 36 rehab days — if they’re lucky.”

Dr. Kristi Kirschner, an expert with more than 30 years of experience in spinal cord injury rehab programs, notes that rehab stays are now only a shadow of what they used to be. “When I started back in rehab in the late ’80s, it would not be uncommon for someone with quadriplegia to stay in the hospital for six to nine months. We had people going home on a trial basis and then coming back. It was a different world where the newly-injured had time to discover problems and then talk to staff about sex when issues came up.”

FacingDisability.com was specifically



Carrie shares an intimate moment with her beau in a quaint restaurant .

created to connect families who suddenly have to deal with a spinal cord injury with the experience of others. It gets 150,000 unique visitors per year. The website contains 1,500 videos of family members and experts answering questions about SCI. Among the most highly viewed videos are those on marriage and children, intimate relationships, and sex and fertility.

You've probably never heard of Diane Rowles, but she's something of an Internet superstar. She's a no-nonsense, pull-no-punches, straight-talking expert on sex and SCI. What Rowles offers in a series of Q-and-A videos on FacingDisability.com is an easy-to-understand how-to guide to the joys of sex after SCI.

One out of every 10 visitors to the website watches Rowles. Her popularity highlights how hungry people are for solid information and believable materials on sex. Her most frequently viewed videos answer these questions: "What's the first thing to know about having sex after SCI? What are common psychological obstacles to sex that women face after SCI? Can women still get pregnant after SCI? What do people do with a catheter during sex? How should expectations about sex change after SCI?"

YouTube: TMI

Another Google challenge: the topic of spinal cord injury and sex has over 6,400 videos available on YouTube. Accord-

ing to Nielsen ratings, YouTube reaches more adults than any cable service. It's fast, and it's free. But navigating through it all is a challenge.

"A lot of the time people are searching and searching in the middle of nowhere through YouTube or something — for videos that pertain to themselves and their specific injuries but can't find what they want. Visitors to SpinalPedia.com can search a section under "Life" called "Dating and Sexuality" for videos about women

"It makes it possible to rediscover your sexuality without having to talk about it with people you wouldn't have discussed it with before your injury."

and sex, says Tiffany. She adds, "There are videos that give really frank advice, and clips that discuss positions that go from PG-13 to bordering on R-rated."

"Watching videos is such a great way for people with SCI to figure out their lives. It's like being there with them and talking to someone and learning from them — it's very sterile learning any other way," Tiffany says. "But when you

see a video, it's like, wow, it just kind of hits home a lot harder and sticks with you better. There is just something about video; you can't do any better than that when it comes to conveying a message."

Rachelle Friedman, who sustained a C6 SCI at her own bachelorette party in 2010 when a friend playfully pushed her into a swimming pool, finds videos helpful for another reason: you're not face-to-face. "It makes it possible to rediscover your sexuality without having to talk about it with people you wouldn't have discussed it with before your injury. You want to keep intact how your loved ones perceived you before your injury as much as possible. This is where the Internet becomes helpful."

Female Orgasms and SCI: They're for Real

"I was mostly curious about orgasms after my injury," says Friedman. She has a lot of company. For women with SCI, orgasms have been a subject of speculation, but scientific information is difficult to find, unless you know where to look for it.

The pioneering researchers who studied orgasm in women with SCI were Marca Sipski-Alexander and Barry Komisaruk with Beverly Whipple, Mitchell Tepper, and their team, who conducted trials independently and also collaboratively in the 1990s, proving that orgasm was possible [see NM, "Reclaiming Your Health," Oct. 2001 and "Pleasure Principles," Oct. 2002]. In the early 2000s, Komisaruk published a study that pinpointed a specific path to female orgasm — the Vagus nerve — which can be activated by deep stimulation of the vagina and cervix, either by a partner or through self-stimulation, using a sexual device such as a dildo.

"When women with paralysis came to the lab for our study, most of them were shocked to discover that they could still feel their vagina and cervix. They had been told in the hospital that they could not have an orgasm due to their injuries. They were told their sex lives were over ... and they never tried," says Komisaruk. "It was extremely emotional. They suddenly burst into tears, and so did we." He adds that the level of a woman's injury, and the length of time since injury, did not affect her ability to experience an orgasm.

Women who have tried the tech-

nique report: “It’s definitely orgasmic.” “It feels like a tingling.” “The bottom line is — it works.”

“Sometimes the loss of sex is the most upsetting and conflict-causing consequence of SCI,” Komisaruk says, “tearing apart families and relationships.”

The good news is that these days, successful sex for women after a spinal cord injury comes down to finding the right information. Friedman sums it up: “You can learn anything online. And connecting with the experience of others is priceless.”

Related Resources

FacingDisability.com — specifically created to connect families who suddenly have to deal with a spinal cord injury with people like them. You can watch personal videos of people answering questions about sex, dating, and maintaining a social life in a wheelchair after SCI.

Streetsie.com — a website with hip forums titled, The Mad Spaz Club — Where all the Cool Wheelchair People Hang Out. Contains content about sex and dating with pictures of women and



Michele met her boyfriend in the workplace, just as so many other women with or without disabilities do every day.

men in their chairs in intimate poses.

SpinalPedia.com — a social mentoring network and video archive that allows the spinal cord injury community to motivate each other through individual experiences.

Newmobility.com – NM has led the way in covering issues unique to women with SCI/D. For an archive of articles on body image, health, self-esteem, sexuality, fashion and more, visit www.newmobility.com