

IVUN Joins Those Studying Sexual Activity and Chronic Illness

Deshae E. Lott, PhD, Bossier City, Louisiana, deshaelott@hotmail.com

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The mysterious nature of the human body keeps us engaged scientifically as well as experientially. When our bodies veer from the norms, it offers us more to explore, which can be both exciting and challenging. Sexuality rests among those fascinating and complicated aspects of human existence.

Dr. Rosemary A. McInnes, Sex Therapist at the Australian Centre for Sexual Health in Sydney, argues that, “Relationship and sexual satisfaction are important boosters of quality of life, a crucial concern for patients who live with chronic illness. In a life restricted by illness, sex can be a powerful source of comfort, pleasure and intimacy, and an affirmation of gender when other gender roles have been stripped away. For patients with chronic illness and their partners, a satisfying sex life is one way of feeling ‘normal’ when so much else about their lives have changed.”

As true as this is, health care practitioners, families and even those of us who use vents don’t necessarily converse freely on just how those of us who use vents respond to our sexuality and act upon it, or how we might improve our abilities to act upon it. No physician, nurse, or physical, occupational or respiratory therapist, or social worker ever has approached the topic with me.

While dialogue about vent users’ sexuality may be lacking within the health care system, resistance to this type of dialogue rests among some of us vent users, too, not just society at large.

International Ventilator Users Network contacted me and proposed a study on this topic because new vent users periodically pose questions to the organization about the sex lives of other ventilator users. The opportunity to collect and then present information that might enhance others’ quality of life appealed to the teacher in me.

With my husband, I created a survey to find out about sexuality among my

fellow ventilator users. Many of you responded openly with intimate details. However, one vent user told me to mind my own business, that there was no place for such research, and that it invaded people’s privacy. Given how often we deal with being the object of others’ gazes, I relate to the desire for privacy when it comes to intimacies. I am honored by and proud of respondents’ forthcoming reports, which offer hope and benefits to those who wish to keep reading.

The Survey Respondents and Their Self-Reported Sexual Activity

With the help of many of you who responded to my call, I present findings from our recent study about vent users and sexuality in the hopes that it will engage us all further in discussion about this important aspect of our health and quality of life. This study was conducted by an Internet poll.

Over the period of a month, 48 survey responses were gathered, resulting in 43 valid responses. While most respondents live in the United States,

Meet Deshae: Deshae E. Lott, PhD, teaches in the English Department of Louisiana State University in Shreveport, and her husband, Jeffrey D. Sadow, PhD, is a political scientist and professor at LSUS. They authored “His Choice: My Life” and “Her Life: My Caregiving,” *Ventilator-Assisted Living* (Vol. 19, No. 3), Fall 2005.

multiple responses also hail from Canada, Great Britain, and Israel. And, via personal narrative, representation also comes from Japan.

The gender distribution is 51% female (all indicating they practiced sex heterosexually), with an average age of 48 and 15 years on ventilation (with four respondents indicating over 50 years using some form of mechanical ventilation to survive).

Over a third of the respondents live with the effects of polio, and almost as many live with some form of muscular dystrophy (MD). Most of the remainder, 14%, live with a spinal cord injury (SCI). The majority of respondents use ventilation almost or as many as 24 hours a day, but 30% report using it fewer than nine hours a day. Almost one quarter of those survey respondents who report sexual activity use a form of noninvasive mechanical ventilation (NMV).

An array of sexual activity takes place among the sexually active group in our survey:

- 82.1% report they engage in vaginal intercourse; most often the respondent utilizes positions of abled partner on top or the “spoon” position (the male entering the female from the rear while both lie on their sides).
- 88.0% report they receive oral intercourse.
- 44.2% report giving oral intercourse.
- 14.0% report having anal intercourse.
- 51.2% have their genitals stimulated by their partners in ways other than vaginal, oral and anal intercourse (for example, by genital touching).

- 51.2% stimulate their partner’s genitals in ways other than vaginal, oral and anal sex (for example, by partner-induced genital touching).

Although our respondents could name as many erogenous zones as they like, they cite the neck as the most common erogenous zone (13.1% of total responses), followed by breasts and testicles (9.8% each), and the clitoris and the penis (8.2% each).

Regarding sex without a partner involved, a quarter say they can still masturbate, and 14% still do. No one surveyed has a partner watch them while they masturbate; however, almost a third is at least sometimes in contact with a partner when the partner masturbates, and over a third watches their partner masturbate. Twenty-one percent of our respondents at least sometimes engage in simultaneous/mutual genital touching.

Some differences noted in behaviors among our survey respondents include the following:

- Older respondents and those with less daily time using ventilation are more likely to be sexually active.
- Women are more likely to receive oral intercourse.
- Those without feeling are more likely to give oral intercourse.
- Those with permanent catheters are more likely to receive oral intercourse (these catheter users also reported engaging in vaginal intercourse as well).
- Those with edema are more likely to be sexually active and to be stimulated by partners.

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The most-often reported problems among our respondents for various kinds of sexual activity include:

- Vaginal intercourse: One-third indicated positioning; a quarter fatigue.
- Receiving oral intercourse: Almost half say fatigue; a third positioning.
- Other stimulation from partner: 30% say positioning; 20% say fatigue.
- Stimulate partner in other ways: three-fifths say they lack strength.
- Male masturbators report fatigue and erectile problems.

Although the sexual partners of a 52-year-old vent user with Duchenne muscular dystrophy (DMD) must be mindful of his circuitry and agreeable to a lack of spontaneity, they and he did not find these issues especially limiting. However, he shares, “I don’t have a sex life now mainly because I have considerable gastro-intestinal discomfort most of the time and don’t think it would be very pleasurable.” Another narrative respondent noted that as his diabetes medication causes erectile dysfunction, he no longer engages in sexual activity.

Personal narratives also offer unforgettable examples of social ignorance and prejudice vent users must overcome for healthful sex lives. Robert Mauro’s autobiography *Sucking Air, Doing Wheelies: Memoirs of a Fifties Polio Survivor* (2005), for example, details an encounter with a psychiatrist who exhorted that Mauro indeed *should* feel ashamed to use his vent in front of other people because doing so would be akin to “shitting” in their living rooms.

Another male with the effects of polio, age 66 and a 24/7 vent user for 22 years, conveys that during his teenage

years his home-school teacher suggested they skip the part in the textbook about sexual education but later would insist they cover the section on driver’s education, when the student had no intentions or means of driving. Of his teacher, he writes, “He probably thought, like many people do, that if a person is disabled they lose any interest in sexual matters.”

An inherent sense of inertia exists in any social bias, and the way to engage a momentum for change is for those of us with disabilities to recognize ignorance as ignorance without second-guessing ourselves for being sexual beings. We must work with researchers in the health care professions to raise social consciousness.

So how can we begin the innovation, the transformation in cultural awareness about sexuality and vent users?

We begin by shaping our personal lives, to the degree we can among those of us who can, in ways that allow for free expression and edification.

A 62-year-old male polio survivor who has used a vent for 45 years gives us a good start, “My view is that the ability to love and to be close to and intimate with another person is the result of one’s psychological makeup and not of one’s physique.”

A 49-year-old female with limb girdle muscular dystrophy (LGMD) and a vent user for 18 years proposes, “I think the most important [factor] is the partner’s knowledge about mechanical ventilation and his attitude to it.”

Mauro eloquently sums up his philosophy after a lifetime of personal experiences and observations: “The best couples, the couples who had been together for years, were the most

Those of you who responded have provided us with information that will aid in further educating health care professionals and fellow vent users. A more complete report on these findings can be seen at www.post-polio.org/ivun/val_20-4lottreport.pdf

creative. They were the ones willing to explore the possibilities, to make compromises, to take the time to work things out – in bed and out of bed. They found ways to please each other. Satisfaction was not guaranteed, yet they worked together to achieve it.” Such couples, he states, nurtured their relationship by nurturing one another.

While these attitudes might sound deceptively easy or simple, they are places for us to begin increasing cultural understanding: learn to love ourselves as we are and know we’re lovable as sexual beings; help our partners learn about our needs and feel good about providing for those needs; nurture our partners and enjoy with them the adventure of being an innovator when it comes to sex and exploring the involved bodies.

Among those of us who still engage in sexual activities, despite complications and limitations, we do face challenges. As stated earlier, many report difficulties with to positioning, fatigue, and energy to sustain stimulation or arousal. Those of you who shared more via narrative elaborate on these matters. The same LGMD person quoted above also tells us that “sometimes my husband complained, needing more time and being more careful than before without the ventilator.”

Indeed, we have to slow down. Like most everything else in our lives, sex takes more time. Mauro’s book acknowledges how challenging it can be when partners vastly vary from one another in energy levels, activities considered fun, and physical ability. If his lover lies upon his chest during or after intercourse, he struggles to breathe.

A wife writing of her sexual activity with her vent-dependent late hus-

band, who had Charcot-Marie-Tooth, explains, “He could not tolerate any weight on his stomach or chest as this restricted his breathing further so we had to adopt a head-to-toe position ... [to] achieve penetration.” Moreover, his face mask made kissing difficult.

Similarly, Mauro’s mouthpiece interferes with kissing and oral sex to some degree; just like one survey respondent – a 41-year-old male with DMD who uses a vent 24/7 – Mauro must pause for air during these activities. Those individuals answering our survey and sending us personal narratives more often than not tend to find ways to work with their physical limitations as they engage in sexual activities. But this is no small task. So, just how do we manage to “do it”?

Survey Respondents’ Means of Enhancing Their Sexual Activities

Indeed, we are “doing it.” The how part testifies to our determination and creativity. One survey respondent, a 50-year-old female with the effects of polio who uses a vent 24/7, repeatedly answers that the solution to problems in her sex life is “try to be more creative.”

In a personal narrative, a 59-year-old male polio survivor who has used a vent 24/7 since 1989 and has been in a committed relationship since 1997 shares that they explored ideas from the *Kama Sutra* and adult videos. He continues, “We laughed and had a ball finding a way to enjoy intercourse and oral sex. ... Too often people see someone using a vent and ... have no idea how sexy we are and how we can share sex with someone we love.

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Love finds a way. You just need to be patient, experiment, and as my mom once said (in another context), ‘If at first you don’t succeed, try, try, again.’ And it is so much fun to try, try again.”

Reading documents or watching films with sexual content can give us ideas which we can try and modify for our unique situations. But what, specifically, are we trying? Over a quarter of our survey respondents say they use some kind of sexual aid, with over a third saying they use vibrators, and almost a third using lotions or lubricants including Astroglide and massage oil.

When offering solutions for enhancing sexual activities during intercourse, respondents recommended rest and repositioning. Male masturbators say to try accessing stimulating sensory input (such as pictures, films, etc.) and to rest during the process.

Positioning, rest and sensory input all enhance the quality of our sexual experiences by and large. Besides using pillows, we adjust our positions by having sex in various venues: on kitchen tables, sofas and commodes, (which allow for height adjustments), as well as on shower seats, in wheelchairs, in van seats, and, of course, in bed. Stabilizing the ventilator tubing so that it does not move too much while moving into the right position, or sustaining a position, ranks among a number of respondents’ pre-sex preparations.

To a lesser degree, other planning on our part improves our performance. Some respondents use Viagra, and another reported shaving her clitoral area to enhance stimulation.

One wife writes, “We had to turn up the respiration speed on the vent to

cope with his exertion.” His normal rate was 11-12 bpm, but we increased the rate to 15-18 bpm prior to commencing sexual activity in order to avoid the need for interruption.

A 49-year-old with LGMD similarly notes that sexual intercourse proves easier for her when her vent is set on the assist control mode: “An assist control mode makes [me] feel comfortable. I could take as many breaths as I needed.” These results suggest that it could be incredibly helpful to vent users if the appropriate medical personnel advised them, their partners, and their caregivers on safe adjustments to ventilator settings when engaging in sexual activities.

Another way around logistical problems is recruiting able-bodied persons beyond our partners to help with the processes. The taboo of voyeurism and our own inner resistance to impositions on the intimacy we share with a partner make it hard for us to request outside assistance. But some people bravely do just that, embracing it as a means to greater sexual fulfillment, and adjusting their comfort thresholds accordingly.

A 52-year-old with DMD, for example, requested positioning help from personal care attendants with his two long-term relationships. A 33-year-old survey respondent with SMA who’s needed a vent 24/7 for 20 years reports that, “My partner’s head is resting on my stomach in bed. My penis is placed in her mouth by an assistant. Her head is moved by an assistant until I have an orgasm.” And a 27-year-old female with SMA who for seven years has required up to 16 hours daily using the vent writes that when she and her partner have sex,

“We have to usually go to a hotel and get a suite so our nurses/aides can be in the livingroom if we need assistance. We use pillows to aid in positioning. Make sure his tubing is attached to his trach securely. I make sure my trach ties are secure.”

Health Professionals' Tips for Enhancing Vent Users' Sexual Experiences

Health care providers, too, have begun to offer safe logistical advice on sexual activity. McInnes suggests that medical practitioners remind persons with disabilities that “sexual activity doesn't require a partner” and to “try different things.”

In “Sexual Health and Chronic Illness” *Clinics and Family Practice* (2004), licensed clinical social worker Patricia M. Lenahan, suggests ways for us to cultivate more positive sex lives. She urges us to understand it's a myth that sex is necessary harmful to one's health and may cause illnesses, that it weakens the potency of therapeutic drugs and treatments, or that alcohol and drugs improve sexual performance. She also wants us to know that communication issues and degree of affection between partners plays a key role in level of satisfaction; she implores us to “identify communication issues that may affect sexual behaviors” and to “experiment with positional changes to ease breathing difficulties.”

She advises couples “to adjust their sexual positions so the patient can assume a less active position” and “feel less closed in.” She registers facts that our survey respondents also give as their reality: the need to time sexual activity for when we are least fatigued and to “acknowledge that rest periods may be needed” during sex.

In John R. Bach and Joan L. Bardach's chapter “Neuromuscular Diseases” in *Sexual Function in People with Disability and Chronic Illness: A Health Professional's Guide* (1997), they reveal that of “the major issues that concern quality of life and life satisfaction in severely disabled ventilator users, the only issue in which the majority of subjects reported dissatisfaction was their sex lives.” They encourage physical and occupational therapists to discuss sexual positions and contraceptive devices, and to give specific suggestions about them and the use of lubricants, vibrators or even surgery to eliminate contractures interfering with sexual positions.

I highly recommend those of us requiring ventilation look at the complete fact-filled article “Chronic Illness and Sexual Functioning” in *American Family Physician* by Margaret R.H. Nusbaum, DO, MPH, University of North Carolina at Chapel Hill School of Medicine, and her colleagues, Carol Hamilton, EdD, PA-C, Emory University School of Medicine, and Patricia Lehahan, LCSW, University of California, Irvine, College of Medicine. (See www.aafp.org/afp/20030115/347.html or contact IVUN.)

It's up to us to explain our disappointments with as well as our gratitude for health care professionals' efforts in the hopes that we thereby make the realities of living with a disability a little easier for those who follow us, as well as ourselves. Those of you who responded to my call for this piece may count yourselves among the movers and shakers in the sexual revolution for vent users. Here's to our greater sexual fulfillment! ▲