Sex It Up

How to treat and defeat impotence

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There was no swang! It was as if the wiring had been cut,“ says Roger, an HIV positive psychologist -- and consummate cruiser -- in San Francisco. ”I’d pass a guy on the street and think, ’Hey, he’s hot’ -- but it would remain just a notion in my head without traveling down my body.“ If sex is a fond but fading memory, you may have it, too: Sexual dysfunction. Impotence, impedance, hypogonadism, anorgasmy and diminished libido are the decorous medical terms; on the street it’s the dreaded limp-dick syndrome and the parched-pussy predicament. But it all boils down to this: It’s a minor miracle when you can get it up or on at all, and seven out of 10 people with HIV share Roger’s complaint. Since the advent of AIDS and its phobic fallout, people with lethal genitalia have had to affirm and defend their right to Eros. ”We tend to view sex as a quality-of-life issue. But in fact, it can be a matter of life and death. I’ve known HIV positive people who lost their will to go on when sexual problems were added to seroconversion problems,“ says Paul Kondratenko of Pittsburgh, who has had impotence issues for years. ”Sexual dysfunction is ignored as a health issue, but it has caused enormous suffering." Impotence is the elephant in the PWA living room.

Often, the causes of sexual dysfunction can be so deeply rooted that psychotherapy, medication or erection by artificial means is necessary. There’s not only the mass of physical ills (testosterone deficiency is major; others include autonomic neuropathy, toxicity of AIDS meds and side effects of antidepressants), but also the mental morass known among helping pros as post-traumatic stress syndrome. Cumulative grief, the sense of oneself as “damaged goods,” anxiety about situations such as HIV disclosure, accidental transmission and financial predicaments due to unemployment and medical bills -- these can squelch even the most ardent passion. “For many, there’s an unconscious, and sometimes conscious, association between sex and death. HIV confirms that sex is bad, after all,” says Dr. Walt Odets, a leading therapist in San Francisco. “Especially in mixed-status couples, the HIV positive partner may suddenly feel they’re a danger to those they love.”

On a par with the nightmare of developing an opportunistic infection or drug resistance, most people with HIV dread infecting others. “Though I wasn’t sick, for the first year after I became positive I could only masturbate by myself,” says Darin, a San Diego lawyer. “Whenever I tried to have sex with another person, my dick went limp.”

Such disagreeable manifestations as weight loss, Kaposi’s sarcoma lesions and premature aging can shatter the most solid self-esteem. Ronna Deed of Los Angeles, who has had HIV for over a

decade, says, “When I started getting that legs-on-eggs look -- skinny legs, shrinking breasts, bloated stomach -- I began doubting my self-image and didn’t feel sexual.”

Aggressively prescribed for HIV-related symptoms of clinical depression and anxiety, antidepressants tend to cause one problem while solving another. *The Journal of Primary Psychiatry* estimates that as many as half of all people taking a selective serotonin re-uptake inhibitor (SSRI) -- sold under the rhapsodic names of Prozac, Zoloft, Paxil and Luvox -- experience inhibited sexual response (“That little ’We’re driving in for the big one’ tingle just never happened,” says Roger). Drug companies aren’t keen to broadcast this perturbing fact, and many consumers are willing to trade fantasies of one-way trips off the Golden Gate Bridge for a between-the-sheets aura of cold mashed potatoes. Some people reduce SSRI side effects by lowering the dose and/or adding synergistic meds, although this risks reducing the drug’s effect. Others swear by “sex furloughs” -- skipping weekend meds, then resuming monasticism on Monday. But because libido may be due to wishful thinking. Two new SSRIs, Serzone and Remeron, are reportedly more sex friendly.

Natural remedies offer an alternative (or supplement) to these designer drugs. Doctors in Germany have long prescribed St. John’s Wort (the extract is called hypericin). San Francisco’s Pat Miller, on the herb for more than a year, reports that her irritability, anxiety and sense of dread have all been greatly mitigated. Blue-green algae has also won raves from many. “Better health and increased energy boost libido,” says Lisa Burklehammer, a licensed acupuncturist in San Francisco. “And all three come from a commitment to a healthy lifestyle -- eating good food, getting enough sleep, less stress, more exercise and, if necessary, supportive measures such as acupuncture and Chinese herbs.”

The pharmacopoeia of pills that has leased health and hope to many a protease Lazarus can sometimes wreak havoc with lovemaking. “When you put all these friggin’ toxic chemicals into your body, there’s all sorts of effects,” says Greg, a 37-year-old San Franciscan. Despite low CD4s and a high viral load, his sex drive was fine until he began a three-drug protease cocktail last year. Within weeks, sex was barely a blip on the biological screen. His funk became so unbearable that he made a unilateral decision to stop the meds last March. “Two weeks later, there was a dramatic change -- my sex drive came back with a vengeance,” Greg says. But because of an increase in his viral-load levels, by June he’d begun a 3TC/d4T/Viracept combo, plus Prozac for depression. Once again, dick and desire are not reliably in sync.

Though the effects of impotence in men are more obvious -- and better researched -- HIV positive women also suffer. When Ronna began taking Crixivan, she says, “on a visceral level I felt it affecting my hormone levels. When I called Stadtlanders [Crixivan’s distributor], they said they hadn’t done studies on women. This is a big issue for me. We don’t know how drugs are metabolized in relation to our hormones.” In her mid-40s, Ronna says, “My premature menopause, which I think was caused by HIV, has brought on a progressive decrease in libido. There’s also diminished lubrication -- it hurts more to have sex. Other women I talked to agree. One says her orgasm wasn’t bells and whistles.” Discomfort during vaginal intercourse may also be caused by a bacterial imbalance or candidal growth, which can be treated effectively.

Energy-boosting herbs and vitamins -- such as vitamin B-12 injections, ginseng, Ginkgo biloba -- and DHEA, a precursor to testosterone formation, may have a lascivious effect. Matthew Sharp, director of Healing Alternatives in San Francisco, likes yohimbine, an African herb that stimulates erections. “Doctors can prescribe it in pill form,” he says, “but I use a tincture. I used to take it daily. Now I only take it when I’m planning to have sex.” But beware: A recent *Consumer Reports* article raised questions about yohimbine’s safety.

Creeping impotence is more than a definite downer. It can be a grave warning that loss of body-cell mass, which can ultimately lead to death, is underway. Failure to treat the cause -- testosterone deficiency -- can sabotage the best-laid plans to prevent or reverse wasting. “When a patient complains that his erections are less frequent than or not as hard as they used to be, I ask if he ever wakes up with a hard-on,” says Dr. Mary Romeyn, a San Francisco AIDS specialist who routinely checks testosterone levels upon patient intake. “If yes, then the problem is in their mind. But in my experience, people with HIV generally have a problem in their hormones.” Testosterone, which stabilizes an enzyme essential for a fully rigid erection, is deficient in as many as half of all men with HIV. When Tom, a San Francisco therapist, discovered his testosterone levels were low (470 ng/dL, with normal ranges from 300 ng/dL to 1100 ng/dL), he opted for a supplement injection in his butt. The hormone, suspended in linseed oil, slowly dissolves into the bloodstream. “Two days later I couldn’t walk -- it was so painful,” he says. “On an Internet AIDS chat line, someone suggested I get two smaller shots, one on each cheek. You’d think the nurse would’ve already figured that out.” Two weeks later, Tom was horny again. “Now I give my 33-year-old boyfriend a run for his money.”

Women with HIV also have lower than normal testosterone levels. For several years, Ronna Deed has been on estrogen and progesterone replacement therapy. To enhance her sex drive, every third day she’s supposed to take Estrotest, which contains testosterone. “I feel more alert, more sexually attentive,” she says. “But it makes me nervous, and makes my arms feel weird, so lots of times I don’t take it.”

Running total testosterone levels upon diagnosis -- and repeating them regularly -- should be a given. But too many doctors, faced with a “normal” reading, assure the patient that hormone treatment is unnecessary. The bottom line: The level may be normal, but it won’t solve sex problems. Dr. Judith Rabkin, a leading researcher at Columbia University, issues this critical caveat: “Patients who experience significant improvements in sexual functioning tend to have higher testosterone levels -- usually between 1,000 and 1,900 ng/dl -- compared to levels below 1,000 for those who don’t experience improvement.”

Testosterone shots are generally given every two weeks at a dose of 100 to 200 mg. “The drawback of injections is that they’re cyclic, with a rapid peak and dropoff. Everyone wants shots for the weekends. My waiting room looks like a casting office or party on Friday afternoons,” Dr. Romeyn says, with a laugh. Referring to testosterone’s bonus ability to help people with HIV gain and maintain lean body weight, she adds, “I’m threatening to print t-shirts that say ’Body by Romeyn.’”

But Dr. Marc Hellerstein, a University of California/Berkeley expert, warns his patients against injections: They pose a too-great risk of shutting down the body's remaining hormone production and, ultimately, creating impotence where it doesn't exist. Instead many men stick Testoderm patches onto their shaved scrotum; to keep them from ending up in underwear or other places, preheat by holding the patch over a lightbulb or in front of a blow-dryer for half a minute before adhering. Androderm patches, an alternative, can be stuck to any smooth body part but are larger, must be used two at once and can cause icky itches. Easier and cheaper, testosterone-spiked creams or gels are rubbed several times daily onto the skin. While this form of hormone replenishment is still in clinical trials, a skilled pharmacist can prepare a compound for you. For women, such as Ronna Deed, whose testosterone is plummeting due to premature menopause, these creams may restore libido better than Estrotest.

The most serious risk that testosterone supplementation poses is stimulating already-established prostate cancer. Lesser problems include hair loss (a balding friend quipped, "No, I'm not losing my hair -- I just prefer to use my testosterone in other places"), testicular atrophy (countered with human chorionic gonadotropin -- hCG) and acne. (But many guys concur that a pubescent skin eruption is a small price to pay for the Big O.) Women get to experience so-called masculinization, such as body hair, a deepened voice and that infamous itchy, swollen clit -- and of course, equal-opportunity acne. The major complaint is tension and irritability, though the "roid rage" associated with bodybuilders on megadoses of steroids is generally absent.

Nota bene: Problems with getting and staying hard may be a nerve thing -- and unrelated to blood supply to the penis. In fact, autonomic neuropathy is an impotence inducer far more common among people with HIV than is generally known. Reversing vitamin deficiencies and the use of nerve-growth hormone are two possible treatments.

"If you can't get your penis to work there are still plenty of other ways to fuck and make love. It shouldn't stop there," says Dr. Romeyn. "We all need loving and touching. And you don't need a member that stands on command in order to have a rich and powerful sex life, though it can sure help!"

Men for whom sexual performance is the *sine qua non* of masculinity may be loathe to seek treatment. Impotence can become so fraught with fright that some may resort to artificial means to regain a semblance of a sex life. Some adventurers are already familiar with sticking their dick inside a plastic cylinder, pumping blood into it, then putting a tension ring around the base. Vacuum pumps are effective, but hinder romance and spontaneity. Surgery -- implanting a pair of semirigid rods or inflatable cylinders in the erectile tissues of the penis -- is expensive and can cause irreversible nerve damage.

While sticking a needle in one's dick may deter many, it has become routine for Paul Kondratenko. He can usually manage a partial erection, but on off-nights it's erect with Caverject, a penile-injection system of Prostaglandin E1. "The first time they shot me up at the hospital, I sat there for two hours trying to read or fall asleep with this raging hard-on." Paul laughs at the memory of his first synthetic boner. "The nurses periodically would come into the room to check it out. I was

elated that it worked, but I kept wondering, 'When will this go down?'" Except for the cost, Paul is pleased, saying his stiff looks, feels and acts like the real thing -- "except you're stuck with it for an hour or two," so reservations are required. Gone are impromptu wanks in the gym sauna or the morning quickie.

As with other pleasures in life, too much Caverject can be a bad thing, especially since the long-term effects are still unknown. Three injections a week is the maximum; otherwise there's a danger of priapism -- the phallic equivalent of the *Terminator*-meets-the EverReady Bunny -- and the possibility of a permanently curved penis. Muse, a urethral suppository of Prostaglandin E1 that is inserted into the urethra, is just out.

When Paul's six-month Upjohn Patient Assistance Program for Caverject ends, it will cost him $21 per boner, totaling more than $250 a month -- way beyond his SSI payments. "I believe that impotence can be treated successfully and economically," Paul says, adding that buyers clubs could procure Prostaglandin more cheaply. "The trouble is getting the department of public assistance and the insurance companies to cover such treatments. Sex is not considered a life-or-death issue," he says. "Besides that, my doctor says some urologists are reluctant to deal with [gay] AIDS patients."

This unprofessional, not to mention homophobic, attitude -- as in "Treating HIV positive gay men with testosterone is like giving Typhoid Mary a job as a cook," a comment Rabkin reports a colleague made -- is not rare. Consider the recent example of one Dr. William Fisher of the University of Western Ontario, Canada. In a letter to *The Journal of Sex Research*, Fisher writes: "The act of administering testosterone to stimulate sexual desire and function in a population of persons who carry a fatal, sexually transmitted pathogen requires ethical scrutiny of the most serious sort." He frets that HIV positive men with dementia who are taking testosterone might -- deliberately or not -- infect others, citing a study of eight HIV positive men who, on testosterone, had unprotected anal sex. But Fisher failed to note certain facts that the report made clear: All unsafe sex was by mutual consent; most of it was between positive partners; when the couple was of mixed status, it was the man with HIV who was the bottom.

Fortunately, such dark-age prejudices as Fisher's are countered by other, more enlightened ones: "With the advent of combination therapy and early treatment," Dr. Romeyn says, "it's thrilling to see people returning to a sexual life, and testosterone supplements are marvelous. We stress that it's important for people with HIV to have sex. Period! End of discussion."
