



Chronic illnesses like CFS can **wreak havoc with your sex life** and give your partner one more reason to resent you and your illness. But, when addressed appropriately, **issues of sexuality and intimacy** don't have to sabotage your relationship. Want to know how to improve your love life? Read on.

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Sex & CFS

What is the most important concern that patients with chronic illness are least likely to talk to their doctors about? It just might be sex.

Sexual issues affect people on a daily basis, but they are often reluctant to discuss them with their physicians or other health care professionals. For patients with CFS, many of whom have numerous other issues and symptoms to address during a limited doctor's visit, it's easy to understand why sexual concerns take a back seat to other issues.

Recently, however, at Albany Health Management Associates Inc., the organization I founded to address issues related to the growing epidemic of chronic illness, an increasing number of patients want to discuss some of the sexual issues they're

dealing with in their private lives. It's heartening that people seem to be feeling freer to talk about a topic that is so laden with taboos and sensitivities.

American culture is full of mixed messages about sex. On the one hand, our culture is very conservative about issues of sexuality and reluctant to discuss them openly. In contrast, we have a billion-dollar sex industry that—whether we like it or not—brings sex into our lives on a daily basis. This cultural dichotomy between the pervasiveness of sex and the taboos that still permeate American society makes sexuality a complicated subject. When chronic illness gets added to the mix, the issue becomes even more complex.

When patients come into our office to talk about sex, they never say, "We're having

too much sex. Can you help us?” What they tend to say is, “We don’t have sex anymore,” or “We’re not having sex often enough.” Then we begin to explore the details of what this means and examine the expectations of each partner. We ask a variety of questions, such as “Who is the primary sexual initiator?” and “Why do you feel the sexual relationship has changed?”

Why couples might be having less sex

Any couple may stop having sex (or stop being as sexual as they want to be) for a variety of reasons. When one person is chronically ill, a couple can be especially vulnerable.

The most common reasons these couples may not have sex are physical ones. For people with CFS, sex can be painful. Patients may feel exhausted and lack the energy for sexual interaction. Women may experience vaginal pain or dryness during intercourse, and male patients may have trouble maintaining an erection. Chemicals released during orgasm can actually help relieve pain and improve mood, but the adrenaline release may also be exhausting. Many patients with CFS, even if they have the energy to have sex at a particular moment, may be concerned about the physical repercussions that can occur in the following 24 to 48 hours.

CFS sufferers or their partners may experience a lack of sexual desire for a host of reasons. Sometimes the healthy partner stops initiating sexual contact because he (or she) feels protective. One man whose wife suffers from CFS and fibromyalgia admitted, “I’m afraid

I’m going to hurt her.” In a relationship where one person is ill, that partner may be perceived as more vulnerable, and the healthy person often takes on the role of caretaker. This can change the power balance in a relationship, which in turn changes the sexual balance. People who are chronically ill may experience a somewhat childlike state as a result of the extreme physical and emotional changes inherent in illness. While this is a normal psychological reaction, it often complicates the sexual relationship when the “adult” or “caretaker” in the relationship has trouble reconciling this role with that of sexual initiator.

Conversely, the person who is ill may feel guilty or confused about wanting sex or initiating sexual activity when fulfilling other roles in the household or relationship is problematic. It’s hard to explain to your partner that you feel like having sex when you don’t feel like preparing a meal or going to the grocery store.

In fact, patients and their partners may experience a wide range of emotions about the change in their roles and the different dynamic of their relationship. Patients may experience feelings of guilt because they aren’t able to do what they could before, or because they believe their limitations are a burden to loved ones. At times their partners may feel resentful that their own needs are not being met, or that they must take on additional responsibilities the ill person is no longer able to manage. Both partners may feel angry, even quite angry, that their formerly healthy, active sex life is just one more thing they have lost to CFS. Such anger, guilt and resentment—

whether conscious or unconscious—can wreak havoc on a couple’s sexual relationship.

Strategies and solutions for rediscovering sexuality

The psychological and interpersonal issues involved in a sexual relationship can be difficult, but they become even more problematic when they are unspoken. Couples can improve their sexual relationships by communicating openly about their concerns. If a lack of desire is an issue, explore the reasons why one or both partners may feel disinterested, or why there might be a hesitation to initiate sexual contact. Perhaps you’re self-conscious about the changes in your body due to CFS, or you may be worried about disappointing your partner. Often the very act of speaking candidly about fears and concerns is enough to bring acceptance and reassurance, to rebalance the power in the relationship and to allow sexual contact to be resumed.

How can a patient with CFS think about feeling sexy *in* bed when sometimes even getting *out* of bed is a huge challenge? It certainly isn’t easy. Sometimes patients can look for “windows of opportunity” when energy is higher or symptoms less severe. It may help to have rituals that you know make you feel sensual or romantic—such as taking a long, hot bath or practicing meditation or relaxation. It may help to create special times that are separate and distinct from daily caretaking



routines. For example, an ill partner may require assistance in doing the laundry or other routine tasks, but the couple can still manage to create an adult oasis where they engage as equal partners in the sexual relationship.

Like any other activity made more difficult by CFS, sexual activity may require the use of pacing techniques. Setting aside time for sexual intimacy with your partner—and time for recovery from any exacerbation of symptoms afterward—is possible with some creative scheduling and reprioritizing of other tasks. Many people with CFS set aside a date night and “rest up” for it, both before and after. If this seems to lack spontaneity, remember that even people who don’t have a chronic condition often must plan time for sexual interaction.

It’s also essential to address the physical concerns that affect your sexual relationship. If sex is painful, talk to your doctor. There are a variety of products that can help with lubrication and sensitivity. New treatments have been developed that can enhance sexual desire and response. In addition, a lack of desire may be influenced by medications you’re taking to treat CFS. Many drugs have an impact on libido, lubrication or the ability to maintain an erection or achieve orgasm. Discuss these questions with your doctor, who can help you explore ways to improve sexual function.

Couples can discover new positions and other techniques to reduce pain and enhance pleasure. Those who cope with chronic illness often need to explore different ways to be sexual, as sexuality naturally evolves and changes throughout the life span. Just as people have been taught to integrate birth control into their sex practices, and to integrate protection from sexually transmitted diseases, it’s natural that our sexual activity would evolve based on our physicality, which changes as we age. Your partner might be big or small, tall or short, heavy or light. All of these might be characteristics that can change your sexual practice.

If thinking about these issues or beginning to talk about them with your partner is too difficult, or if you’re concerned about how to do this, it may be a good idea to find help. Talking to a counselor or therapist about these issues on an individual or couples basis can be very helpful.

Sex and the four phases

It’s also important to note that the sexual needs and experiences of a patient in the early phases of the chronic illness experience can be considerably different from those of someone who has been ill for several years.¹ Research supports the concept that four phases of adaptation occur in chronic illnesses like CFS², and these phases and their characteristics pertain to our sexual selves as well as other aspects of our lives. Clearly, they also affect the partners of people with CFS.

For example, in the first phase (crisis), CFS patients are usually not interested in sex; they are in crisis and understandably overwhelmed with all the changes wrought by their illness. Partners are typically understanding in this phase; they recognize the urgency of the situation and want to help.

In the second phase (stabilization), some patients may have a budding interest in sex again, but they may be unsure how to handle it. They might wonder if they have the strength for sexual activity or fear that it might worsen their symptoms. Partners in this phase typically react in one of two ways. Some partners feel protective and, as referred to earlier, may have difficulty reconciling a sexual role with one of caretaker. Others may feel resentful or angry about the ongoing changes and limitations brought on by the disease. “I want my old wife back” is a common sentiment for husbands of CFS sufferers in this phase. If these issues and feelings are not addressed, sexual intimacy can get removed from the relationship.

In Phase 3 (resolution), CFS sufferers may experience a renewed interest in sexuality. Patients and their partners must learn to move out of any unhealthy patterns developed in earlier phases and begin to negotiate how and when to initiate sex. Learning to use pacing, regular rituals and other strategies can make sexual intimacy possible and satisfying for people with CFS and their partners.

During Phase 4 (integration), patients reintegrate a sexual life that accommodates the physical and emotional changes caused by chronic illness and begin to explore how to find a fuller expression of their sexual selves. In this phase CFS sufferers learn how to be sexual beings who are also ill, and they understand that these things are not mutually exclusive.



It's still possible to appreciate our sexual selves despite the additional challenges of chronic illness. CFS must be viewed as just one more thing that we adapt to sexually. The need to make these accommodations shouldn't be seen as a failure, but simply as a necessary process of discovering what works for a particular couple.

Sex doesn't have to be a thing of the past just because you have CFS. ■

References

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SEX AND THE SINGLE CFS SUFFERER

What if you're single and you have a chronic illness?

When you're dating someone new, issues that relate to your illness will likely come up even before you enter into a sexual relationship. And once you're involved in a relationship, you handle your concerns about sexuality as do married or established couples. The problem, if you're single and suffer from CFS, boils down to how you talk about your illness.

How much disclosure is necessary and appropriate? This is a common concern for anyone with a chronic illness who is dating. How much should you share and when should you share it? It can be frightening to expose yourself in this way, risking rejection or other upsetting reactions.

Many people disclose too much too soon. That can leave you feeling naked or vulnerable, and you also risk overwhelming the other person. Before sharing the details of your situation, try to get a sense of what your new friend can handle. One good way to do this is to find out about the person's history. Rather than disclosing your health concerns right away, discuss other personal topics that may reveal how comfortable your new friend is with sharing. Try to learn what issues may be emotionally charged for that person and how he or she deals with adversity. If there's a history of illness in your friend's family, pay attention to how she or he has responded to it and coped with it. Such knowledge can help you decide what to share.



Once you decide to begin revealing more about yourself and your illness, test the waters by sharing something small.

The response you receive can help inform you about how the person may deal with more extensive details of your illness.

How do you know when someone is handling disclosure about your illness well? In all honesty, such knowledge develops over time. Some individuals can give you a positive response initially—for fear of hurting your feelings—and then withdraw later. Others may not know how to respond, or they may find it difficult at first, and then grow more comfortable and understanding of the situation.

Only you can judge whether someone may make a good partner and whether he or she can cope with the challenges that are inherent in a life with CFS. A good, caring partner is one who accepts you and your limitations and shares the intimacy of facing life's challenges together.