

The Dating Game

Having lupus doesn't mean saying no to love

By Mary Dixon Lebeau

For Erica DeMeerleer, Valentine's Day 2002 was anything but romantic. In fact, the events of that week nearly broke her heart.

DeMeerleer, an account executive for Comcast, was 25 and involved in a two-year relationship at the time. She had moved from her hometown of Bellingham, Wash., to Seattle for her work, but was trying to maintain the relationship long distance.

"It was a period of high stress for me," DeMeerleer recalls. "I was adjusting to the new home, struggling with high rent payments, and trying to keep my relationship going." She was also coping with incredible pain, which she thought was a symptom of the rheumatoid arthritis she had been diagnosed with six years earlier.

Then came the week that shook DeMeerleer's world. "Three days before Valentine's Day, my boyfriend broke up with me. Then a few days afterward, my doctors told me I had lupus," she says.

"I was sure nobody would want to deal with my problems and that I would probably always remain single," she says. "I remember thinking no one would ever love me."

Learning that you have lupus is always hard, but when you're single, you face an additional set of fears. You may struggle with when and how to discuss lupus with a potential partner—and worry about how he'll react once you do. You may even wonder if you could keep up a healthy romance at all, especially when you're feeling fatigued or self-conscious. Is it possible to look for love—and actually find it—while dealing with all this?

Fortunately, the answer is a resounding yes. The key is the same as in any relationship: communication. "The number one issue in any relationship is communication," says Robert Phillips, Ph.D., founder of The Center for Coping in Hicksville, N.Y. and author of *Successful Living With Lupus* and *Coping With Lupus*. "With lupus patients, it depends on how well the person diagnosed is able to communicate what they're experiencing or what they need without applying pressure to the other person."

It may take work, but with good communication, lupus patients can have a "happily ever after"—as DeMeerleer can attest. Just one year after that heartbreaking Valentine's week, DeMeerleer met Zeb and fell in love; the couple will celebrate their second wedding anniversary in October.

"It works because he's very open and honest, which compels me to tell it like it is," DeMeerleer says. Honesty is key to the strength of their relationship. "We're working hard on something great," she says.

Sharing and caring

Usually the road from “glad to meet you” to “happily ever after” is a long one, and in the best cases, a variety of conversations will be held along the way. For singles with lupus, one of those conversations will reveal the diagnosis. This discussion, however, does not have to happen right away.

“There is no rule of thumb for when,” says Phillips. “It really shouldn’t be a part of your introduction. For example, you wouldn’t say, ‘Hi, glad to meet you, I have lupus.’ I suggest you wait to get to know the person and see if there’s chemistry.”

“When you reach a point in the relationship when you’re naturally sharing things about your life, lupus would be one of the things you share,” he adds.

Eileen Lynch, a Seattle-based paralegal, understands the reluctance to have such a conversation. Diagnosed at 22, Lynch avoided dating while she struggled to accept her condition. “I shied away from dating because I didn’t want to burden someone,” she recalls. “Then, when I returned to dating, I didn’t have successful relationships because I was so guarded and couldn’t open up.”

But a friend opened Lynch’s eyes to the opportunity she had been given. “He told me that I was actually lucky because I had a built-in meter,” Lynch says. “If someone didn’t want to be with me because of lupus, then he wasn’t good enough for me to begin with.” Lynch decided to put that meter to the test and started dating again, meeting men through friends or on online dating sites.

“Usually I would talk about lupus early on, within the first couple of dates,” Lynch says. “It explained so much—such as my periods of fatigue, my many doctors’ visits, or why I lived with my parents—that I found it hard not to tell.”

Deciding how to start the conversation may be even more difficult than deciding when. Phillips suggests making sure you keep the other person comfortable with the information you choose to reveal. “The best way to get someone new comfortable with your lupus is to show them that you can handle it,” he says. “If you complain or act as though you can’t handle it, your partner may be more hesitant to remain in the relationship.”

The person on the receiving end of the conversation will initially be curious how lupus will affect his life, and that’s natural, Phillips says. “The casual approach to the subject is usually the best received. Don’t make this an earth-shattering revelation. And don’t assume you’ll be rejected.”

Don’t be surprised if there is a cooling-off period after you first talk about the lupus. Often, the other person needs time to do his own research on the subject and consider its implications. “I didn’t even know what lupus was. Is it contagious? How does it work? These questions all ran through my mind,” says Derek Cheshire, a salesman for Microsoft in Seattle who learned of Lynch’s lupus on their third date.

He did some research online and brought his questions and doubts to Lynch. “We did a lot of talking, and as we dated, I noticed her limitations—the effects of diet and stress, sunlight and sleep,” he says. “I had concerns about our future, but they’re risks I’ve decided to take.”

Cheshire and Lynch are now engaged and planning an autumn wedding. “I think of Eileen as my fiancée, not as a lupus patient,” Cheshire says.

Pillow talk

Of course, the conversation doesn’t stop with your first discussion about lupus. As the relationship progresses, you will need to talk about other issues that will affect you in the future. Even the newest relationships may be affected when symptoms of the disease or side effects of medication take their toll.

“Does fatigue affect dating? Does McDonald’s sell hamburgers?” says Cherianne Takalo, 23, of Damascus, Ore. Although she jokes about it now, Takalo knows first-hand that dating can be no laughing matter for a person with lupus. Her long-term college boyfriend walked away from their relationship soon after she was diagnosed. Both were athletes, but Takalo found keeping up with their physical activities painful. “He said I wasn’t fun anymore,” she remembers.

Explaining side effects of medication, such as weight gain, puffiness or hair loss, can also seem daunting. Some may avoid the conversation as long as they’re feeling and looking well, but honesty is always the best choice for any lasting relationship.

DeMeerleer has been relatively healthy, but she wanted Zeb to know what could happen in the future. “I showed him pictures of when I was on prednisone, looking like a Cabbage Patch Kid. I told him this could happen again some day. I told him I may end up in a wheelchair.”

For most young couples, such conversations will also include intimate issues and the discussion of children. “If someone is a potential mate, physical intimacy is usually approached slowly, as the relationship builds,” Phillips says, adding that the conversation should build similarly. Assure your partner lupus isn’t contagious, and discuss any pain you may be experiencing. If you’re at a point in your relationship where you’re physically intimate, your partner will be anxious to please you, so this information is often welcomed.

Many women with lupus experience Sjogren’s syndrome, which affects the glands that produce moisture in the body. “If a woman is experiencing vaginal dryness, she should be proactive. She can carry lubricant the same way some women carry condoms. You want to be prepared,” Phillips says.

Potential spouses should also become educated about the effects lupus may have on pregnancy, childbirth, and parenting. Be clear on your preferences and your openness to other possibilities, such as adoption, before beginning the conversation, suggests Joy Hart, Ph.D., professor of communication at the University of Louisville. “One should know the medical specifics and be ready to talk about them with a partner. Be prepared to answer questions and allow your partner processing time,” she says.

Just the way you are

It's natural to fear rejection because of the implications lupus may have for your partner, but keep in mind that relationships fail all the time—for a variety of reasons. “Rejection can occur whether or not lupus is part of the mix,” says Phillips. “If someone rejects you, try to change your thinking. They may not be rejecting you personally; they're just deciding not to pursue you for whatever reason. It's okay—not everyone will be interested in you. It's their loss. When you're ready, move on.”

Also remember the advice Lynch received, and consider lupus a built-in monitor to measure the sincerity of your relationship. If lupus scares your partner away, it may be a sign he'd run when times get tough for other reasons as well.

Just remember that real love will stand the tests of lupus, and times of adversity will strengthen a worthwhile relationship. “Lupus doesn't mean the end of the world. It's just part of our life,” says Zeb DeMeerleer, Erica's husband. “Who knows? I could get cancer tomorrow. Life is full of surprises.”

And one of those surprises may be this: Lupus does not spell an end to your dating and romantic life. Sure, lupus may scare some people off, but those who stick around will be the ones worth getting to know. Listen to your meter—and your heart—and remember that any worthwhile relationship is based on open, honest communication.

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