

## Lupus: Up close and personal

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Lupus is killing Susan.

It's an arresting message line for any e-mail. But when it comes from someone you've known all your life, it's a kick in the stomach.

"Dear Daphne, I feel like I am appealing to Make a Wish Foundation. My dream is to raise \$\$\$\$ to find a cure for lupus and raise awareness so people with lupus will receive timely treatment. . . .

"I have so little time to make a difference because lupus has been attacking my brain for several years. I have been told that I am starting to get dementia and risk having a stroke. I have mild to moderate brain damage in the cerebellum, which affects coordination, movement and balance.

"I also have damage to the cerebral part of my brain, which affects my cognitive functions. I sometimes become confused, lost, disorganized and my judgment is sometimes impaired.

"I can feel the impatience of others when I have trouble speaking. Thankfully I can still remember all of the fun times with you . . . ."

Both our parents and grandparents were neighbours and friends, so Susan Milliken and I have known each other forever. We never lived more than a few blocks apart, growing up in Regina.

We went to the same elementary school and then to a private high school because the public high school had more students than desks.

But it's the summers at Katepwa Lake where both our families had cottages that we both remember best.

One prepubescent summer, along our other girlfriends, we put on a synchronized swimming show at the Main Beach. It was notable not for the performance, but for the flotsam of Kleenex that we'd used to fill out our bathings suits. Susan's idea.

We staged mock weddings at the Anglican church with those same girlfriends, each of us taking a turn, acutely aware that this was undoubtedly sinful. Susan's idea.

It was Susan who dared us to walk through the church's cemetery at night.

I'm not certain whose idea it was, but it was during the summers that we smoked our first cigarettes up in the hills, went to our first dances, drank our first forbidden alcohol, and made our first underaged attempts to get into the bar.

But one summer, I was certain Susan would die. She hurtled toward our dock on a Sea-Doo, its steering mechanism broken. She jumped. The boat flipped. Susan bobbed



CREDIT: Ian Lindsay / VANCOUVER SUN  
Susan Milliken Tuesday in her Burnaby home.

to the surface. Hysterical.

It was the only time I've ever seen her frightened.

Susan was always fearless, athletic, intensely competitive and, yes, stubborn. And she's always had this incredible laugh that's a mix of mirth and cynicism. She's had it even before we knew what cynicism was.

She says she's always been vain. I don't recall that. But that's the thing about memory. Each of us remembers differently. We remember some things and not others, different details. It's only when we talk to people we shared those times with that we get a clearer version, a truer one.

Our lives diverged after high school. We went to different universities. Susan married and had the first of her two children by the time I went east to do a second degree.

Susan moved to British Columbia, divorced, remarried, advanced in her career. We've both lived in and around Vancouver for a long time now, but we've rarely seen each other.

About 10 years ago, Susan organized a reunion for the Katepwa girls on Gambier Island and we fell back into the old roles of childhood, fearless Susan leading the way.

She still drove the boat like a demon. She was first to go tubing; first to suggest skinny-dipping; the first to burst into laughter. The first always.

Despite the promises to stay in touch, we didn't. Then came the e-mail last month.

"I have been told there is nothing that can be done for the small vessel damage caused by my immune system. And it is not just my brain that is affected, my blood cells, my skin, my muscles and possibly my bladder and kidneys.

"My story is far from unusual. It takes on average, five years for children, women and men to be diagnosed with lupus. The saddest part is they often suffer permanent organ damage before they receive treatment. And even with treatment, some people die from lupus or the side effects of the drugs."

We met recently at a Burnaby cafe, close to where she lives. She was well-rested, knowing that conversation - the thinking and talking - would sap her energy. She still bristles with energy, grey eyes lively. I hadn't expected that because she takes a daily cocktail of eight drugs including a chemotherapy drug. The side effects include everything from bladder cancer to blindness, leukemia to breast cancer, lymphoma to internal bleeding.

Over lemon Italian soda and a muffin, Susan told me that shortly before our reunion at Gambier, odd things had started happening to her.

She drove through a red light and nearly hit a car.

One foot ended up on top of the other one day in the bathroom. She couldn't extricate them and couldn't get her arms out to break the fall. She crashed into the toilet.

She started seeing things that weren't there. Walking with a colleague at lunch hour, Susan pointed to a canoe in Vancouver's inner harbour. There was no canoe.

"I was 39 and I felt like I was in a dryer, tumbling."

At work as a financial manager, simple tasks became trials. Susan couldn't remember how to send a fax one day. Another, she forgot to lock the cabinet filled with confidential documents.

"I was having trouble talking. I would lose track of thought. I put the wrong words in a sentence. I'd miss words. It was like being tongue-tied."

She went to the first of 20 doctors. A CT scan showed nothing unusual. Maybe an MRI, the doctor suggested. Susan paid for it herself because the wait-list was so long. Patience is a virtue neither Susan nor I possesses. Nothing showed up. Well, maybe a small lesion on the brain.

She'd had a hysterectomy before this all began. So when the first few doctors were flummoxed by the symptoms, a couple suggested it was just "a woman thing."

One asked her to write down all her symptoms. She did, but when Susan gave the doctor her list, he diagnosed her as neurotic.

One said she was psychosomatic. Another called her a hypochondriac. Susan made an appointment with a psychologist for treatment. The psychologist convinced Susan that she was physically, not mentally, ill.

Different doctors gave new diagnoses including fibromyalgia and multiple sclerosis.

Then, finally, after more than a decade, she was told she had lupus.

Lupus is a mysterious, chronic, autoimmune disease that can attack any organ or tissue in your body. The best guess is that it's caused by a combination of genetics and environment. And, yes, in some ways lupus is a "woman thing" because women are more likely to have it than men.

"No two cases are the same," according to the Mayo Clinic's website. Small wonder that, so far, there is no single diagnostic test.

Lupus presents in dozens of different ways. Symptoms include: pain or swelling in joints, muscle pain, fever, rashes, chest pain, hair loss, pale or purple fingers or toes, sensitivity to the sun, swelling in legs or around eyes, mouth ulcers, swollen glands, tiredness, anemia, headaches, dizzy spells, depression, confusion, memory loss and seizures.

It's diagnosed only if someone has four of the 11 most common symptoms at the same time. But symptoms come on quickly and disappear again. Nobody knows how or why they flare and dissipate; possibly it's stress and lack of sleep.

Complicating Susan's diagnosis is that lupus chose her brain.

"The only way they can be certain that I have it is a full brain biopsy and I'm not volunteering for that," she laughs.

But doctors are convinced that lupus is inflaming her brain's blood vessels, slowing the vital flow of oxygen to its most essential parts - the frontal lobes and the cerebellum.

The cerebellum controls our movement and keeps us from keeling over.

The frontal lobes are our emotional control centre, our rational mind, our impulse control centre. Memory, language, motor function and even spontaneity reside there. The frontal lobes are our personality.

Lupus is attacking the platelets, the blood's clotting mechanism, and making it more likely that she'll have a stroke. Susan has already had a few TIAs (trans-ischemic attacks or mini-strokes) that have left lesions on her brain.

"I don't drink much, but this is something that could drive you to drink," Susan says, another laugh busting out of her. "I've got a shrinking brain. The tissue is dying because of lack of blood supply. It's literally getting smaller."

There is no cure for lupus, yet. The best hope for Susan and others is remission. But nobody really knows why or how that happens. Drugs developed for other ailments such as cancer, heart disease and malaria can slow the damage. They include things like blood thinners and steroids. Some work on some people. Some don't.

The latest drugs Susan's taking help. She feels better and her last scan showed no new brain lesions.

Of course, all of this is expensive - all of the drugs, tests and a team of doctors that includes a neurologist, rheumatologist, ophthalmologist, urologist, dermatologist, allergist and "a very supportive family physician."

"Thank God that I have disability income which pays for my drugs now and will help cover my care costs when the time comes. This did not happen without the fight of my life."

In the late 1990s, Susan's symptoms were getting worse. Fatigue, confusion and the time it took going to doctors convinced her to cut back to part-time work and move to a lower position that she had once supervised. Later, she took unpaid sick leave.

Even though her employer was aware that she was being tested for a serious autoimmune disease, Susan was fired in 2003. It was a "non-culpable dismissal," an acknowledgement it was not her fault.

Susan appealed her firing. After eight days of hearings stretched over an 11-month period, an arbitrator ordered Susan reinstated to her job so that she could apply for disability coverage.

It took three years before she got her first long-term disability payment.

The money is a godsend even though it's less than it might have been because of the time she'd spent working part-time and the unpaid leave. Susan says she's luckier than many of the 50,000 other Canadians with lupus.

Some are too sick, too depressed or too drained after fighting for a diagnosis to battle for a pension. Others are misdiagnosed with chronic fatigue or fibromyalgia, which aren't eligible for disability coverage. Still others keep working so they can afford the drugs needed to stave off lupus's progress.

"If I wasn't so stubborn, I probably would have given up. I guess I thought if it could happen me, it could happen to a lot of other people and I wanted recognition for people with lupus that we are entitled to disability pensions."

She says the fight for disability coverage was more devastating than her diagnosis.

"Not be believed, that was the hardest part. That, and the sense that people would think that I would try to cheat the system. I only started to feel normal again after I met other women who had lupus. To be understood was such a relief."

She met them through the B.C. Lupus Society. She's now a member of the society's board.

With as much time and energy as she can muster, Susan does what she can to raise money for research and raise awareness so that others don't suffer financial and personal devastation because no one believes they are really ill.

But her full-time job is staying healthy, eating properly, getting plenty of rest and exercise.

She's taken up dancing. Susan and her husband, Bill, started with line and swing dancing with "an older crowd who had a hard time accepting that I had more trouble learning it than I did."

They signed up for Latin dancing, but got kicked out. It was Bill - not Susan - who couldn't move his legs the way the instructor demanded.

Before Susan had lupus, she did everything. She easily balanced family, work and home. Now, she says, Bill does almost everything.

"I told Bill he can divorce me," she laughs, then pauses.

"I guess I know he won't, which is why I can laugh about it now. . . . My GP told me to plan for the future. But I don't know what that really means.

"I would have wanted to go to the U.S. to some place warm. But now we probably won't be able to go because of the difficulty getting health insurance and I also need to stay here because there is good medical care for me now.

"This is a big responsibility on Bill to pick up the pieces for me. It's sad for my children [who are now in their 30s]. And there are people who don't always understand that I can't do things. They think I've turned into a more self-centred person - which I am. But I've never been so self-centred as I am now."

"What really makes me sad is that I am not the person I once was and I am terrified of the person I will become. My family and friends suffer when they see me having trouble thinking and talking . . . or if they allow themselves to think about what the future holds. Knowing I will become dependent and out of it is my worst nightmare. I have always been independent and I can't stand the thought of being a burden on others.

"I don't grieve for myself as much as for others who have not been able to live their lives to the fullest. I really feel badly for the children who develop lupus; the young mothers; the young people who will never be able to have children or challenging jobs; the parents who are afraid their children may never lead normal lives; the children who have lost their mothers; the husbands who have watched their wives die; and the women who are now alone because their disease drove their husbands and some friends away."

On World Lupus Day - May 10 - Susan helped organize a 5K and 10K run in Burnaby's Central Park to raise money for research.

"I had no time and no drive to train. But I still like to think that I'm athletic and I had all of these sponsors. So I ran.

"I collapsed 20 yards from the finish line and I heard somebody ask, 'Should I call 9-11?' I was sure that I said, 'No, don't. I'm not going to have a stroke doing this.' But Bill says I didn't say anything. Bill said I was hunched over like a gorilla with my arms straight out before I face-planted into some dandelions. But I didn't hurt myself."

She laughs that laugh.

That's the Susan I know and the person I can't bear to lose.

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