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The Best of 2023

My Husband Is Dying: Advice from the Cancer Wars

The emotional and physical toll on both of us during our last year together

By Leida Snow | September 28, 2023 | Cancer

The Best of 2023

Through Dec 29, we're looking back at the 10 stories that most captivated our readers in 2023. The Next Avenue editorial team is pleased to highlight this as one of our most read stories of the year.

Everybody has a sell-by date, but some folks know theirs in advance. About a year ago, my husband and I had a meeting with a doctor who was new to us. Nice looking man with an open face. He saw our expectant looks and stopped mid-sentence. Looking at Lou he said, "Has no one mentioned that you have stage 4 cancer?"

Lou and Leida's wedding day, 1982 | Credit: Courtesy of Leida Snow

No one had. We knew there was an issue. Lou has one kidney from birth, and at his yearly checkup, the kidney specialist said to talk to a cancer doctor. But he didn't seem overly anxious.

I was grateful that finally someone was speaking truth. The hardest to hear was that Lou had, probably, about a year to live. It was as though someone had taken a very sharp knife and plunged it into my stomach.

The oncologist explained that Lou had cancer cells in his liver, but they were not those expected to be there. They were squamish cells, usually associated with other locations. That meant they had spread (metastasized) from somewhere else. But they didn't know where they had come from.

A Rare Form of Cancer

Lou has cancer with unknown primary (CUP). It affects 2% to 5% of diagnosed cancers. The doctor's next words tore at my gut: Because the

primary source is unknown, there are no data-based, targeted treatments. In other words, for those with CUP, treatment is a guessing game.

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We had gotten the news at NYU Langone, a top-flight institution where we see our specialists. The overwhelming advice was to go to Memorial Sloan Kettering (MSK) in New York, the Gold Standard, we were told.

Given the restricted time frame, we expected MSK to build on NYU's findings. But they had to re-do tests, to validate the results. Over the following months, I swallowed my anger and frustration, as the days filled with tests, biopsies, CT scans, MRIs, x-rays and hours spent waiting. The immunotherapy and chemotherapy had zero effect on killing any disease. I hugged Lou close as he comforted me when I couldn't control the tears.

Recommended

The Prostate Cancer Spouse

The diagnosis is often minimized, but shouldn't be. The effects on a relationship can be profound.

Lou suffered all the side effects — extreme fatigue, drug induced lung infection, steroids to deal with that, removal of huge amounts of fluid from his lungs, and, best/worst of all, the loss of over 30 pounds. Lou has never been fat. Now he is emaciated. I try not to show him how scared I am.

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There was the offer of one clinical trial. A hope glimmer. But it had mind-blowing side effects and wasn't aimed at cancer with unknown primary. Lou decided to pass. I steeled myself to be strong for him.

So now we've enrolled in what's called Home Hospice. It's basically a space where there is no treatment, but you still hope for a magic bullet. Where I watch my husband become less every day.

Not long ago, I heard a crash in the bedroom to find my 6'2" formerly strong darling dazed on the floor. Lou said he'd bent over to get his shoes and then started to fall without being able to control what was happening. The wall behind him was blood smeared. He had hit his head.

Feelings of Helplessness

Panic. Heart racing. Cloths to press on his head. An ice pack. The hospice said to do what I was doing. Asked if Lou wanted to go to the hospital. No. Didn't know if I could get him up. But I did. The cut wasn't deep, but I thought the bleeding would never stop. On his physician's advice, Lou is no longer taking Eliquis, a blood thinner.

Last year I wrote an article for Next Avenue that flagged that falls can be the beginning of the end. Now it is shattering, personal knowledge.

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I've cancelled almost everything. Since hospice, there's minimal interaction with MSK and the long waits. We had to scrub our last session at MSK's Center for Integrative Medicine. The acupuncture helped Lou to relax, but he was too exhausted to attempt to go.

A Lonely Road

It didn't feel right to phone and cancel. I went to the appointment and spoke to the doctor. He counseled me to take care of myself. He asked me to keep in touch. His caring for Lou, and for us as a couple, is something I will always remember.

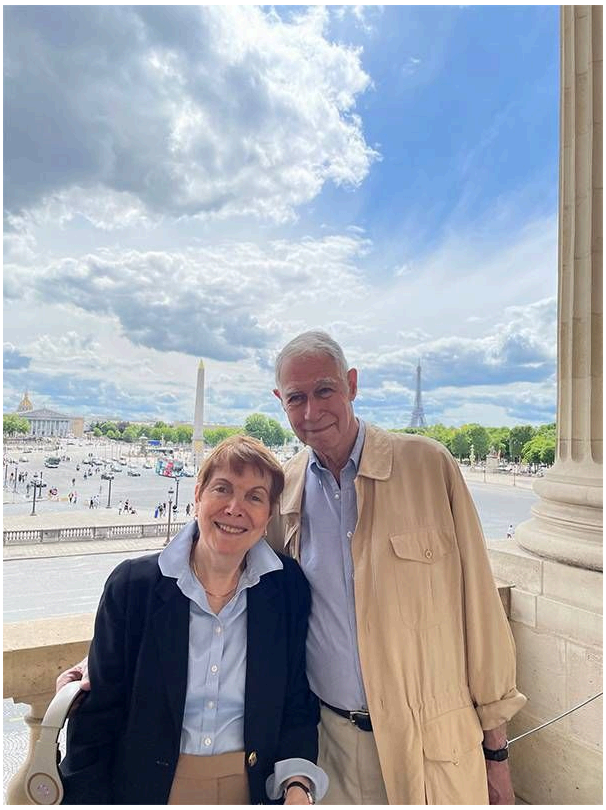
Lou doesn't want to spend whatever is left of his life in a hospital, and I want to respect his wishes. My insides churn with helplessness.

My own NYU internist has scheduled a monthly video visit to check up on me, especially since I've lost more than 15 pounds unintentionally. And the local rabbi calls this agnostic at least once a week. Some friends have disappeared, but there are those who keep in touch. And, yes, I do have someone I can talk to. But it is a lonely road.

Over a year later, my 87-year-old husband has outlived his prognosis and is a shadow of what he was. But he is here. And I want him here.

Some people get inspired after a diagnosis. They reach for a goal or get everything in order. Lou is frustrated and bored, but he is too worn out to do much of anything. I want things however he wants them.

Mostly, he wants to sleep or read the newspaper or hug me. That's what I cling to. That he'll be there to cradle me in his arms me as long as possible. Sometimes we go to the sofa and lie with my head in his lap. Lou believes his job is to take care of me, and some of his distress is that he can't anymore.



The couple on a trip to Paris, one of their favorite places. | Credit: Courtesy of Leida Snow

Sleep? Not so much. Exhausted. Deeply. What to do? Besides cry. Besides wish I could do more for this man who's been my life for over 41 years. Because I can't imagine my world without him. He's my rock and my biggest fan, the one whose faith in me is stronger than my own. His all-embracing love is where I am home. Whatever I want to do, wherever I want to go, I want to share those experiences with Lou.

That's the hardest part of Now. Because I'm with him in this no-man's land, where we can only cling to each other and wait for the inevitable.

Of course, we would have tried anything, gone anywhere when we first heard Lou's diagnosis and the medical predictions of our future. But if I'd known then what I know now, I would have encouraged Lou to make a different decision.

Regretting Endless Tests and Treatments

There are cancers that can be targeted. Cancer with unknown primary is not one of those. I hope anyone reading my words never faces what's in front of us. But if you find yourself in this nightmare, here's what I would say: Don't spend whatever time you have going to doctors, submitting to endless tests and treatments, waiting in anonymous rooms filled with distracted, unhappy people. Sitting on uncomfortable chairs, being so vulnerable. Dealing with

all-business staff that has all the time in the world, while your time is limited. And waiting. Waiting. Waiting.

> **If I had known then, what would I have done? I would have gone back to Paris with my husband, or we could have gone to the Broadway shows we missed.**

If I had known then, what would I have done? I would have gone back to Paris with my husband, or we could have gone to the Broadway shows we missed. We would have reminded ourselves how lucky we were to be able to walk home from the theater. We could have taken in New York's magisterial skyline from celebratory dining spots.

Now Lou is beyond tired. His legs give way and he falls, can't get up. Sometimes I'm not strong enough, and we have to call for help. His MSK doctor says he's fallen too many times and is not safe at home. Emotional overload. The doctor wants me to move him to an in-patient hospice. Lou knows not being home is a possibility. He is disconsolate.

No. I am not going to rush into anything. Moving furniture to make room for a hospital bed, even though Lou says he won't use it. Never-ending efforts to schedule health aides. Medicare comes through with 15 - 20 hours a week. We now need 24/7. Trying not to think too far ahead.

Welcome to the third ring of hell. You may have read that because of COVID many health care workers died/changed careers/moved away. At the same time, more and more people need qualified help. Hours are spent trying to figure out what's possible.

Recently my darling said, "What a terrible burden I've put on you." I thought my heart would crack. "I don't feel it as a burden," I said, startled by my truth. What is breaking my heart is the fear that I won't be able to help him,

that I won't know what the right thing is. Fortunately, the hospice physician and woman covering for him are knowledgable and compassionate.

So far, there is no pain. One blessing among the horrors. But he is suffering, and we are looking at a future of unknown — though not long — length.

Struggles of a Caregiver

As I'm writing this, Lou is visibly deteriorating. He can no longer turn himself easily in bed or rise to a sitting position without help. He can barely stand for a moment with assistance while he is moved from the bed to the wheelchair.

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I can't imagine how people navigate this without a caring partner, but anyone taking on the caretaker role should know in advance: there is mighty little guidance. It's learn-on-the-job. Case workers and nurses may or may not be thoughtful and compassionate, but you have to think of the questions to ask because too often no one volunteers information.

Are you willing to stay in because you don't trust that the aide will keep your loved one safe? Or because the aide didn't show up? Are you prepared to spend hours of your time trying to find coverage even though the agency assured you they would always be able to come through? Can you handle the blowback when you cancel what isn't working? Can you deal with the additional cost? Are you prepared for the never-ending laundry? Can you function with catch-as-catch-can sleep, only a few hours each night?

My husband is dying. But he's not gone yet. A few nights ago, he agreed to the hospital bed. He understood that if I don't get some sleep, I won't be able

to be there for him. He hates the bed. Misses me at night. I miss him too.

Lou eats little, sleeps at odd hours, is restless at night. The aide has to wake me. Lou's speech is now slurred. It's hard to understand him. He is angry. He forgets. He wants the hospital bed and the strange people in the apartment gone. He wants me with him all the time. I am terrified.

Addendum: The Death of My Husband

In the daytime, he dozes, wakes, starts to read the newspaper, dozes, wakes, tries again to read. My plan was to write how I would put my arms around him, wanting him to know how much I love him. I was going to share how he would reach out to put his arms around me, wanting me to know how much he loves me.

On September 17th, Lou slept most of the day and night. He mumbled about wanting to go home. I held his hand, said he was home and I was with him. I used to call him my giant, and I told him that I would still choose him out of all the giants in the world. I said I would always be with him and he would be with me. He smiled, squeezed my hand and moved his lips to kiss me.

The next day, he woke and surprised me, wanting to brush his teeth, shave, shower. The aide helped him into the wheelchair and into the bathroom. Afterwards, I warmed some chicken soup. He reached for it and gulped down almost half a cup. Then he lay back to rest. Suddenly he was gasping for breath. And then he was gone.

I am numb. The aide gently repeats that Lou is not breathing. A convulsion of tears. I thought there were none left. Touching him. Taking his hand. Stroking his forehead. Kissing him. What do I do now? I am lost.

Call the hospice. They will send a nurse to sign the time of death. Call the funeral home. They will come. Then what? Vast emptiness. The rabbi calls and says I have to embrace life. Says that's what Lou would want. Rationally I know he is right. Somehow, I will find a way. I just can't imagine how.

This year, for our anniversary, June 27th, we had to cancel reservations at a restaurant with spectacular Manhattan views. Lou said it made no sense to go when he couldn't eat much. He was devastated to disappoint me.

I said: "We'll always have Paris."

> **Editor's note:** Lou Sepersky died on September 18, 2023 at age 87.

Leida Snow is an award-winning journalist and communications coach. Follow her @LeidaSnow Read More

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