Amid His Family's Fatal Cancers, an Author Finds Genetics, Grief and Hope

After losing his mom, two sisters, a brother and a nephew to various cancers, Lawrence Ingrassia wrote *A Fatal Inheritance*. Here, he shares some healing insights.

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Not long ago, mainstream science was skeptical that cancer could be hereditary. Malignancies, it was widely believed, were caused by viruses, environmental toxins and carcinogens. Indeed, those factors do often lead to cancer, but thanks to discoveries in genetics beginning in the 1990s, we now understand, for instance, that certain genes work to regulate cell division and suppress tumor growth. Mutations in those genes, which can be hereditary, increase the risk for cancer. Perhaps the best-known examples are BRCA1 and BRCA2, the so-called breast cancer genes. (Everyone has these genes, but only a small proportion have the mutations that cause cancer.)

Lawrence IngrassiaCourtesy of Vicki Ingrassia

There’s also Li-Fraumeni syndrome, affecting the p53 gene. It’s a much rarer disorder and one of the subjects of Lawrence Ingrassia’s book A Fatal Inheritance: How a Family Misfortune Revealed a Deadly Medical Mystery. Ingrassia, a journalist who worked at The Los Angeles Times and The Wall Street Journal, lost his mother (she was 42), two sisters (at ages 24 and 32), a brother (69) and a nephew (39) to various cancers resulting from the syndrome.

"A Fatal Inheritance"Courtesy of Henry Holt and Company

As Ingrassia writes in his book: "The story of Li-Fraumeni syndrome and, more broadly, of cancer research isn't one story, but two. It is both a heartbreaking story of family loss and an inspiring story of scientific achievement." Indeed, he documents not only the story of his family and others but also of the researchers. It makes for an educational and emotional tale.

We spoke with Ingrassia for this installment of our Can Heal column—that life-affirming declaration is right there in the title of our magazine: Cancer Health—and we discussed grief, caregiving, genetic testing and hope.

People with Li-Fraumeni syndrome have a 50% chance of passing it on to their children. There's now a genetic test for it. In 2015, at age 63, you got the test as part of a clinical trial designed to study the psychological effects of testing positive. However, you tested negative, which wasn't a surprise, since most people with the condition develop cancers at younger ages and you'd enjoyed a healthy cancer-free life. Do you recommend folks get tested if they think their family is at risk?

Deciding whether to get tested—and then deciding, if you're positive, whether to have children—is really personal for all sorts of reasons. My recommendation is to at least consider getting tested because knowledge can be power, and you can make informed decisions. If you learn you have it, then you can get screened for cancers, because early detection is the best way to beat these cancers and prolong your life. And then you can get your children tested and screened. Just waiting for stuff to happen is a strategy that you can regret.

With so much cancer in your family, it's surprising you never made the genetic connection.

Our dad was a research chemist, and our supposition was that he had brought home chemicals on his clothes, tiny particles we ingested and that later manifested itself as cancer. Of course, there really are a lot of chemical carcinogens, so that's logical. And once you convince yourself of something, it's hard to actually think of alternatives.

You've been a caregiver many times over. What advice do you have for a person whose loved one was just diagnosed with cancer?

First of all, it's OK to be afraid and angry, but it's important to show your support in whatever way they need. Different people need different things. My youngest sister, who died at 24, said she didn't want to see us crying. That was hard. But if anyone had to cry, you went out of the room. With everything she was going through, that would have been too much for her because that

would have been putting the sadness back on her.

You could ask the person: “Can I do some research for you?” “Can I go to your doctor appointments with you and take notes?” That can be helpful.

Also remember that there are many, many cancer survivors out there. Indeed, the progress in many types of cancer is dramatic in so many ways, and yet people go into it thinking, This is a death sentence. But it isn’t necessarily—you can live quite a long life.

That’s the thing to tell people: You can get through this. It’s not going to be easy, but there are a lot of cancer survivors, so talk to other people. You aren’t alone. There are support groups and associations, all sorts of information. As I mentioned in the book, Facebook support groups are important, especially if you have a rare condition. Until Facebook came along, there might be one or two families in an entire city, and you would feel alone. But now, you can go online and there’s emotional support but also advice.

You mentioned in the book that after your sister died, you began looking at family photos at Christmas. Is this a ritual you hold on to?

I still do it. Looking at old family photos can remind you of what you lost but also of what you had. It is an enduring thing—these memories you’ll always have. Seeing my mother beaming at us as children—you don’t get that unless you look at that photo. Seeing me and my siblings in various settings, like in the kitchen sharing food or at weddings or dancing and talking together with friends. Life is a real tapestry, truly. And the photographs help capture that. They can be reinforcing and life-affirming. I’d encourage people to do that. Yes, you might have some tears, but I think you’ll come out of it feeling deeply moved as well.

I do try to remind myself how fortunate I and my family have been. You can’t ask, “Why me?” about the bad things without asking, “Why me?” about the good things. I also try to remind myself: Yes, cancer has devastated my family, but other families have other things. Life brings us all sorts of difficult things and happy things, and you have to recognize that.

Any final words of advice?

For me, it has been helpful to embrace grief. Among my most vivid and intense memories are those times I spent with my sisters and brother during their cancer treatments and final days. I never felt closer to them. Decades later, in my mind’s eye, I can still recall so many details—sitting

next to them, holding their hands. Recalling these things, not letting go, helps keep them alive in my memories.

Also, I find it life-affirming to remember the last gesture of my youngest sister. In her final days, she arranged for delivery—after she died—of flowering plants to me, my brother and sister, some good friends and even her oncologist with a one-word message: “Forward!” Even as her time was cut short, she wanted us to keep going. I think that is true of all our loved ones who die. They want us to be happy and live full lives.
