

How people with compromised immune systems are staying safe amid coronavirus

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For Janine McAlonan, the fear of keeping loved ones safe during the coronavirus outbreak is terrifyingly familiar.

McAlonan's 13-year-old daughter, Lexi, has battled a rare form of lymphoma for years. Recently, she relapsed. And though she's entered in

a clinical trial, with weekly intravenous treatments to boost her [immune system](#), Lexi's ability to fight off disease is severely compromised.

Early this month, Lexi's oncologist at the Children's Hospital of Philadelphia was recommending that she continue to go to school and live as normal a life as possible in between treatments, McAlonan said. But then the first cases of COVID-19 started emerging in the region.

"Within literally 48 hours, the tables turned. It was like, Lexi should be inside, not around anybody," McAlonan said. "Then I started panicking."

Lexi can receive some of her treatment at home in South Philadelphia. But McAlonan's fiance works in a supermarket, and is considered an essential worker even as other businesses close and employees work remotely to slow the spread of the [coronavirus](#). Her oldest son, 20, works at a pizza shop and is still on the job, too. Using social distancing to lessen their chances of contracting the virus isn't possible through their jobs.

"My fiance has to go to work. He's on the front line. What do we do to protect Lexi?" McAlonan said. "It's just scary - (the [coronavirus outbreak](#)) is like the oncology world we live with every day, but even more (serious). I lived like this for four years. I can't live in fear like this again."

But that's exactly what she and other families with immuno-compromised members are bracing for as the coronavirus outbreak worsens. For many medically fragile people, self-isolation is an especially difficult task—their conditions require frequent in-person doctor visits, or treatment that can't be administered at home.

That's partly why it's so important that the healthy people practice social distancing as well, experts say—to avoid spreading COVID-19 to people

whose immune systems can't handle the virus, or whose medical needs make it impossible to completely self-isolate.

"All of these healthcare organizations can come up with [best practices](#) and strategies," said Siddharth P. Shah, the director of ambulatory nephrology and dialysis programs at Penn Medicine, whose patients are among those who must continue to leave the house to receive treatment. "But nothing is going to be more powerful or valuable than (the general public) reducing the spread and reducing the burden of the disease."

Physicians who treat other conditions that require daily or weekly treatment have also made efforts to help their patients stay on their course of treatment.

For patients with addiction, periods of abstinence can mean death by overdose if they start using drugs again. Last week, the federal government has relaxed its restrictions around the distribution of methadone, an opioid-based treatment medication that helps reduce cravings and also maintain patients' tolerance to prevent overdoses.

Under normal circumstances, the opioid-based medication is taken daily under supervision at a special clinic. Under the new guidelines, stable patients living in states that have declared coronavirus emergencies can take up to 28 days' worth of methadone doses home, in order to reduce lines at clinics.

Patients with kidney disease are being urged to continue their dialysis treatments—because skipping can be fatal in and of itself, said Holly Kramer, the president of the National Kidney Foundation.

"Dialysis is a life-sustaining procedure," said Kramer, a physician at Chicago's Loyola University Medical Center. Missing one or two treatments can cause shortness of breath, fluid buildup and leg swelling,

she said. "But if you miss many treatments, you could die."

Hemodialysis treatments, which clean patients' blood via machines in special clinics, are generally administered four hours a day, three times a week. Many dialysis patients are older, or have other medical conditions that put them at risk for serious complications from the coronavirus, Penn's Shah said, which makes strict safety measures especially necessary.

Clinics around the country have begun isolating patients with any signs of sickness and asking as many patients as possible to wear masks at the clinic, Kramer said.

Home treatments are possible through a form of dialysis called peritoneal dialysis. But patients must undergo surgery to insert a catheter before starting, and Kramer said she was worried that as hospitals fill up with coronavirus patients, it would be difficult to get kidney patients in for those procedures.

Healthier patients with immune system issues—like people who are HIV positive and have a low viral load—can also experience uncertainty and fear because of the coronavirus outbreak, said Ronda Goldfein, the executive director of the Pennsylvania AIDS Law Project.

"There's a universe of HIV—a continuum," she said. "There's people who are disenfranchised from care, living outside, struggling with addiction—it's an incredibly dangerous situation for everyone who's sick and outside. And then there are people who have turned the corner on HIV, living their lives in full with a solid prognosis. But all that is contingent upon everything working right."

Many of Goldfein's clients living with HIV still depend on medication and regular healthcare, she said.

"People have a good life expectancy as long as they can get their meds, as long as their meds can be delivered to their pharmacy, as long as their meds can continue to be manufactured," she said. "Something like (the coronavirus) reminds us that if the system collapses, all the gains (HIV patients) have made could collapse as well."

Goldfein said her center is working to serve clients remotely and has set up a legal hotline for new cases.

Before the city and state ordered most businesses to shut down over the outbreak, one client called Goldfein's office to report that their employer had asked all staffers to continue to come to the office amid the coronavirus outbreak—unless they had an underlying disability. Goldfein's client asked if they should reveal their HIV status: "They were like, 'What do I do? Risk getting exposed (to the virus), or say I have a disability?'" said Goldfein.

Families of cancer patients say that daily life under the coronavirus eerily mirrors the lifestyles they've already been leading: staying inside, washing their hands constantly, and worrying about possible infections.

Jodi Reich's 3-year-old daughter, Phoebe, is in remission from leukemia, but still has to receive chemotherapy treatments semi-regularly. Unlike other parents, she can't put off a chemo appointment in the same way that another mother might reschedule a routine check-up. Last week, Reich took Phoebe to CHOP for her monthly appointment, but made sure to have her wear a mask and stay in a stroller. They moved through the main hospital "lightning-fast" until the family made it to the oncology ward, Reich said.

"We need to practice social distancing, and be that much more careful about what we do," Reich said. "I haven't been outside myself other than going to CHOP. I've heard that not everyone is abiding by the social

distancing. But we have to."

At 3, Phoebe is used to staying inside and stringent hygiene protocols to keep her safe. "She's used to me being on top of germs," Reich said. "I take out the hand sanitizer, and she puts out her hands."

For older immuno-compromised kids, the coronavirus outbreak is a bit more difficult to live with. Lexi, Janine McAlonan's 13-year-old, has been struggling with anxiety. And she misses school and friends. Because her cancer treatment caused her to lose her eyesight, staying occupied has been that much more difficult, McAlonan said.

"She has a lot of anxiety from what she's been through. It comes and goes—will she get (the virus), will she not get it," McAlonan said. "I try to explain to her that you'll stay in, you'll be okay. And she's like, I don't want to stay in, I don't want to be cooped up."

For now, McAlonan is doing what she can to keep the family as socially-distanced as possible in their South Philly rowhome. That means she and the younger kids stay home, and no one leaves the house over weekends, when her fiance isn't working.

On weekdays, when her fiance arrives home from his supermarket shift at 4 a.m., he showers immediately, and then stays away from Lexi until it's time to leave for another shift. Meanwhile, McAlonan has begun sleeping in her daughter's room, to avoid further contact with her fiance. And if anyone develops symptoms? "You have to go on lockdown, basically," she said her daughter's doctor advised.

She wishes more people would take orders to stay inside seriously: she was shocked to see Philadelphians continuing to congregate outside in recent days, despite the city's stern warnings.

Cancer treatment centers across the region are also taking protocols to keep patients safer.

Karen Knudsen, enterprise director of the Sidney Kimmel Cancer Center and executive vice president of oncology services at Jefferson Health, said that the center is continuing treatments for patients but limiting visitors, using telehealth to conduct more appointments, and screening patients for signs of sickness before they come in for chemotherapy treatments.

These practices are especially key for bone-marrow transplant patients, whose immune systems are suppressed as part of the treatment.

Still, Knudsen said, the center's patients have been resilient.

"Cancer patients are a really different group of people," she said. "They live, already, with uncertainty. That's their daily existence. They understand all about taking precautions. Caregivers and families have already adopted that lifestyle of, Let's limit exposure to infectious agents. At some level, cancer [patients](#) are really well positioned to make lifestyle adjustments the general public has not."

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