Cancer, COVID-19 and Proceeding With Caution

Cancer patients undergoing treatment and those with suppressed immune systems eye the future—and the COVID pandemic's wane—warily.

February 22, 2022 By Diane Mapes and Fred Hutch News Service

As the U.S. enters its third year of pandemic life, people's emotions and responses are all over the map, much like vaccination and booster rates. While some believe omicron and the COVID-19 pandemic have both peaked, others fret that worse variants loom.

Millions more have decided "they're done with it," but it's still very much up in the air whether this new coronavirus is done with us. Mask mandates are dropping, protests and tempers are flaring even as infections, hospitalizations and death rates continue to strain the healthcare system.

But an estimated 7 to 10 million immunocompromised Americans can't dismiss COVID-19 with a weary shrug.

Cancer patients in treatment, organ transplant recipients, people with HIV and other diseases like multiple sclerosis or rheumatoid arthritis or Crohn's aren't always able to produce adequate antibodies from vaccines and boosters, either as a side effect of their treatment or of the disease itself. So they're extra susceptible to infection and death from COVID-19. Even moreso if they have underlying health issues, co-morbidities like obesity or heart disease.

How can they stay safe and what do they want their increasingly COVID carefree neighbors to know? We checked in with patients and providers for survival strategies amid yet another pandemic transition.

Anger, Worry and Despair

With mask mandates and other public health measures either dismissed or never in place in most of the U.S., immunocompromised patients and their caregivers are frustrated. Many feel unsafe mingling with the unmasked.

Dr. Kelly Shanahan, a metastatic breast cancer patient and advocate from Lake Tahoe, California, said her county "sucks." The full-vaccination rate is stuck at 60% and local restaurants don't require proof of vaccinations. So despite three shots and a booster, she can't dine out and has to wear a mask everywhere.

“I roll my eyes, a lot,” she said via tweet.

Ron Cooper, a 73-year-old prostate cancer patient from Louisville, Kentucky, cracks wise to temper his frustration.

“It would be better if someone like me could wear a scarlet ‘C,’” he said, explaining his vision for a T-shirt for vulnerable patients with “I have cancer” on the front and “Six feet, please!” on the back. “People are right up in your face no matter where you go now. No courtesy. People like me, and especially blood cancer patients, really take their lives in their own hands when they go out of their house.”

More than a few are angry at the lack of empathy and civic duty shown by a surprising number of people. Especially since these patients are very used to living with uncertainty and sacrifice; ditto for wearing masks to prevent infection — or death — from a cold, flu or COVID-19.

“I am frustrated, angry, discouraged that ‘freedom’ for some trumps safety for the many,” one colon cancer survivor tweeted. Other patients say they feel nervous, scared, even despair. Some have taken to social media to educate those who don’t understand why “high-risk people are freaked out and upset.”

Others can no longer speak for themselves at all.

“I have patients who’ve seen delays to their transplant,” said Dr. Jim Boonyaratanakornkit, an infectious disease expert at Fred Hutchinson Cancer Research Center in Seattle. “And delays can cause progression and death.”

Feeling ‘Dispensable’

One of the hardest things immunocompromised people have had to face isn’t COVID-19: it’s the all-too-prevalent attitude that they’re “dispensable.”

“I wish people would be more mindful about how they’re talking about the pandemic in relation to compromised and high-risk populations,” said Anna Clutterbuck-Cook, a 40-year-old reference librarian and historian from Boston. “Even if you’re talking in the abstract, we’re right here. We’re hearing that.”

Clutterbuck-Cook was diagnosed with stage four colorectal cancer in March of last year, after a diagnostic delay due to the pandemic. While friends and colleagues have been supportive, Clutterbuck-Cook said she’s frustrated by the public dialogue about risk.

Adam Hubrig, who identifies as disabled and immunocompromised, wrote in a blog post for the Disability Visibility Project that he’s “been told, almost daily since the earliest stages of this pandemic, that it’s only people like me that are dying, that people like me are somehow a completely acceptable sacrifice for ‘the economy’ and a ‘return to normal.’”

Editor and multiple myeloma patient John Gluck shared his concern, as well, in a January essay in

the Washington Post, writing “even as the disease is spreading at an unprecedented rate, we’re doing less to combat it. That’s a dangerous combination, especially for the vulnerable.”

Those who state that the pandemic is over or claim “everyone will catch COVID-19 eventually” aren’t actually thinking about everyone, these patients point out. They’re thinking of themselves. And maybe flirting a bit with eugenics.

“For people who are immunocompromised or high risk — our risk analysis is different,” Clutterbuck-Cook said. “I understand a lot of the emotions of just wanting to be done with this. I’d love to be done with it, too, to not have to postpone activities because the risk is so high.”

Case in point, she was hoping to go to her sister’s wedding in March — but it’s in Texas, which lacks mask mandates and has banned vaccination requirements.

“There was a brief window of time where I thought If I’m done with intense chemo and caseloads are low, I could fly to the wedding,” she said. “But that doesn’t seem possible now.”

She doesn’t necessarily blame the individuals who refuse to mask or get their jabs, though.

“The local governments aren’t taking steps to mitigate the problem and the individuals are taking their cues from that,” she said. “Even if specific people around me are being careful, you’re always part of a broader social context where people aren’t taking precautions. My sister is totally understanding about it, but it sucks to not be there.”

Sadly, even people masking in support of the immunocompromised — or even patients trying to protect themselves — are accused of overreacting or “virtue signaling” in our ever-more-politically-prickly nation.

> I have an immunocompromised 14yo daughter (no spleen due to a blood disorder). Everyone in our house is vaxxed/boosted, she has had her 4th shot too. We continue to wear n95 masks indoors, avoid going out to eat/crowds. I hate that people won’t care for her, and others like her.
>
> — Teresa Strand (@TeresaStrand15) February 9, 2022

Vaccinations and Boosters

But even as public health efforts end, patients can take their own steps to protect themselves.

Hutch clinical researcher and infectious disease expert Dr. Catherine Liu said, first and foremost, individuals who are vulnerable should make sure they get all necessary vaccinations.

“Some of the patients in our cancer center haven’t gotten their boosters,” she said in a recent Science Says event. “For immunocompromised individuals, we’re recommending three doses of the primary series and a fourth dose as a booster.”

This advice echoes the Centers for Disease Control and Prevention which revised their guidelines in early February. According to new guidance, “people who are moderately or severely immunocompromised should receive a booster dose at least three months after the last (third) dose of an mRNA COVID-19 vaccine.” Previous guidelines called for a five-month break between the last dose and the booster.

“I’ve taken every shot,” said Ben Young, a 67-year-old prostate cancer survivor and liver transplant recipient who takes immunosuppressing drugs each day to ensure his body doesn’t reject the organ. “I had my third and now I’m getting ready to do my fourth. It was recommended by the transplant clinic.”

Young, who lives in Everett, Wash., and works as the director of marketing and grants for the Communities of Color Coalition, said when it comes to people being considerate of his compromised health, “Some are and others aren’t.”

Is he bothered by the very vocal anti-maskers, anti-vaxxers or others who believe their freedoms are being trampled by state or federal mandates?

“I don’t want to get caught up in that exceptionalism,” he said. “I want others to treat me as if they’re treating themselves. If they do that, then I’m good. I’m going to protect myself and if I see it’s a bad situation — or close to a bad situation — I’m going to stay away.”

Preventive Therapies for the Vulnerable

In addition to vaccines and boosters, new options are becoming available.

New York educator Edie Miller, diagnosed with a slow-growing lymphoma in 2012, went through months of chemotherapy when her disease became aggressive last summer.

“I’ve barely left my house except for hospital visits,” she said. “The COVID death rate for people like me is about 15%.”

Fortunately, Miller’s fragile health qualified her for a prophylactic long-acting monoclonal antibody combo called Evusheld, specifically designed for moderate or severely immunocompromised people.

“I got a call from my oncologist’s office on a Sunday evening that they had 120 doses and I happily got the injections,” said the 61-year-old, who is fully vaccinated. “One in each cheek! I go for a follow-up dose in 6 months. They told me it boosts my Covid immunity by up to 77%.”

Infectious disease expert Liu encouraged other vulnerable patients to ask about the drug, which is intended for those who have not been exposed to or have COVID-19.

“It reduces the risk of developing symptomatic COVID by 80%,” Liu said. “It’s not a replacement for vaccination but it supplements it, offering another layer of protection. If people can access it.”

The challenge is the supply is limited, a familiar refrain in a time of shortages and supply-chain issues.

Boonyaratanakornkit reiterated the drug’s effectiveness — and its short supply — adding other important caveats.

“You have to be extremely high risk and even then, you may need to be put on a wait list,” he said. “And patients with heart disease may have a slightly higher rate of heart complications after Evusheld as compared to placebo. But it is an option to provide protection against COVID-19.”

Additional anti-COVID-19 drugs are under study in clinical trials, including the monoclonal antibody sotrovimab (Xevudy), approved for treatment in an Emergency Use Authorization by the Food and Drug Administration.

Boonyaratanakornkit is one of the principal investigators on a Phase 1 Fred Hutch/Seattle Cancer Care Alliance trial testing sotrovimab’s effectiveness as a COVID-19 preventive in blood stem cell transplant patients. New treatments and preventive therapies are still sorely needed, he said, because the virus continues to mutate, rendering some treatments — like the monoclonal antibody Regeneron — unusable.

“The FDA revoked the EUA for Regeneron as treatment,” he said. “If the virus is resistant to it as treatment, it will be resistant for prevention. As a result, we had to close a study using the Regeneron antibodies for prevention and have started a new one with sotrovimab, which is thought to still be effective for the main omicron variant.”

But the field, he stressed, is changing very quickly.

The research team, which includes Hutch scientists Drs. Alpana Waghmare and Michael Boeckh, is giving sotrovimab as an infusion to transplant patients before their “conditioning,” rigorous chemotherapy and/or radiation to eliminate a patient’s immune system before transplanting a new healthy one. The trial, dubbed COVIDMAB, is now open and currently enrolling; patients will be followed for six months to determine the drug’s efficacy. Read more about COVID-19 clinical trials here.

“After a transplant, it can take months for our immune systems to recover,” Boonyaratanakornkit

said. “The hope is a single dose provides months of protection. That’s the purpose of the study — to see how long the antibodies last.”

A larger additional trial of the same drug may be in the works, as well, he said, something he welcomes.

“Our patients are at greater risk because they don’t respond to a vaccine as robustly,” he said. “So having another preventative measure to tide them through the pandemic, especially when there are surges of variants and this pattern of waxing and waning outbreaks like we’re seeing now, is crucial.”

> Many in my area did not comply with mask mandates and did not get vaxxed. I just do what the oncologist says and continue to mask up and get the fourth shot next month. Had covid twice already and it’s no joke with lung cancer
>
> — Mary_Cosby’s_Boundaries (@king_lisa) February 8, 2022

Strategies for Survival

What other strategies are patients using to get through this new period of COVID-19 chaos?

Cooper, the prostate cancer patient, has reworked his schedule so he can stay safe in Kentucky, or as he now calls it, “The Wild West.”

“Things were going great with the mask mandate and social distancing,” he said. “But then the state Supreme Court stopped the mandate and now only about 5 to 10% of people mask up. For me, it’s meant going to stores early in the morning like at 7 a.m. when nobody’s there.”

The former newspaperman also relies on humor to keep his spirits up and speak his truths as a cancer patient, posting jokes on his blog, CancerLite.com, and attending virtual “Lunch and Laughs” with other patients at Gilda’s Club.

“It has been my redemption in a secular sense,” he said. “It truly has. In the meantime, I’m wearing a mask to protect myself. And I am angry; I journal about it a lot. But if the folks yelling about liberty and freedom are to hear my voice at all, it’s going to be with humor. So I try to be as

diplomatic as I can, to be firm yet funny — sometimes humor can wriggle its way through."

Clutterbuck-Cook said she's found comfort tapping into different patient communities.

"It's been really helpful to be in touch with people dealing with chronic illness or disabilities," she said. "It's helpful to be connected to people who are out there doing activism right now, even following them on social media and hearing how they're framing the situation. That modeling is really helpful."

She also tries to look at what's going well, as opposed to what's gone south. Boston, for instance, has an indoor mask mandate, which makes her feel much safer.

"I've been thinking a lot this year about how much privilege I have," she said. "I had paid sick leave; I have good insurance. I didn't have to put off any surgeries or put off chemotherapy treatment. That's not always available to everyone who gets a diagnosis like this."

Hutch infectious disease doctors encourage those who are immunocompromised and immunosuppressed to keep being vigilant.

"Continue to take precautions and limit your exposures," Liu said. "Nothing will be 100%, but vaccines will help and Evusheld will help. Having everyone around you — your loved ones and especially your caregivers — get vaccinated is also really important."

Silver Lining

Boonyaratanakornkit also stressed staying "super aware of your surroundings."

"We have to mitigate COVID-19 from multiple fronts," he said. "Masking, social distancing, vaccination — it may not be fully effective in this population, but it will be partially effective — and then the monoclonal antibodies, which hopefully will become more available over time." (Indeed, the FDA just authorized use of bebtelovimab, another monoclonal antibody, as a treatment for vulnerable patients.)

Those practices, used in tandem, can "stack the deck," he said, so patients can either dodge infection completely or mitigate it so it's only mild.

Even if vaccine rates don't rise, the combination of people who've caught COVID-19 over the last six months and those who've been vaccinated means a large majority of Americans have some protection to dramatically reduce the spread — and the risk of catching the disease — in the coming weeks.

In the meantime, cancer patients and other susceptible folks continue to move forward with caution and even find the occasional silver lining in their N95s — like the fact they're not getting sick with the usual colds and flus. Indeed, CDC data shows a drop in flu rates.

"I will be wearing a mask forever," tweeted @CancerFinalGirl, a brain cancer patient from Los

Angeles. “I’ve really enjoyed NOT getting sick from external diseases the last few years.”

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