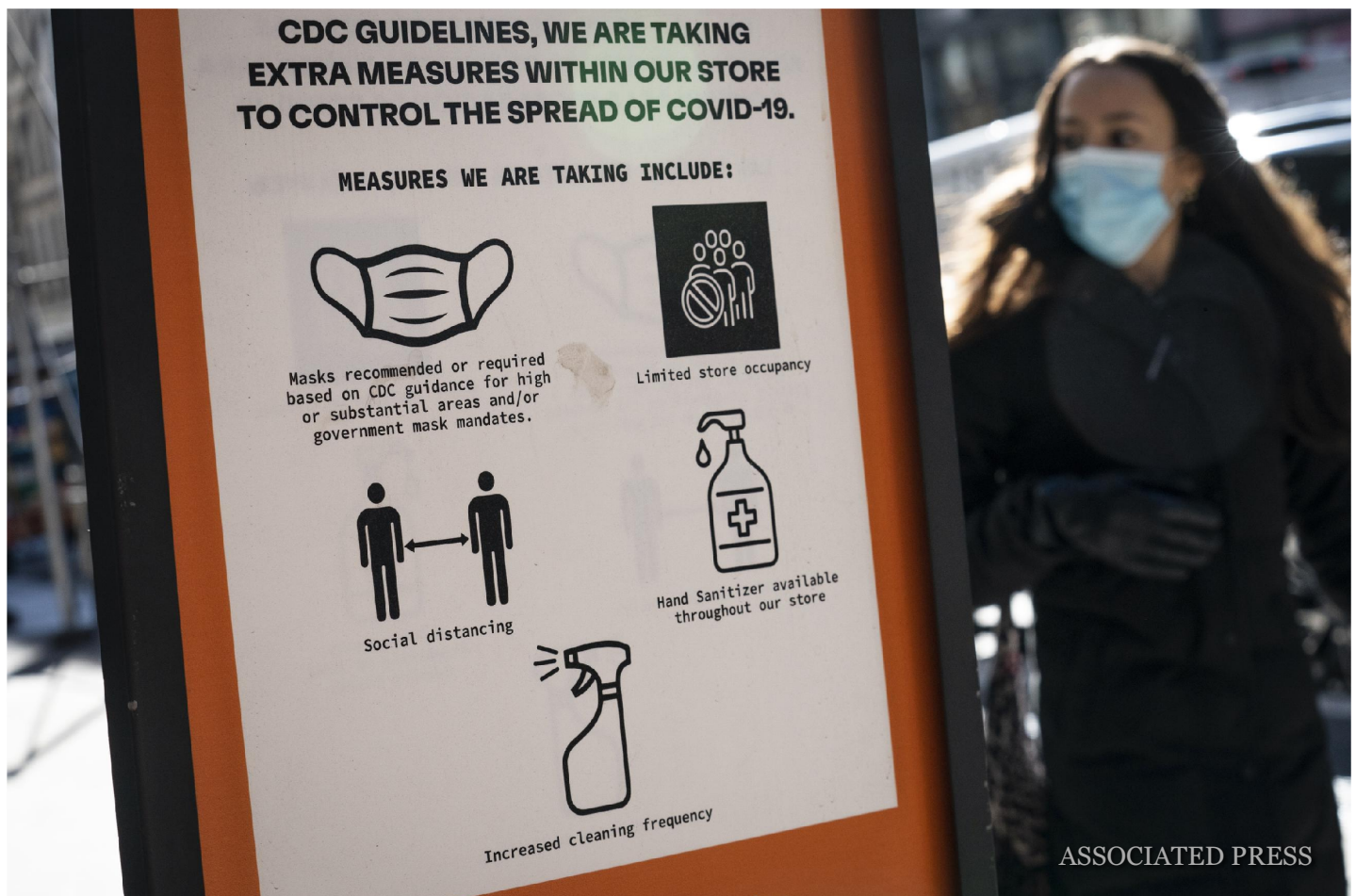




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# Vulnerable patients prepare to navigate post-pandemic world

High-risk people will likely stay cautious as COVID-19 recommendations and restrictions roll back.



(AP Photo/John Minchillo)

## Erin Durkin

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**W**ith COVID-19 mask recommendations easing up, people still at elevated risk for the disease are assessing what the future holds for them in the pandemic.

Multiple groups representing people with kidney disease, cancer, and other conditions that put individuals at high risk of a severe infection told *National Journal* that these patients will probably take extra precautions when it comes to COVID-19.

For them, wearing masks and avoiding crowded situations will likely continue. The lifting of mask requirements is making some patients nervous and causing them to take more precautions, said Jamie Sullivan, senior director of policy at the EveryLife Foundation for Rare Diseases.

“The mask mandates were helping provide some comfort in getting back to doing some of the things out of the house that you hadn’t done before,” Sullivan said. “The community was doing them because they knew if they went into that store or they knew that everyone was going to be masked, they felt more comfortable. And so without that certainty, there’s certainly going to be less of that happening.”

Under new Centers for Disease Control and Prevention [guidance](https://www.cdc.gov/coronavirus/2019-ncov/your-health/covid-by-county.html)

(<https://www.cdc.gov/coronavirus/2019-ncov/your-health/covid-by-county.html>), released at the end of February, masks are not recommended for many Americans in counties with low-to-medium levels of COVID-19. But people in counties with high levels of COVID-19 are recommended to wear masks. High-risk individuals in areas with a medium level of COVID-19 are advised to consult their doctor.

A few days after the shift in recommendations, President Biden gave his State of the Union address in front of a mostly mask-less Congress. “Folks, if you’re immunocompromised or have some other vulnerability, we have treatments and free high-quality masks,” Biden said. “We’re leaving no one behind or ignoring anyone’s needs as we move forward.”

But some patients are fearful that the world will do just that.

“Unfortunately for them, it’s a little more daunting and it creates health concerns for them as individuals,” said Joseph Vassalotti, chief medical officer at the National Kidney Foundation. “I think that’s the general thought, and some feel like they’re being left behind ... that society has moved on and forgotten about them.”

Vassalotti added that the foundation has been advocating for kidney patients to be prioritized for vaccine doses, monoclonal antibodies, and oral antiviral treatments.

Biden is pressing Congress to fund another COVID-19 supplemental to boost the supplies of treatments. The White House had requested \$22.5 billion last week, with \$12.2 billion going to the procurement of antivirals, monoclonal antibodies, and vaccines for near-term prevention and treatment.

On Tuesday, Senate Majority Leader Chuck Schumer announced a proposal for a lower level of funding for COVID-19 efforts: \$15 billion. The plan is to include the supplemental aid with a government-funding omnibus that must pass by March 11.

“We cannot discount the fact that a new variant can come,” Schumer said in a press briefing. “We have learned a lot from the three variants. But we’ve also learned if we’re not prepared, it can return to the days of lockdowns and closed schools and life not being normal.”

Biden also announced during the State of the Union last week a new “Test to Treat” initiative to allow people who test positive to receive antiviral pills immediately.

Sullivan suggested that the CDC “got ahead of themselves” by relaxing the guidelines before services like “Test to Treat” were set up. “Thinking through the timing and making sure that some things were in place as they made these changes, not after the fact, would have been ideal,” she said.

Sally Werner, chief experience officer for the Cancer Support Community, said that the CDC recommendations were “bound to happen” and that the “cancer world kind of braced itself for that moment.”

Werner emphasized the importance of the CDC and federal government providing COVID-19 information for specific diseases and conditions.

“I think the more specific they can get with diabetes, with cancer, with heart disease, with respiratory illness—pretty much anyone who has a chronic or comorbid condition is going to have questions about these changes and how to handle them,” she said. “So I think that our CDC and our federal government could get much more down in the weeds and address the clinical needs of those specific populations.”

Getting disease-specific information can add clarity to the term “immunocompromised,” said Arif Kamal, chief patient officer for the American Cancer Society. “I think it’s important for the CDC and others, as everyone is continuing to try to do, to learn where the nuance matters,” he said.

“Hopefully over time there will be guidelines for those who are on agents that are suppressing their immune system, versus those who have a condition that suppresses their immune system, versus those who have a constellation of diseases and diagnoses that may do that as well,” Kamal added.

To understand patients who live with underlying conditions or take medications that impact their immune response, public-health agencies need to include them in discussions, said Shilpa Venkatachalam, associate director for patient-centered research at the Global Healthy Living Foundation, which helps educate patients living with chronic illnesses.

“We want to encourage institutions, governors, state institutions, public-health institutions, to bring into the conversation patients and patient groups like ours to determine ways to stay on top of risk and protecting these populations,” Venkatachalam said, “because there are different things that have to go into consideration when we’re thinking about people who have underlying conditions and who are on specific immunosuppressive therapies.”

Multiple advocates told *National Journal* they will be keeping an eye on telehealth flexibilities as federal officials consider pandemic-era policies.

“Many of the dialysis machines that people have available to them are managed by remote medicine, so you can have a medical center monitoring many home patients,” said Paul Conway, chair of policy and global affairs of the American Association of Kidney Patients. “They get the benefit of home, but you’re also being able to get diagnosed and in some cases have your fluid levels remotely managed by kidney professionals, by kidney experts.”

“We think that they’re not just a one-off; this is going to take hold, and it will actually expand,” he added.