

For Covid Long-Haulers, a Little-Known Diagnosis Offers Possible Treatments—and New Challenges; A disorder called POTS offers some treatment paths, but they are often arduous

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FULL TEXT

Tracy Tobiczky, a 46-year-old flight attendant, has been home on medical leave since contracting Covid-19 in March. She was diagnosed with POTS in July. PHOTO: Brittany Greeson for The Wall Street Journal
Some patients with long-term Covid symptoms are getting more potential treatment options as doctors diagnose them with a little-known syndrome called POTS.

It's a disorder of the autonomic nervous system that can have a variety of causes, and it existed before Covid. One common trigger is an infection, such as a virus. Now some doctors believe that the coronavirus is triggering the disorder in some people, providing an explanation for debilitating symptoms including dramatically elevated heart rates from small movements, dizziness and extreme fatigue after even minor physical activity.

The good news, experts say, is there are protocols and treatments for POTS, which stands for postural orthostatic tachycardia syndrome. They include a guided, very gradual return to physical activity; compression stockings or abdominal compression to prevent blood pooling in the lower half of the body; increased salt and fluid intake if blood pressure is low; and sometimes medications to regulate blood pressure, heart rate and blood volume. But the diagnosis also brings new challenges: Even gentle attempts to resume physical activity are proving especially arduous for many post-Covid patients, for reasons that aren't yet clear. So progress is often quite slow. And it's rare for POTS to completely go away even with treatment. It remains unclear whether patients with post-Covid POTS will follow similar recoveries to people with non-Covid POTS.

It's not known how many post-Covid patients may develop POTS. Outside of Covid, POTS is estimated to affect up to 1% of the world's population, according to a 2018 study in the Journal of Internal Medicine. The disorder can affect men and women, but most POTS cases are diagnosed in women between the ages of 15 and 50.

Johns Hopkins has run a POTS clinic program for more than three years. After seeing an increasing number of post-Covid patients with POTS-like symptoms, it decided to open a new clinic dedicated to them, says Tae Chung, director of the Johns Hopkins POTS clinic. Doctors elsewhere are also identifying more post-Covid patients with POTS-like symptoms and case reports are being published in medical literature.

POTS is generally diagnosed with what's called a tilt table test, which measures changes in heart rate when someone goes from lying down to upright. If heart rate increases by 30 beats a minute or more when patients stand and they have symptoms such as lightheadedness that is worse when standing and often disabling, they are believed to have POTS.

Tracy Tobiczky, a 46-year-old flight attendant in Brownstown, Mich., has been home on medical leave since contracting Covid in the spring. In July, she was admitted to the University of Michigan Medical Center after weeks of experiencing a skyrocketing heart rate even while resting. Doctors diagnosed her with POTS.

Before Covid, Ms. Tobiczky says she used to walk 4 to 5 miles every day. Now, she gets dizzy when she stands. She says she can't sit up for more than an hour because of chest pain and shortness of breath, which she likens to feeling like she's drowning. "It leaves me laying on the couch or laying in bed all the time because I can't get up to

do anything," she says.

Ms. Tobiczuk sits on her couch at home. She says sitting up for extended periods of time results in chest pain and shortness of breath. PHOTO: Brittany Greeson for The Wall Street Journal

After being diagnosed with POTS she started wearing compression stockings every day and an abdominal binder. A nurse comes to her house to give her sodium chloride infusions to help increase blood volume.

She takes three medications: one to increase her blood pressure, a beta-blocker to reduce her heart rate, and a mild steroid. "With the three of them together at least now I can walk to the refrigerator and go to the bathroom," she says.

She has had two rounds of physical and occupational therapy but didn't make much progress. "I would do it and then that night I will have debilitating fatigue," she says. "My husband had to carry me upstairs. It's a tiredness where I feel like I'm almost dead."

Ms. Tobiczuk's treatment for POTS includes three medications, compression stockings, and increased salt and fluid intake. PHOTO: Brittany Greeson for The Wall Street Journal

Now, she is working on trying to exercise with a bicycle attached to her couch and with wall stands and leg lifts for about 10 minutes or less a day. "I try so hard because I'm an athletic person," she says. "Every day is a struggle." Amro Stino is an assistant professor and co-director of the autonomic lab at the University of Michigan Medical School and one of Ms. Tobiczuk's doctors. Dr. Stino says he's seen about half-a-dozen post-Covid patients who have POTS, generally young women who were previously very active.

Doctors caution that post-Covid patients need to get a complete work-up evaluating their heart and lungs before receiving a POTS diagnosis to rule out other conditions. If a patient has myocarditis, another common post-Covid condition, increasing salt and fluid intake could cause further heart damage by stressing the heart.

Elevated heart rates also have other causes, including blood clots in the lung, which Covid has been linked to. "One of the reasons I'm creating a special clinic is to make sure these symptoms are not coming from other causes, especially from blood clots," says Dr. Chung at Johns Hopkins.

POTS recovery rates vary. A recent study out of Italy of 42 patients published in the International Journal of Environmental Research found that most patients showed some improvement in symptoms after two years but still have the condition. "It's a chronic condition," says Lauren Stiles, president of Dysautonomia International, a nonprofit group, and a research assistant professor of neurology at Stony Brook University School of Medicine. Some experts believe POTS may be autoimmune in some cases. Several studies have indicated that patients with POTS have antibodies that are attacking the autonomic nerves in the heart and blood vessels.

Benjamin Levine, a professor of internal medicine at UT Southwestern and director of Texas Health Presbyterian's Institute for Exercise and Environmental Medicine, developed the "Levine protocol," an exercise intervention program for POTS patients.

He thinks it might be premature to be diagnosing Covid patients with conditions like POTS so soon. Some athletes, for example, might instead be suffering from muscle atrophy and deconditioning caused by inactivity while convalescing from the virus. "It doesn't mean they have POTS but they can certainly have a POTS-like physiology," says Dr. Levine.

Other experts say deconditioning may exacerbate symptoms but isn't causing them. Brent Goodman is an autonomic neurologist who runs the autonomic laboratory at Mayo Clinic's Scottsdale, Ariz., location. He is working on a report on six post-Covid patients who developed POTS.

Although normally patients need to have six months of symptoms to be diagnosed with POTS, Dr. Goodman says the earlier treatment is started, the better the recovery. "In the real world, if we identify autonomic dysfunction three weeks from symptoms onset we're going to treat it," he says.

Symptoms of POTS

POTS can cause varying symptoms including:

Abnormal heart rate increases

Blood pressure fluctuations

Difficulty exercising
Lightheadedness or dizziness when standing up
Extreme fatigue
Brain fog or difficulty with concentration
Headache
Shortness of breath
Muscle pains
Damage of the small nerve fibers in the hands or feet, which can cause burning pain, numbness, and tingling or sensations of coldness.
Gastrointestinal issues
Write to Sumathi Reddy at sumathi.reddy@wsj.com
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