

In for the Long Haul

Eliza Hobson

The following story grew out of a Seacoast Village Project ‘Lunch & Learn’ webinar on February 2, 2021

In the beginning of March 2020, Reverend Heidi Heath of Exeter, New Hampshire got a sore throat and fever. These were early days of COVID-19 in the United States, soon to be defined as a global pandemic. Reverend Heath assumed she'd caught a run-of-the-mill bug. Within a week, she felt ready to resume her work at Phillips Exeter Academy as interim chaplain and Director of Religious and Spiritual Life. She looked forward to putting on her running shoes again to get back to regular exercise.

But this vibrant 37-year-old was in for an unwelcome surprise. Just days after her illness appeared to end, she was suddenly slammed by profound exhaustion. “It was like nothing I’d ever experienced before,” she recalls. “It was overwhelming.”

Heath’s fever soon returned, it became difficult to breathe and her joints developed arthritic-like aches. “It felt like I’d been hit by a train!” she recalls. “It didn’t feel anything like the flu.” At the time, COVID testing wasn’t easy to get, so, to be cautious, she isolated herself. Her symptoms worsened, her heart raced on trying to climb stairs, she had trouble recalling common words and soon needed help with daily tasks. When a COVID test became available, the results were negative. “It didn’t occur to me that the results might not be reliable,” she says now. “That’s really important to keep in mind!”

Fast forward almost a year. It’s February 2, 2021, and members of the Seacoast Village Project are gathering on Zoom for the monthly “Lunch and Learn” webinar led by Village member Dr. Karl Singer. He’s a geriatrician, medical director of the Rockingham County Nursing Home and a public health officer. Each month he updates Village members on current knowledge about COVID-19. This month he’s invited Reverend Heath to speak. While her health has been improving, she still suffers from what’s now called ‘Long COVID’. It’s a frequently disabling condition that can follow acute cases of COVID-19 in adults of all ages around the world. Sufferers call themselves ‘long haulers’.

“We’re just starting to put the data together about this puzzling condition,” says Karl Singer. “We don’t know yet how common it is. Studies are all over the place: anywhere from ten to fifty percent of acute COVID-19 cases are followed up by these persistent symptoms, depending on the population studied and severity of illness. What we *can* say for sure is that around the world, the research is reflecting Heidi’s story.”

Last spring, shortness of breath and severe joint pains limited Heath’s every move. She had trouble thinking clearly. For a while she was able to do some work from home. Medical tests

revealed no diagnosable conditions such as Lyme Disease. But they did show levels of inflammatory proteins in her blood eight times higher than normal and an elevated white blood cell count. By June she was no longer working.

Long COVID resembles conditions such as chronic fatigue syndrome (CFS), fibromyalgia and other poorly understood, long-lasting neurological syndromes. Dr. Anthony Komaroff of Harvard Medical School has been studying these conditions for decades. His research is getting renewed attention since Long COVID was identified: he recently headed a panel on Long COVID at the National Institutes of Health. Today, he is a guest at the Village webinar.

“Chronic Fatigue Syndrome was identified in the 1980s, but medical tests do not reveal a cause for it,” he says. “All too often doctors turn patients away because they don’t know how to treat it. Only recently have doctors begun to recognize that it is a legitimate illness, but the best we know how to do currently is try to treat the symptoms.”

In the quest to treat Heath’s debilitating pain, doctors referred her to a rheumatologist. It was an unusually good call. Though little was known about Long COVID last spring, this specialist had already treated a number of other patients in her condition. (Many ‘long haulers’, even today, are hard pressed to find doctors who help.) Suddenly, she was not so alone.

Initially, the drugs the specialist prescribed failed to help, but then came a turning point. Heath’s pain levels dropped considerably with use of the drug hydroxychloroquine. This medication grabbed headline news early in the pandemic when it was briefly tried and then rejected as a treatment for acute COVID-19. By the time it was prescribed for Heath, she was well beyond the acute stage of her illness. “It was prescribed to me as part of an arthritis regimen for systemic inflammation, which is one of my long COVID symptoms,” she explains. “While this drug treats malaria, it also has long been used to treat systemic inflammatory response for conditions like rheumatoid arthritis and lupus.”

“While it has really helped me,” she adds, “I’m not back to normal. I still can’t run, but I can work now, as long as I listen to my body and respect its limits.” Heath recommends advice from an online support network of long haulers called ‘Body Politic’. “The social supports it’s given me are as important to my recovery as my medical treatment is.”

Recently, the National Institutes of Health and researchers in other countries received funding to study Long Covid. The chronic syndromes studied by Dr. Komaroff, by definition, last more than six months. “What’s clear as of two months ago,” he says, “is that a substantial number of people who got acute COVID-19 have symptoms six months out.” Reverend Heath describes her case as “a seven month long roller coaster ride.” It’s a ride with no known end yet in sight.

There’s a lot to study when it comes to Long COVID, says Karl Singer. “Like Heidi, many long-haulers weren’t all that sick to begin with. Some actually had no symptoms of acute illness. Many never saw a doctor.” Depending on the person, severe symptoms can affect multiple bodily systems. Formerly robust adults of all ages are experiencing life as invalids and clinging

to fragile hopes that they'll get better.

Anthony Komaroff estimates costs to the United States of chronic fatigue syndrome and similar conditions is between \$17 to \$24 billion dollars a year in medical and disability payments. "The number of long haulers could easily equal the number of people in the U.S. who already have CFS," he estimates, "as many as 2.5 million." This year, he'll be keeping a close eye on the Long COVID studies. "We hope that the new research may lead us to better understand the origins of many chronic conditions and come up with improved treatments for them all."

Today, Reverend Heath is creating an array of professional online services she can provide from home, as she learns a tough lesson: how to live with uncertainty. "I don't know what my new baseline will end up being," she says with candor. "I may get back to my old normal...but I may not".