

Insight



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Haunted by long Covid

Many South Africans are suffering from debilitating symptoms long after contracting the virus, a condition not well understood by the public or health professionals, who are searching for answers, writes **Claire Keeton**

An athlete in his 20s doing a postgraduate degree contracts Covid. Months later the stats whizz struggles to multiply three by four or walk across a room with a bag of groceries. A medical researcher in her 40s lies in bed for nine months and is flattened for the next

nine after a severe Covid infection. A top economist in his 60s feels his head gets hot and he cannot think clearly.

"Sometimes I lie on the couch and I feel that if a fire alarm were to go off I'd just lie there, too tired to move," says an arts professional.

"For an hour or two in the morning I'm OK but by 10am my day is done. I want to say words but it feels like my brain has disconnected and the words are scrambled," says the 40-year-old, who has been battling crushing fatigue, breathlessness and brain fog since May last year, but is slowly improving.

"I feel about 30% human – imagine a cellphone with a battery that charges only 30% and then the apps keep crashing," she says. "That's how I feel."

South Africa has an invisible epidemic of people whose lives are being ruined by severe long Covid – a disease that lasts more than three months after infection and is difficult to diagnose and treat.

Mlindeli Gabela, 40, answers my call in a pharmacy while buying painkillers. Before he got Covid, he would carry 30kg sacks of seeds across the bakery floor where he worked as a mixer. Now he can only walk across a flat surface and has lost his job. "I liked to cook but I can't stand up any more," Gabela says.

A mother of three has a tube snaking up her nose as she needs supplementary oxygen to get through the day. Pain keeps her awake at night and she is off work on temporary disability. "I feel like my brain has misted over and I've fallen down a black hole," says the 45-year-old.

STIGMA OF DISBELIEF

People with long Covid suffer crippling symptoms, compounded by a stigma of disbelief. Some lose their jobs or relationships in the fallout. Health-care workers, colleagues, friends and family find it hard to grasp how debilitating the symptoms are.

Unlike HIV or diabetes, routine blood and lab tests fail to detect the disease, described in a recent study as "compromising quality of life more than some advanced cancers".

Wits professor of medicine Francois Venter says a minority of people with long Covid suffer devastating symptoms. Most recover over months or years, though some are left with subtle impairments, for example to memory.

Reinfection with the virus and being unvaccinated increase the risk of developing long Covid, he says.

"The bottom line is that long Covid is not some made-up thing, though tests look normal. It is a new entity, it is real and it has horrible effects," says Venter, the executive director of Ezintsha, which is running one of Africa's first long Covid studies.

Meanwhile, Stellenbosch University physiology professor Resia Pretorius has pioneered a blood test to detect long Covid which has been peer-reviewed and published and is gaining international attention.

COMPLICATED DIAGNOSIS

Long Covid triggers up to 200 symptoms and increases the risk of chronic illnesses, making the diagnosis complicated.

International research shows that 10%-20% of people who have a severe case of Covid go on to develop lasting symptoms. With more than 4-million confirmed cases of Covid in South Africa, this means tens of thousands may have had or have mild or



Graphics: Nolo Moima

severe long Covid.

"The most frustrating thing about long Covid is that every blood test or scan comes back normal even though you have never felt so unwell and weak in your life," says Natalie Theunissen, a grade 1 teacher who was a department head.

"During teaching for 30 years I was sick only a few days. Long Covid has thrown me into a huge health storm and I have no idea if it will end. I've lost my independence ... Some doctors just shrug their shoulders, though mine are trying to find solutions. Others think antidepressants will solve the problem," she says.

"The gaslighting for long Covid sufferers is huge," she adds.

Unlike many long Covid patients, medical researcher Jenny Pfeiffer-Coetzee has recovered enough to throw herself into work again and even ride a horse, though she is ready for bed by 4pm. "I am an academic and before I couldn't think or write. Now I can go at 500 miles an hour, but then I might collapse

and sleep for a week.

"I struggle to keep my oxygen levels up. I have chronic asthma, a continual struggle with joint pain and lingering chronic pain. A couple of months ago a horse crushed my foot and the drugs for that helped my speech," she says of the bizarre twists the disease takes. "One woman I know finds that everything smells like roadkill: perfume, a new baby and even the aroma of food."

Wasila Jassat, research lead for a study on long Covid at the National Institute for Communicable Diseases, says: "About 44% of participants have persistent symptoms which impact on their daily lives 12 months after having Covid."

'SYMPTOMS ARE REAL'

South Africa's biggest health insurer, Discovery Health, reports that 20% of its members had four or more long Covid symptoms. Shirley Collie, its chief research actuary, says: "A high proportion of members are reporting symptoms many months post recovery.

Headaches and breathlessness are exceptionally common, and the symptoms are real."

Hoosain Khalfeey, a pulmonologist at Life Vincent Pallotti Hospital in Cape Town, has studied patients admitted to ICU during the pandemic.

"The patients who were ventilated often recovered very well, showing dramatic improvements ... and have gone back to work," he says. "My best buddy was on a ventilator and he pulled through. Half a year later he was playing tennis."

But the recovery of patients put on high-flow oxygen seems more mixed. Some have recovered fully, others lead comfortable lives while mildly impaired, and a small group are languishing and on supplemental oxygen.

"Some people have flashbacks and post-traumatic stress," says Khalfeey.

"In the majority of cases we find nothing ... but we treat what we can hard and fast," he says, noting the treatment may overlap with chronic fatigue syndrome. Long Covid is diagnosed by elimination –

Khalfeey first rules out all other possible causes of illness, from myocarditis to vitamin D deficiency.

Studies show the risk of long Covid is higher for those who had severe Covid, those who have comorbidities, those who have lower socioeconomic status, older women and those who did not rest enough after infection, says Venter.

University of Cape Town professor of respiratory medicine Keertan Dheda, who established the post-Covid clinic at Groote Schuur Hospital in July 2020, says doctors there report a steady decline in patients and post-Covid pneumonia.

While the most common and severe symptoms are respiratory, Dheda says many patients with long Covid suffer a range of symptoms, such as musculoskeletal pain and fatigue.

Jaco Laubscher, a physician at Mediclinic Stellenbosch, is treating hundreds of patients for long Covid, their folders stacked on his desk.

Economist Iraj Abedian, 67, was one of them. In January 2021 he got Covid and recovered but, after a vaccine jab in June, he experienced long Covid symptoms "such as brain fogging, a feeling of heat in my head at nights and vascular swelling around my ankles".

'BRAIN FOGGING DISAPPEARED'

He started Laubscher's treatment in December under close supervision. "Within three weeks I felt the difference ... my brain fogging had disappeared and my memory and concentration recovered. The feeling of heat in my head had gone," says Abedian, who does yoga and likes gardening and walking.

"Most importantly, the worry and stress of not knowing what was happening to my body have gone," he adds.

Long haulers desperate for a cure are flying in from Australia, Canada, the US, UK, Sweden and the Netherlands to see the "boertjie in the Boland".

"I would not be doing this if I didn't see the results," says Laubscher, who uses high-risk triple anticoagulant therapies – as yet unproven in scientific trials. "People are watching over my shoulder and the pressure involved is tremendous."

He reports that only four of his 570 patients have recovered completely without any treatment.

Venter says: "Long Covid can be very disabling, so patient and health worker desperation is understandable ... I hope the doctors publish their experiences quickly, and that proper studies are done weighing the benefits and harms, especially using drugs with potentially dangerous side effects."

Laubscher says the patients who come to him within six months of experiencing long Covid symptoms have a better chance of recovery than those with longer-term illness. Any systemic infection, such as flu, can knock long Covid patients back to zero, he says.

"The majority of my patients are young, healthy people who had no comorbidities, until they crashed, usually after a mild infection with Omicron," Laubscher says.

'MOST IMPORTANT BIOMARKER'

After Laubscher diagnoses long Covid based on clinical presentation, he verifies the presence of microclots by examining the results of the research test developed by Pretorius.

Pretorius, who has international collaborators from Harvard, Yale, Mount Sinai and MIT, says: "In January 2021 we ran a proteomics test to see what was inside the blood of long Covid patients ... and now we have a diagnostic tool to test long Covid."

The blood of these patients is sticky and thick, like honey, Laubscher says.

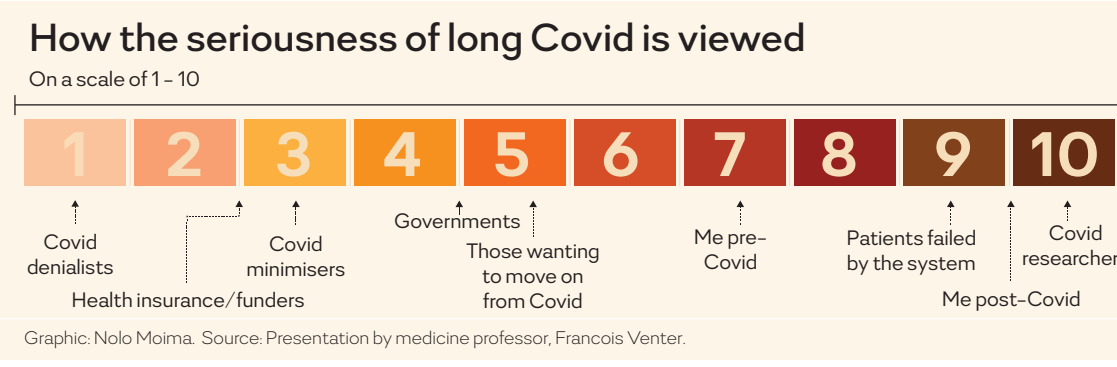
One of his patients, a sales executive from Johannesburg, is glad he started the treatment last May even though he developed severe nose bleeds and had to cease using anticoagulants. "The treatment reduced the number of long Covid symptoms and lessened the severity of the few remaining ones," says the man, who suffered shortness of breath, chest pains, pain in his lower legs and loss of feeling in his feet.

Khalfeey says: "The medical fraternity is yet to produce convincing evidence [of treatments] which have been shown to improve outcomes. We must be guided by scientific evidence."

Long Covid is so complex that it is "hard to come up with a silver bullet" that will treat all the symptoms, he says, though time does heal many sufferers.

"I feel like a ghost of the person I used to be," says a 51-year-old with long Covid. Like vast numbers of South Africans, she is hoping for treatments to catapult her back into the living, breathing world she used to inhabit before the pandemic.

I feel about 30% human – imagine a cellphone with a battery that charges only 30% and then the apps keep crashing. That's how I feel
— A long Covid sufferer



* Some names have been withheld for privacy reasons