

Testimony from Vinciane

(patient who delivered the letter to the Chairman on the 8th of December and whose situation has since deteriorated)

My name is Vinciane, I'm 47 and I've been with Covid Long since October 2020. I'm a single mother with 2 children aged 19 and 18. I live in Poitiers. I'm going to have to leave my flat, which I had to sell, at the end of June because I have no money left to pay the instalments. I don't know where I'll be in 2 months. I studied to become a nurse, which I was able to do until October 2020.

I used to be very sporty, rarely ill, my role being to look after others and help them cope with illness. I had a good life, children, friends, a job I loved and a place to live. That was life before the Long COVID came into my life.

Today, I've lost everything.

I have major memory loss, I get words mixed up, and I get very tired at the slightest physical or intellectual effort. It's very difficult for me to wash, read, walk, cook, do the shopping, drive or do any administrative work. I had to ask one of the Association's volunteers to write my testimonial I can't do it any more.

My children have gone from being a dynamic mother to a person they no longer recognise, slumped on the sofa, and no longer able to go out on the usual outings. It's been very difficult because at first, they didn't understand why I'd become a zombie when nothing can be seen from the outside and when on TV and the radio they hear people saying that the Long COVID is nothing, that it doesn't even exist. But I'm lucky that they love me and remember the mother they had before, and their hearts tell them to stand by me and support me.

However, I did everything I was asked to do, as recommended by the government: I met with the designated referral doctors in Poitiers at the hospital. It was explained to me that it was due to depression, after a differential diagnosis. I agreed to take antidepressants, even though they increased my symptoms and produced very debilitating side effects. I also went to a day hospital for exercise rehabilitation. After a few months with no positive effect, this was stopped and the hospital referred me to a physiotherapist who had no more results despite his investment.

No investigative tests related to the Long COVID have been prescribed (scanner, MRI, etc.). Despite the help of my GP, my occupational physician and my employer (an association), the CPAM referral physician decided in March 2023 to stop paying me my daily allowance, because "I had no care and no prospect of improvement", and refused to initiate proceedings to obtain invalidity.

As a result, I no longer have any income, which is why I've sold my flat.

I've been refused long-term care because I haven't had any effective rehabilitation and I'm not being paid for it. I'm going to appeal against the CPAM doctor's decision, but that takes a lot of energy, which I don't have any more, and in Poitiers, this application, even if it's urgent, always takes several months to be processed. I don't have the time or the money.

Fortunately, there are a few people who help me, like the ApresJ20 association, which allows me to take part in a free discussion group, even though I know that in a few months, I won't be able to afford the gas to go there. Because that's my life these days, having to count every penny because I'm ill. Many sufferers are in the same situation as me, in the process of becoming poor because their Long COVID is not being taken care of or is not being taken care of properly by doctors who have no

resources, are untrained or have a total lack of knowledge about the disease, consultations are closing down, information on official regional websites has not been updated for 18 months or has even disappeared.

Fortunately, last week I was seen by a neurologist in town who agreed to examine me like any other patient, without any preconceived ideas. He told me that I would be a danger to my patients if I went back to work. Because the Long COVID had indeed affected my head or rather my brain. I have subcortical and polyalgic syndrome.

So, Mr Minister, I'd like to tell you that I believe in Health with a capital H, because it's the profession I've chosen. But today I no longer understand my Ministry. How can you leave 2 million people on the side of the road, facing the same ordeal and the same descent into hell as I am? How can you say that appropriate treatment exists when it is only cosmetic? How can you say that this disease doesn't exist? When are you going to realise that I'm ill because Covid is attacking my brain and my whole body, and that I need care and protection, and so do my children? I don't know what tomorrow holds for me. What I do know is that I had the strength to fight with what little strength I had and that I know the medical world. But what do other patients who don't have these abilities do? Well, they give up, they're ashamed and risk ending up on the streets like me and my children. Mr Minister, what are you doing for us? Listen to us, believe us, allow us to be cared for by trained carers who show empathy, to have access to ALD, to RQTH...

Allow me to keep hoping, Minister, but please answer me quickly, because I'm running out of time and in 2 months time I'll be out on the street with my children because my Long COVID has not been properly taken care of by the existing structures.