

Hello everybody. My name is Ann and I'm the chairwoman of post-COVID, the Flemish patient's association for people with long COVID. I'm very honored to speak to you today.

My journey with COVID started with me getting sick in March 2020. I started to work again in April, but I wasn't fully recovered and had my first relapse at the end of May. I haven't been able to work since. I've tried several times, but my neurological symptoms are too severe. I need all my cognitive capacities to do my job, so I have to be patient and wait until the dust, or in my case the brain fog, settles.

We live in confusing times and it's even more confusing when you don't get better from what was supposed to be a bad case of the flu. I remember that around this time, a year ago, there were hardly any scientific papers on the subject. I read anything that I could find. I even looked for articles on SARS, MERS and the Spanish Flu, because I needed more answers on what was happening to me and so many other people like me.

I'm very grateful when I see how many scientists are doing their best to get these answers and although there is still a lot to discover, it's good to know that we don't have to carry our burden by ourselves anymore. It is such a relief to find so many allies who stand by us.

However, there are still some issues about long COVID that I would like to address today. The first one is about inclusion criteria. Although I understand why most researchers only include people who have a positive test and thus proof of their infection, I would like to ask them to broaden the scope of their research and also include people who have the same clusters of clinical symptoms, but no positive test. The majority of people with long COVID don't have one and it's creating an unnecessary divide between us. We need more studies that prove that a diagnosis based on clinical symptoms is sufficient.

The second issue is about our neurological symptoms. All too often they are reduced to depression and anxiety. Yes, some people with long COVID do get depressed and are anxious, but it is not the majority of our group and it's important to distinguish between primary and secondary symptoms. At this moment for instance, there is insufficient work being done on objectifying and explaining the widespread complaints about brain fog. Because of this blind spot in COVID-research, the highly prevalent neurological symptoms remain largely untreated and are all too often categorized as purely psychological in origin. I hope that scientists will look at this, for patients increasingly frustrating blindspot, as a challenge to discover more about the human body instead of dismissing symptoms that don't fit pre-existing theories.

COVID is a multisystemic disease. People can develop diabetes, cardiac, respiratory and other problems. It's important that we look at all these symptoms while looking for a cure for people with long COVID. Revalidation programs that only focus on one part of the body don't suffice, because it reduces our problems into separate symptoms, completely disregarding their interconnectedness. There is an urgent need for the development of a multi-disciplinary care pathway for primary and secondary care to guide us through the labyrinth that is the Belgian healthcare system.

As I said before, we live in confusing times and as long as we don't have all the answers about this atypical disease, it is more important than ever before to involve us, the patients. We see the blind spots in current research and care approaches. We know what we need and we know why certain things don't work. Research projects that really involve the patients have tangible knowledge advantages over projects that don't. We ask you to use our experiences, not only as patients, but also as people with certain areas of expertise. Among the hundreds of thousands Belgian long COVID patients we have doctors, nurses, researchers, economists, politicians, ... and many of them want to help solve the mystery that is long COVID.

The final point that I would like to make is about empathy and compassion. As patients we draw confidence from events like today, focusing on new avenues of research, geared towards finding answers to the many mysteries and challenges COVID-19 posed to humanity. But sadly enough, forward-thinking science and care are the exception to the rule in the daily life of long COVID patients. More often than not, our caregivers and daily environment is skeptical or even outright dismissive of our struggles, disbelieving our symptoms or reducing their origin to some type of depression, instead of them being caused by a COVID-infection.

This culture of disbelief can at times be harder to deal with than the disease itself. It also leads to counterproductive care, glaring oversights in the research landscape along on top of conflicts with employers, friends and family members. The battle against long COVID is hard and drawn out. As long as the culture of disbelief persists, we undermine the efforts of patients to regain their former activity levels.

That's why the most important thing you can do for patients is: "Believe us".

- Believe us when we say we had COVID, even if we don't have a positive PCR-test to prove it. Almost two out of three Belgian COVID-patients never had a positive test. Please don't dismiss them, because their struggle isn't only with the disease, but also with the culture of disbelief.
- Believe us when we tell horror stories about certain caregivers, as those stories are a daily reality for many patients. A large group of caregivers still believe COVID is a lung disease that takes at most 4 weeks to recover from. The way they treat their patients is often inexcusable.
- Believe us when we tell you about our symptoms, even if you can't find a cause at first sight. We often hear stories about symptoms being dismissed because they don't mesh with preconceived notions. This approach makes it impossible to discover the full scope of this disease.
- Believe us when we say that certain treatments, like graded exercise therapy, often have adverse effects in long haulers, even when some patients benefit from it. Long Covid has different sub-categories of patients, so a one-size-fits-all treatment just doesn't work.

I could go on for a long time listing all the barriers patients face because of disbelief, but I won't, because there is a simple solution. Just "Believe the patient" and use our expertise to help fight this disease. Thank you very much for your time.