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'Long Covid' can have severe repercussions on the work and income of sufferers, but some organisations are trying to help. The Netherlands-based C-Support organisation provides support and advice for patients suffering from long Covid; it assists their reintegration into work and helps them to keep their jobs. Meanwhile, the Netherlands Trade Union Confederation (FNV) is advocating the introduction of a financial compensation mechanism to benefit those infected in the course of their work.

Long Covid and the difficult return to work

Pien Heuts
Journalist

For those employees unable to return to their former jobs, for the self-employed forced out of their homes because they cannot pay their bills, for all those in debt, the impact of 'long Covid' is not merely physical. As Diana ter Mull, aftercare adviser at C-Support, explains, "We are seeing some really distressing cases." In her role, she is confronted on a daily basis with patients overwhelmed by devastating fatigue as well as cognitive disorders such as poor concentration and memory problems, or patients who barely respond to stimuli. She goes on to explain that, "In addition to feeling ill, these people have to deal with the disease's often serious impact on their work and income. What can you do if you are at risk

of losing your job because of a long-term illness? Or if you can no longer make the repayments on your mortgage because your sickness benefit does not cover them? Or if you are self-employed and have no sickness insurance cover? People suffering from long Covid, like any other long-term illness, have to deal with a myriad of different rules and regulations, and all the while the disease's effects often prevent them from seeing the wood for the trees. It's our job to help them see things more clearly. If patients have a better grasp of the overall situation, they will feel less stressed and will be able to invest more energy in their recovery."

A tailored approach is essential

Since October 2020, people who have been suffering from Covid-related complaints for three months or more can turn to C-Support for help. This foundation operates on behalf of the Dutch Ministry of Health, Welfare and Sport and provides guidance and support for long Covid sufferers. Together with the patient, aftercare advisers take stock of the symptoms and their consequences in all aspects of life. These may encompass physical and mental health issues, social life, work and income. Medical advisers assess a suitable way forward for improving the situation and assist patients in their search for the appropriate care



providers. In this context, a tailored approach is essential. In the Netherlands, patients suffering from long Covid are entitled to claim a refund, for a one-year period, of costs incurred as a result of physiotherapy, occupational therapy or psychological support. C-Support also facilitates intervention by lawyers, employment specialists or financial advisers in order to help resolve work- and income-related issues. So far in 2021, C-Support has already advised and supported some 8 000 long Covid sufferers.

“We are acting as a kind of relay in the care and support system offered to the victims of long Covid,” explains C-Support Director Annemieke de Groot. “We form the bridge between the patients, on the one hand, and the health professionals, occupational doctors, local authorities and provider organisations on the other. Problems do, after all, crop up regularly in all these areas. Our aftercare advisers, who operate across the entire Netherlands, accompany patients, as required, to meetings with

occupational doctors, employers or the local authorities, or with the bank to agree a payment arrangement. And, as we still know very little about long Covid, we’ve been involved in drawing up new guidelines for occupational health. The health problems suffered by sick employees are often downplayed. The sick frequently come up against a lack of understanding. How they are feeling on the inside cannot always be seen from the outside.” (See boxed texts.)

Long-term illness

In 2007, between 50 000 and 100 000 people in the Netherlands became infected with Q fever. The disease, caused by the transmission of bacteria by goats, had also taken hold in Germany, France and Switzerland. Those infected presented with a high temperature, pneumonia and sometimes meningitis. For a long time, patients were not taken seriously, and considerable time passed before a link was established between Q fever and the pathologies in question. A political discussion on the government’s inability to caution against the dangers of what are known as “zoonoses” led to the creation of Q-Support (C-Support is a sister organisation of Q-Support) in 2013. Annemieke de Groot explains: “As is the case with Covid-19, a large number of patients recovered, but others continued to be ill for a long time: they could barely function physically, let alone do work of any kind. Q fever had an enormous impact

“The health problems suffered by sick employees are often downplayed.”

Marjolein van den Diepstraten (age 41)

- Dietician in a care organisation
- Has suffered from Covid-19 since December 2020

“I feel guilty for being ill for so long.”

Before Marjolein van den Diepstraten contracted coronavirus, she could do everything. She was not fazed by a mere 120-kilometre roller-skating challenge. She went to the gym almost every day and enjoyed a busy social life. She thought she could manage when she developed flu-like symptoms in December 2020. Almost one year on, her extreme tiredness persists. If she exerts herself too much, she gets a headache and falls ill. Some days, simply getting out of bed requires too much effort.

“I have my ups and downs, and that is hard to deal with,” she comments. “Instead of making steady progress, it fluctuates. So, in occupational therapy, I learn how best to divide up my energy so that I can avoid suffering a massive setback each time. With the physiotherapist, I try to work on my physical condition. Now I can walk for just short of an hour. Hitting your limits like that is really hard going. I was still in good shape of course, but I had this massive problem.”

Before falling ill, Marjolein worked 32 hours a week as a dietician. Now, she works 20 hours a week. During lockdown, she tried to keep in touch with her clients by means of video calls. “I feel guilty for being ill for so long. Especially when colleagues have to take over my consultations when I’m too ill to do them myself. My employer has shown understanding with regard to my situation. I’m putting a lot of pressure on myself to work more efficiently. My whole life revolves around work now. I’m taking so much time to recover that my social life has pretty much disappeared. I’m also worried about what will happen if I continue to suffer from long Covid. One aftercare adviser at C-support is helping me at the moment to look into what I can do if my salary drops after one year’s sick leave. You’re effectively punished for something that you caught at work. This is really hard for me to handle mentally.”

“Workers have borne the brunt of the often woeful working conditions prevailing during the coronavirus pandemic.”

Bianca van der Heijden (age 50)

- Administrative assistant in a care organisation
- Has suffered from Covid-19 since April 2020

“Losing my job is a serious blow for me.”

Bianca van der Heijden was critically ill. After two weeks in hospital, she had to spend nine months in home isolation. Her body was making virtually no white blood cells, meaning that an infection could have proven fatal for her. Her blood test results are still not as they should be. She is also battling against extreme tiredness, headaches, intolerance to stimuli such as sound and light, and concentration difficulties. Bianca explains, “When I’m tired, I can’t find my words. And I’m much more emotional now than I was before coronavirus. I cry over nothing. No two days are the same, which is annoying. One day, I can be just about all right, and the next day, or sometimes even a few hours later, I feel absolutely dreadful.”

Bianca’s employers insisted that she should call every day to let them know how she was, even when she was very poorly in hospital. When she told them in late 2020 that she wanted to work again from home, she discovered that the atmosphere had changed. “There was no work for me any more, my job had gone; they wanted to get

on these people’s lives, that is to say, physically, socially and financially. At that time, and still now for that matter, we were in a position to offer patients help and advice, to train professionals and to drive research over a number of years. The patient must remain the focus of our concerns, and we have to turn our attention not only to the disease itself but also to the environment in which it develops.”

When the Covid-19 pandemic broke out, Q-Support therefore already had a model it could use to support and guide patients with long-term conditions. “We saw and still see the irreparable damage and suffering experienced,” adds de Groot, “with patients dragging themselves from one

rid of me. What a slap in the face that was, when I’d worked there for over 25 years. I was told by the FNV that they could lay me off only after two years’ sick leave. The period I took off as sick leave in 2020 for an operation on my wrist has been added to my sick leave for coronavirus, meaning that my job will come to an end in December 2021. I’m 100% disabled as far as my current employment goes and am now working at 75% in a different location. As things stand, I’m working four and a half days a week. It’s tough. Some days I can’t tolerate the light from my screen or phone. I’m in bed by 8 o’clock, and weekends are spent recuperating. I feel guilty towards my husband and my family.”

Bianca approached C-support in October 2020. “They listen and understand the impact of long Covid. I finally feel that I’m being taken seriously. Besides that, when you have a long-term illness, you have to deal with a whole series of legal formalities. I was completely out of my depth, but they helped me to find the right physiotherapist and occupational therapist. And they also advised me to appoint a lawyer, once it became clear that my employer was seeking to terminate my employment forthwith. The aftercare adviser also attended meetings with my line manager who suddenly became as meek as a lamb. I’m utterly shocked to be losing my job because I contracted Covid at work. As if losing my health wasn’t bad enough ...”

healthcare practitioner to another without actually making any headway because the disease is poorly understood. Since gaining extensive experience from dealing with Q fever, which also presents a very varied clinical picture, we were able to identify long Covid more rapidly. We’ve learnt the lessons of the past. We’ve realised that effective monitoring is vital. With Q fever, we could see how it was difficult sometimes for sufferers to return to work.”

Recognised occupational disease

No one knows this better than the FNV union federation. In the healthcare and welfare assistance sector in particular (hospitals, care homes, home care and care for the disabled), approximately 190 000 staff have been infected to date (in other words, roughly one carer in six), often because of a shortage of personal protective equipment. It is not without reason that, in April 2020, Covid-19 was recognised in the Netherlands as an occupational disease, i.e. a disease probably contracted in the workplace. Trade union members suffering from ill health caused by Covid-19 contracted at work can have recourse to the FNV’s Occupational Diseases Office (BBZ). “We examine each case to see whether a liability claim could be made,” explains Marike Schooneveldt from the Occupational Diseases Office. To date, over 100 people have come forward seeking redress against their employer. They include healthcare workers as well as cleaners, security officers and public transport or nursery staff. Liability actions often take years to play out. The causal link between occupational exposure and damage to health must be proven.”

To support workers who have fallen ill because of their work and whose illness persists, the FNV also advocates the setting up of a government-financed coronavirus fund. “Workers have borne the brunt of the often woeful working conditions prevailing during the coronavirus pandemic,” explains

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Patrick X (age 37)

- Teacher in special needs education
- Has suffered from Covid-19 since September 2020

"Fingers crossed, I'll end up feeling fit and well again."

Teacher Patrick X was struck down twice with Covid, first in September and then in December 2020. He was very poorly. Furthermore, his raging fever presented a risk on account of his heart problems. Since his vaccination, he feels his problems have been alleviated slightly. "I've kept working as much as possible, but I'm just as tired as ever. On occasions, I was too tired to drive home, or my students would tell me that I was explaining something to them for the third time. There's always this blanket of fatigue weighing down on me. Once her maternity leave had ended, my wife didn't go back to work straight away so that she could

take care of everything at home. She didn't go back to work full time until this summer."

Patrick began his rehabilitation four months after his first bout of Covid-19. He does not know whether the physiotherapy is helping him. Sometimes he is able to do the exercises, other times not. The important thing is that his body's oxygen level, which was too low, is now increasing because of his movement, which in turn gives him more energy. "I think the fact that I kept working enabled me to keep going through it all. During the summer holidays, I noticed that resting made me feel worse. You have to keep busy. I had to miss days and meetings at work, and my colleagues took over the extracurricular activities. The occupational doctor's advice that I should only work half days wasn't very helpful. Having to rearrange everything makes that arrangement very stressful and extremely time-consuming. Fingers crossed that, one day, I'll be feeling fit and well again. For now, that's all we can hope for."

Jolanda Visscher (age 52)

- Taxi driver
- Has suffered from Covid-19 since February 2020

"I feel that I have to defend myself all the time."

"I stared death in the face," Jolanda says as she recalls her stay in hospital in February 2020. When she returned home two weeks later, there was not much left of the person she was. The home care workers and district nurses came and went. Her children, who are teenagers, struggled to do what they could for their mother who was confined for months on end to the hospital bed set up in their living room. She feels frustrated that she can do very little herself. She has to ask for help with everything, when once upon a time she would have painted or decorated the whole house herself. "I don't go anywhere without my wheelchair. In spite of the rehabilitation process, I always have trouble

concentrating, my muscles are like mush, I have permanent pain in my diaphragm and chest ... as if a concrete block were laid across my chest. The worst of it all is that people think it's all in my head, or that I'm play-acting. I feel that I have to defend myself all the time."

From the financial perspective too, Covid-19 has caused considerable damage. Jolanda's one-year contract working as a taxi driver has not been renewed. She claims a temporary sickness allowance from the government and, further down the line, might receive a very small disability allowance. "We are currently around 400 euros out of pocket every month. I sometimes borrow money from my daughter. Nobody is willing to acknowledge such a situation. I sent an email to Prime Minister Rutte urging him to get his hand in his pocket for businesses generally as well as for me. Through no fault of my own, I've found myself in a nightmare. My son, who is autistic, said to me: *If you had died, I would have killed myself.* We often forget the impact that long Covid has on families. My children have made a huge personal sacrifice to help me."

Rian van Nispen, FNV spokesperson for care and well-being. "We have, on a number of occasions, referred the minister to his responsibilities. One group of workers with long-term problems is significantly worse off financially. After one year of illness, these people receive only 70% of their salary, and they also lose the payments made in respect of irregular work. A survey that we conducted in spring 2021 indicated that a quarter of the carers who fell ill in the first wave had suffered, or expected to suffer, a financial loss."

But, according to the FNV, those falling ill in other key-worker occupations should also be able to access this fund. And Rian van Nispen points out that "This is clearly about obtaining a benefit, not damages. If people think the benefit is insufficient in relation to the loss or harm suffered, the option must remain for bringing an action for damages against the employer."

The intervention fund that the FNV has been backing for quite some time now could be based on the model for the Asbestos Fund or the Fund for diseases caused by exposure to solvents (psycho-organic syndrome). In the Netherlands, victims who contracted these diseases at work receive a benefit that may amount to as much as 21 847 euros. Furthermore, the employer is held liable. As Rian van Nispen goes on to explain, "For a large group of patients with long Covid, receiving 20 000 or 30 000 euros would be a relief. This is also apparent from the survey we are conducting among healthcare workers. We also have a moral obligation in this regard: we cannot just stand by and do nothing, first applauding the healthcare workers and then abandoning them to deal with their problems alone." ●

"Covid-19 is a lottery: some people suffer few ill effects, while others fall seriously ill and may never recover."