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# Non-profit calls for more support for chronic fatigue patients

by [Andy Furniere](#),

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## Summary

The founder of the Wake Up Call Movement is asking for more support and recognition for people with chronic fatigue syndrome, a range of conditions thought to affect 25,000 people in Flanders alone

## Chronically exhausted

Stop the Diagnosis CFS is the remarkable name of the first Flemish campaign to create more awareness about chronic fatigue syndrome (CFS). The founder of the non-profit Wake Up Call Movement, CFS patient Gunther De Bock, explains the purpose of the campaign and how CFS affects his life.



You may have heard of the condition but probably have little idea what it entails, except for causing extreme tiredness. According to De Bock, medical experts are also largely in the dark about the nature of CFS.

"CFS is a collective term for diseases characterised mainly by abnormal chronic physical and mental fatigue," he explains. Diagnoses are carried out on the basis of a list of questions known as the Fukuda criteria. If you're diagnosed with CFS, it means that doctors don't know the exact cause of your problems and can't provide a precise treatment.

Figures from the European portal [Orphanet](#) indicate that CFS affects between 0.4 and 1% of the population, meaning there are about 25,000 people in Flanders with the syndrome.

## Adjusted lifestyle

De Bock says British researchers found that about 50% of CFS diagnoses are wrong. "So about half of patients are actually suffering from a disease that can be identified and treated," he says. The range of

diseases causing CFS symptoms covers diverse psychological and physical disorders. Among them are depression, burnout, cancer, multiple sclerosis, glandular fever and many rarer conditions.

“But it’s expensive to test patients for a range of disorders, including rarer ones,” says De Bock. “Because the Belgian medical insurance agency Riziv won’t provide funding to carry out all these tests for patients with extreme fatigue symptoms, doctors have to diagnose them with CFS.”

After diagnosis, patients in Belgium can receive two kinds of therapies that are paid back by Riziv: cognitive behavioural therapy and gradual exercise therapy. They also have to adjust their lifestyle within certain physical limits.

But these therapies suggest, says De Bock, that CFS is a psychosomatic disorder, caused by mental problems rather than physical illness. “For certain patients, this kind of therapy can help,” he says. “But many patients need more thorough testing to find a proper biomedical treatment.”

According to a 2008 report by the Belgian Health Care Knowledge Centre, therapies provided between 2002 and 2004 by CFS centres at hospitals had a very limited effect on the condition of patients – no more than that of a placebo. There was no clear effect on their exertion capacity, quality of life or chance of returning to work.

## Expansion of treatment

Reform led to the establishment of new multidisciplinary diagnostic CFS centres last September, with the idea that hospital specialists will collaborate more and GPs will play a more central role. But De Bock fears the reform will have little effect, since the centres will still have to focus on the psychosomatic therapies recognised by Riziv.

So he is calling on the government to expand the treatments recognised by Riziv and to no longer use the Fukuda criteria, as he believes they are too general. He wants to see them use the more specific Canadian criteria, which emphasise the extreme exhaustion after activity, known as post-exertional malaise.

More research is also needed, says De Bock. A very promising study is being carried out in Norway, where an accidental therapy was discovered when a women receiving chemotherapy for cancer was also relieved from her chronic fatigue symptoms.

In an open letter to Belgium’s public health minister, Maggie De Block, CFS experts from five local universities recently demanded more government support to establish CFS research chairs at universities.

After two hours of shopping, I feel like I’ve run a marathon

- Gunther De Bock

To help CFS patients in Belgium financially, the [Wake Up Call Movement](#) is calling on the government to improve social security provisions. “When CFS patients have to give up their jobs because of their health problems, they have difficulty receiving social security support,” De Bock explains.

The syndrome also has a major impact on patients’ social lives, adds De Bock, who was diagnosed with CFS in 2001. “Because there is little known about it and the effects are not very visible, many people in your professional and personal environment think you’re exaggerating your problems. Going out also takes so much effort that it’s impossible to do it regularly, which increases social isolation.”

De Bock had to give up his job after falling ill and now has to sleep at least 12 hours a day. After even a short outdoor activity, he needs to spend days recuperating at home. “After two hours of shopping, I feel like I’ve run a marathon,” he says.

To create more awareness around CFS, the movement is organising [campaign shows](#) in Mechelen, Bruges, Hasselt and Antwerp. Apart from providing information, the events include performances by Flemish singer Mira and stand-up comedian Jens Dendoncker.

*Photo: Up to 25,000 people in Flanders have a chronic illness such as chronic fatigue or fibromyalgia  
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