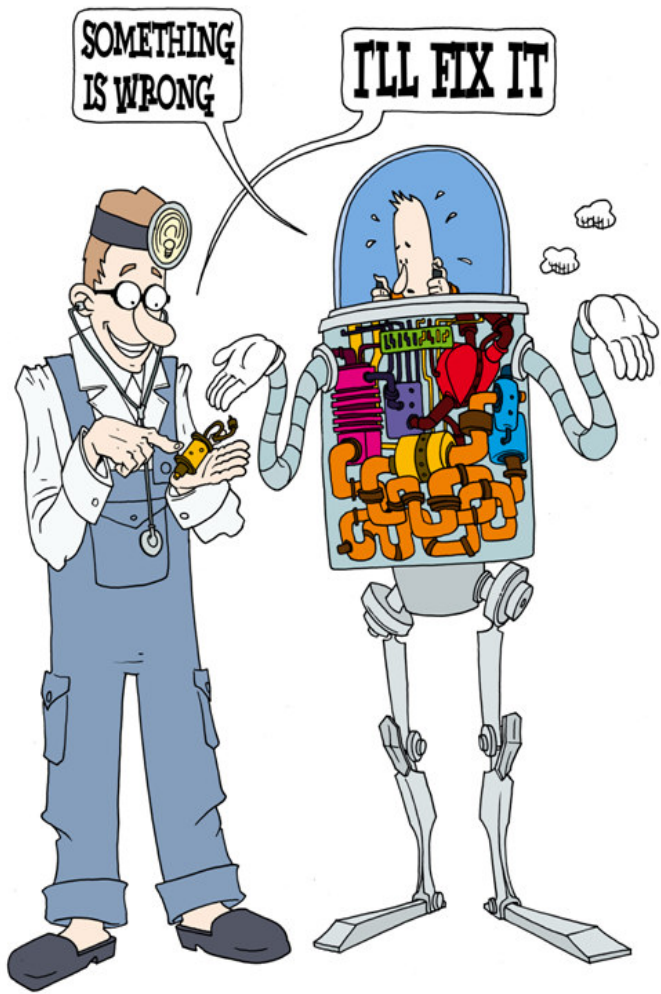


When the body says stop



The are many causes for functional disorders.



It would be easier if the body were just a machine

When the body says stop

His stomach hurts. His head feels like it's about to explode. The dizziness is almost unbearable. His heart is pounding. His muscles are sore. The fatigue is like a heavy blanket covering his entire existence.

This is how Peter* was feeling. He was 42 and usually never sick.

In Denmark, it is estimated that around 300,000 people are suffering from a functional disorder. This means that functional disorders are just as common as e.g. depression. However, there are still many people who do not know what a functional disorder is – both among patients, relatives and doctors.

A lot of people consider the body, mind and social aspects to be three separate entities that do not have much to do with one another. Nonetheless, scientific research indicates that it does not make sense to split up a human being like that.

All illnesses take place in the *entire* human body and involve both the physical and the psychological aspects. At the same time, everybody is affected by what is happening in their immediate surroundings. Some diseases are therefore best understood if you look at them through a so-called bio-psycho-social model where you consider both the physical, the psychological and the social aspects.

** Peter is a fictive character based on our experience with many different patients, who have given their consent to reproduce their medical case history. Peter's story is representative of people suffering from a functional disorder, but has been rewritten and anonymised to obscure any personal details.*

Thought that the body could easily be ‘fixed’

‘I have always thought that whenever something was not working right you had to locate the error, get it fixed quickly and then move on,’ Peter says. ‘For example, once I had a knee injury from playing too much football. It was really cool how the doctor could simply use an arthroscope to look into my knee and then get it fixed. A bit like a mechanic. So for me, it was pure logic that my stomach needed to be fixed when it started to hurt and something probably was wrong with it.’

Peter went to see his GP who took some blood tests and checked his stomach. But all tests were normal.

‘I told him to take some more tests because I could feel that something was completely wrong with my stomach.’

The doctors performed a gastroscopy of Peter’s stomach, which also did not show anything abnormal. But the symptoms did not go away. In fact they got worse.

‘I felt trapped in a body that was not working properly. And nobody knew how to fix it,’ Peter says.

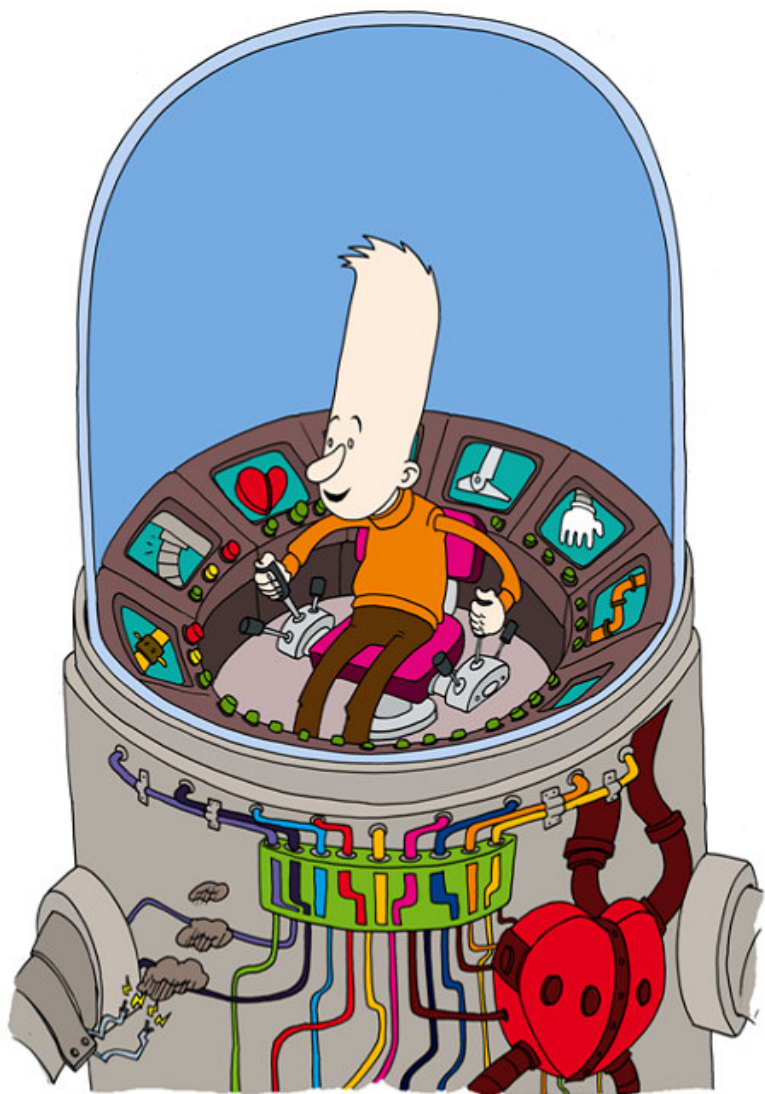
Symptoms

Everybody is experiencing symptoms as part of everyday life – symptoms that are not signs of any physical disease. When you are suffering from a functional disorder you have severe symptoms that lead to worries or affect your daily life. The symptoms have become the disease.

In some cases there are many symptoms and they can be divided as shown in the table below. Some people with functional disorders experience that their symptoms change or move around in the body.

Typical symptoms of a functional disorder	
General symptoms	Fatigue. Trouble concentrating. Headache. Trouble remembering. Dizziness.
Symptoms from stomach and intestines	Frequent loose stools. Abdominal pain or bloating. Abdominal tension or heavy sensations. Diarrhoea. Eructation. Nausea. Burning sensation in the chest or upper
Symptoms from heart and lungs	Palpitation. Chest pain. Breathlessness without exertion. Hot or cold sweats. Dry mouth.
Symptoms from the nervous and musculoskeletal systems	Arm or leg pain. Muscular aches and pains. Pain in the joints. Numbness or a localised feeling of weakness. Back pain. Moving pain. Disturbances of skin sensation.

We still do not know exactly why some people get a functional disorder. However, extensive research over recent years makes us begin to understand some of the mechanisms that are at play.



The brain is our control tower that operates and monitors the entire body. The brain is protected by a “filter” that screens out unimportant signals, and only lets important ones get through.

Brain and body

The brain is like a control tower which controls all organs and functions, and which at the same time receives a great amount of signals and messages from the entire body. We are aware of only a very few of these signals.

We can explain it like this: The brain is protected by a 'filter' that filters out unimportant signals and only lets in the important ones. Under normal circumstances, the filter is working without us even thinking about it.

When researchers scan a brain's activity, you can e.g. see that there is a changed perception of pain in people suffering from a functional disorder.



It is thought that patients with functional disorders have a defect in the brain's filter causing the body to be in a constant state of alert.

Many new signals

There are many indications that the brain of people with a functional disorder is starting to pick up many of the signals that are normally filtered out. This means that the brain will pick up new signals e.g. from the stomach, without it being a signal of a stomach disease. At the same time, the body is probably sending more signals than usual.

When you are suffering from a functional disorder, your body is in some sort of state of alert. In a state of alert, the body produces many stress hormones. Many of the symptoms from a functional disorder are the same as we experience in connection with stress.

Peter gets more symptoms

'I started to wake up during the night because my heart was pounding,' Peter says. 'When I was out for a run I couldn't breathe. I've always been doing a lot of exercise so it didn't add up. When I started to feel dizzy I got really scared. I think my GP got worried too because he sent me to see a heart specialist.'

There was nothing wrong with Peter's heart. But the symptoms didn't go away. He started to feel pain in his muscles and most parts of his body and he was overcome by fatigue, which challenged his ability to function in everyday life.



The are many causes for functional disorders.

Cause

Rarely, there is a single cause of a functional disorder. In general, several factors are contributing to the disorder.

Some people are congenitally vulnerable. It is in their genes that they more easily than others develop a functional disorder. Some people develop a functional disorder after great or long-term stress, e.g. a divorce, illness in the family or social problems. Sometimes an infectious disease or an accident can cause the development of a functional disorder. However, usually there are several factors at play at the same time.

Before falling ill Peter was under a lot of pressure from many sides

‘Finally, my GP said that I had to trust that nothing had been overlooked during the many physical examinations and tests. He said that I was suffering from a functional disorder. At that time, I was on sick leave and could only take short walks without my symptoms getting worse.’

It turned out that Peter had been under a lot of pressure at work over a long period of time. His company was doing layoffs and every day he felt that he had to prove that he was good enough. Moreover, his daughter was facing learning disabilities, which meant meetings with teachers and setting aside extra time for helping her with her homework.

This caused a conflict between Peter and his wife. She did not think that he took their daughter’s problems seriously enough, and she decided to cut back on her hours at work. That meant that the family was now even more dependant on Peter keeping his job since they would not be able to pay their mortgage if Peter lost his job. Shortly before the abdominal pain began, it was established that their daughter was dyslexic. She was granted extra help and both Peter and his wife felt that they now could put down many of their worries.

‘I thought that it was strange that I got sick just when I finally had time to think of myself.’

Treatment

The most effective treatment is a combination of:

- **Graded exercise therapy**
- **Cognitive behavioural therapy**

Medication can for some patients reduce pain and physical discomfort.

Most patients will benefit from the treatment. Studies show that some are cured and a great deal will feel significantly better. Only a few will not benefit from the treatment.

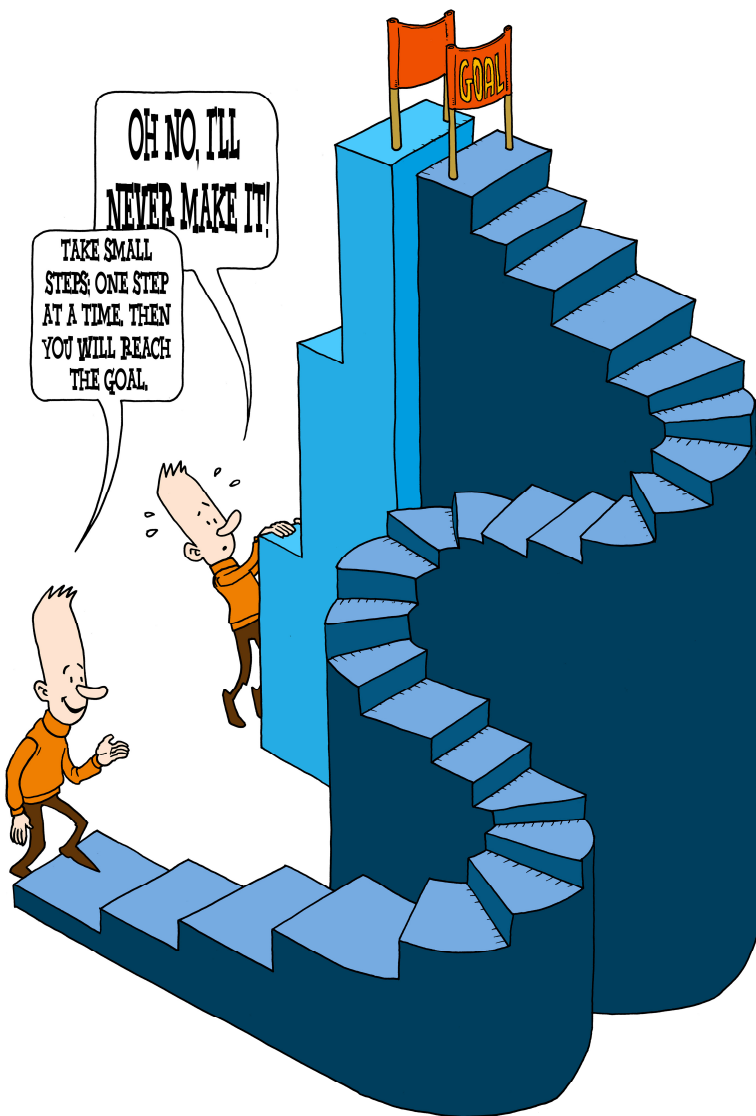
Treatment with graded exercise therapy and cognitive behavioural therapy is hard work. The more motivated you are, the more you will benefit from the treatment.

Graded exercise therapy

In graded exercise therapy, you are physically trained at a realistic level.

Most people with functional disorders have experienced a great deterioration of their physical fitness, and many have really high standards for themselves. Some have previously been very active and it may be hard to accept that you can no longer manage what you used to.

In graded exercise therapy, you practice how to come closer to your goals one step at a time. It is important neither to start up too ambitiously nor at a pace too high. Eventually, you will be able to manage more and you will feel how the rehabilitation process increases your level of energy and endurance.



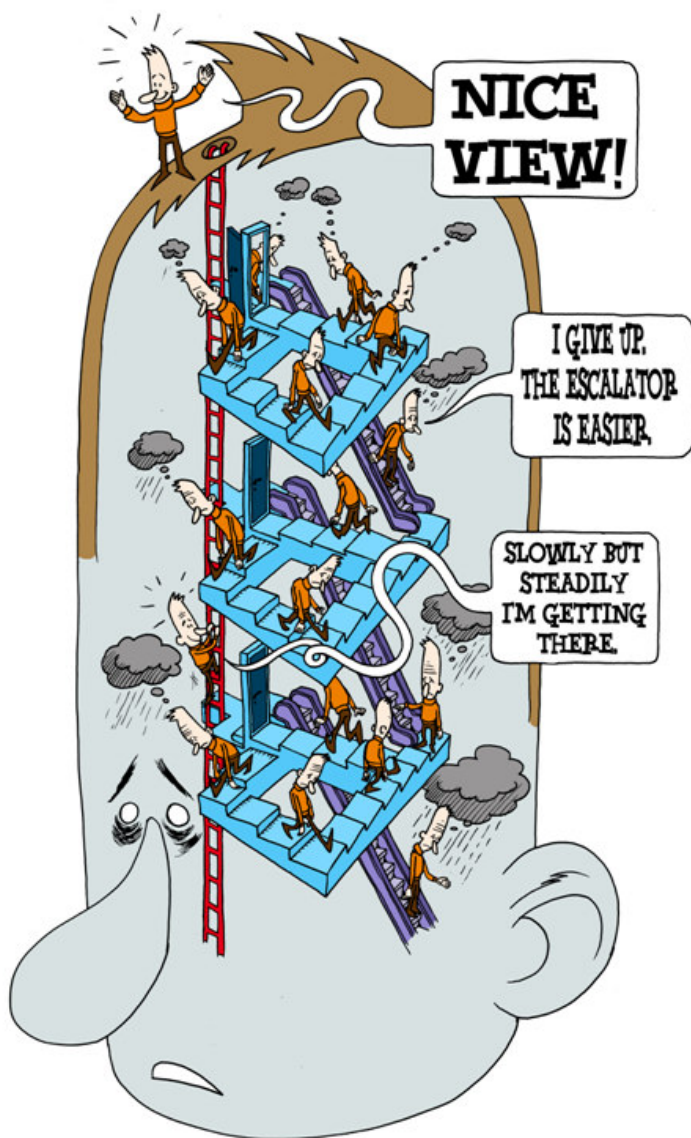
In graded exercise therapy, it is important to proceed gradually to get challenged without getting strained.

Peter was referred to group therapy

‘It was actually a bit shocking meeting others who felt the same way as I did. I had thought that I was the only person in the whole world who felt this bad.’

Peter found out that his symptoms got worse when he was stressed or strained. He started seeing his symptoms as the way his body tried to say stop – instead of seeing them as signs of illness in his heart or stomach. He learned to set personal boundaries, realistic goals and change the thoughts he was stuck with.

‘Naturally, I hoped that the treatment would be a miracle cure. But I found out that it was hard work. The doctor was actually merely a helper. It was me who had to do all the work, but I could feel that it was helping. Slowly, I started to feel better.’



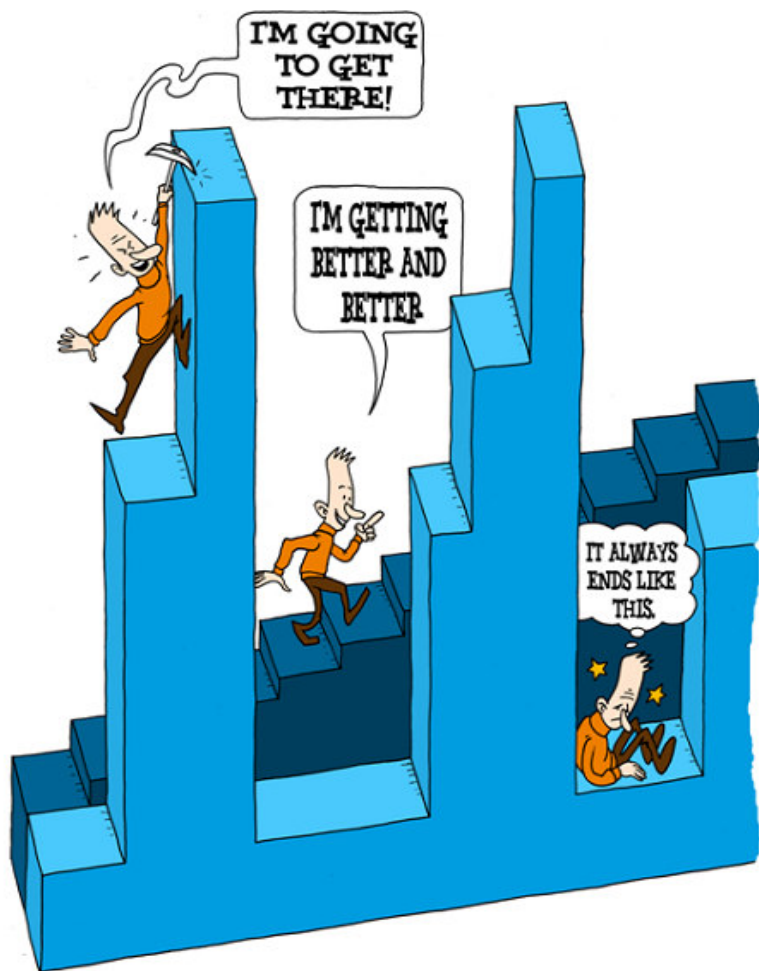
Cognitive therapy is hard work.

Cognitive behavioural therapy

Cognitive behavioural therapy focuses on the thoughts you have about yourself and your situation.

Many people suffering from functional disorders have developed disadvantageous thoughts about themselves and their illness. Some may think that the body is fragile and cannot cope with normal strain. Others will think that the many physical symptoms are completely unpredictable and cannot be controlled. These thoughts might escalate and you will get filled with negative thoughts. Negative thoughts have a worsening effect on the functional disorder and they affect your ability to cope with the symptoms.

Through cognitive behavioural therapy you learn e.g. ways to stop these trains of thoughts, and you gradually learn to think in another and more favourable way.



Many people with functional disorders are ambitious and want to be able to cope with everything. This can result in setback and aggravation. The art is to avoid strain and to set realistic goals.

Living with a functional disorder

Not everyone with a functional disorder will get cured, but basically all will get better. Those who will not get cured can learn to live with the functional disorder, the same way that one can learn to live with other chronic diseases, such as asthma.

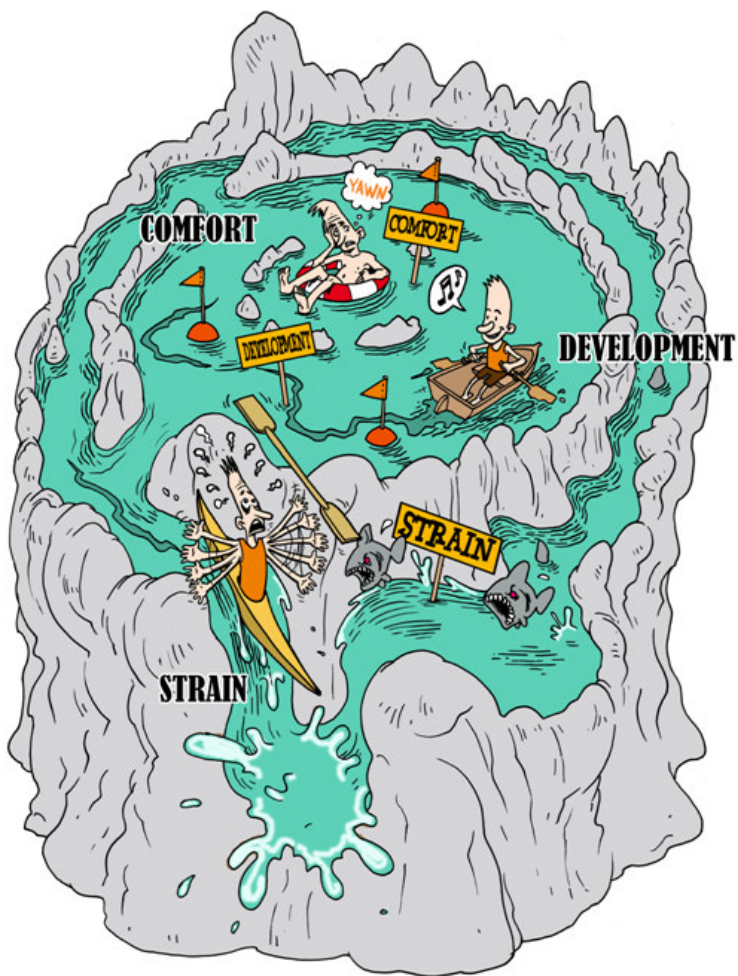
It is important for people with functional disorders to avoid strain and too much stress. It is likewise important to let yourself be challenged and not be afraid to get closer to your own limits. A part of the people with functional disorders will often have a fluctuating activity level, which may lead to a worsening of the symptoms.

Peter's challenge: Finding the balance between activity and rest

'I have always been the kind of guy that never settles for half measures. When I started to run, I was quickly fit enough for a marathon. At my job, I never left anything half-finished. When I was working on the house, I didn't stop until it was perfect.'

Peter was slowly starting to feel better during his treatment. But he had some relapses as well.

'The hardest part was my own impatience. I simply wouldn't accept that the progress was that slow. When for the first time I felt that I was getting better, I was so excited that I went for a 5 km run. That meant that I had to stay in bed the whole next day.'



**The art is to seek challenges without getting strained.
And without coming to a standstill.**

Setting the right level of challenge

If you are to live with a functional disorder, it is important to avoid both too many and too few challenges.

It can be explained by dividing your life into 3 zones:

1. In the inner zone, you experience *comfort*. Here you relax and recover. But you do not make any progress. If you exclusively stay here, you will eventually come to a standstill and your body will decay.
2. In the next zone, there is *progress*. Here you are challenged to an extent where you start moving towards the goals you have set for yourself, and you will experience recovery and progress.
3. In the outermost zone, you are exposed to *strain*. Here you are challenged to an extent where you transcend your own boundaries. If you stay here too long, you may eventually get chronically ill.

Some people with functional disorders have a tendency to fluctuate between either a level of challenge too low or a level of challenge too high. This will often lead to a worsening of the symptoms. An appropriate challenge is necessary to feel good both physically, mentally and socially.

Symptoms are Peter's stop signals

'I feel great now,' Peter says.

'I'm back at work and everyday life is working for me again. But I can feel that I still have those symptoms just beneath the surface. If it's too busy at work, if my calendar is too booked, or if my daughter is going through some difficulties the symptoms will return. First I will get stomach pain, and if I don't react to that I will get dizzy. I know my body so well now that I consider the symptoms to be red STOP signs, and if I don't stop and listen, I know that they will only get worse.

I can't say that I know my illness 100%, and it's not like I never do anything I won't regret the next day. But I'm working on it. I get a little bit better at it every day.'

If you would like to know more:

www.functionaldisorders.dk

When the body says stop

Information about functional disorders

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WHEN THE BODY SAYS STOP

A functional disorder is a disorder with physical symptoms which make everyday life difficult. The exact cause is unknown, but it can be seen as a disorder where mind and body for various reasons are not functioning properly. In Denmark it is estimated that approx. 6% of the population or around 300,000 people are suffering from a functional disorder.

This leaflet is addressed to people who would like to know more about functional disorders. You can find more information on www.functionaldisorders.dk

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