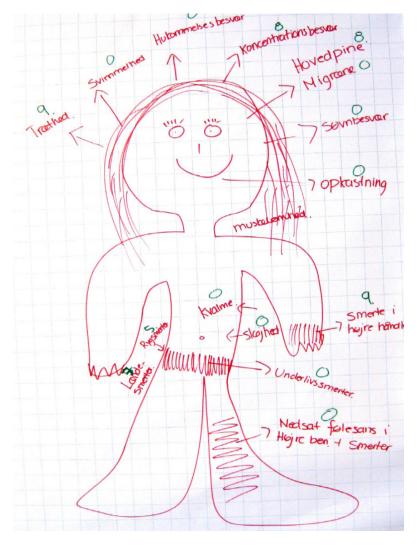
Bodily Distress Syndrome (BDS)



Patient drawing of her symptoms

(Fatigue, dizziness, memory impairment, concentration difficulty, headache, migraine, insomnia, vomiting, muscular pain, nausea, feeling seedy, pain in right hand, abdominal pain, back pain, lower back pain, reduced sense of feeling in right leg and pain in right leg.)

The Research Clinic for Functional Disorders and Psychosomatics
Aarhus University Hospital 2011

About bodily distress syndrome

Bodily distress syndrome is a new diagnosis used for research purposes, so you probably have not heard about the illness before. Individuals with bodily distress syndrome (hereafter BDS) experience daily bothersome physical symptoms. Typical symptoms are headache, pains in the back, muscles or joints, stomach trouble, breathlessness, excessive fatigue and many more. In some individuals, the distressing symptoms are so pronounced that they cannot go to work. Even normal daily chores such as shopping, doing the dishes or vacuuming can become impossible because of the symptoms.

Many patients with BDS have gone through numerous examinations by their GPs, by specialists, or at hospitals without the doctors finding a good explanation for their symptoms. Unfortunately, some patients feel that they have been misunderstood and that some doctors become less sympathetic when they notice that no signs of well-known disease have been found. Some patients report having been told that they are not 'genuinely' ill, that the symptoms are imaginary, or that it is a 'mental' problem. Most patients find this extremely distressing. Some patients with BDS have received diagnoses such as fibromyalgia, whiplash associated disorder, irritable bowel syndrome, chronic pain disorder or others. Today, we regard these subtypes of BDS.

We emphasise that BDS is a genuine disorder and that the symptoms are not imaginary.

How is BDS diagnosed?

Based on an interview and your medical records, a doctor at our department assesses your symptoms. The doctor decides the severity of the symptoms and whether your symptoms could be due to other disease, for instance if pains in the joints are better explained by arthritis or if breathlessness can be explained by asthma. If the symptoms are better explained by another disease, it is not considered part of BDS. The diagnosis is thus only made on the basis of the symptoms, their severity and duration. Presently, no examinations such as blood tests or a scan can determine if an individual has BDS.

During the interview, the doctor investigates if symptoms from the following 4 groups are present.

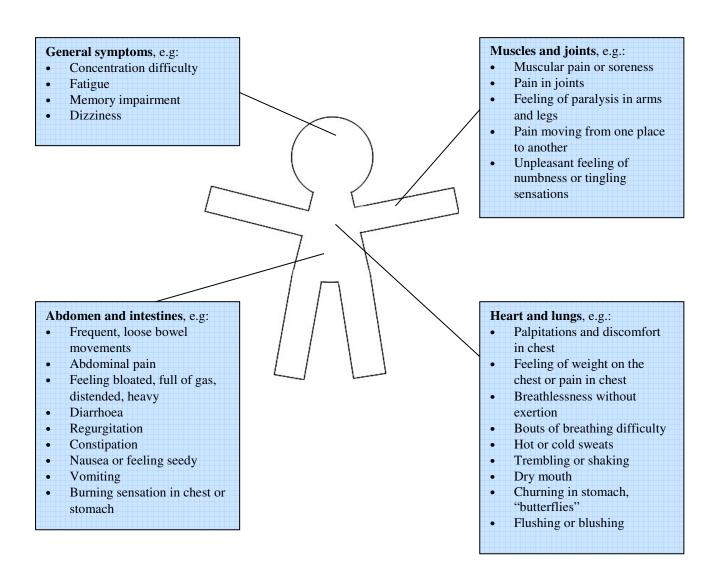
Group 1: General symptoms such as headache, dizziness, fatigue, memory impairment and concentration difficulty

Group 2: Symptoms from abdomen and intestines

Group 3: Symptoms from muscles and joints

Group 4: Symptoms from heart and lungs

These symptoms are investigated:



BDS can be divided into a single-organ and a multi-organ type. The difference between the single-organ and a multi-organ type is the number of organ systems involved. Not all the symptoms need to be present at the same time, but they must have been present within the past two years.

Additionally, the symptoms must be so bothersome that they interfere with daily life. The majority of patients with severe BDS can overcome a lot less than before they got ill. Although all patients with severe BDS have symptoms from more groups, the symptom(s) from one single group can be more bothersome than the symptoms from other groups. Patients with severe BDS experience completely different problems in daily life according to the nature of their most bothersome symptom whether it be e.g. paralysis, back pain, or loose bowel movements.

This means that although there are many common traits among individuals with BDS, the illness manifests itself in many diverse ways.

We know that 1 out of 3 patients with severe BDS also have an anxiety disorder or a depression. If you suffer from an anxiety disorder or a depression at the same time as BDS, this makes life even

more difficult. It is therefore important to discover this in order to provide the appropriate treatment.

Other names for BDS

Every hospital department has patients with symptoms that cannot be attributed to a medical or a surgical diagnosis. Doctors call such symptoms *functional symptoms* or *functional disorders*, but some also call them medically unexplained symptoms.

Various medical specialties use their own diagnoses for patients with functional disorders. Some patients with BDS receive the below-mentioned diagnoses, which can give rise to confusion. You may have received one or more of the following diagnoses:

- Fibromyalgia
- Chonic fatigue syndrome (CFS)
- Irritable bowel syndrome (IBS)
- Chronic pain disorder
- Somatisation disorder
- Multiple chemical sensitivity (MCS)
- Whiplash associated disorder (WAD)

However, recent research suggests that the different diagnoses are all subcategories of one single illness, namely BDS.

Several studies have shown that the patients, in spite of different diagnoses, often have the same symptoms. For instance, a patient with fibromyalgia can also be bothered by abdominal pain and fatigue. And a patient with chronic fatigue syndrome can also be bothered by muscular pain and palpitations.

The many diverse diagnoses in this area seem to be evidence of BDS having several faces as mentioned above.

BDS is a new research diagnosis and therefore unfamiliar to many doctors. Most doctors do know the different diagnoses mentioned in the above box, but they are unaware that they can be viewed as one single illness.

General practitioners may use the term "somatisation" about symptoms that cannot be explained. Therefore, both *somatisation disorder* and *bodily distress syndrome* are mentioned in the papers we send to your general practitioner.

What are the causes of BDS?

Unfortunately, our knowledge about BDS is limited, and it will probably take some time before we fully understand the disorder. We know that the cause of the disorder is very complex and that several factors are involved in the onset of BDS. There are five known factors that influence BDS: (i) the brain, (ii) heredity, (iii) other disease/injury, (iv) illness worries, and (v) longstanding stress or strain.

The brain

We know that part of the explanation can be found in the brain – and thus not in the body although that is where the symptoms are felt. Research has shown that other parts of the brain for registering pain are involved in patients with BDS compared with healthy individuals.

Also, there are demonstrable biological changes in the brain.

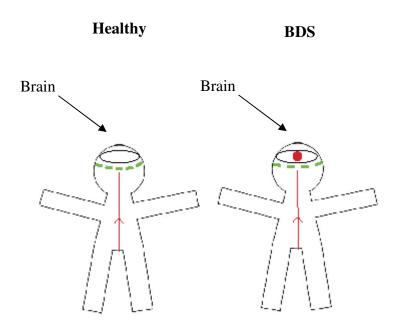
The filter theory

In order to understand the filter theory, you need to know that the sense of feeling is located in the brain.

You only get a bodily sensation when it is registered in the brain. This means that if you place your hand on a hotplate, you do not register the pain until the brain has received a message from the nerves in the hand.

Research suggests that patients with BDS have an increased sensibility towards bodily signals. The body sends signals to the brain constantly. Healthy individuals have a filter that stops a lot of the signals before they reach the brain meaning that they do not register these signals as the filter only lets the most important signals get through.

Research shows that this filter is malfunctioning in individuals with BDS. The filter has holes that let more signals get through to the brain. This could explain that you can have a normal scan of for instance the back, but still feel pain.



Altered symptom coping in the brain

Some studies also suggest that the brain copes with bodily signals differently in patients with BDS compared with healthy individuals.

Heredity

Heridity in BDS has not been investigated specifically, but several studies show that some families are more prone to suffer from many symptoms than others. When there is a tendency to have bothersome symptoms within families, this is among other causes due to heredity factors.

Other disease / injury

In some cases, BDS appears following a disease or injury. A typical example of this is whiplash. In connection with a car accident, the neck can get strained. Most individuals will experience a sore neck for a couple of weeks, and then the soreness will gradually subside.

In some individuals, the pain persists and gets worse, and more symptoms from other places in the body can appear. In these cases, a more chronic condition is developed, namely BDS.

Illness worries

Illness worries are thoughts about your illness or symptoms that make you worry that you may be seriously ill. We know that illness worries can affect the course of many diseases, for instance following a blot clot in the heart, and also in BDS.

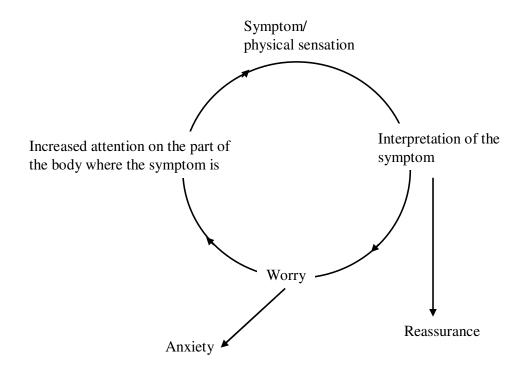
Example

When you feel a symptom from your body, for instance back pain, you will often have thoughts about whether this will affect you both at this particular point in time and also in the future.

Examples of thoughts about back pain

- 1. "My back aches. It will probably pass within a few days".
- 2. "The back pain is a sign of bad health. I need to be really careful or it will get worse.
- 3. "Oh no, I wonder if I have a cancer tumour in the back".

As these examples show, you can have many different thoughts about the same symptom. Some thoughts have a reassuring effect (example 1), while others cause worry (examples 2 and 3). If the symptom causes a lot of worry it gets worse, and you can enter a "vicious circle" that automatically continues. You end up being more ill and more bothered by the symptom.



Long-standing stress and strain

We know that exposure to long-standing stress and strain increases the risk of getting BDS. This is particularly true of stresses in childhood, but also strains in adulthood. Many people with BDS have for years exceeded the limits of what they are capable of. If you exceed your limits over a long period of time, you can react with stress, which can trigger BDS.

How do we treat BDS?

BDS is treatable. It is possible to rehabilitate the body, to learn to be less worried about your symptoms, and learn strategies to cope with stress and strain. At the same time, medical treatment can change the symptom experience in the brain so that the symptoms are less bothersome. Some of our patients get completely well, others experience that their symptoms are relieved and that they get more energy. You can discuss with your doctor which kind of treatment is the best for you.

What can you do yourself?

There is a variety of things you can do to get better. You can read about those things in the folder "What can you do while you wait for treatment? Bodily Distress Syndrome (BDS)".

Own notes

Here you can make notes of the things you want to remember from your conversation with the doctor.

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