

I COULD HAVE BEEN DEAD



Eight years ago 51-year-old Bettina Buhl contacted her GP with an extreme fatigue but it took six years before the correct diagnosis was made. Over the years more and more serious symptoms appeared. Symptoms that could have resulted in fatal outcome for Bettina.

On an ordinary everyday life Bettina Buhl drives her daughter to gymnastics in the local sports hall, just a few kilometers away from their place of residence. Bettina has driven this trip many times, but this afternoon she experiences trouble finding way in the traffic. She ends up driving to the side, because she simply does not know how she approaches the hall. After keeping quiet for some time she turns on the GPS, being guided the last piece and her daughter was dropped off by the hall.

- Fortunately, my daughter didn't notice anything, because she was busy with something else but I actually became very frightened. The first thought was that I might have a tumor in the brain or maybe I was having early Alzheimer's or dementia. I felt this indescribable "brain fog" and my brain was simply not functioning normally.

At this time it is already long time ago since Bettina went to her GP the first time. At the age of 43 she contacted her GP with a paralyzing fatigue - feeling tired into every cell in the body. For a long time the fatigue was the only symptom and Bettinas GP therefore took different blood tests but without any conclusion.

A lot of symptoms

Over the years more and more symptoms appeared. In the early stage Bettina felt generally uncomfortable, she felt sick with pain in muscles and joints and she had a constant headache. She continued to work, but she slept as soon as she came home. At some point the symptoms became of more neurological character and Bettina experienced often that she was having trouble speaking and expressing herself, she was generally distracted, and then she completely forgot basic things like names. In the same period Bettina had pain and pins and needles in the hands and feet which at times could become completely numb.

When I was going to ride my bike to work I had to stop several times, because I did not feel there was any blood supply to my fingers and when I was going to sleep at night, I had to stack myself up on pillows because I couldn't stand the pain if my feet hit the mattress, it was very painful. It is the same pain a sclerosis patient experience and if I had not been treated on time, I had probably developed severely permanent neurological damage, but I could also have been dead of my B12 deficiency.

During the very long investigation process Bettina is referred to the rheumatology department. Here she goes through tons of examinations and blood tests during a period of three and a half years, but they do not succeed in making a diagnosis even though it just requires an ordinary blood test to determine the B12 of a human. In that sense it is not a very resource-demanding process, but it was not done at any time. On this background Bettina's GP instead decided to put her on stress sick leave in three months.

It must be a mistake

The 5th of March 2015 is the turning point. At this time Bettina has been ill for six years in total, but nevertheless she returns to her job after the sick leave. When she's on her way to her working desk after breakfast, she thinks she is in a very bad shape because she suddenly feels a shortness of breath. Minutes later she collapses. Fortunately, Bettina works at the University Hospital in Odense, and when she at the same time feels an excruciating chest pain her doctor colleagues suspects she is having a heart attack.

- My colleagues transported me quickly to the emergency room where tons of examinations, scans and blood test were done. They examined me in all ends and edges, but a B12 sample was not drawn here either.

Bettina is sent home with the message that she had a little fluid around the heart, and even though she takes painkillers subsequent days, she continues to feel very bad. On request from a colleague Bettina contacts her GP once again and a lot of samples are taken and at this time the B12 test is also requested.

My GP calls me at home the same day and says there has been a mistake. My B12 is unmeasurable low so they must have made a mistake at the laboratory. She tells me that one can't have that low B12 result. It is usually not possible to survive this without sitting in a wheelchair and have severe neurological damage. Therefore she draws a new blood test the following day, but it shows the same low result.

Back to life

After six years Bettina is diagnosed with pernicious anemia, which is an autoimmune disease, where the body breaks down itself. This means that all the B12 Bettina eats through the diet is not absorbed in the body. Bettina has not had the disease for a lifetime, yet it is probably genetically inherited hence her mother afterwards have been diagnosed with B12 deficiency too and her grandmother probably had the disease too. Bettina was treated initially with four B12 injections to

give her a boost, but she felt no relief and she felt no benefit of the treatment at that time.

- When I get the fifth injection I wake up in the morning and dots to my husband beside me and I say, "Now I'm normal again." It was like a miracle. The brain fog was gone. I woke up in the morning and felt good and I have not had a headache since.

Today Bettina gets B12 shots every third week, and in the intermediate weeks she takes sublingual B12 tablets. On this treatment almost all her symptoms are gone. She has experimented with longer intervals than every 3 weeks between injections but that's not possible without especially the neurological symptoms coming back.

"I am very aware that I have been extremely lucky and privileged. Firstly, because I'm still alive, but also because I'm not disabled and I have not lost my work ability like many other patients with this devastating disease. Over the many years that passed by I had forgotten how it was to be me because the symptoms were unfortunately defining me. I was just alive before, but I was not living. I am living know.

Text to images:

Today Bettina gets B12 injections every 3rd week.

"I am very much aware that I have been extremely lucky and privileged"

When should you suspect B12 deficiency?

The condition should be suspected in all persons with unexplained low blood hemoglobin (anemia), unexplained neuropsychiatric symptoms and / or gastrointestinal symptoms such as glossitis, poor appetite and diarrhea. One should pay particular attention to persons which is at risk of developing vitamin B12 deficiency:

- Elderly people with increased risk of atrophic gastritis.
- Vegetarians and vegans.
- People with bowel disease.
- Other groups at risk are people with autoimmune diseases such as Grave's disease, thyroiditis and vitiligo
- As well as people who use acid inhibitor drugs (proton pump inhibitors, H2 blockers) or metformin

Comments from Bettina (not included in the article):

At the time of diagnosis my blood tests were as underneath. Please note that I have pernicious anemia without anemia. The pernicious anemia diagnosis was confirmed by endoscopy – atrophic gastritis.

Cobalamin;P : **<61 pmol/L** (130-700 pmol/L)

MMA;P : **not measured**

MCV;B : **97 fL** (82-98 fL)

Hemoglobin;B : **9.4 mmol/L** (7.3-9.5 mmol/L)

Folat;P : **25 mmol/L** (5.0-30.0 mmol/L)

Parietal cell antibody;P : **Positive**

3 months after my PA diagnosis I was also diagnosed with Graves disease (subclinical hyperthyreosis) – very low TSH, but normal T3 and T4. Slightly elevated TRAB antibody.

I did not have any classical Graves disease symptoms at all but Thycapzole was prescribed for approx. 1 1/2 year due to the very low TSH. Now I am drug free and I have normal thyroid results. I don't have any TRAB antibodies anymore. Was it pure luck or maybe adequate B12 injection treatment that “cured” my subclinical Graves disease?

I do also have Raynauds disease and autoimmune urticaria/hives since I was a little child.