

Web headline: With a revolutionary new treatment, Bart de Beurs got rid of his years of compulsions

## **Newspaper headline: Anxious brain on the charger**

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With the push of a button, Bart de Beurs got rid of the anxiety disorder he had been struggling with for years. Then the quest began: who was he now?

Niki Korteweg, 15 april 2022 – NRC

<https://www.nrc.nl/nieuws/2022/04/15/verlost-van-angst-met-stroomstootjes-in-het-brein-a4113831>

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Forget it, Bart de Beurs thinks to himself, standing in the white-tiled hall of the Amsterdam UMC hospital. It won't work. I quit. It was all for nothing anyway. The many scans of his 68-year-old brain. The surgery, just a few weeks ago, when they bolted his head to the operating table in a rigid metal frame for eight hours. The two holes that they drilled into his skull. The electrodes they stuck deep in his brain, the cable they tucked away under the skin of his neck, the pulse-device they implanted in the cavity under his left collarbone. He looks for Ria's comforting eyes. He has made up his mind. He is going to arrange the forms. He wants to die.

Let's have some coffee first, Ria decides. And then, they step into the elevator anyway, heading to the consulting room of psychiatrist Pelle de Koning. He awaits them, sitting behind his iPad. They have barely set foot in his office when De Koning enters the settings for the pulse-device in Bart's body. His index finger hovers above the 'enter' key...

For forty years, every single day Bart starts with checking off a list. Things he has to do. People he needs to call. For instance his brother, to check whether he has good car insurance. Or his brother-in-law, to check whether he has cleaned the gutter to prevent leaks. Employees to ask if they have thought of that highly important insurance clause. Business relations.

Often the lists are the same as the previous day's. He writes them over and over again, neatly lining up all the scribbled additions. One last call to make sure. Check that thing again. Get back to someone one more time. He asks his secretary the same thing three, four, five times. She does wonder why. But then again, he is the insurance director of a multinational company. Avoiding risks is one of the most important job requirements.

### **Lists of lists of lists**

But where most people get peace of mind from checking off a list, Bart only finds peace when *making* a list. As soon as he takes his pen off the paper, the fear creeps up. Did I say it right? Did I understand correctly? Did I write it down correctly? Shouldn't I ask again? They

become lists of lists of lists. He *has* to call again, check again. It's the only way to curb his anxiety, to keep from going crazy.

No one around him knows how bad it is; not his parents, not his in-laws. Not his colleagues at the insurance department of Gist-Brocades in Delft, nor his work relations. To them, he's just a demanding, tenacious insurance executive, or an important client. You don't argue with someone like that. To his family and friends, he is the one who takes care of problems with money or with the tax authorities, the one who has everything under control. They find him a nag maybe, a pain in the ass sometimes. Bart knows that. But his urge to control is stronger than his sense of shame about nagging.

Talking about it makes it worse, Bart notices. He prefers to keep it to himself. And his wife Ria even more so. It's best to push away sorrow and despair, and just keep going, is her motto, from the very first time Bart turned pale and was overwhelmed by an indescribable fear. That was in the hospital, in 1975, next to the bed of their infant son with meningitis. Bart had rushed there immediately after a panicked phone call from Ria. Everything was fine now, the doctor had said. But then another fear took over Bart's mind: had he turned off the light in the office?

Outwardly, Bart played the clown. Was there a party? "Ha, Bart is coming, we can have fun!" friends knew. Bart cracked jokes, jumped on tables, and dominated the conversation. When they lived on Curaçao, he once even climbed a lamppost and pretended to fall. He felt wonderful in those moments. That way he didn't feel the fear and misery. He didn't have to show his true self.

*Already in the car on the way back, he turned back into the silent brooder with his grumpy face*

This immaturity infuriated Ria. Because as soon as they would be in the car on their way back, he would revert into the silent brooder with his pouty face, the worrier that she lived with day and night. The man who was sleeping all the time because of his medication, who didn't feel like doing anything. The control freak who was always fiddling with papers, making phone calls like a madman. Who would drive 160 kilometers back and forth to the office in Delft in the evening, just to check something. Who would furiously snatch the phone out of her hand, yell at her to get lost, and slam the door of his home office in her face.

If he had that compulsion, nothing could stop him.

Treatments - he's tried them all. Psychotherapy, trauma therapy, exposure therapy. Antidepressants, antipsychotics, antianxiety drugs. Acceptance exercises. Group therapy. Nothing helps, and certainly not the 'nonsense' about his domineering father who sent him away from the nice school - where he is headmaster himself- to a miserable LTS (vocational technical school) where Bart has to become an electrician. Or about his emotionally unavailable mother, about his childhood among ten siblings. It doesn't stem from his childhood, Bart thinks. It feels like a circuit error in his brain.

It becomes unbearable. All the joy in his life gets overgrown by the indomitable fears. All his energy is consumed by the debilitating compulsion. He can no longer stand seeing the desperation on Ria's face, or hearing the snarling of people who have had enough when he calls *again*. Deep down he knows. It would be better for him and for those around him if he is no longer around. Bart wants to arrange euthanasia. At his next appointment with his psychiatrist Ton van Balkom, on August 2, 2011, he is about to bring it up. But before he can start talking, his doctor tells him about one final option. A revolutionary new treatment at the Amsterdam UMC: deep brain stimulation.

### **Rechargeable battery**

Deep brain stimulation is a technique in which dysregulated brain cells are permanently stimulated with low amounts of electrical current. A neurosurgeon drills small holes in the skull. Thanks to an fMRI scan of the brain, he knows exactly where the intended brain area is in the patient on his operating table. In that brain area, or areas, he implants one or two thin electrodes that look like the cords from the small wired headphones of a mobile phone. Under the skin of the neck, the wires run to a stimulator with a rechargeable battery implanted in the cavity under the collarbone.

The treatment has been approved in Europe and the United States for almost two decades for movement disorders such as Parkinson's disease and dystonia, and for chronic pain and epilepsy. The stimulation suppresses the severe symptoms of these conditions. Worldwide, an estimated 400,000 people wear a deep brain stimulator, says psychiatrist Damiaan Denys of Amsterdam UMC. The vast majority have it against a neurological disorder, such as Parkinson's.

But the treatment is also increasingly used against psychiatric disorders. This type of psychosurgery has been a regular treatment for obsessive-compulsive disorder (OCD) and for the tics of Tourette's syndrome since 2013 – Denys started treating his obsessive-compulsive patients with it in 2005. In addition, the technique is being tested in scientific studies against severe depression, anxiety disorder, aggression, addiction and eating disorders such as anorexia or binge eating in severe obesity. The results are promising. “Of the compulsive patients, in about 15 percent the symptoms have completely disappeared. In 15 percent it does not work, and in the rest the symptoms have been halved.”

Despite its potential, deep brain stimulation is still rarely used for psychiatric disorders. “About 600 people worldwide have now been helped against psychiatric disorders such as depression and OCD,” Denys estimates. “In the Netherlands, only hospitals in Amsterdam - in collaboration with Tilburg - and Maastricht are performing the procedure, Groningen will start soon.”

*Don't do it, Ria says after the psychiatrist's proposal. How will you end up?*

Unbelievable, says Denys. Because the prognosis for people with severe, untreatable psychiatric disorders is bleak, he points out: four out of five people die by suicide or euthanasia. “Yet there is great resistance to use the technique, both among the public and psychiatrists,” he says. “Psychiatry is not naturally associated with the brain. In fact,

psychiatry is moving in the other direction, away from medical treatments, and towards treatment through psychotherapy, mental well-being and lifestyle.”

Don't do it, Ria says after the psychiatrist's proposal. How will you end up? Bart will be the first patient over the age of 65, it is still an experimental treatment. And for a young man in his treatment group it didn't work. He now has bumps on his head without any improvement. The Amsterdam UMC wants Bart to follow other therapies and have group discussions first. But Bart feels it with every fiber of his being. This is what he wants. It's this, or death.

On October 3, 2014, he lays clamped to the operating table, anesthetized, and the drill enters his skull.

### **Heaven – and the price**

Four weeks later, at the Amsterdam UMC, De Koning presses the enter button with his right index finger. And Ria notices it immediately. Bart's eyes change. The gloomy look disappears, they start to shine. Bart feels that the current through his brain chases away the tormenting forty years of ever-present fear. He is liberated! He can start living!

He still gets goosebumps when he thinks back of that moment, eight years ago. A death wish at 9 o'clock in the morning, and walking out of the hospital whistling at 11. It feels like heaven on earth.

Delighted, Bart and Ria walk through the corridors of the hospital. Suddenly Bart turns around. He walks back, jerks open his doctor's door. Startled, the psychiatrist and the next patient look at him. "I'll buy a giant teddy bear for your newborn!" Bart shouts.

They drive back to Soest, to their beautifully renovated house in the meadows. In the car, big plans take shape in Barts mind. He is going to study law, buy a piano, learn to play it, they will go on a trip around the world, to South Africa and beyond.

But for some, it's not heaven at all. Bart is manic, wanting everything, doing everything and saying everything that comes to mind those first weeks. After forty years, Ria is suddenly married to another man – three years after their wedding the compulsions started, so she hardly knows him without them. All those years he listened to her, he was insecure, she decided everything. Now he has his own opinion, his own ideas about where he wants to go on holiday. He buys his own clothes.

The worst part: he gets aggressive. Not just a little impatient or annoyed. Out of nowhere, he ignites in blind rage, cursing and screaming and smashing things when she says something he doesn't like. It is threatening and frightening. It is a side effect of the stimulation.

Is this the man I'm getting back, Ria thinks. Then I'd rather have the other one.

It gets so bad that Ria calls up the doctors to ask if the power can be turned down a notch. It brings up one of the many ethical dilemmas that treating physicians have to deal with. Can you turn down the power a bit if a partner or family member asks it, for their own safety? No, that is only allowed if the patient wants it himself.

The next issue is: do you ask the person if he wants this with the power on, or with the power off? In which situation can you assume someone is 'himself'? For example, there is the story of a seriously ill parkinson's patient who had to be admitted to a nursing home. Thanks to deep brain stimulation, that was no longer necessary, but he became so manic that he had to be admitted to a psychiatric clinic. With the power on, he absolutely did not want to go there; he felt great. Should his doctor ask him permission for admission in a home with the power on? Or with the power off?

Fortunately, with the power on, Bart is as afraid of his violent temper as Ria. In therapy, the couple learns to cope with it.

Many marriages fail for less. They have been close to an end, Ria and Bart, in the first years after the operation. But Ria firmly believes you can't tell someone you love: deal with it on your own, I'm off.

After DBS surgery, it can take months to find the ideal setting of the neurostimulator. With as few symptoms as possible and as few side effects as possible. The doctor can choose which contact points on the electrode are on or off – with the most modern electrodes there are sometimes as many as 64. In addition, he can vary the strength of the current and the duration and frequency of the pulses. This allows him to determine the size of the area that is being stimulated. In Bart's case, the current is eventually set to 2 milliamps. Lower is not possible, the maximum is 7 milliamps.

### **Controllable via wifi**

Rapid technological advances are making the stimulation increasingly precise, easier to control and less invasive. Not only are there electrodes with dozens of contact points. The latest experimental stimulators are so small that doctors can place them in the skull bone. They can be controlled via wifi, the batteries are rechargeable and their lifespan is increasing.

A brand new development is the so-called *closed-loop* stimulation, in which the stimulator only delivers power at the moment it is needed. In epilepsy, for example, that moment is when an epileptic attack starts. With this technique, in addition to the electrodes that deliver current, there is also an electrode that registers changes in the brain that indicate that the seizure is imminent. "The device determines what the stimulation should look like based on fluctuations in certain neurons," says psychiatrist Damiaan Denys at Amsterdam UMC. "That technique is emerging rapidly now. It would be a huge breakthrough."

This form of deep brain stimulation was approved in the US in 2013 for the treatment of epilepsy and has now been used in 2,000 people. In recent years, experimental studies have also been conducted with it in psychiatric disorders. In October, American researchers used the new technique to relieve a woman of her [severe untreatable depression](#).

Denys hopes to use closed-loop stimulation in people with obsessive-compulsive disorder (OCD) one day. "It saves power, so batteries can last much longer. Now we have to replace them every fifteen years. In addition, we learn an awful lot with this technique about what happens in the brains of people with these disorders." Together with his colleagues, Denys investigated which neuronal activity foreshadows an anxiety attack and the compulsive behavior that follows. Eleven of his compulsive patients, who had previously received a brain

electrode, switched off the power for his research. They performed the action that provoked their obsessions, such as touching the toilet floor with bare hands. This then triggered their compulsions: washing their hands.

Denys had hoped to pinpoint a particular brain region from which the obsessions of people with OCD began. “The idea was: you have one particular pattern for compulsive disorder, another pattern for depression, another for schizophrenia.” But in reality this appeared to be much more complex. To his surprise, there turned out to be a different area or neurobiological signal in each of the patients. Closed-loop neurostimulation in psychiatric disorders will likely need to be tailored to the biology of each individual patient.

At the same time, Denys suspects that there is one common denominator. One underlying effect of the stimulation that provides recovery in all psychiatric conditions.

*His hypothesis: deep brain stimulation works in all psychiatric disorders  
because it improves a fundamental circuit of self-confidence*

### **Circuit of confidence**

Sixteen years ago, he thought the general underlying mechanism was addiction. An addiction to the actions or the behavior in OCD, or for example in anorexia. “So we stimulated the *nucleus accumbens*, a brain region that plays a role in addiction and reward. But then, we asked patients what had changed.”

“Almost all patients say: I have more self-confidence. A sense of control returns through the stimulation, the confidence that things will be okay. Only later do the compulsions disappear,” says Denys. His hypothesis is that deep brain stimulation works in all psychiatric conditions because it improves a fundamental circuit of trust and self-confidence. That would mean that you could stimulate the same area in any psychiatric condition. Denys: “By stimulating the nucleus accumbens, we see effects in anorexia nervosa, depression, OCD and addiction. From a brain perspective, there are no differences between those four disorders. But that is such a paradigm shift. That is very complicated to accept for the conservative scientific world.”

In this line of thinking, closed-loop brain stimulation registers where in the brain of an individual patient an abnormal brain signal arises at the moment the complaint starts. That is different for everyone. And then you stimulate every patient in the same place to increase self-confidence.

### **Bumps on the head**

That is still in the far future, says Denys. “Plus, closed-loop stimulation imposes ethical issues. It is a complete violation of your free will. A device in your brain that independently changes your behavior. Those are cyborg-like concepts.”

Besides such ethical points, there are also safety issues. The wireless control of the modern stimulators harbors a potential danger: *brain-jacking*. This is what international researchers point out in a [review article in 2021](#). In theory, malicious people can hack the device and change the settings. We should talk about this before accidents happen, they argue.

### *He wants to tell other people his story*

Bart has been living with the neurostimulator for eight years, he is 76 years old now. He wrote a small book, *Operation Anxiety - How deep brain stimulation saved me*. In December 2021, he self-published it. It is on the kitchen table in his house in Soest, where Ria has also joined the conversation. He wants to tell his story to other people struggling with an obsessive-compulsive disorder. For a long time, Ria didn't want to read it, and neither did his children. She doesn't want to stir up all those emotions from the life that lies behind them. She was okay with him writing it, though. If this little book would only prevent *one* patient from taking their own life, that would be marvelous, she says.

Two bumps on top of his balding head reveal the place where Bart's electrodes were inserted. The cord and the neurostimulator are not visible. "Even if it would leave me with fifty of those bumps on my head, I would still have had surgery," he says. Every three days he charges his stimulator for a few hours in the morning, while sitting at his computer. In his study he demonstrates the charger, a device that looks like a walkie-talkie. The adapter, connecting the charger to the mains with a thick black cord, resembles that of a laptop. Bart unplugs the charger and connects it to an antenna, a round flat disc that he places on the skin above his neurostimulator. The stimulator in his body now charges via induction. The blinking battery icon on the charger is slowly filling up.

Still, every day he relishes the freedom, the sensation of being free from that extremely terrible fear. He bought something he always dreamed of, a vintage car. And not just any car: a Mercedes 380 SL convertible. The couple tours the neighborhood, through Germany and Belgium. Bart no longer makes lists. Not even a packing list for the upcoming trip to Spain. "Ria makes those," he says. He can't even imagine what it felt like anymore. It's as if he's talking about someone else.

Until one day, things do seem to go wrong. Ria notices that Bart is nagging about the electricity of their apartment in Amstelveen. It must be checked. He goes on and on about it. Bart wants to go to the apartment at all costs. Now. Terror strikes them both. Does it no longer work? Has the new Bart disappeared?

But no, he's still there. He forgot to charge.

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*Talking about suicide can be done at the national helpline 113 Suicide Prevention. Phone 0800-0113 or [www.113.nl](http://www.113.nl)*

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