



## Wendy – Chronic pain

Wendy is a gregarious, active single mother, who as well as having a good laugh, loves to kickbox and clay target shoot and is a cub scout leader. She is also a chronic pain survivor.

“At times I thought I was going to die, things were getting that bad. My life was on pause for so long with pain, that when it came off pause I thought: I don’t want to go to my deathbed saying ‘I wish I had done, I wish I had done . . .’. Now when I go to my deathbed, people are going to say ‘you know what, she did everything.’ And thanks to the neurostimulator, I have.”

It’s hard to believe that just over a year ago, Wendy, at breaking point from five years of agony, lost custody of her beloved son Dylan and came close to ending her life.

Wendy’s experience with chronic pain has taken her lower than she ever could have imagined, but with the help of a neurostimulator, she has managed to totally turn her life around.

“I still have medical problems, but I’m alive. I have my son. I have a fantastic life now. I’ve never been this busy and active. It’s just such a turning point for me.”

Wendy’s experience with chronic pain began five years ago when what should have been a simple operation to fix a hiatus hernia and reflux went drastically wrong, leading to her oesophagus being so tightly restricted that no food or liquid could pass through to her stomach. She had corrective surgery to repair the damage but by then it was too late, she had been left with permanent oesophageal achalasia, a failure of the muscle to relax completely. It would go into almost constant spasm whenever she ate or drank; it was excruciating.

“I said to some people ‘it’s just like that movie Alien where the alien comes out of the chest,’ it would be that bad. The pain had gone from just being in the sternum, to radiating and pulling out from the sternum going through my back, up my arm, up my neck and into my jaw.

“My whole oesophagus is so uncoordinated it is useless. When it tries to push things along it just goes into spasms. I was getting myself to hospital every three days, sometimes less, for pain relief. But I couldn’t go without eating or drinking – what was I going to do? I even stopped eating to avoid the pain, leading people to believe I had anorexia.”

Unfortunately for Wendy, because her condition is rare, she also found trouble convincing doctors about the extent of her pain. They had never heard of the condition, and some believed it wasn’t real.

“I have been through the whole range: I’m a malingerer, I’m a Munchausen’s patient, I’m a drug addict, I need a psych referral.

“It was so frustrating. You explain ‘my chest is getting ripped apart; I have pain going up my neck, my jaw. Do something for me!’ and they try to give you an antipsychotic. I’d ask for a benzodiazepine and morphine, and they’d say ‘how come you know about medications?’ One doctor actually said it straight out: ‘you’re a drug addict’. I ended up having to carry a letter from my gastroenterologist with me.”

Wendy was not quite 30 years old, struggling to hold down three jobs (one of which eventually left her off the roster), studying for a nursing qualification and trying to be a good mum to then five-year-old Dylan. The pain was weighing her down.

“It really impacted on my life. I couldn’t concentrate on my studies, I couldn’t concentrate on work. I would make stupid mistakes. I couldn’t sleep, I couldn’t eat. I kept on asking ‘why me, why me, why me?’

"I had no patience with my son. He's got Attention Deficit Hyperactivity Disorder and a few other learning difficulties and I had no patience. Constant pain leaves you so angry, tired and sometimes irrational.

"Poor Dylan would get fobbed off to here and there because I spent so much time in hospital. He was getting so upset. He thought 'mum's going to hospital, she's going to die.' It damaged him."

The pain continued to worsen and Wendy was admitted to hospital for seven weeks. Her prognosis was dire.

"They thought I was dying. Mum rang around the family and said 'I don't think she's going to make it, everything is shutting down'. Even the doctor said 'I don't think she's going to leave here.'

"I said to the doctor one day – 'why don't you just let me die? You wouldn't put an animal through all of this?' I had no quality of life.

"I actually had to learn to walk again because malnutrition had set in and I was stuck in bed for five weeks. I lost all the muscle tone and couldn't hold myself up. It was tough but I did it. The first lap around the ward on my own without stopping got me a standing ovation from another ward's nursing staff."

Eventually Wendy's gastroenterologist put her on a regime of morphine injections and diazepam.

"I kept a pain diary from that stage. I look at it now and if I add up all the morphine I was taking, it was about 300 mg a day, plus all the diazepam. Then I'd still go to the hospital, it wasn't enough.

"The drugs helped to the extent that I still had the pain, but just didn't care anymore. That was bad in itself. It's alright in a hospital environment, but when you're at home trying to function, and live and care for someone, it's not ok.

"I was becoming an absolute whinging cow of a person to be around because of constant pain. Nobody wanted to be around me because all I did was whinge and complain and act weird – but to me, I was acting normal."

A year later, Wendy's gastroenterologist suggested the neurostimulator. Wendy refused point blank, fearing more surgery and the fact that the device would be placed on her spinal cord. She continued with the drug therapy until one day she reached a point lower than she had ever thought possible.

"I was in so much pain – I felt so sick. Dylan had been away at camp. He'd come home and eaten three bowls of sugary cereal, and he was just jumping on me. I thought 'I can't deal with this anymore'.

"I rang the suicide line and I said 'Help me. I'm going to end his life and I'm going to end mine, then we would both be at peace'."

Wendy was assigned a case worker with the Department of Human Services who assumed she was a drug addict and abusive parent, unable to look out for Dylan's welfare. Realising that she had to find help in order to keep her son, she tried various pain clinics, but was faced with a six-month wait. Then her psychologist told her of a rehabilitation physician specialising in pain. He made an immediate appointment for her, and they went out of their way to accommodate Wendy.

“When I first met Dr Rawicki I instantly trusted him. He said ‘you’ve got two options left: the neurostimulator or we stick a needle in your stomach and hope to God it works, but I don’t think it will.’

After much deliberation, Wendy agreed to trial the neurostimulator.

“The trial was on 05/05/05. I thought ‘that’s an omen – but is it good or bad?’ I was terrified.

“We did the trial, and instantly I had about a 95 percent decrease in pain. I thought, ‘this is all psychosomatic. It’s just because you want to believe it works’. But it did actually work.

“During my stay in hospital I ate like mad, knowing that the pain was covered.”

An infection meant that Wendy had to have the trial implant removed after four days. She then faced a seven week wait for the permanent implant. The wait was unbearable.

“I ended up doing something really dumb without thinking of the consequences. Two weeks afterwards I just had too much pain one night. I thought ‘I just want the pain to stop’. I didn’t want to die; just the pain to stop for a while.

“I took 250 mg of morphine. I ended up in hospital and was treated like a dog by nursing staff for overdosing. That’s when they decided ‘you’re not a fit parent’ and I lost custody of Dylan.

“I got out of hospital and rang my specialist. I told him ‘I’ve lost custody of my son, I don’t think I can do this’. He said ‘I’ll do you next week.’”

Wendy had her permanent implant and hasn’t looked back.

“My doctor saw me four weeks later and said I looked like a different person. And I was.

“My whole outlook has improved now that I’m not on pain medication and have my pain controlled enough that I can deal with it. My whole psyche has changed. I don’t whinge and complain anymore. I keep smiling and laughing. People ask ‘why do you keep on smiling and laughing when so much has happened to you?’ I have now got so much to be happy about.

“We got rid of the child protection worker after three months. The ombudsman sent her packing and I got Dylan back really quickly. Having the implant was the best decision I have ever made.

“My life before was nothing; stay in bed, cry, sleep, fight with my son. The neurostimulator gave me back my life. Dylan and I have a fantastic relationship and are best friends. We’ve both grown so much. I’ve almost finished my diploma of nursing and have taken on so many new activities. Everything and anything I’ve always wanted to do, I’m doing. All with a smile on my face.”