

# Outside the Pill Pack

## Perspectives on Surgical Treatment Options in Parkinson's

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Deep Brain Stimulation (DBS) and Duodopa have been alternative treatment options for Parkinson disease for many years. However, with both being surgical in nature, many feel unsure, anxious, or even afraid of looking into these as a way to treat their Parkinson's. Deciding to move forward with a new/different treatment can be both anxiety-inducing and stressful. I interviewed two clients who have each gone through one of the procedures. I spoke with Kathy Franz about her experience with DBS and Stephen Brown about his journey with Duodopa. Their personal stories may offer valuable insights and help you make a more informed decision. Quotes have been modified for brevity.

### A Perspective on Deep Brain Stimulation

**Suwan Kim (SK):** Can you share your journey with Parkinson's including how you decided on Deep Brain Stimulation (DBS) as a treatment and what the overall process was like?



**Kathy Franz (KF):** I got Parkinson's when I was 48 it took 3 years to get a confirmed diagnosis. I sailed along pretty good for quite a long time, and then my Parkinson's started to get a lot worse, I was referred to the Movement Disorder Program (MDP). That's where my DBS journey began.

The process was lengthy. I had to undergo assessments to ensure I was a good candidate for DBS. Then came my actual surgery date, The surgery itself was a challenging day. You are awake during it, which was tough as I was so focused on everything that was happening around me. Thankfully, the nurse was there to talk me through it, and I was able to listen to music throughout. They turned on the device a

few weeks after and since then, my life has changed dramatically.

**SK:** How did DBS impact your quality of life, and what were the most significant benefits or challenges you encountered following the procedure?

**KF:** After DBS I have been able to significantly reduce my medication to about a fifth of what I was taking. I've also reduced other medications that I was using to manage medication side effects. The most significant change is that I'm finally STILL. I'm not moving all the time anymore, and I can do things I love again, like baking and reading. It might not sound like much, but I couldn't read books before because the pages would shake too much. Now, I can read without shaking or moving. My balance has also improved enough for me to ride my bike again. After getting DBS, I've noticed some drooling and speech changes, which could be from the surgery or just Parkinson's. But overall, the positives far outweigh any negatives.

**SK:** What were your main concerns and expectations before undergoing DBS, and what is the most unexpected thing to have come out of it?

**KF:** The thing that I wanted the most was to be still.

Before DBS, I was constantly moving, less than 20% of the day I was still. Now, I've achieved that stillness.

What surprised me the most was the reduction in medication. I expected to cut back a little, but going to a fifth of what I was taking was unexpected. There were also some things I didn't know after the surgery, like needing to turn off the device for certain medical procedures, but that's manageable. It's awesome because when I shut it off, you can see an immediate difference.

**SK:** Looking back, is there anything you wish you had known before starting the DBS process, and what advice would you give to someone considering this treatment?

**KF:** I had heard about DBS for a while and kept saying I wasn't going to do it. In hindsight, I could have been more proactive and done it sooner, but I don't think it would have made a huge difference. I just can't get over how much of a difference it has made. I love my new, still self.

If you're offered the surgery, I'd say go for it. You can ask the doctors too. I was told about it many times, but what changed my mind was hearing about someone else's success with it. Also, when I asked if we could increase my Prolopa, my doctor said, "No, we can't increase it anymore. You are too dyskinetic." That's when I decided, "Okay, fine, I'll have the surgery." Someone even said to me, "You don't have Parkinson's anymore." But I tell them, "No, I still have Parkinson's. It didn't take it away, but my symptoms are so much better."

## A Perspective on Duodopa

**Suwan Kim (SK):** Can you describe your journey with Parkinson's and how you decided to start Duodopa as a treatment option?

**Stephen Brown (SB):** My Parkinson's was first diagnosed in 2014. At that time, medications were manageable, but as time moved on, I had to take more, waking up every 1.5 to 2 hours at night. I struggled with medication absorption and my diet, which led to me losing about 60 lbs. I tried various medications before being considered for Duodopa, but none worked. So, when Duodopa was suggested, I accepted.

**SK:** What were your expectations or concerns starting the Duodopa process?

**SB:** I hoped the positives would outweigh the negatives, and they definitely have with Duodopa

for me. I was looking for some relief for the handful of pills I was taking every single day and wanted to improve my off periods. Duodopa has helped significantly with that.

I would hate to scare anybody off, but they've got to do an operation in your stomach. For me, the first operation didn't work, but the second one worked fine. I worried about having complications with the stoma, but everything turned out positively.

**SK:** What is it like to manage the Duodopa device and how does it compare to how you were taking Parkinson's medications before? Are there specific benefits or challenges you've experienced with Duodopa?

**SB:** In terms of managing the device, the good thing is the Duodopa pump is user-friendly, so you're not going to screw up much if you hit something wrong, and the dose is calibrated by the nurse. The interesting thing is that the cassettes must be refrigerated and stored between 2°C—8°C.

I use two different cassettes, one during the day and one at night, so I've had to adjust to sleeping on my back, which was new for me. This also makes daily cleaning of the lines interesting, but the Duodopa support team provides everything needed to facilitate this. They give you ways to wear it, like vests or packs. I use the vest, and I wear it all the time, so that simplifies dressing.

Managing the device comes with its challenges, like dealing with the tubing. The tubing is long to allow movement, but it can get tricky, especially when dressing. The equipment is durable, and I've had no issues with it wearing out after a year and a half. The only mental challenge is ensuring that the tubing doesn't twist and block the flow. But a positive is that if you're having problems, the nurse will help you navigate any challenges.

**SK:** How has Duodopa impacted your quality of life, and do you have any advice for anyone considering this treatment option?

**SB:** Duodopa has definitely improved my situation by reducing the extremes of my Parkinson's symptoms and limiting the swings. However, even with Duodopa I still have a problem with nutrition and have to watch my diet, as certain proteins, creams, and red meats can be problematic. But I don't regret switching from taking pills. It's far better for me.

Overall, the experience has been positive. So, the bottom line is, if you're in a situation where you need there's nothing to consider. You get it.