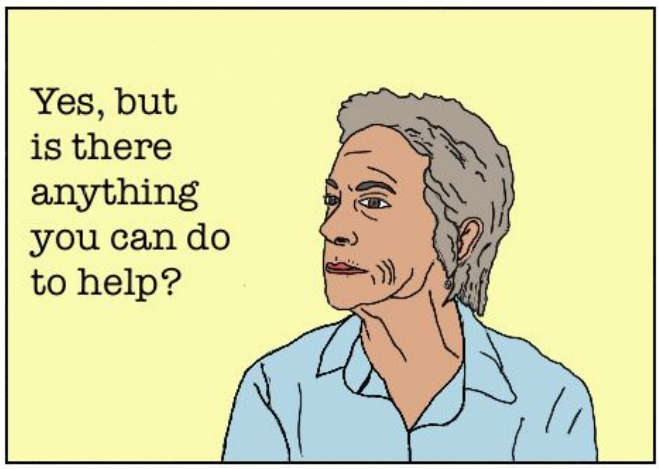
Parkinson's disease:

even when things go wrong, there is hope

No, it's not going well. My pills have stopped working. In the morning, it takes me forever to start my day. I also have dyskinesias* that prevent me from doing things around the house. I'm discouraged.

*involuntary movements

Unfortunately, I think we've reached the limit of what standard treatments can achieve in terms of symptom relief.

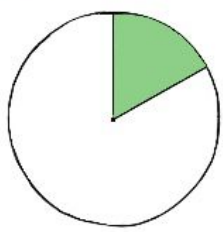


Advanced treatment may be considered when a person meets one of the following **criteria:**

Taking **levodopa/carbidopa**

5 Times/day or more

At least **2h** **OFF** time/day



At least **1 h/day** of dyskinesia

It is important to remember that these treatments **do not cure** the disease, but they do **improve symptom control**.

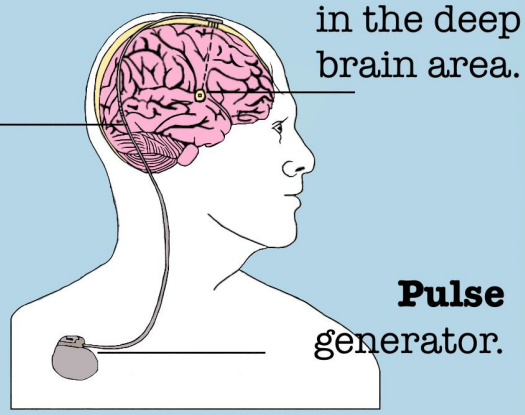
What are the advanced treatments?

There are **two** main **classes** of advanced treatments:

Deep brain stimulation (DBS)

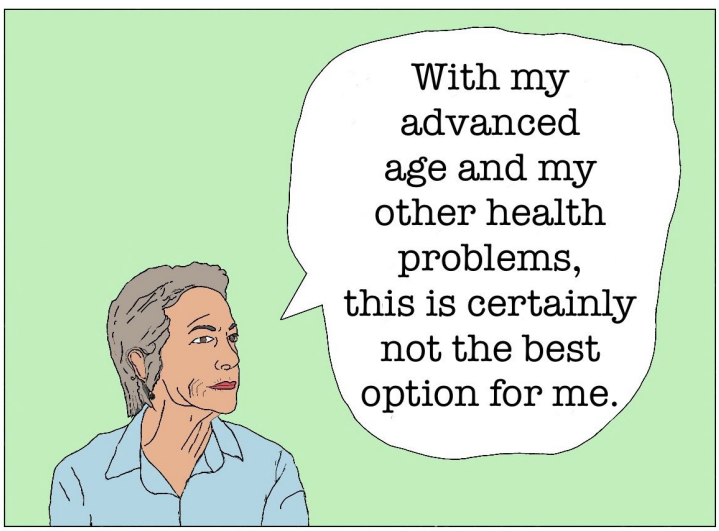
Drugs delivered continuously through a pump

D.B.S. involves sending **electrical impulses,** via electrodes, to a specific area of the brain. The **electrodes** are connected to a **neurostimulator** under the skin.

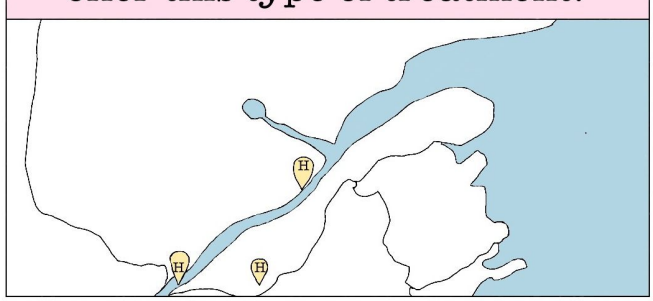


People who usually respond well to D.B.S.

A) are generally under **70 years-old;**
B) have had a disease with **typical symptoms** for at least **5 years;**
C) **respond well** to levodopa/carbidopa tablets but have significant **motor fluctuations** or **refractory tremor;**
D) can **tolerate** this type of **surgery;**
E) **do not have**: significant cognitive problems or changes, moderate to severe depressive symptoms depression symptoms, significant speech problems, severe postural problems or frequent falls.

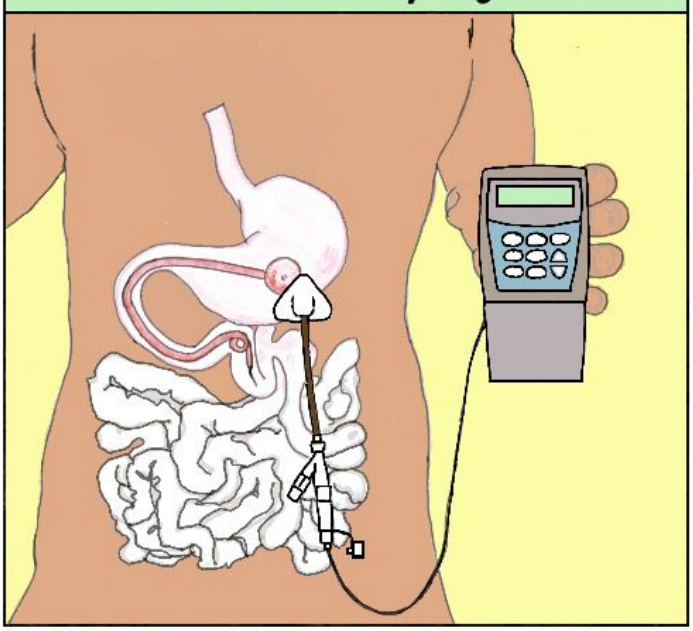


You're right. And if you had been eligible, I would have had to refer you to another neurologist because only certain hospitals offer this type of treatment.

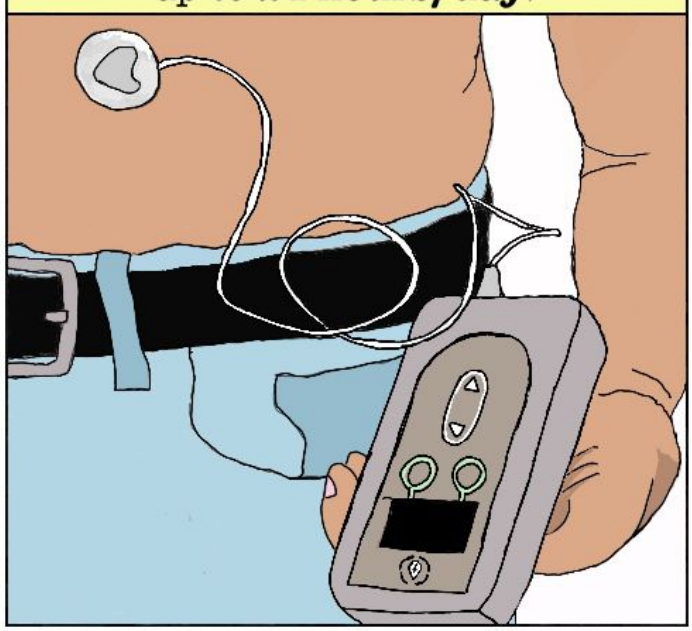


Continuous pump therapy may be an option for you.
This type of treatment can overcome the problems associated with irregular intestinal absorption of levodopa taken in pill form, and results in more stable concentrations in the blood and brain.
Two types are available.

The first is **levodopa/carbidopa** gel administered **into the intestine** via a tube connected to the pump. The drug is administered continuously, generally for **16 hours/day**.



The second is **foslevodopa/ foscarbidopa** administered **under the skin** of the abdomen via a tube connected to the pump. The drug is administered continuously for up to **24 hours/day**.



The advantages of these treatments are:

- **Better control** of motor fluctuations
- Possible improvement in **quality of life** and **independence**
- **Fewer pills** to take each day
- Can be used during evaluation for D.B.S.
- **Reversible:** return to pill therapy possible (if pump problem or by choice)

The disadvantages of these treatments are :

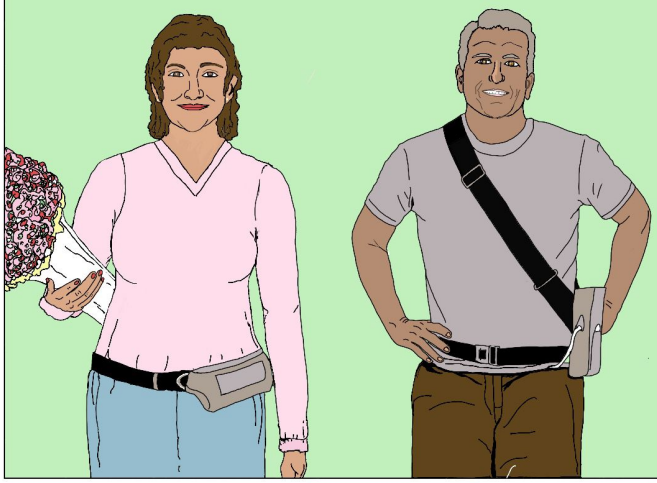
- The **same side effects** as with levodopa/carbidopa pills
- Other disadvantages are related to the **pump's mode of administration**

What you need to know...

1. A **period of adjustment** is required to master the pump's operation and get used to wearing it. You need to learn how to handle the medication and the pump;

2. A **delay** of several weeks should be considered before reaching an **optimal dosage** of the drug;

3. There is a **risk of infection** at the device insertion site;



4. There is a **risk of displacement** of the delivery device, which could lead to poorer symptom control;

5. After a certain period of time, it is necessary to **change the delivery device** to ensure that it is working properly and efficiently;

6. The pump can be **removed** for **hygienic care** and **bathing**.

Hum...all this deserves reflection....
Would you have any documents on the subject so that I can discuss it with my husband?

Yes. I can also put you in touch with people who receive these treatments: you could ask them your questions.

A few tips

1. Check if these treatments are **offered** in your **area;**

2. Ask to be **referred** to another neurologist if necessary;

3. Have **realistic expectations** about the advanced treatments;

4. Invite **someone close** to you to **support** you in your search for information and décision-making.

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References:

1. Developing consensus among movement disorder specialists on clinical indicators for identification and management of advanced Parkinson's disease: a multi-country Delphi-panel approach, 2018
2. Review: Deep brain stimulation in Parkinson's disease, 2009
3. Product Monograph with Patient Information-levodopa/carbidopa intestinal gel, 2022
4. Product Monograph with Patient Information-foslevodopa/foscarbidopa solution, 2023

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