

"YOU HAVE PARKINSON'S DISEASE"

WHAT WE KNOW NOW

By

We Are In The Same Boat

First and foremost, Parkinson's Disease is different for everyone so what works for one may not work for another.

Radical Acceptance - it is what it is and fully acknowledging the diagnosis sooner rather than later could be helpful in slowing the progression

Know that it is a progressive disease but chances are you can slow it down.

When you have PD, staying healthy is like a full time job. It takes a lot of time and energy to go to all the doctor appointments and exercise often but you have to do it.

Medications - Your drugs are going to be your best friend.
You will have to take meds, like it or not. Take your meds as instructed.

Exercise - varied exercise could be equally as important as your meds.
There is more and more evidence that hard exercise slows the progress. Find something: boxing, dance, bicycle. Join a class. It could be the best thing you do in slowing the progress and might even help lower the dosage of drugs. Vary your exercise...high intensity for sure but mix in some breathing exercises, meditation, stretching, yoga or tai chi. Helps with balance in the body and mind. It helps reduce stress which is super important.

DBS - Deep Brain Stimulation - learn about it as it could be in your future.
IT can be life changing for some but as with all things that have to do with your body, it depends on your body and symptoms and how it responds.

Neuroplasticity: The brain's ability to reorganize itself by forming new neural connection.
An emerging body of evidence suggests exercise triggers several plasticity related events in the human PD brain. This is one to research.

Insomnia - often an issue.
Sleep is crucial. Sleep will help decrease stress, increase energy and help overall well being.

Nutrition - Eat healthier than you have ever eaten
It may decrease inflammation and give you more energy which in turn may help PD symptoms. Perhaps keeping sugar and dairy to a minimum and gluten free (gluten can cause inflammation even if you don't have celiac disease). It won't hurt to try and see if it works). Also maybe keep caffeine to a minimum although some say it helps the brain. It makes some jittery.
Eat lots and lots of fruits and veggies which helps also with constipation, a common PD issue.
Drink water all day long.

Take care of your whole body
Don't ignore other aspects of your health. Something as simple as a bladder infection can speed up the progression of a neurological disease. PD patients have a higher rate of

melanoma. Be aware and see your dermatologist at least annually for a check up. It's all one body...take care of all of it.'

Be sure your neurologist is a movement disorder specialist.

Understand that you are in a partnership with your doc and remember that you have the most to gain so you have to put the most into the relationship. Take care of your eating, sleeping, and exercising.

Research , research, research...with caution. Consider the claims and the medical evidence. That being said, never stop learning. Don't spend a lot of time researching individual blogs, websites, etc. Start with the medical schools, research organizations, organizations whose only concern is PD.

There are many suspicious claims of successful treatments. There are a lot of sites that can be misleading but there is also a lot of good information and inspiration out there.

If there's one thing to know about Parkinson's Disease. It's this: there is a lot we don't know. Cure - still far in the future

There is more hope for meds that will slow the progression or stop it

You can't ask too many questions.

Be open minded.

Do your research and consider alternative treatments. Although we are not recommending or recommending medical marijuana, massage, acupuncture, acupressure may help some people.

Go to local symposiums.

Join a support group, even if you don't want to.

Talk with other PD patients. They are a wealth of knowledge and can learn from you too. You might be the inspiration they need.

Recognize that your disease didn't just happen to you. It also happened to your spouse, kids, friends, family. Give everyone time to come to grips with it and then let them know that you are still you. Form a team ASAP. You and your neurologist are the leaders of family, caregiver (s), fitness trainers, physical therapists, support group, etc

Keep a PD journal of meds and symptoms.

It might be helpful to use a number scale to track the changes in your symptoms. It will help your doctor manage treatment.

Accept your limitations

If you fall and hurt yourself it causes problems for the whole team.

Things like falls and accidents can be devastating. Accept help and make lifestyle changes (i.e. one story home, not driving, hiring a caregiver) when needed.

Brain games - help maintain the cognitive skills

Try some brain exercises to rework neural pathways and keep the brain healthy. Try eating, brushing your teeth or coloring with your non-dominant hand. Play Wii games like tennis with your non-dominant hand. Try crosswords, Sudoku, puzzles, scrabble or reading.

Socialize - absolutely critical - It is good for the mind, body and soul.

PD is a life sentence...but it is not a death sentence.

Your future may look different than you had planned but you still have a future. Make the quality of the journey the best it can be and be thankful for every day.

Pray, meditate, breathing exercises - all good

Tip - Email your doc the day before your appointment - list your agenda.

Time saver for everybody.