

The ripple effect of the diagnosis of Parkinson's

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The shock

A diagnosis of Parkinson's is a milestone...

- **For the person who receives the Dx, but also for spouses, children, friends and colleagues**
- **The age of the person at the time of Dx and the relationships with close ones will tint their reactions**



For many of you...

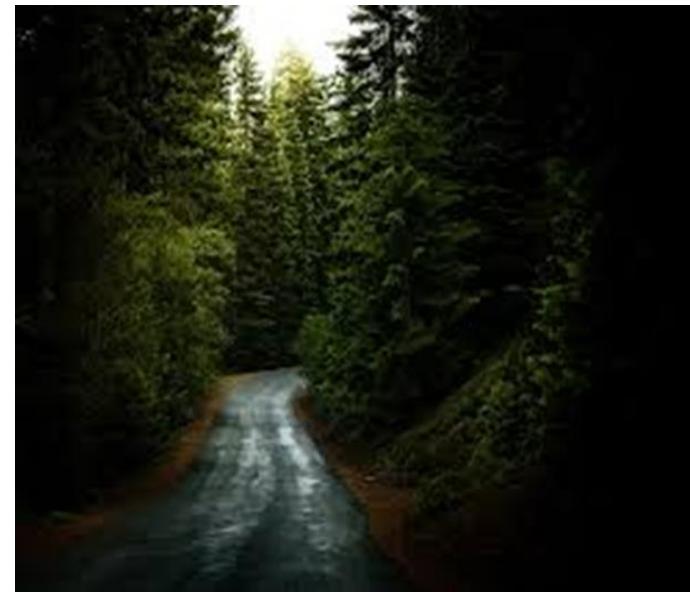
- Several difficulties, many doctor's appointments
- Lots of worries
- Finally, a diagnosis
- The shock
- Now we know what to blame



...but so many questions arise...

Emotions and questions

- Emotions on a roller coaster
- Sorrow, sadness, hurt
- Fear, denial
- Anger
- What is Parkinson's disease ?
- What will happen ?
- Should I talk about it ?
- Should I inform my children?



Unfortunately, there is no road-map
for this uncharted journey

Challenges

- At the beginning, all appears unachievable, as an overwhelming challenge
- Approach the new reality slowly
- Seek information
- Make allies: spouse, family, friends, health professionals
- Support and exercise groups
- Beware of possible depression



If you ever feel depressed, don't wait,
talk to your Doctor: depression
can and must be treated

Allow yourself time

- Allow yourself and all close ones time to take in the news, to learn and to get familiar with PD, to understand what it may mean for each one, eventually
- To avoid unsettling, don't rush anyone
- Thus the future will be tamed slowly, and life will find again its true meaning



« A family affair »

- It is often said that Parkinson's disease is a family affair because it may eventually affect most in the family
- Among those impacted are children of all ages, from young children to teenagers, to young and older adults, depending
- And sometimes, even one's own parents



Why inform children

- Children are observant. If kept ignorant, they may fear something worse
 - Inform children with honesty
 - Demonstrate a positive and optimistic attitude that they will adopt
 - Children need parents to rely on for information, and reassurance
- Regardless of your child's age, your focus should be on reassurance.



What and how to say

- Share the diagnosis in simple and appropriate terms for the child's age and maturity level
- Let children know that PD is not contagious, nor shameful
- Reassure them that it is not fatal
- Talk about research that is made all over the world into new treatments
- You can also stress that exercise is an important component of your treatment that they can do together with you !

Why inform friends, colleagues and neighbours

- To avoid unease and discomfort
- Communication is the key to understanding
- Chosen and gradual information
- Openness to answer questions
- One's positive attitude will be reflected by others
- Support
- Parkinson's awareness



Help close ones to help

- Family and friends often don't know how, or feel incompetent at helping
- Don't deprive them of the pleasure to accompany you in your journey. Accept their help !
- Family and friends of the PWPD and their caregivers depend on an open, honest, respectful and mutual trust
- Let them know how much their support, empathy, and « good ear » are important to you



With or without PD, challenges for all

The difference in taking up challenges is:

- Attitude
- Information seeking
- Ability (and sometimes the will) to look ahead, to face the challenges
- Communication
- Network
- Spirituality



Information

- **Information is the key to the means for living well with Parkinson's**
- **Will you want to use the key ?
and the means ...?**



Communication

Good communication is essential to one's successful and healthy growth, and to maintain personal, couple and family stability

« ..a relationship into which respect, tenderness and affection can be expressed freely and warmly. »

Parkinson Canada



Communication = Sharing

- **Sharing joys, fears, needs and limits, emotions, gratitude and love, leads to complicity that is essential to quality of life**
- **It is as important to share joy and good times as it is to share fears and moments of distress**



Communication is also

Intimacy, complicity, happiness and the comforting pleasure of being together

A fulfilling relationship through a chronic disease is one of the most important elements of quality of life



Complicity and togetherness

- Sing oldies to exercise the voice
- Dance to improve balance
- Whatever works for you, be adaptable to the moment and the day, and enjoy yourselves !



Don't let Parkinson's take over

all the space in your lives

- Explore hobbies and develop passions
- Have projects
- Dance and sing
- Keep informed
- « GET INVOLVED »



More than Parkinson's

- May your relationship be more than Parkinson's !
- Each of you is more than PD; you had a life before it
- Nourish each other and enjoy interests that fueled your relationship before the disease

“Stay Compassionate. Laugh Together. Compassion and humor will carry the day”

*Elaine Casavant, R.N., member, PDF People
with Parkinson's Advisory Council,
care partner, Lansing, MI.*



Spirituality

- Feed your souls
- The « ways » are different for each one
- Faiths and beliefs are personal
- Meditation, reflexion, prayer
- Beauty and magic of nature

They all bring

Peace

Balance

and Serenity



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Helpful hints

- Plan your days ahead
- Avoid stressful deadlines
- Make realistic objectives
- Review your expectations, don't try to do everything “like before”

Eventually, if choices have to be made, choose what brings you the most pleasure !



...what if...

Before we end, I wish to suggest one other question to ask yourselves, one last thing to reflect on, every now and then...

One that could make a difference at times...

**...WHAT IF THE OTHER
PERSON WAS ME...?**





**Thank you for your
warm welcome and for
your attention**

Take care !

Ginette Mayrand

