



PD is in the house: Impact on children/teens/young adults

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Parkinson's Disease is a family affair

"How will
PD affect
my kids?"
*Person with
PD*



"I don't
want this
to
change
their
lives"
*Care
partner*



Clinical Observations



Want more information rather than less

Want more information early on

Want to know what to expect



Common emotions...

"It's ok Dad.
You don't
have to
come to my
soccer
game."
age 10

"We used
to play
baseball
together."
age 9

"Am I
going to
get PD
too?"
age 13

"Sometimes
I don't want
to bring
friends
home if
Mom is off."
age 11

Positive Impacts

Maturity Strong
Empathy Coping
Independence Growth
Responsible
Compassion
Accountable
Valued
skills
Pride
Confidence

“The one thing I know is that I would not be where I am today if it wasn't for all the stuff that I went through and continue to go through, probably benefitting me for the rest of my life” age 16

“Being a part of meetings and appointments when I was younger made me feel important and like I could help” age 23

How to best support children/teens and young adults

Share the diagnosis


- the process
- provide information
- what might happen
- practice

"I am not sure how and what to tell my kids."

Person with PD

"I want to protect them"

Care Partner



How to best support the children/teens and young adults

"It's
challenging
but we are
all living with
it"
age 17

**Check in with
yourself**

Connect with others

"It's not the
end of the
world. We
are all
coping"
age 15

How to best support children/teens and young adults

Communicate

"I think it is much better for the kids to know all the possibilities even if it worries them for a period of time."

age 16

"As my mom's Parkinson's progressed my access to information about the disease did a great deal for calming my concerns."

age 23

Parenting with Parkinson's Disease

“Sometimes I slip into solo parenting mode”

Partner of person with PD

“I am not sure if my teenage daughter's angry outbursts are because of me and the PD or because she is a teenager”

Person with PD

“I try not to let on to the kids that I am scared sometimes”

Person with PD

Ideas to promote family wellness

“My mom has made it as normal as possible”
age 14

“We can’t do things the way we used to. We are finding new ways to spend time together”
age 15

“I am not sure but I think this thing called PD has helped our family to help each other”
care partner

“I think we are working hard at living life well with PD but I still worry about the kids, my health ,the future”
Parent with PD



Books

- "Radical Acceptance: Awakening the love that heals fear and shame within us" *by Tara Brach*
- "Etiquette of Illness" *by Susan Halpern* (chapter specifically for chronic illness and children)
- "How to help children through a Parent's serious illness" *by Kathleen McCue*
- "Raising an Emotionally Healthy Child When a Parent is Sick" *by Paula Rauch and Anna Muriel*
- "Parkinson's Disease and Parenting: A practical guide to family life with Parkinson's disease" *By Elaine Book and illustrations by Pascal Girard.*
Available upon request elaine.book@vch.ca



Online articles

- <https://www.kars4kids.org/blog/parenting-chronically-ill-spouse/>
- <http://dailymom.com/nurture/raising-a-family-with-a-spouse-suffering-from-a-chronic-disease/>
- http://www.igliving.com/magazine/articles/IGL_2012-06_AR_The-Impact-of-Chronic-Illness-on-the-Family.pdf

Online resources

- www.designingacure.com Articles specific to parenting can be found under the tab “Living Well” and then under the tab “Relationships”.
- “Parenting and Parkinson’s” Webinar available on line at <http://parkinson.org/Living-with-Parkinsons/Resources-and-Support/PD-ExpertBriefings-Webinars/Archives>
- Parenting and Parkinson’s tips www.parkinson.org/FactSheet



Thank you!