

Parkinson's Disease and Parenting

A practical guide
to family life with Parkinson's Disease



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We hope this booklet provides you, parents with Parkinson's Disease (PD) and your significant others, with some guidance and ideas on:

- What, how and when to tell your children about the diagnosis of PD
- Some common feelings and reactions children may have to the diagnosis and living life with PD going forward
- Coping strategies for you and your family
- Information designed for you to share with your children...facts about motor and non-motor symptoms, common feelings they may be experiencing and what they can do to live life well with PD.

Dedication:

This book is a result of the many people who share their experiences with us. It is also the result of careful review and valuable contributions made by people with PD, carepartners and teens/young adults as well as health care professionals working with people with Parkinson's Disease (PWP) and their families.

With appreciation, we acknowledge:

Noel and Mac MacDonald, Martina, Rob and Alli Jussila, Robyn Levy and Naomi Amren, Rebecca Miller, Dr. Soania Mathur, Pat Boileau, Grace Blackthorne, Simon Hawke, Dr. David Morley, Dr. Jon Stoessl, Luc Bossé, Seth Book.

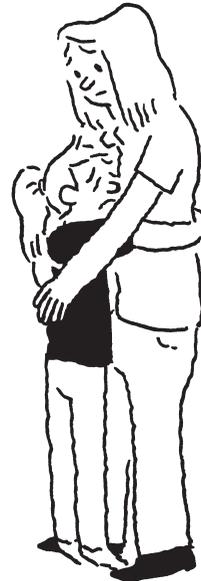
This book is in part a result of a generous donation from the Pacific Parkinson's Research Centre, Vancouver, Canada and the McGill Movement Disorder Clinic, Montréal, Canada.

For simplicity, the word 'children' will be used but refers to younger children, adolescents, teens and young adults as well.

Information in this booklet is for educational purposes. It is not intended to replace the advice or instruction of a professional health care practitioner. Contact a qualified healthcare professional if you have questions or for further consultation about your individual situation.

At time of printing, all information in this book was deemed accurate.

February 2019



You, Your Family and Parkinson's Disease

It is often said that Parkinson's Disease (PD) is a family affair because it changes life for everyone in the family, including children of all ages. PD is often assumed to be something that happens to older people. The reality is that 5-10% of people with PD are diagnosed before the age of 50. Many people with PD have children, teens and young adults in their lives. As a person with PD, you may wonder about the impact PD will have on you and your family. Your feelings regarding your children may range overtime from a sense of calm and confidence to worry, fear and anxiety.



You are not alone. Parents with PD share similar concerns and questions. Some of the more common thoughts and questions from parents with PD include:

How do I tell my children about the diagnosis?

I do not want this to change their lives.

How can I help my children cope?

How can I talk with my children when I am so scared?

Do I really have to tell the children? What is the benefit?

I want to protect my children.

This was not the plan!

What am I to do now?

Supporting your children will require preparation, awareness of the age, stage and personality of your children as well as acceptance of your own limitations. Having PD in the family also provides an opportunity to teach your children valuable life skills and lessons, to focus on important values and a chance to create and cherish time together.

Children who are experiencing parental illness, specifically PD, may have unique needs as a result of the course of this illness – ongoing, progressive, degenerative with an unknown cause and currently no cure.

Little has been written on the specific needs, coping strategies or concerns of children of people with Parkinson's Disease (PWP). We can draw on the experience of many families and also from research about what helps children deal with a parent who has a chronic illness. We know that children regardless of age generally want more information rather than less, want more information early on about PD and want to know what to expect as the disease progresses. A better understanding of the condition can lead to less fear and distress.

In a family living with Parkinson's, your children's adjustment may be related to:

Specific symptoms – Some symptoms are embarrassing, some are debilitating and some are more challenging than others (for example, parental depression, anxiety, impulse control issues). The potential for negative impact is real.

Family structure – Are you a mom with PD under the age of 35 and married to a man without PD? Or perhaps you are a family with two dads and you're both over 50. You may be a single mother approaching 40, or a divorced dad with 2 kids or a 60 something year old man in a second marriage with a young family. Each of these family situations can affect the impact of PD on your family in a different way.

Support system – The availability of supports (siblings, friends, relatives, counselors) is important in meeting your children's needs and in creating your "team" to help you manage PD in your family's life.

Progression of PD – As you are well aware, PD symptoms change over time and new challenges may emerge as the illness progresses. Children will continually be faced with making new accommodations and potentially taking on new responsibilities.

Cultural influences – Your family's cultural understanding of health and illness as well as roles and responsibilities for providing care may also influence the experience of coping well with PD in your home.

Having PD in the family does not always mean there will be adjustment problems for the family. The good news is that children often adjust very well to a parent's diagnosis of PD. Adults in their lives can help them not only to adjust, but also to thrive. Families with protective factors (circumstances that help people deal more effectively with stressful events and lessen or eliminate risk) are in a good position to create healthy environments for optimal development. These protective factors can be nurtured.

Protective factors include:

Parental resilience – A parent's resilience is the ability to constructively cope with and respond to challenges. It is about creatively solving problems, building trusting relationships, maintaining a positive attitude, and seeking help when needed.

Knowledge of Parenting and Child Development – It is important to have accurate information available when you need it and when it is relevant to your life and your child's life in order to better understand and have appropriate expectations of behaviors. Knowing more about parenting and development can put you in a better position to meet your children's needs.

Social and Emotional Competence of Children – A child's ability to interact positively with others, to self-regulate, and to effectively communicate their emotions has a great impact on the parent-child relationship.

Social Connections – Having friends, family members, neighbors, and other members in a community provides emotional support to families at times of need.

Concrete Support – Parents benefit from having access to the types of concrete supports and services that can reduce stress and make sure basic needs continue to be met. For example, help with grocery shopping or driving children to activities as well as access to health professionals.



How does PD affect children?

Research into the impact of Parkinson's Disease on children is still very new. We are starting to learn more about children's unique needs and how those needs may change as PD progresses. Just as symptoms vary and change over time for each person with PD, so do the reactions, emotions and needs of each child within the family.

Despite the limited research on the specific needs, coping strategies or concerns of children of people with Parkinson's Disease, we can draw on the lived experiences of many PD families and also from research on the impact of other parental chronic conditions.

Common feelings some children may experience include:

Shame or self-consciousness about the unusual presentation of PD, especially as a result of reactions by friends or even strangers.

Anxiety about the stress in the parent's marital relationship caused by PD. Children may sense tension between parents due to the diagnosis and/or the symptoms of PD .

Sadness, fear, anger and grief regarding the changes and losses of experiences with the parent with PD or limitations of future experiences.

Loneliness as the healthy parent is more focused on and spends more time with the PWP.

Worry about their risk of developing PD themselves (is this contagious or genetic), worry that parents feel guilty about the impact of PD on the family, financial worry if family income has changed due to working less or being on disability pension, worry about the impact of PD on their own future aspirations and decisions.

Feeling overwhelmed by caregiving responsibilities.

Frustration with activity restrictions including finding it harder to socialize as they do not want to bring friends home or feel bad about going out.

Positive impacts

A diagnosis of PD will present new challenges for your family, ones that you never expected or wanted. It is important to recognize the potential for positive effects for children. Living life with a challenging parental illness can strengthen family relationships, lead to improved coping skills for children and provide a sense of pride, confidence and maturity with a well-developed sense of empathy and compassion. Children may be more accountable to their family and home responsibilities fostering more independence than children in families without PD. Being helpful can give them a sense of value in the family, leading to a sense of comfort and security. With good support, the challenges created by having a parent with a health issue may lead to new opportunities for children to grow in unanticipated ways. Having PD in the family can actually promote healthy personal growth.

Becky's story

Becky's father was diagnosed with PD before she was born. Now 16, her childhood was affected by his disease as it changed day to day and often hour to hour. She learned about putting the needs of others before hers, working cooperatively with her family members and the value of a positive attitude. With strong family support, continuing with her avid interests and connections to her faith, her experience with PD in her family has contributed to her decision to pursue a career in medicine.



How to best support children when you have PD

Break the silence. Have you been nervous about what, when and how to tell your children about the diagnosis? Parents may think PD is not affecting their children and often worry that giving too much information could frighten them. However, breaking the silence can decrease the anxiety children may have about changes they have already noticed in the parent with PD. Children tend to be very perceptive, sensitive and intuitive and often know that something is not quite right. Without information about what is actually going on, they can imagine things much worse than the true diagnosis of PD. If your children hear about the diagnosis from someone else or overhear conversations you are having with others, trust may be damaged between you and your child. Secrecy can be more harmful than sharing the truth when talking about health issues with children. Children may be more afraid of the unknown, and actually do better with age appropriate information about what's going on.

Whatever the age of your children, think about:

- sharing the diagnosis and the process of how it was diagnosed
- providing information about PD, taking into consideration the age and developmental stage of your children
- using language that is understandable to the child and focuses on symptoms and behaviors that the child can relate to
- communicating to the best of your ability what might happen
- finding ways to allow your children to help and be involved rather than isolated
- practicing what you are going to say with a close friend or family member before talking to your children

By sharing the diagnosis and appropriate information, your children will be able to:

- trust that adults will give information that is needed
- work through feelings
- be included rather than isolated
- feel safe asking questions
- help in a way that works for everyone

Many children indicate they would like to better understand PD sooner rather than later in order to better understand the needs of the parent with PD earlier on in the disease. If you have more than one child, most likely they will be at different developmental stages or have different coping styles. It may be easier for you and some your children to have some discussions about PD separately.

Mark's story

Mark, newly diagnosed with PD at age 50, and his wife Dianne struggled with “if and when” they should tell their children, ages 12 and 15. Wanting to protect them and to prevent upset in their lives, not sharing the diagnosis with their children was their initial reaction. With some time to understand and adjust to the diagnosis themselves, Mark and Dianne felt calmer and decided to share the diagnosis with their children openly and honestly hoping to build and model family support and coping skills. Mark began with how he was diagnosed and Dianne supported him by adding details as he needed. They let the children know that Mark and Dianne believed that they could handle the information, that they will answer any questions, that they will try to keep life as normal as possible and that Mark and Dianne are there to take care of them. They shared hope and optimism as they talked about good medical care with many treatment options and ways for the family to live life well with PD.

“As my mom’s Parkinson’s progressed, my access to information about the disease did a great deal for calming my concerns.”

Mac, age 20
(age 3 when his mother diagnosed)

“I think it is much better for the kids to know all possibilities even if it worries them for a period of time. Chances are that if they know about it and are prepared for it, it will never even happen.”

Simon, age 16
(his father was diagnosed before he was born)

Danielle’s story

Danielle, age 10, lived with her father who had PD for 4 years. Her father decided to bring her to his annual neurologist visit because he had sensed a change in her recently. While she knew he had PD, she had become increasingly worried that he was going to die as a result of some of the physical changes he was now experiencing. By bringing her to his visit, her father created the opportunity for her to meet the team of health professionals including the neurologist and social worker. Her worries and fears were discussed and accurate information was shared with her. She left feeling relieved and comforted to know that she had someone to talk to in the future.

“Being a part of the meetings, appointments, and care made me feel important and like I could help - which was integral to me letting go of a lot of my feelings of helplessness and uselessness that I struggled with around the time she was first diagnosed.”

Naomi, age 23
(age 13 when her mother was diagnosed)

Check in with yourself. Your attitude about PD is very important. Children often model after their parents and learn about coping from their parents. How you share the diagnosis with your children can influence their perception of what the diagnosis of PD means. The way the diagnosis is presented (matter of fact,

hopeful), the timing of the discussion (not after a stressful day or right before bed, during school exams), the tone of voice and the choice of words used can affect the way children cope from the start. Promote an honest, authentic and hopeful attitude when talking about the research, possible new treatments and specialists working hard to improve life for PWP.

Share how you feel. This can be tricky. Do you hold in your emotions in an effort to remain positive for your children? Is this healthy? Or do you allow your children to see and hear what you’re feeling? It is ok to share your emotional reactions and most children say they need a balance. Show your children that it is normal to have feelings (mad, sad, confused, scared) and to express them appropriately. This gives them permission to do the same. Sometimes what you do is more powerful than what you say. Encourage them to share how they feel and let them know you can handle it. Asking for help yourself, either for emotional support (from family, friends, counselor, or clergy) or for practical support (carpooling, exchange of chores) sets a good example.

Communicate. Communicate honestly, openly and frequently about PD. Communicate about how it affects the family and discuss issues and worries. Find solutions to problems together and of course highlight what is working well. Replace fear with knowledge, acknowledge feelings and provide the reassurances children need. It is helpful to let children know what tasks or times of day may be challenging for the parent with PD. Questions they may have include “What happens if you go into hospital?” “Will we have enough money if you have to stop working?” “Can you still drive me to soccer practice?”

Quotes from children of people with Parkinson’s Disease

“My mom has made it as normal as possible.”
“My mom’s outlook has helped us manage well. Her attitude has been the most healing for all of us. She is inspiring.”
“It’s not the end of the world. We are all coping.”
“It’s all a challenge but we have to live with it.”
“We can’t do things the way we used to. We have to find new ways to spend time together.”

Questions are good! Provide a comfortable environment for your children to ask questions. It is important for you to understand the questions they are asking so ask for clarification if you need. Check in with your child and ask what they are thinking about. This can help you to better address the actual question they have on their mind (“Tell me more about ... or “What did you mean when you said...”)

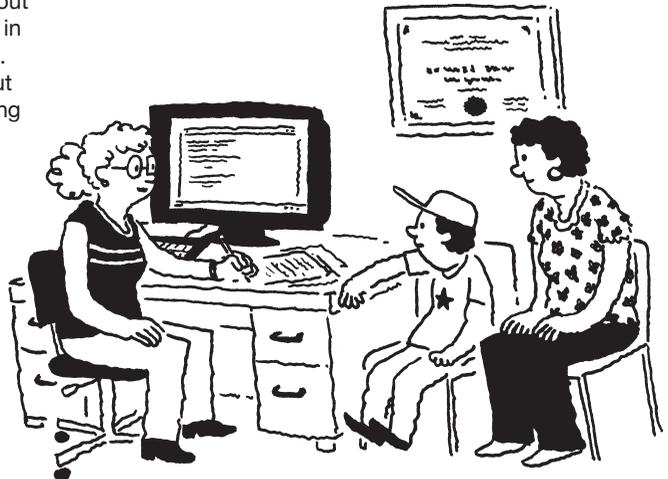
It's ok not to know the answer. You may not have all the answers or may not know how you want to answer a particular question immediately. Tell your children it is a good question but a hard question. Let them know you will get back to them with an answer once you have thought about it. This allows you to deliver a thoughtful, good quality answer. Do make sure you follow up with their concerns. Some questions are difficult because they bring up emotions in you and you may want to take a break and finish the conversation later. Some questions are difficult to answer because no one knows the answer and uncertainty is hard for anyone to face. It is ok to acknowledge that you find not knowing difficult too. Offer ideas for coping with uncertainty such as keeping busy, remaining optimistic, gaining as much information as possible, thinking of back up plans, focusing on a daily gratitude and planning fun in everyday,

Don't force it. Be prepared and understand if your children do not want to talk or if they do not have questions. They can still be listening without responding. Sometimes it is more comfortable to talk about difficult topics while not face to face. This may be in the car or while walking the dog or making a meal. Or even by text... not recommended but it is about meeting them where they are at. Consider providing printed information as an option as well.

It does not have to be you. Your children may want to talk about PD and its impact but not with you. Ensure that they have someone to talk to. This could be a friend, parent of a friend, teacher, coach, relative, member of clergy or health care professional.

Timing is everything. Think about when is a good time to talk for you and for your children. Perhaps not when you are tired, before a test or rushing out the door. Try to include something positive or hopeful or a coping teaching moment in difficult conversations. Find an opportunity to focus on what still exists... love, time together, shared interests.

Straight talk! Euphemisms can be confusing. Use the words Parkinson's Disease and use easy to understand language to describe it. Tell your children the truth about what you know and how it is impacting life today. Provide the information based on the developmental level of your child. You can consider looking at books with pictures of the brain to better explain PD or get a book about PD that is written specifically for children. Expect older children will go to the Internet for more information so caution them to use recommended websites rather than simply doing a google search of “Parkinson's” (see resources). Consider having someone for them to talk to about what they have read or images they have seen online.

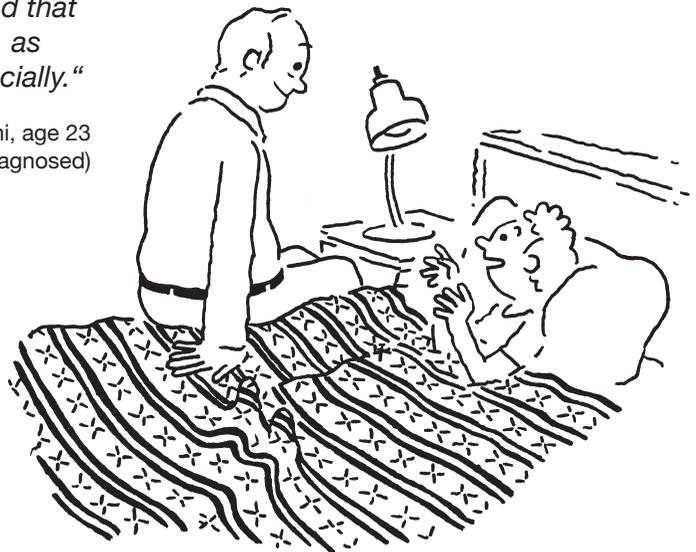


Connect with other adults in their lives including teachers, coaches, neighbors, and extended family who can offer support as needed. Let them know about the diagnosis as soon as you feel comfortable. They can keep an eye out for changes in your children that may be related to PD in the family. Help those adults to understand PD and to convey the same messages that you are delivering with accurate information as well as the philosophy and attitude you wish to have reinforced with your children. Many people, with the best of intentions, may ask your children about their parent with PD on a regular basis out of concern. This may or may not be helpful to your children. Offer guidance to those caring individuals as to what suits your children best and how best to support them. The children may actually prefer to have conversations be about themselves!!!

Encourage your children to continue to be involved with hobbies, interests and friends. They need reassurance that they can and should have fun and lead their own life. This leads to healthy coping strategies. As teens grow into young adults and are approaching decisions about education or employment opportunities, be mindful that they may need support, encouragement and validation to make choices that are right for them and their future.

“I feel like a huge part of the ongoing struggle I experience is the feeling that I must be close by to my mother, and that I can’t lead a fully independent life, as she needs me in the long run especially.”

Naomi, age 23
(age 13 when her mother was diagnosed)



Empower children by encouraging them to be involved in a fundraiser or PD Awareness project. Examples might include a bake sale “Pastries for Parkinson’s” or “Pajama Day for Parkinson’s” to raise funds and awareness by having educational material available at the school, community, sport or religious center. Contact your local PD society for ideas and materials.

Coach your children on how to share information about PD with others like friends who come to visit. Help them figure out how to answer common questions such as “Is PD contagious?” or “Why does your dad have an angry look on his face?.”

Consider connecting your children with peer support. They are not the only ones with parents with PD. If you are part of a young onset support group, ask other members if they have children and if they might want to arrange an opportunity for the children to connect. Social media may be more comfortable with the layer of anonymity and convenience that it provides.

Ryan's story

Ryan, age 14, has no recollection of life before PD as his mom was diagnosed when he was 3 years old. At this time of his developmental stage and his personality traits, opening up to friends for support was not an option. While he did seek professional counseling support, he also found support with a web based friend while playing online video games... supportive and anonymous.

Preserve the parental role. Certainly in the early stages, it is vital for children to continue to see their PD parent as a parent with the same expectations and approaches to parenting, enforcing the same discipline and boundaries. In two parent families, the "well parent" should try not to shield the PD parent from usual involvement with the children. Stability and consistency will create a sense of security and

normalcy in the home. With time and progression of the condition, the ability to perform daily parenting responsibilities may vary due to both motor and non-motor symptoms. With the unpredictability of PD, there are changes and interruptions or delays in day-to-day life. Limitations coupled with guilt of not "keeping up" sometimes leads to relaxed parenting and discipline. Try not to compensate by becoming overly permissive and letting behaviour standards drop. Discipline is a signal to your children that they are important. Try not to make promises that you cannot keep. Parental judgment and decision-making may be affected and changes may be necessary in what the PWP's parental role will look like. Remember, children don't need to be taken around to 20 different activities a day to feel loved. Creating new doable options to spend time together is just as valuable and meaningful.



Information to share with your children

What is Parkinson's Disease?

Dr. James Parkinson, a doctor living in London, England, first wrote about Parkinson's Disease in 1817 when he noticed a patient of his who had a shaky arm. Parkinson's disease (PD) is a slowly progressive (changing) neurological (brain) condition that can affect a person's physical movements and other functions within the body. Sometimes these symptoms or changes are visible, and sometimes they are things you can't see, but still affect your parent.

In Parkinson's, the area of the brain that is affected is the substantia nigra. This is the area of the brain where the neurotransmitter (chemical messenger) called dopamine is produced. Dopamine allows nerve impulses to travel smoothly from one nerve cell to another. These nerve cells send messages to the muscles in the body to begin movement. In PD, the cells that produce dopamine start to die off and, when dopamine levels fall below 50% of the normal amount, the symptoms (physical or mental signs) of Parkinson's appear. Parkinson's disease looks different in different people and not everyone will have every symptom or the same symptoms.

Parkinson's Disease is not contagious. We are not sure how or what causes Parkinson's, but you can't get it from touching someone or even being around them. It is uncommon for PD to be genetic (inherited or be passed down in your family).

There are different treatments for improving (or lessening) the symptoms of PD including many kinds of medications (pills) as well as surgery. You may see your parent taking pills throughout the day, at the same time of day and every day. Sometimes before taking the medications, you may notice your parent has worse symptoms and then they get better after a bit of time. Treatment for PD is always improving. Researchers and scientists are constantly looking for new ways to help your parent with PD. There are doctors, nurses, social workers, physiotherapists, occupational therapists and speech therapists available to help people with PD live a happy and active life.

How does Parkinson's Disease affect the physical body (also known as motor symptoms)?

There are 4 main motor symptoms in PD:

Slowness of movement (also known as bradykinesia) – People with Parkinson's move more slowly and this can affect all parts of the body. This might include slower walking, trouble dressing or writing and speaking softer. You may notice this in your parent especially when they are just about to take their medication.

Shaking (also known as tremor) – This often happens in the hand or arm and usually happens when your parent is not using their hand or arm ...like when their hand is resting in their lap.

Stiffness (also known as rigidity) – Stiffness means that the muscles are tense and harder to move. This can make it difficult to get in/out of a car or to get up from a chair. It can also affect the face muscles which can make it difficult to smile. You may think your parent is angry because of how their face looks...ask them...it could just be the PD!!

Poor balance - People with Parkinson's may walk slowly, get stuck in their tracks (also known as freezing) or lose their balance. They can also be unsteady and can fall more easily.

Other symptoms (also known as non-motor symptoms) can include:

- Drooling
- Unable to taste or smell
- Swallowing problems or choking
- Constipation (difficulty making a poo)
- Body pain
- Fatigue (feeling tired)
- Quieter voice
- Smaller handwriting
- Depression and anxiety (feeling sad and worried)

Remember not everyone gets every symptom.

How does Parkinson's Disease affect thinking and feelings (emotions)?

Depression – About 1 out of 2 people with PD can have depression and it is caused by changes in the brain as well as an emotional reaction to having PD. Depression is when you have many feelings of sadness, loss or hopelessness with less interest or pleasure in activities you once enjoyed. It can interfere with doing things at home, at work or with the family. Medications, exercise and talking with a counselor can help with depression. Staying involved in activities that bring happiness can also help improve depression.

Anxiety – About 1 out of 2 people with PD can feel anxious. Anxiety is having feelings of constant worry or nervousness. It can be present every day and throughout the day or it can come on suddenly which is called a “panic attack”. Some people with PD become more anxious when they are “off” (unable to move well while waiting for their PD medications to work). There are medications that can be helpful for improving anxiety and even changes in PD medications which may improve movement can then reduce anxiety. Exercise and remaining busy during the day with a routine and activities that are enjoyable are also helpful.

Apathy – Apathy is a lack of interest, enthusiasm or motivation. If your parent feels apathy, they may find it hard to get up in the morning or do household chores or even participate in activities they once enjoyed. There are no medications for apathy but having regular activities planned, volunteering, exercising, visiting with friends and family and getting good sleep can help improve feelings of apathy.

Difficulty with thinking clearly – Changes with memory or concentration can happen in PD. This slowness in thinking can make it hard for your parent to plan activities or follow a conversation or make decisions. There are medications that can help with this but exercise for the body and for the brain (crossword, scrabble, reading, puzzles) are great too! Think about doing these activities together with your parent!

Impulse control behaviors – These are activities that are done a lot and that your parent may have trouble stopping even though they realize that they should. Examples of impulse control behaviors include overeating or shopping more than usual or spending way too much time on the computer. This is usually because of the medications and once the medications are changed, the behavior generally gets better.

Other possible symptoms that can happen

Sleepiness – This means feeling fatigued (tired) and sleepy or sleeping too much during the day. This can happen because of the medications for PD or from not sleeping well at night.

Insomnia – Insomnia happens when it is hard to fall or stay asleep. People with PD often have trouble sleeping through the night, often due to some of the discomfort from the symptoms. Insomnia can lead to your parent feeling tired or sleepy during the day.

REM (Rapid Eye Movement) sleep behavior disorder This happens when a person with PD “acts out” their dreams. While asleep, your parent may move a lot, punch, kick, shout or talk. This can happen in 1 out of 3 people with PD.

Restless leg syndrome – This is the urge to move the legs due to pain or uncomfortable sensations. You might see your parent bouncing their legs up and down. This tends to happen more in the evening or at night. Standing or walking around can help.

Dyskinesia – Dyskinesias are uncontrollable movements and are a side effect (a result of) of PD medication. Dyskinesias can make your parent move around, twisting their body and moving their arms and legs.

Hallucinations – Hallucinations happen when someone hears or sees things that are not really there. Hallucinations in PD are almost always visual (seeing something that is not there) and are often not scary. A spot on the floor might look like a bug or the person with PD may see people or animals that are

not there. Most people with PD are aware that the hallucinations are not real but that can change with time. Hallucinations generally start many years after the PD begins and can be caused in part because of the medications and because of changes in the brain related to PD.

Delusions – Delusions are false beliefs that are not based on fact or reality. They are very real to the person with PD. The person with PD may believe they are being told lies or they become incorrectly worried about a physical symptom. Delusions do not happen to everyone with PD and if it does happen, it is often after many years of having PD.

How will PD affect me?

Things will change over time as the PD continues and daily life may start to look different. The symptoms will change and as a result family plans, finances, your responsibilities and how you feel will change too.

You may have to do things to help your parent that you did not have to do before like helping around the house or hands on help with your parent. There may be chores like making meals or cleaning and you may not like it. It is ok to feel angry, sad, resentful, frustrated, embarrassed or guilty for having these feelings. Talk about your thoughts and worries with your parents or with a counselor or anyone you feel close to and together you can find solutions.

Remember your mom or dad is still your parent and is the same person you know even if they behave differently because of PD. They do not want to or intend to frustrate or anger you, though that may happen. The challenging behaviors are because of the disease and many of those behaviors are not within their ability to control.

The things your parent with Parkinson's can do and the things you can do together may change over time. While your parent will always be your parent, PD might mean that you have to change what you can expect of your parent and your family life. Try to think about different ways to stay connected with your parent and think of new activities that you can do together. Perhaps it is learning family recipes with

your parent giving directions and using your hands! Consider doing activities together that help the PD too like exercise (walking), board games, crosswords or scrabble.

“My mom and I watched TV together, which was a great activity because it didn't require movement or talking.”

Mac, age 20
(age 3 when his mother diagnosed)



What can help you and what can you do?

Family meetings. Think about having regular family meetings, maybe every week or once a month. Use the time to share with your parent(s) how Parkinson's makes you feel. They can also explain some of what they are going through and together you can find ways to help each other. Plan something fun after a family meeting like a movie or pizza night!

Talk to someone. You may have concerns or worries that you don't feel comfortable talking to your parents about. Find someone who you feel comfortable to talk with like a friend, relative, teacher, coach or counselor. Sharing your feelings might help you to feel better and the person might have some good suggestions too.

Get involved. Sometimes we feel better when we can DO something to improve a situation. Organize a fundraiser (Pajama Day for PD) or raise awareness (celebrate World Parkinson Day on April 11) and teach others about PD at your school or in your community. Your local Parkinson's Disease society can give you some ideas and educational materials.

Connect with other people your age. You are not the only one with a parent with PD. If your parents are in a support group, they may know other people with PD who have kids that would like to hang out or connect on social media. Even your parent's doctor may know of other kids to talk to. There are kids all over the world with parents with PD!

Cope with stress. Finding ways to cope with stress is important for you and for your parent. Exercise, stay involved in your favorite activities, eat well, get rest and continue to have fun! Try to create a disease-free zone when you need a break and to recharge your battery!

"Parkinson's affects my life so much I try and do things that are not related in any way to it."

Simon, age 16
(his father was diagnosed before he was born)

Start a journal. A journal gives you a safe place to express your thoughts and feelings...thoughts and feelings that you may not want to share with anyone. Sometimes this expression allows you to better understand why you think and feel the way you do and may even help you solve a problem. You can write or draw, write poetry or simply write random words, or even include images that reflect how you feel. There are no rules to how you use your journal.

Here are some prompts to get you started:

Today was hard because....
Today was good because....
Today I am proud of myself because....
Today the thing I did nice for someone was....
I am grateful for....
I am most frustrated by....
I wish people could understand that....
List things that are helpful to remember on a bad day
List questions you need answers to
Write down the words you need to hear
Think about what inspires you
List 5 things that make you smile (make 1 happen everyday)
I am looking forward to....
What was the funniest thing you saw or heard this week?

Be informed about PD. If you want more information, consider looking at these websites rather than googling "Parkinson's Disease". It is a good idea to look at the websites with someone who can help you understand the information and answer your questions like a parent or grandparent, aunt or uncle, teacher or counselor.

www.parkinson.org
www.parkinsons.org.uk
www.parkinson.ca

Living life well with PD in your family

In general, children want to feel secure in knowing that you will be able to manage whatever comes your way, that you will get the help you need, and that despite PD in your family, you will all be ok, maybe different, but ok.

As you raise your children, there will be challenging times or behaviors that are more likely related to their social and emotional developmental stage and are completely unrelated to PD in the family. It is not always about the Parkinson's! This can be hard to accept at times as you may feel guilty about the impact of PD on your family. But it is important to remember that going through puberty, dealing with friendships, figuring out school and all things associated with growing up are normal realities in a child's life. Managing the stresses in their own lives can also make it more challenging for them to then cope with PD in the family as well.

Once again, the age and stage of your children will influence the information you share, their adjustment and the types of support that might be helpful.

Children, like adults, may need time to grieve the changes and ongoing losses in their life. They should be given permission to do so and not be expected to always hold it together. Sometimes your child may have to work through the sadness before they can adjust to a new reality.

You know your children best. From past experiences you know something about how your children will best handle information and change. Look for clues as to how they have handled other challenges in the past and what kind of support was helpful.

If you notice your children are struggling in more than one of three areas (family, school, friends) and the problems persist for more than a few weeks or seem to be worsening, professional help from your family doctor or counselor is recommended. You are not alone. You do not have to be the only source of support for your children.

Taking care of yourself (this is for the person with PD and care partner!) by practicing positive behaviors will decrease your stress and anxiety and will set a good example for your children. Maintain your interests and passions, exercise regularly, stay healthy, get counseling, ask for help as you need it and allow others to help when offers are made. Often when you are depleted is just when your children need you the most...so create those opportunities to replenish yourself.

Take each day as it comes and let the expectations of what you 'should' be doing fall by the wayside. Try to live in the present, creating balance in your life with a focus on your blessings.

Recognize and accept that you may not get everything right as you navigate this road with PD. Children can live with your imperfect attempts and you can forgive yourself for not being perfect. Children can become resilient and confident adults despite and often as a result of challenges and adversity. No one welcomes the changes that PD brings. Yet hidden within the losses is the potential for unexpected positive growth and the development of healthy coping skills.

"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."

Simon, age 16

(his father was diagnosed before he was born)



Self reflection exercise

What am I doing well now?

What are some areas that I would like to work on? If so, what positive action can I take in that area?

Is there something in my life that I could use some help with? If so, are there people (personal contacts and professional) that I could ask for help?

What I am grateful for?

“Sometimes you have to take a step back to take a step forward in the right direction”

Author Unknown

Key observations from clinical practice...

- Many children indicate they would like to better understand PD in order to better understand the needs of the affected parent earlier on.
- Some children express guilt related to asking for help from parents as their parents are dealing with the considerable burden of PD. It is a good idea to set up regular “check in” chats.
- Most children do not know other children who have parents with PD.
- Most children do not talk with friends about issues arising from their parent’s PD.
- Majority of emotional support to children comes from within the family.



Resources

Online Resources

“My Parent has Parkinson’s. What does it mean?”
Tip sheet available at www.parkinson.org/FactSheets

“Parkinson’s and Your Children/Teenagers” - Tip
sheet available at www.parkinson.org/FactSheets

www.designingacure.com - A website developed by
Soania Mathur, a family physician who was
diagnosed at the age of 27 and is raising three
children. 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-Webi-
nars/Archives](http://parkinson.org/Living-with-Parkinsons/Resources-and-Support/PD-ExpertBriefings-Webinars/Archives)

“Parkinson’s in your life: A guide for teenagers” Tip
sheet available at www.parkinsons.org.uk

www.parkinsons.org.uk/information-and-support/
Look under tab « relationships and family life » and
then « talking to children and teenagers ».

[http://www.pittsburghhealthcarereport.com/helping-
kids-cope-when-a-parent-is-sick/](http://www.pittsburghhealthcarereport.com/helping-kids-cope-when-a-parent-is-sick/) This site is not
Parkinson’s specific but has some good general
information.

[http://www.mghpact.org/for-parents/parenting-prin-
ciples/developmental-perspective/overview](http://www.mghpact.org/for-parents/parenting-principles/developmental-perspective/overview) This site
details how to support children at different ages. See
bar on left side of page for age specific tips.

Books for Children

“I’ll hold your hand, so you won’t fall: A child’s guide
to Parkinson’s Disease” by Rasheda Ali

“Shaky Hands: A kids guide to Parkinson’s disease”
by Dr. Soania Mathur

“Parkinson’s in the Park: For children of Parents with
Parkinson’s” by Jessica Christie

Books for Parents

“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

“The Etiquette of Illness” by Susan Halpern with a
chapter - Talking to Children about Illness

References

Protective Factors - Strengthening Families, a project
of the Center for the Study of Social Policy
www.strengtheningfamilies.net

US Department of Health and Human Services Admi-
nistration for Children and Families/Strengthening
Families and Communities 2009 Resource Guide:
[http://www.mghpact.org/for-parents/a-dozen-les-
sons-learned](http://www.mghpact.org/for-parents/a-dozen-lessons-learned)

The Etiquette of Illness by Susan Halpern

Impact of a Parent’s Neurodegenerative Disease
and Care on the Daily Life of Children [http://dx.doi.
org/10.5772/interchopen.68839](http://dx.doi.org/10.5772/interchopen.68839)

Parkinson’s Foundation - www.parkinson.org

Notes

About the Authors



Elaine Book has worked in the field of Social Work for over 30 years in a variety of community and hospital settings. She has worked with individuals, families and as a leader of support groups. She is the Center Coordinator and Clinic Social Worker for the Pacific Parkinson's Research Centre, a Parkinson's Foundation Center of Excellence, at the University of British Columbia in Vancouver, Canada.

Elaine has become a leader in the PD community, serving as a speaker at support groups, a presenter at neurology meetings, a faculty member and Co-ordinator of the Allied Team Training Program, a mentor with the Parkinson Foundation, a planning committee member of the World Parkinson Congress (2016, 2019) and a member of the Parkinson Canada Medical Advisory Council.



Pascal Girard has been a social worker with the MUHC (McGill University Health Center) in Montréal, Canada since 2014.

In 2016, he joined the MUHC Movement Disorder Clinic, a Parkinson's Foundation Centre of Excellence. He works with the patients and their families to provide supportive counseling and assist with multiple needs at all stages of the illness. Pascal has also been working as a professional cartoonist/illustrator since 2006.

Parkinson's Disease and Parenting:

A practical guide to family life with Parkinson's Disease

I would have loved to have my parents read this 20 years ago when my brother and I were younger, so that they would have known that it is ok to talk to us about PD symptoms and how they affect our/my dad's life.

Alli (age 22, her father was diagnosed when she was a young child)

How great it is to have a resource like this. I know it's going to help so many families!

Naomi (age 23, her mother was diagnosed when she was 13 years old)

I was diagnosed with YOPD when my daughter was 9 months old. Being a parent is challenging enough. Being a single parent with PD – it's a handful! But having a resource like this book lets me know there are others struggling and succeeding with the unique joys and worries of having PD while trying to be the best parent I can be.

Becca (YOPD parent)

The book will be a very valuable resource for families. What you've written is great and has lots of information. Wish it had been around 20 years ago...

Martina (spouse of PWP with two young children when her husband was diagnosed)

This is an invaluable resource for parents with Parkinson's disease and their wider family unit. The author has incorporated a wealth of experience and knowledge into an accessible booklet that provides advice for families experiencing Parkinson's and how this might affect their children. Given the potential impact of having a parent with Parkinson's, such guidance is long overdue.

Dr David Morley, Senior Research Scientist, University of Oxford

Managing the motor problems of Parkinson's, while not always easy, may be the least of one's challenges. The social worker is one of the most critical members of the Parkinson's team. Elaine is an extraordinary colleague who has helped hundreds of people living with Parkinson's and been a tremendous resource to the broader Parkinson community. In this book, she draws upon her vast experience to advise on a need that is largely overlooked (or worse, actively avoided) - how Parkinson's may affect your relationship with your children, how to share the diagnosis with them and how to continue being a loving and effective parent. This book is a must for anyone with Parkinson's who has children, and for anyone involved in the care of people with Parkinson's.

Dr. Jon Stoessl, Movement Disorder Neurologist, University of British Columbia