

Young-Onset Parkinson's Disease: Advice for Physicians From Individuals Living With YOPD (2nd Edition)

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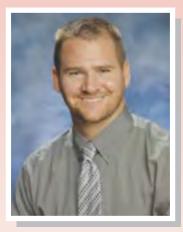


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ACKNOWLEDGEMENTS

people living with young-onset Parkinson's disease (YOPD) who took part in this project, dedicating hours of their own time, inviting me into their lives and sharing their wisdom with me for others to read. Without all of you, the project and this booklet would not have been possible.

Working with the Parkinson Society Canada, we collected feedback on the first edition of the booklets from people living with Parkinson's disease, their family members, and health professionals. This feedback helped us to identify



Dr. Michael Ravenek

specific areas where the first edition could be improved, and so we thank all of you who took the time to read the initial edition and complete the survey.

Beyond those who took part in this study, there is a mass of people that deserve thanks and acknowledgement for their contributions. My doctoral advisory committee, consisting of Dr. Sandi Spaulding, Dr. Mary Jenkins and Dr. Debbie Laliberte Rudman were instrumental in providing feedback on my research and this booklet as it progressed from an idea to a product.

I would also like to thank Dr. Soania Mathur for writing the foreword to this booklet and providing constructive feedback on the development of certain sections, including some of the tools provided at the end of this booklet. Lily Cappelletti at the Michael J Fox Foundation also deserve thanks for sharing some of the images that were included in this booklet.

Of course, I cannot end these acknowledgements without thanking my wife, Kelly, for her unwavering support and feedback on my research and this booklet as they moved through different stages of development.

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The evaluation survey conducted on the first edition of the booklet, and the subsequent changes made that appear in this edition, could not have been completed without the support of the staff at the Parkinson Society Canada and Parkinson Society Central & Northern Ontario, including Debbie Davis, Grace Ferrari, Marina Joseph, Alex Petef and Julie Wysocki.

Further, funding for the printing of these booklets was provided by Parkinson Society Canada and Parkinson Society Central & Northern Ontario.







FOREWORD

s physicians we are not immune to the burden of disease as I experienced at the age of 27 when what initially began as an intermittent, mild rest tremor evolved into a diagnosis of Young Onset Parkinson's disease. Over the last 15 years I have not only come to accept this diagnosis but also to live well despite the daily challenges this disease presents. Having a medical background gives me a rather unique perspective on how chronic disease affects our life experience and what patients need to do in order to maintain their quality of life.



Dr. Soania Mathur

A diagnosis like young-onset Parkinson's disease, is usually met with a myriad of emotions, predominately anger, uncertainty and fear. As the bearers of this news, we in the medical profession are held to a certain level of expectation. That expectation is also part of the modern version of the Hippocratic oath which states: "I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug," a statement that the vast majority of physicians hold true. Although competent and complete care of the patient is paramount, it is this "art of medicine" that makes a significant impact on a patient's ability to cope and move forward following a life-altering diagnosis such as Parkinson's.

And they must move forward. Patients cannot be passive bystanders and expect to live well with Parkinson's. There are many interventions that motivated individuals can implement in order to lessen the physical, emotional and social impacts of this condition. And as physicians we play an integral role in this process. Likewise the effectiveness of a physician's management strategy is enhanced by a patient's involvement resulting in improved health outcomes.

By encouraging your patients to engage in self-care, setting goals and designing care plans, this disease can be better managed leading to an improvement in quality of life parameters. Because that is what is truly important – quality of life. Until a cure is found, we must do what we can to maintain our patients' independence, productivity and positive life experience. We must empower them to take back some measure of control in what may seem to them to be an uncontrollable situation.

To facilitate this level of involvement particularly in the newly diagnosed patient requires education, support and a multi-disciplinary approach. They are facing a progressive illness in the prime of their lives, at the height of their careers, while raising a sometimes young family and as they are building their financial security.

At the time of diagnosis, patients often look to the medical community to serve as a primary source for information and guidance, which although not unreasonable, is sometimes difficult due to time constraints and the number of vital clinical issues that need to be addressed in the time allotted. The testimonials in this booklet attest to the fact that patients do understand to some degree these limitations but feel dissatisfied with their clinical encounter if they leave with what they feel is insufficient information. So if there is not enough time within the appointment, then reliable and informative written material, community or online resources serve an important role.

We can learn a lot from patient narrative and from the input of those interviewed for this booklet, I am reminded of one important caveat - that although we may diagnose any number of patients with a chronic disease such as Parkinson's on a daily basis, for that particular patient and their family, it is the one and only diagnosis. We cannot underestimate the significant impact of those simple words "You have Parkinson's Disease" and the feelings of fear and confusion that inevitably follow. This booklet and the testimonies herein are reminders of this important role we play in supporting our patients throughout this experience.

Dr. Soania Mathur

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WHO IS THIS BOOKLET FOR?

"I think when you get the diagnosis, your life sort of stops. I remember leaving the doctor's office and I must have ran out because I remember his secretary saying 'Don't run.' But there were some people in the waiting room and I just needed to blow. I needed to get out of there. I went into the hallway and I was pacing and I said 'What does this mean? Now what?' ... Because at that point you don't really know what it means ... You have to deal with your kids, you have to deal with your job, you have to deal with getting up every day and all the things you're supposed to do and then deal with this at the same time. And there's no instruction book on how to do that. You don't know where to turn."

Shanna Mellins

s a resource for physicians, this booklet is full of advice from those who have been living with young-onset Parkinson's disease (YOPD) and were willing to share their reflections based on their own experiences. As alluded to in the passage from Shanna above, the needs of those with YOPD are unique. Being diagnosed with a chronic, progressive neurological condition in the prime of life is likely to be a very emotional experience. One of the challenges in creating a booklet on YOPD is the great variability in how the term has been used in the past. In most cases, this variability has been created by researchers trying to operationalize the participants who are to take part in a study. For some, YOPD has meant a diagnosis prior to the age of 40 and for others 45 or even 50. Within my research, I gave people living with the disease the option of self-identifying as someone living with YOPD. This is why the characteristics of those who took part in my study may not meet previously used definitions of the disease. What this illustrates, however, is that characteristics other than age, like employment and parenting, also play an important role in how one operationalizes the term 'young' in their own mind. Further, some researchers have also defined a third classification of the disease, juvenileonset Parkinson's disease, as occurring when a diagnosis is made before the age of 20. The needs of this very rare third group would be even different, and were not considered in the construction of this booklet.

How Was This Booklet Developed?

his booklet is a product of the work completed by Dr. Michael Ravenek and the participants in his study investigating the experiences of individuals living with YOPD. Thirty-nine individuals who self-identified as living with YOPD, primarily from Southwestern Ontario, took part in the study over a two-year period from the fall of 2011 to the fall of 2013. To contribute to the study, participants had the option of participating in a series of interviews with Dr. Ravenek and engaging in online and/ or in-person groups discussing issues related to their experiences and the evolving results of the study.

At the conclusion of the interviews in the early stages of data collection, participants were asked specifically what advice they would give to someone newly diagnosed with the disease, as well as what advice they would give to a diagnosing physician. Additionally, the focus group and interview participants in the later stages of this project reviewed the advice compiled and added to this knowledge base with their own thoughts and experiences.

Subsequent to the creation of the initial version of this advice booklet, 66 individuals from across Canada completed a survey evaluating the booklet and provided feedback on how to improve the content. These individuals included people living with Parkinson's, family members, and health professionals. This second edition represents the collective voice of the participants and the advice they would relay to physicians, as well as the feedback from the survey respondents. Advice that participants wished to relay to others newly diagnosed with YOPD is presented in a separate booklet.

Participant Passages

he specific passages included in this booklet were taken from participant interviews and group discussions, as they do a good job illustrating the main pieces of advice that were raised by all of those who took part in this study as a whole. Additionally, the passages represent responses from participants with a range of experience living with YOPD, from 1-year to 11-years post diagnosis. Brief demographic information about the participants whose advice was included in this booklet is provided below, along with pseudonyms (false names) to protect the identity of these participants.



Name	Age Diagnosed	Years Living with YOPD
Denis Bartoo	53	5
Joella Kline	45	10
Patti Bradner	48	7
Danny Pirie	54	2
Jordan Chicholm	47	11
Shanna Mellins	45	1
Trevor Lyon	41	9

INTRODUCTION

this booklet is not intended to be prescriptive in how diagnostic encounters with young adults with PD should be handled, as every person and situation is unique. Information appropriate for one person may not be appropriate for another, as within YOPD there is great diversity of ages represented, as well as differences in life experiences, education, personalities, etc. Rather, the purpose of this booklet is to highlight specific areas of the physician-patient interaction that all physicians should consider in their encounters with individuals with YOPD. These areas were emphasized by individuals with YOPD who took part in this study, reflecting on their own experiences being diagnosed and living with the disease. The passage on the opposite page from an interview with Denis captures the essence of this booklet and the advice that participants in this study had for physicians. That is, a diagnosis needs to be relayed with compassion and the information presented should provide hope and give the patient tools to manage with YOPD as they learn to adjust living with their condition. This booklet is organized into five sections, with each section building on the one previous to it, emphasizing this message.

"Physicians need to realize that they are a human just as the patient is, and they need to think about how they would like to have such a message delivered to themselves with a certain level of caring, a certain level of information, a certain level of professional distance being maintained, a certain level of hope to be instilled for there being resources to assist a person in their journey."

Denis Bartoo

1. THE DIAGNOSIS IS AN EMOTIONAL EXPERIENCE

"You just overwhelmed them with what you told them. It was good that it wasn't a lot of worse things, but you're still overwhelmed. If somebody tells you that they weren't, they are not telling you the truth."

Danny Pirie

t the centre of the advice dispensed by participants was the need for physicians to better appreciate the emotional nature of the diagnosis experience for individuals with YOPD. The figure below is a creative representation of the most common words used by the participants who took part in this study to describe their diagnosis experiences.

disbelief numbing frightening scary devastating panichelpless traumaticoverwhelming life-altering shock

Speaking of the appointment where she received her diagnosis, Joella recalls:

"I was a mess and I don't think they realized that. I mean this is a totally life-changing thing for this person who you're gonna tell they have Parkinson's. So you've got to spend as much time – I would say at least half of the time not just doing the medical, you've gotta sit down and talk with them and just say, 'you know these are some of the things you might want to think about and you might want to look into.'"

Joella Kline

While acknowledging that physicians have a lot to deal with when delivering a diagnosis, Danny reiterates that the emotional part of caring for a patient with YOPD should never be overlooked.

"They're inundated with all kinds of stuff that I think they tend to forget. They've given you the diagnosis; they started you on the pills, and they think, 'okay this guy is as good as he can get now.' Well, physically he probably is, but mentally I don't think he is there. Don't underestimate the issue of the emotional part because that can be huge, sometimes I think worse than the physical."

Danny Pirie

It was believed that one of the most important things that the physician can do after delivering a diagnosis of YOPD is to normalize the difficult and troubling emotions that patients are likely to experience.

"He did take his time with the diagnosis and he's really great. But, yeah, it's the aftermath – the aftermath, you know. Just say, 'it's okay to be panicking, it's okay to be in shock, you know that's normal.'"

Joella Kline

A second strategy that will help patients to deal with the difficult emotions of a diagnosis is to provide them with information about the disease; and more specifically information that will foster hope and a belief in the ability to manage with YOPD. These points will be discussed in more detail in the sections that follow.

2. THE PHYSICIAN AS A HEALTH INFORMATION GATEKEEPER

Ithough many people access health information on the Internet, in many ways the physician is still seen as the main 'gatekeeper' of health information. People expect guidance from physicians on what to do and where to go for appropriate health information, and neglecting to provide this guidance will sometimes leave patients without the knowledge of where to go to find help.

"He's the one that ultimately gives the diagnosis, provides the treatment and of course people rely on that and a lot of people too much so because they don't have any other avenue to know where to look for information."

Patti Bradner

Of course the most difficult question to answer is "how much information do I provide to a patient?" The participants of this study recognized the difficulty of this situation, as described in the passage below by Patti:

"You don't want to flood them with information because the person may not be ready for it, but there's got to be sort of a way of getting that information as they need it. I guess that's the hard part."

Patti Bradner

3. PROVIDING HOPE THROUGH INFORMATION

pon receiving a diagnosis of YOPD, it is not uncommon for patients to have little or even no knowledge of the disease and, thus, what the future will hold. Often, these patients will think the worst and have concerns about their own mortality. It is important at the point of diagnosis, as described by the participants in the passages below, to inform the patient that YOPD is not fatal and that there are strategies that can be used to manage living with the disease.

"I guess maybe it would be it's not a death sentence. You may think it is, but it's not."

Joella Kline

"I think most people rely on their doctor to have the info. I think it's important that the doctor not give the impression that there's nothing you can do. Parkinson's, there's a lot you can do. Because I think people just think that it's sort of a terminal stamp. I'm not gonna die, but I'll be changed."

Patti Bradner

In addition to calming fears about mortality, it is also important to emphasize the heterogeneity of YOPD to try and reduce fear likely to arise when the patients learn about all of the potential symptoms of the disease and/or see others living in the later stages of the disease.

"One of the things that I hear about is that people are afraid to go to any Parkinson activities because they see older people and it scares them. It is scary if you think about being like that in ten years or so ... Some persons don't go to a Parkinson conference until they realize that everybody is different. Always stress the fact that everybody is different, so they don't waste their time thinking that they'll be like that because you won't be; you might be something completely different."

Jordan Chicholm

Providing Information About Ongoing Research and Clinical Trials

nother way to provide hope to your patients with YOPD is to emphasize the extensive research being conducted to help improve clinical care and the lives of those living with YOPD.

"In order to generate a better outlook for a person newly diagnosed with YOPD, it would be good if the MD delivered a brief statement to the effect that a high volume of research into a better understanding of PD is underway worldwide and that a plethora of exciting and novel treatments are in development with the ultimate aim of finding a cure. Again, words such as this are of prime importance to a person newly diagnosed with YOPD since it will give them hope."

Trevor Lyon

You may even wish to become familiar with the clinical trials and research being done on Parkinson's in your area, so that you can help your patients get involved if they desire. The resources below will help you to locate research and clinical trials being completed in your area. You may also want to consult researchers at your lo-cal university to see what clinical trials are ongoing and recruiting participants.



Parkinson Society Canada – Offers an excellent overview of terms used in clinical research as well as some studies currently seeking participants. To access this information, visit the www.parkinson.ca website or email research@parkinson.ca.



Health Canada's Clinical Trial Database – Acts as a searchable public database of ongoing clinical trials in Canada, largely involving pharmaceuticals and biological drugs. This site is not Parkinson's-specific, so you will have to search using the word "Parkinson's" in the search box in addition to other information to limit your search.

http://www.hc-sc.gc.ca/dhp-mps/prodpharma/databasdonclin/index-eng.php



National Institutes of Health: Clinical Trials – Offers resources to learn more about clinical trials and also acts as a database of ongoing research needing participants and completed research. This site is not Parkinson's-specific, so you will have to search using the word "Parkinson's" in the search box in addition to other information to limit your search. Although the NIH is based in the US, many studies also have collaborators and data collection sites in different parts of Canada. http://www.ClinicalTrials.gov

Fox Trial Finder – After creating an account, you will be able to search for Parkinson's research in a number of different countries, including the US and Canada, searchable by postal code. Even those without Parkinson's disease can create an account and participate in research.

PARTICIPATE IN RESEARCH. BE AN AGENT OF CHANGE.



WWW.FOXTRIALFINDER.ORG

Providing an Information Booklet

here was a desire among the participants to leave the appointment after being given the diagnosis, with tangible information, i.e. a booklet or package. Often this is because of the emotional nature of receiving the diagnosis and not being able to process everything immediately after being told the news. The provision of an information booklet or package was perceived by the participants as a way to 'anchor' them emotionally once they got home and started to process the news. Overwhelmingly, the participants desired a package with resources they can draw on for support, both emotional support and informational support, instead of a package filled with facts about the disease.

With all of the participants,
this was not something done
for them when they were
diagnosed.

The companion booklet to this series, YOPD: Advice for the Newly Diagnosed, has been designed as a potential information package that can be provided to individuals newly diagnosed with YOPD.

"It would have been nice if the doctor had been able to say, 'here's a little package' like a brochure, flyer, booklet or something that you could use to call a person and start that process to find information ... I would have liked to have seen more support early on. I did find some stuff myself, but there was a lot of time missed and a lot of loneliness, as I would call it. And again, the doctor was doing the best that he could, but he didn't take it that step further. It would be nice to have that with all doctors. Just to know that you're not alone, that there are people that you can talk to: that would have been huge in the first week. You do go through quite an emotional ride ... That would be something that would be nice if there was a structured thing saying, okay, once you are diagnosed, or at least strongly potentially diagnosed, 'here's a package.'"

Danny Pirie

4. THE IMPORTANCE OF FOLLOWING-UP AFTER GIVING A DIAGNOSIS

Perhaps just as common as a belief in the importance of being provided an information booklet upon diagnosis was the belief that it would be invaluable for a physician, or the physician's office, to follow-up with a patient after being given a diagnosis of YOPD. Again, the perceived value of this advice was recognized by participants of this study after going through the diagnosis experience and not receiving this type of support themselves.

"I would recommend the doctor schedule an appointment with the patient for a couple of days hence, maybe even a week, to call the patient again and say, 'How are you doing? You're not on this journey alone. How did you make out with contacting the Parkinson's Society? ... That follow-up effort, I think, would be huge in its importance to the patient and it could be the nurse that does it."

Denis Bartoo



"There's not one doctor I don't think that doesn't care about their patients, but I think it becomes – maybe over time they probably diagnose every day. It becomes like you and I having a cup of coffee. I don't think they really totally realize the impact of what they just said to that patient at that moment in time. And it's not that moment in time that bothers me; it's the 24 to 36 hours after that. This person is going to have more issues after they leave the office than when they just sat down ... I would suggest things like a followup visit a week later. It wasn't done for me I can tell you that, but a week or so later just to follow-up and say okay, 'it was pretty big news you just got a week ago, is there anything I can help you with? Do you have any questions?' I wouldn't leave it for three months after. Make time for that patient for another 10 minutes ... I'm not saying overload the doctor more than they are now, but I honestly think that one extra visit for that 10-minute window would be huge for the patient, I really do."

Danny Pirie

Although it would be desirable for the diagnosing physician to be the person following up with the patient, the participants of this study recognized that there are time pressures facing physicians. In lieu of the physician, the medical office could have a dedicated support person to complete the follow-ups by answering questions and helping to provide initial support after diagnosis.

"It would be really nice if you could have a staff member sit down with you and give you some places that you could get information from and just get your feet on the ground a little bit. And sort of run past you what you should be thinking about right now."

Joella Kline

5. INSTILLING A PROACTIVE ATTITUDE

o help patients manage after the diagnosis, seeing that YOPD is manageable and not fatal, it is important to promote behaviors that will help your patients start to be proactive in managing their illness. The importance of developing a proactive approach was the main message in the companion booklet in this series, where individuals taking part in this study relayed advice they would give to those newly diagnosed with YOPD.

Simple things a physician can promote are the importance of exercise, participating in research, keeping a log of symptoms and medication side effects, and keeping track of their questions. Examples of logs that can be provided to patients are provided at the end of this booklet, and are also included in the companion booklet in this series.

In many cases, individuals may have a desire to exercise but not know where to start, or what types of exercise to do. Thus, concrete strategies should be provided to help patients with exercise. For example, it may be wise to refer the patient to a physiotherapist who can provide a tailored program based on an assessment of the patient's current abilities. A second option would be to ask the patient to investigate personal trainers in their community who may also be able to help set up an appropriate exercise program. A number of recent systematic reviews have been completed, investigating the benefits of various types of exercise for people with Parkinson's disease (see references below). Indeed, the reviews document the importance of different types of exercise, including resistance training, dancing, balance training, flexibility training and gait training. However, specific recommendations have not come out of these reviews, as the authors believe that additional research is needed before such recommendations can be made. Thus, a general fitness program tailored to each individual patient would be best.

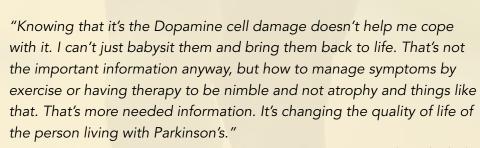
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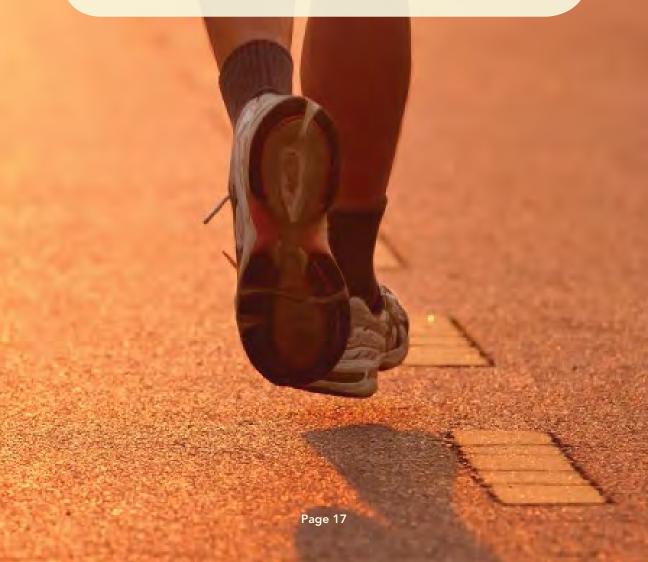
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Jordan Chicholm



RESOURCES

Some Online Resources

he following is a list of some of the resources that participants in this study found useful to consult while becoming knowledgeable about YOPD and the supports that are available. This by no means represents all of the resources and supports available for those living with YOPD, and they will only continue to grow over time.

CANADA

Parkinson Society Canada - www.parkinson.ca

- Regional Offices of Parkinson Society Canada also have their own websites and resources, including:
 - Parkinson Society British Columbia www.parkinson.bc.ca
 - Parkinson Society Saskatchewan www.parkinsonsaskatchewan.ca
 - Parkinson Society Central & Northern Ontario www.parkinsonCNO.ca
 - Parkinson Society Southwestern Ontario www.parkinsonsociety.ca
 - Parkinson Society Eastern Ontario www.parkinsons.ca
 - Parkinson Society Quebec www.parkinsonguebec.ca
 - Parkinson Society Maritime Region www.parkinsonmaritimes.ca
 - Parkinson Society Newfoundland and Labrador www.parkinsonnl.ca
- E-ParkinsonPost: For Canadians Living with Parkinson's http://parkinsonpost.com



Daily Log for Medications, Meals & Exercise

	(Year)	
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NAME	DATE:	PAGE:

NOTE: It is not inquired to track every day between physician appointments as this would be too cumbersome. Try to track 2-3 times per week so that information on both 'good' and 'bad' days can be obtained.

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