

YOUNG-ONSET PARKINSON'S DISEASE

ADVICE FOR
THOSE NEWLY
DIAGNOSED

FROM INDIVIDUALS
CURRENTLY LIVING
WITH YOPD

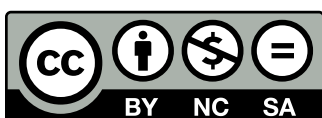
2nd Edition

Young-Onset Parkinson's Disease: Advice for Those Newly Diagnosed From Individuals Currently Living with YOPD (2nd Edition)

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Produced in London, Ontario, Canada

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ACKNOWLEDGEMENTS

First and foremost, I am indebted to the 39 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 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.



Dr. Michael Ravenek

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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FUNDING & SUPPORT

A special thank you goes to Parkinson Society Canada and the Canadian Institutes of Health Research who provided funding for my research in the form of a Doctoral Research Award. The staff at Parkinson Society Southwestern Ontario were also instrumental in supporting my research, helping with recruitment and providing space at conferences to conduct some of my focus groups.

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

You have young onset Parkinson’s disease” – words you were likely not expecting to hear and once spoken, are life changing. My diagnosis came at the age of 27 at the start of my career as a family physician and as I was expecting my first child. That was over fifteen years ago but I can still vividly recall that day and the shock, fear and confusion that followed; fear of the future, confusion about the present.



Dr. Soania Mathur

These are normal reactions to an overwhelming and unexpected life hurdle. And those of us living with the challenge of Parkinson’s disease have all been on the receiving end of this news. For many of us, the journey to taking charge of our disease has been a difficult one. It begins with first accepting what may seem an unfair twist in your life. For me it took close to a decade to recognize that although the diagnosis of Parkinson’s was not within my control, how I faced this challenge was mine to determine. For others in my Parkinson’s community, acceptance came much sooner. In my personal experience, only once you are able to accept your diagnosis, can you move beyond it and begin to take back some measure of control; to make the decisions and interventions that will optimize your health and help you to live well with this disease.

Experience has also shown me that you cannot be a passive bystander and expect to live well with Parkinson’s. You must play an active role in your own management. The suggestions presented in this booklet can serve as cornerstones for you to begin a journey of living well despite the daily challenges you face. Although it may initially seem like an insurmountable hurdle, there are things that you can do to empower yourself, to become an advocate in your own health, to remain productive and engaged, to maintain your quality of life.

It begins with education and becoming an informed patient. Having knowledge of our disease allows us to make sound decisions with our physicians regarding treatment options. This ultimately translates into better health outcomes.

We also need to surround ourselves with support and guidance. The effects of Parkinson's disease are not simply physical. Its impact is pervasive, affecting every aspect of life – physical, social and emotional. We are often at the prime of our lives at the time of diagnosis, at the height of our careers, in the midst of parenting, and trying to build our financial futures. These issues are significant and are more easily confronted when you have a strong circle of support.

Then there is the practical management – keeping a logbook, tracking your symptoms, changes and medications, incorporating exercise into your self-care routine and considering being involved in clinical trials.

This advice and more is conveyed in this booklet by those that have experienced living with this disease first hand. People like you that at some point in time similarly faced this illness for the first time. Despite the fact that our physicians may serve as valuable resources, there is a vast amount of knowledge that can be learned from the experience of others facing the same challenge; insight which is invaluable.

I often think about what I would say to myself at the time I was initially diagnosed now that I've lived with Parkinson's for so many years. I think that the most important piece of advice I would impart is that at some point you have to abandon your fear of the future in order to begin living your present. And with the right information, resources and a multi-faceted approach to management, including self-care, it is possible to live well with Parkinson's.

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

As alluded to in the passage from Shanna above, the needs of those with young-onset Parkinson's disease (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 for individuals living with 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, juvenile-onset Parkinson's disease, as occurring when a diagnosis is made before the age of 20. Bearing all of this in mind, the advice dispensed within this booklet may not be appropriate for everyone. As with advice you receive from any person, you need to weigh the value of the advice in relation to your own personal situation. As such, it is important to read this advice booklet as "suggestions" that may or may not work for you, but at the very least are topics to consider.

How Was This Booklet Developed?


This 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 other individuals newly diagnosed with YOPD, as well as the feedback from the survey respondents. Advice these individuals had for physicians, responsible for the diagnosis and treatment of individuals with YOPD, is presented in a separate booklet.

Participant Passages

The 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 18-years post diagnosis. Brief information about the participants whose advice was included in this booklet is provided below, along with pseudonyms (false names) to protect the identity of each participant.




Name	Age Diagnosed	Years Living with YOPD
Denis Bartoo	53	5
Patti Bradner	48	7
Jordan Chicholm	47	11
Derek Daumer	43	1
Kalvin Giles	53	5
Joella Kline	45	10
Niels Kovitz	37	18
Trevor Lyon	41	9
Shanna Mellins	45	1
Danny Pirie	54	2
Suzanna Viles	27	15

INTRODUCTION

Some of the survey feedback we received on the first edition of this booklet highlighted a desire for more information about the potential motor and non-motor symptoms of the disease and on medication. Although this is excellent feedback, it was a purposeful omission to the booklet based on the advice that study participants had provided during the construction of the booklet. In other words, after receiving their diagnoses, more people expressed a desire for help with managing the difficult emotions stemming from the diagnosis. It was important to develop some knowledge about the disease in the time after the diagnosis, and there are many excellent resources for this information, including the Parkinson Society Canada and other resources listed at the end of this booklet. As a resource for someone just newly diagnosed, another reason for this omission was because of the great variability in symptoms, and medication side effects, that can occur from one person to the next. In other words, the experience of YOPD can be very individual. Therefore, listing all of the potential difficulties that could occur may cause more fear and uncertainty rather than helping in a difficult time.

We fully acknowledge that a booklet can only help so much after receiving a diagnosis. If you are having trouble managing with your emotions after your diagnosis, it is important to understand that there are people you can speak with to get the help you need. What this booklet attempts to do, however, is to give you some insight into what other people living with YOPD have described as advice they would give to someone newly diagnosed. At the very least, the information contained in this booklet might help you to understand that you are not alone in possibly being angry, upset, or scared, and to see some of the strategies that others have used in helping them to manage with the disease.



The advice dispensed by participants living with YOPD for others newly diagnosed focused primarily on the importance of being proactive in numerous facets of life; learning to now put your health and your concerns first above everything else. This mindset and the proactive strategies used, in essence, served to help manage the troubling emotions that can follow after receiving a diagnosis of YOPD. The idea of being proactive stems from the belief that it is up to each person that is diagnosed to make the best of the experience; that is, a sense of personal responsibility is perceived to be important. Given that we live in a society where independence is highly valued, it is not surprising individuals came to see that this responsibility 'to take action' falls on their own shoulders.

Although it was believed that the initiative to make changes and be proactive falls on the person diagnosed, the journey of living with YOPD does not have to be one travelled alone. As we will see in the advice dispensed by those who took part in this project, many of the proactive strategies discussed served to increase the amount of support available to the person. Furthermore, the advice provided about the importance of being proactive did not just cover one specific life area; rather the participants believed that those who are newly diagnosed should become proactive in all areas of their life that can influence their health.

"I have as good a life as I can make it, but do I like having Parkinson's? No. Does it negatively affect me? Yes. Now it's up to me to make the best of it."

Patti Bradner

"Put yourself first. You gotta make sure you're okay before you can do anything for anybody else. You are number one. Take care of yourself first and you will discover that everything else falls into place."

Joella Kline

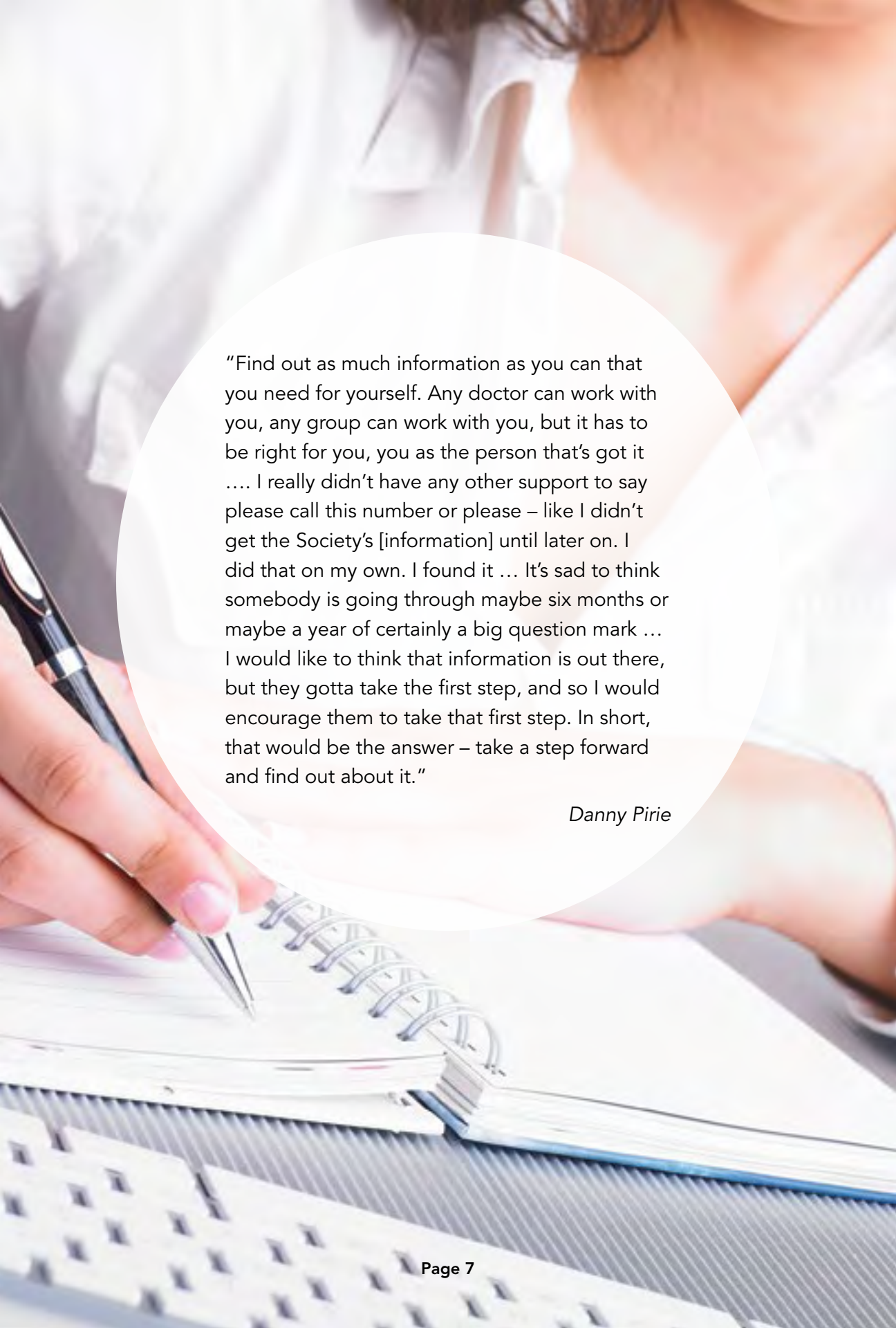
1. WHY GET INFORMED ABOUT PARKINSON'S DISEASE?

One of the common ways that individuals spoke about being proactive was in trying to find out as much information about Parkinson's as they could, so that they had a better idea of what the disease entails as well as the supports and treatment options that were available. A lot of information that they desired in the weeks after receiving their diagnosis was not readily provided to them by physicians. Consequently, they believed that if you are going to become informed about Parkinson's disease, seeking this information on your own is often required and that you should not be afraid to ask questions when you are learning about the disease.

It is important to keep in mind, however, that not everyone will want to learn as much about Parkinson's disease as they can, after their diagnosis. If this is you, then that's okay. In fact, you may have a desire to avoid this type of information. Each person will manage with the diagnosis differently, and having knowledge of the disease will help in its management. Thus, know that resources are available to help you become informed when you are ready. The web resources listed at the end of this booklet are an excellent place to start when you are ready.


"Do the work to understand it and it will help you calm down. The more you know the more power you feel you have."

Niels Kovitz

A close-up photograph of a person's hands writing in a spiral-bound notebook with a black pen. The person is wearing a white shirt. A large white circle is overlaid on the image, containing a quote. The background is slightly blurred, showing a computer keyboard at the bottom.

“Find out as much information as you can that you need for yourself. Any doctor can work with you, any group can work with you, but it has to be right for you, you as the person that’s got it ... I really didn’t have any other support to say please call this number or please – like I didn’t get the Society’s [information] until later on. I did that on my own. I found it ... It’s sad to think somebody is going through maybe six months or maybe a year of certainly a big question mark ... I would like to think that information is out there, but they gotta take the first step, and so I would encourage them to take that first step. In short, that would be the answer – take a step forward and find out about it.”

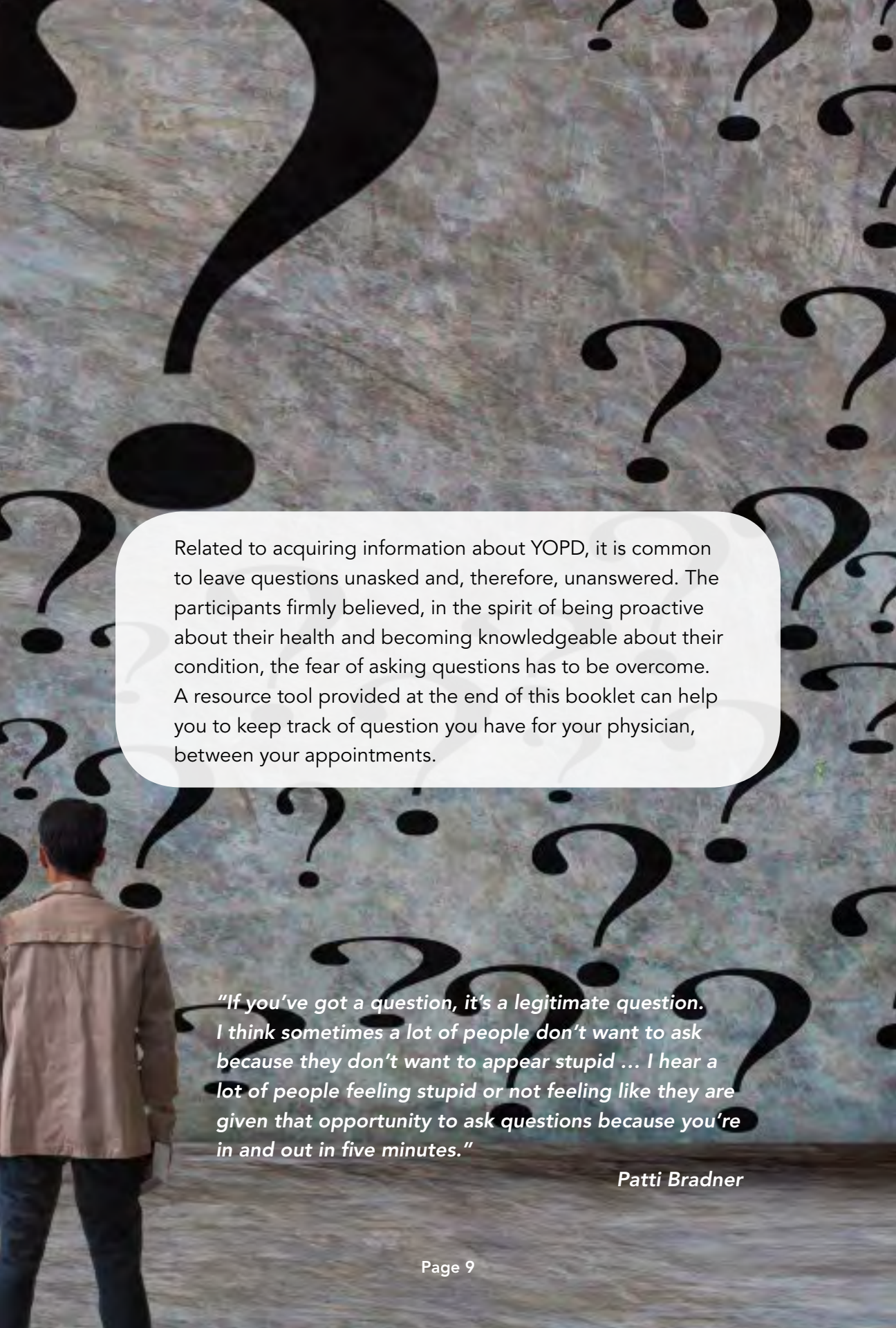
Danny Pirie

The background of the page is a textured, light-colored surface with a pattern of large, black, stylized question marks scattered across it. In the bottom right corner, a portion of a person's arm and hand is visible, reaching towards the edge of the frame.

Once you start looking for information about Parkinson's disease it can be overwhelming because of the wealth of knowledge that is available from a variety of print and online sources. Where does one start and where does one end this search? As alluded to by Danny in an earlier passage, the amount of information that a person will want to know after their diagnosis will vary from person to person. Numerous factors, such as the amount of knowledge a person has of Parkinson's prior to their diagnosis, will influence this search for information. There is no set rule as to how much you have to know right away as learning is ongoing and will continue over time.

"Read as much as you can about your disease. You be the judge as far as that's concerned too because sometimes people don't want to know. But it helped me because I had several things that had gone awry ... So I would say try to find out everything about your disease for now. You know don't go beyond a certain point. It's hard not to know when to stop, but there's just so much out there, there's the internet, magazine studies, conferences, other people."

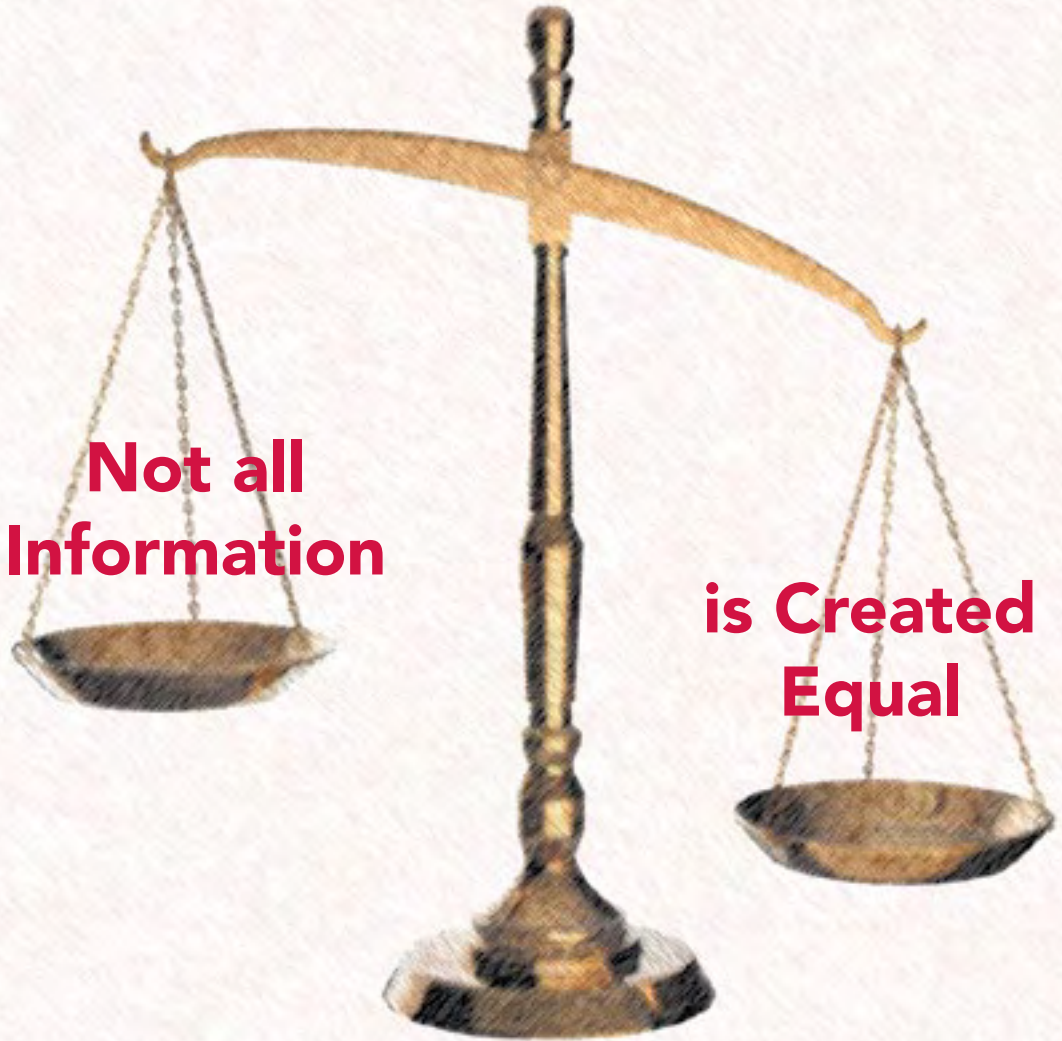
Joella Kline



Related to acquiring information about YOPD, it is common to leave questions unasked and, therefore, unanswered. The participants firmly believed, in the spirit of being proactive about their health and becoming knowledgeable about their condition, the fear of asking questions has to be overcome. A resource tool provided at the end of this booklet can help you to keep track of questions you have for your physician, between your appointments.

"If you've got a question, it's a legitimate question. I think sometimes a lot of people don't want to ask because they don't want to appear stupid ... I hear a lot of people feeling stupid or not feeling like they are given that opportunity to ask questions because you're in and out in five minutes."

Patti Bradner



As important as it is to become knowledgeable about YOPD, it is just as important to understand that some sources are more credible than others. A list of online resources with quality information has been provided at the end of this booklet. If you are ever concerned about the credibility of information you have heard or read, you can always check with your physician to get his/her opinion on the material. A few general rules for assessing the credibility of online information are provided on the next page, which has been previously published by Mike Ravenek in *The Parkinson's Update* (Winter/Spring 2012, Issue 55, p. 10). This is a magazine published by the Parkinson Society Southwestern Ontario and the full article is available online at the Society's website.

The 3 "A's" for Finding Information on the Internet


1. Author	<p>Does the webpage have a clear author?</p> <ul style="list-style-type: none">• A webpage should clearly state who has written the information, whether it be an individual or an organization.
	<p>Are the authors of the webpage trying to sell something?</p> <ul style="list-style-type: none">• Don't be fooled by webpages where the authors are trying to sell you their products, including miracle treatments.
2. Age	<p>Is the webpage current or has it been updated recently?</p> <ul style="list-style-type: none">• A webpage should have a date indicating when an article was written or when it was last updated. Older webpages and articles may not have the most current information.
3. Accuracy	<p>Does the webpage cite references?</p> <ul style="list-style-type: none">• References are usually provided at the bottom of articles and list the sources the author(s) used to pull the information together. When references are not listed, it is impossible to know where the information is coming from and if the information provided is just opinion.
	<p>If so, what types of references are cited?</p> <ul style="list-style-type: none">• Good webpages will list references, but it is also important to look at the references. Are the references from academic journals, (e.g., New England Journal of Medicine), or are they from more opinion-based sources? Can you locate the references yourself?

"You need to read everything with a grain of salt, and make sure that the sources are credible ... there's a lot of bad information on the Internet."

Derek Daumer

Keeping the Information in Perspective

Putting the information you learn into perspective and focusing on the positive aspects of what you are learning was also deemed important by the participants. For example, when learning about YOPD, it is important to keep in mind that it is a chronic disease not a terminal disease. You also may not experience all of the symptoms that you read about. The disease can be very individual with great variability from one person to the next, so even though it is important to know what can occur so that you can recognize changes and can speak with your physician about those changes it does not mean you will experience all of the symptoms of Parkinson's.



"I would want to have learned first of all that it's – there are many different symptoms. Some which can be controlled medically. Some which can't. Some which can be better controlled by diet or exercise of certain types. But the fact that everyone's journey with Parkinson's is basically an individual thing. That the symptoms, the combination of symptoms that one has are unique to you. Someone else may have the same particular symptoms but have them at different strengths or different times of the day or different stages along their life with Parkinson's. So that's the first thing to know that everybody's journey is unique."

Denis Bartoo

"Knowing that it wasn't a life-ending condition; it was an uninvited guest that doesn't go away. You learn that it's possible to adjust your lifestyle and you explore potentials that you have that you never explored before ... If you have to have a disease, it's a good one to have. It's not deadly ... It's not the end of the world."

Jordan Chicholm

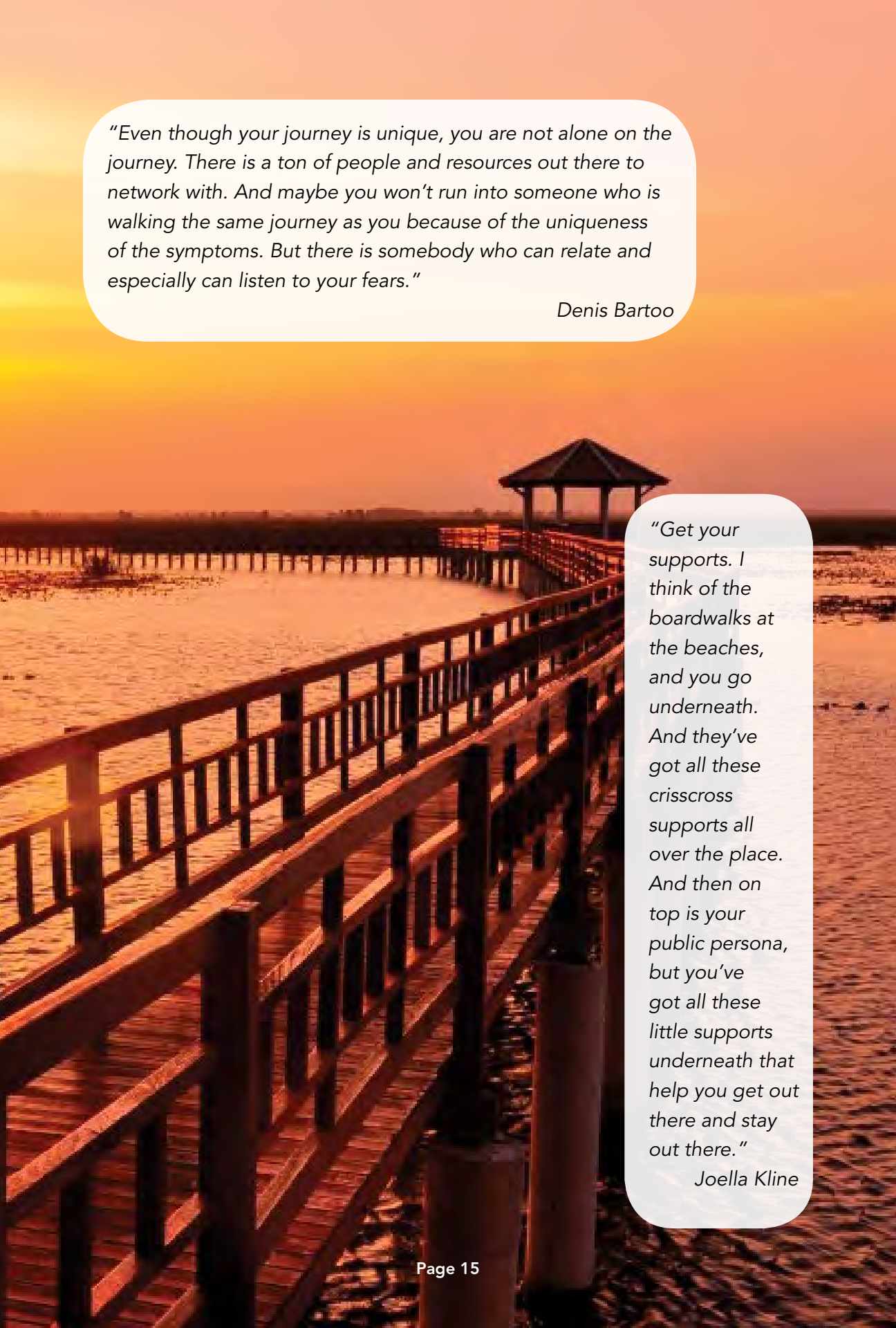
2. SEEK OUT SUPPORT FROM OTHERS

The importance of having a strong support system underneath you while learning to manage with YOPD cannot be understated. While the move to seek out and accept this support is proactive on the part of the person diagnosed, the support itself will help to ease the burden of living with a progressive neurological condition.

In reference to specific types of supports, participants spoke about 'YOPD-Specific' supports as well as 'Family and Friends' as the most important components of their support systems. In some cases, individuals also found it beneficial to seek out the support of a 'Family or Individual Counsellor' to help navigate issues that arise, as well as supports related to 'Employment and Finances.'

These supports will help to complement the support provided by your healthcare team. Beyond your general practitioner and neurologist, you may also want to investigate other health professionals in your area to understand how they may be able to help you. Among others, these could include a:

- Movement Disorder Specialist
- Physiotherapist
- Occupational Therapist
- Speech Language Pathologist



"Even though your journey is unique, you are not alone on the journey. There is a ton of people and resources out there to network with. And maybe you won't run into someone who is walking the same journey as you because of the uniqueness of the symptoms. But there is somebody who can relate and especially can listen to your fears."

Denis Bartoo

"Get your supports. I think of the boardwalks at the beaches, and you go underneath. And they've got all these crisscross supports all over the place. And then on top is your public persona, but you've got all these little supports underneath that help you get out there and stay out there."

Joella Kline

YOPD Specific Supports

Parkinson Society Canada and its regional partners, like the Parkinson Society Southwestern Ontario, were often cited as being an important support specific to the disease for participants. Unfortunately, not everyone was referred to these societies after they became diagnosed, having to locate them on their own after starting a search for information about YOPD.

"Look for support. Because I didn't know there was a Parkinson's Society until I went searching for information and then oh, Parkinson's Society of Canada. Whoa, what's this? So that's one nice thing about having the internet and computers, and all young people do."

Patti Bradner



"I know the Society is there now. I know it now, but I didn't know it then. That probably would have been a big help to call somebody ... somebody who could be like 'is there something I could find for you?' – She's there, she could send you some stuff."


Danny Pirie

Among the many services offered by the Parkinson Societies in Canada are opportunities to meet and speak with other individuals living with the disease. This can occur through a number of venues, including conferences and workshops, support group referrals, and peer mentoring programs. Effectively, these societies act as a 'gatekeeper' for individuals to become more involved in the 'Parkinson's world.'

It is important to keep in mind, however, that not everyone will want to join a support group or attend a conference, after their diagnosis. If this is you, then that's okay. In fact, you may have a desire to avoid support groups and conferences at this point. Each person will manage with the diagnosis differently. Many people do find them beneficial in helping to manage with this disease. Thus, know that resources are available to help you become informed when you are ready. Contacting the Parkinson Society in your area, or visiting their website, will be an excellent way to find out about such programs when you are ready.

"Join a support group of people like you, but not just any support group, because right here is groups from a newspaper and you join in and it's a bunch of 95-year-olds and above. That would not be advisable to a 49-year-old. So if they contacted the Parkinson Society of Canada or the regional offices they might be able to have a young-onset group or have a conference coming up soon that makes it easier for them to get into the Parkinson world."

Jordan Chicholm



As alluded to by Jordan in a previous passage, there is a lot of value placed on the information and insight from other younger people living with the disease. This makes sense given that many of the issues, concerns and priorities are different for younger people living with Parkinson's. The opportunity to speak with and get to know others who have lived with Parkinson's from a younger age was described as an incredible support, even an anchor, for participants.

"I would say talk to people that have it. Just to get a feel of what is going to happen next or even from the mental side of things – There's always the 'what ifs.' Those questions entered my mind, so I'm sure they enter everyone's mind. So that person could say to them, 'I went through those, here's what I did.' The doctor is going to give them the news, but that person is going to go home and the questions aren't gonna come for the next 24 to 36 hours, but then they're gonna flood in. So a mentor or a peer group, yeah, I think that's the key."

Danny Pirie

"When you talk to people who have never experienced it, they don't really know ... they're not living it. When you've never experienced it, I think it's much harder for them to give advice."


Shanna Mellins

"Sometimes the best resource is your support group or someone you know who has Parkinson's."

Joella Kline

Although face-to-face contacts were preferred by participants, those of you using popular social media outlets like Facebook, Google Groups and Twitter will also be able to find support from others with YOPD online. In many cases, Groups or Feeds have been set up specifically for those with YOPD.

As with any online activity, it is always important to keep your own security at the forefront of your mind. Although these services can be used to communicate with others living with YOPD, you should never share personal information in a public online forum (e.g., your address, phone number, etc.).



@ParkinsonCanada
@ParkinsonSWO
@ParkinsonEastON
@ParkinsonCNO



Many national organizations, such as the Parkinson Society Canada, and regional organizations like the Parkinson Society Southwestern Ontario, have their own Facebook and Twitter accounts that can be joined and followed. This is a great way to keep up to date with information coming from these organizations, and the Parkinson's world more generally.


There are many factors that will influence the extent to which family members and friends will act as supports in a person's life with YOPD. The closeness and openness of the relationships participants had with their family and friends prior to the diagnosis being among the more obvious factors. In order for family members or friends to become supports, however, the first step involves the person with YOPD disclosing their diagnosis to those closest to them.

"My wife went with me to the hospital, and then I got the kids together two or three nights later and just was like 'hey guys – dad's got this. We're gonna fight it, and life goes on, but just wanted you to be aware that if you notice things this is why, or if you notice dad taking pills this is why he's taking pills.' We really didn't have a hard time with it in our family, but I know there's got to be some out there that even just to tell their wife or spouse. There's gonna be a change – Your body is gonna be changing, and your demeanor is gonna be changing so they better know what's happening to you or they may think you've become miserable – it could really put a stress on a marriage"

Danny Piries

Family & Friends




A silhouette of a family of four (two adults and two children) standing on a beach at sunset. They are pointing towards the horizon. The sun is low on the right, creating a bright orange and yellow glow. The family's reflection is visible in the water in the foreground.

On a practical level, there are a number of other reasons for disclosing your diagnosis and soliciting support from family members and close friends. First, after disclosing you will be able to share information that you learn about YOPD and doing so will help people come to better understand the disease and the implications it can have on the things you are able to do.

as Supports

"I think the fact to let them, include them, in what's going on. Show them the websites. Talk to them a little bit about your fears. Again, everybody worries about how much do you want to dwell on it so that it gets to the point where that's what your whole relationship's about, but you have to say 'hey, I'm trying to find this information and this is what's out there and no I can't do this because this is how I feel when I do it, but we can do this together because this works better now.'"

Patti Bradner




Second, disclosing will allow you to ask close friends or family members to go with you to medical appointments, which can be very overwhelming for some people. This is illustrated by the passages from participants below speaking about the initial appointment where individuals receive a diagnosis; however, it is still important for follow-up appointments over time as well because of the potential emotional nature of the appointments and the amount of information shared.

"I think if you're going in to meet the doctor to get a diagnosis, I think you should take somebody else with you because I do believe that it's pretty traumatic. It's pretty traumatic finding what you've got. You might think you have a good idea, but when they say the words 'we feel you've got Parkinson's' or 'you've got Parkinson's' or however they word it, it's pretty devastating news. And then when the doctor explains what you're in store for, not everybody's in tune I don't think at that point."

Calvin Giles

"I'd suggest that they ask if there's some family member with you. I was all by myself. If there's someone who could come in and be with you so that you've got two sets of ears, two sets of eyes because right after I think I probably would have been a wreck."

Joella Kline



Although disclosing your diagnosis to others will often open up additional supports for you, in the passage below Derek reminds us that you need to be personally ready to start disclosing outside of the group closest to you. This decision is obviously individual to each person's own situation.

"Don't tell everybody all at once. Don't tell everybody until you are comfortable with yourself. You need to adjust to the news and know what it is before you start telling other people."

Derek Daumer

Employment & Finances

Disclosing your diagnosis to your family will also allow you to start to plan for potential implications on your employment and finances. Employment is a very important issue for younger people with PD, because of the impact the disease can have on the ability to continue to work over time. Setting up a discussion to talk about financial planning is, therefore, important to initiate after receiving the diagnosis. You may even wish to consult a financial planner or accountant to receive professional advice on planning your finances and to review insurance benefits you might have through your employer.

“Look closely at your financials – you just need to know what’s there and what isn’t and what you’re gonna do about it. A lot of people continue to work. They’re lucky they can continue to work. Or they can go on a disability. Especially young-onset because you could use your whole retirement up.”

Joella Kline



Although employment rights for those with a disability have improved over time because of policy changes, such as the Accessibility for Ontarians with Disabilities Act, a number of problems can still occur in receiving workplace accommodation or a disability pension. Given the importance of being able to access these types of programs when you need them, it may be advantageous to seek out the advice of a legal expert for support when problems arise or to just know your rights ahead of time after your diagnosis.

"I would get information from a lawyer if there was one that was willing to help, like an employment lawyer who has dealt with it where people have lost their jobs. Because that's huge with young-onset ... I was fortunate because my employer was very accommodating. However, getting access to a disability pension was another story. You should have heard the way this case worker spoke to me. She brought me to tears. She brought more stress on me than the diagnosis ... they were really pressuring me to go back to work."

Shanna Mellins

Excellent articles and links on both employment and finances can be found within the e-ParkinsonPost (parkinsonpost.com), at YoungParkinsons.org, and through many of the other great resources listed at the end of this booklet.

Family & Individual Counselling

Talking with your children about your diagnosis can be difficult, and depending on the age of your children it may be difficult for them to understand the implications of the diagnosis. If you do decide to disclose to your children soon after receiving your diagnosis, it will be important to always express hope and monitor their reactions over time. In some cases where difficulty arises, it is advisable to find a family counsellor who can help you and your family work through any issues that do develop.



"I ran into problems with my son because he didn't want me to go to school with my cane. And he was just devastated because his dad left, and he was left with a sick mother. And he had a lot of trouble – I mean, he was fine at home; but he didn't want any of his friends to know. So that was hard. That was really hard, and he wouldn't even say the word 'Parkinson's.' He said, 'I don't think you should come to my basketball games anymore.' So that kind of surprised me. I thought how do I deal with this? And sometimes these things come right out of the blue. It's like wow. I didn't expect that to happen ... So you might want to think about getting someone who's a counselor for your family, someone who knows about Parkinson's and other movement disorders. They're out there. You just have to scratch the surface a little bit."

Joella Kline

Although YOPD is a disease that affects the whole family, participants also spoke of the need to sometimes seek individual counselling to help navigate the feelings and emotions that can occur after receiving the diagnosis. Anger, depression and denial, among other difficult emotions, can occur in cycles and at various points in your experience with the disease. Although speaking with family members and friends about these emotions is one option, speaking with a psychologist, a psychotherapist, or a psychiatrist may be able to help in ways that family members and friends cannot.

"Therapy is definitely a good alternative ... You can't do it alone. You're not thinking straight. Your thinking at the beginning of the future and what's going to happen and how's it going to affect me. Everything piles on you at once ... You need someone that's separate, who isn't emotionally attached ... someone to talk to outside of your immediate family ... to help you sort things out."

Shanna Mellins

It is very common for those living with a chronic illness to seek out some sort of counselling, so you should not be concerned about potential stigma in society. If you believe you stand to benefit from it, you should look into it. Depending on the type of counselling, some coverage may be provided by your provincial health coverage (e.g., OHIP) and some coverage may also be provided by supplementary health benefits for those that have them. If you think that you and/or your family would benefit from counselling, you should consult one of your physicians (family doctor or neurologist) for advice and a referral.

3. TRACK CHANGES AND QUESTIONS

One additional proactive strategy that participants spoke about was keeping a journal or a log of your experiences with medications, meals and exercise, specific questions that you have for your healthcare providers as well as main issues affecting your well-being. Examples of logs that can be used are provided at the end of this booklet.

By logging your experiences, such as side effects and wearing off periods or unusual symptoms, your physician will be better able to manage changes in your medication. Given the long duration between appointments to see specialists, combined with the brevity of the appointments, it is easy to forget the questions you wanted to ask. Keeping a log of your questions will help to ensure your questions get answered.

“Take your medication as prescribed, but keep a log of your experiences so that the influences of diet and quantity of medication and timing of taking the medication can be looked at in retrospect and adjustments be made with quickness and accuracy to give you better results from the medications ... The combination of taking the drugs as prescribed and documenting the experience with those and the influence that the timing or the diet helps your quality of life along that early part of your journey.”

Denis Bartoo

"One thing is I think probably most people want all the answers all at once and you're never gonna get all those answers at once. I think you just have to write down your questions."

Patti Bradner



4. KEEP ACTIVE


One of the most common pieces of advice given by those participating in this study was to stay active. Staying active was a way for people to help maintain their level of functioning over time, and there is certainly a body of research that supports the importance of regular exercise. The type of activity done by each individual will vary with their preferences, but the most important thing to do is to *remain active* and *do things that you enjoy*.

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.

Similar to any exercise program that one undertakes, it is important to receive clearance from a physician ahead of time, and to slowly progress the duration, frequency and intensity of the workouts. Working with a personal trainer and/or a physiotherapist in your community would be an excellent option for those who would like to take part in a program that incorporates different activities and progresses at an appropriate pace.

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A person is running on a path during sunset. The person is wearing red shorts and white sneakers. The background is a warm, orange glow from the setting sun, with a blurred path and some greenery in the distance. The person's legs and feet are the main focus of the image.

"Exercise, exercise, exercise. I can't say that enough. Find something you like and just do it ... I'm always amazed at how I'm so much more positive when I exercise and I get up the next morning and just feel great. And it's so unusual for a Parkinson's person to – you know – feel great."

Joella Kline

"Exercise as much as you can ... if you asked me if I learned anything, is to keep active, to keep active and keep involved."

Kalvin Giles

"Exercise is my new drug for Parkinson's. It has made such a difference for me."

Trevor Lyon

5. VOLUNTEER FOR RESEARCH ON PARKINSON'S

Described by a number of participants was the importance of volunteering for research studies that seek to improve clinical care and, more generally, the lives of those living with YOPD. This advice booklet, for example, would not have been possible without the time invested by participants. Unfortunately, many Parkinson's studies have difficulty recruiting enough participants, despite the benefits that can result from the research. Some studies will offer support for participants, to help them with travel or other expenses that may be incurred by participating. This will vary, however, from one study to the next.

"We need to support whatever research efforts are available ... it helps yourself and the cause in general. It can lead to empowerment and also increases your interaction with health professionals. It is hugely disappointing that 30% of clinical trials don't even recruit a single patient and a greater percentage are being delayed because of trouble with recruitment."

Suzanna Viles

"Clinical trials and other research are providing a lot of reason for hope."

Trevor Lyon

If you are interested in learning more about Parkinson's research being done in your area, please use the resources on the next two pages. You may also contact the nearest university in your area, or ask your neurologist, to find more information about ongoing Parkinson's research.



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 **Santé Canada**

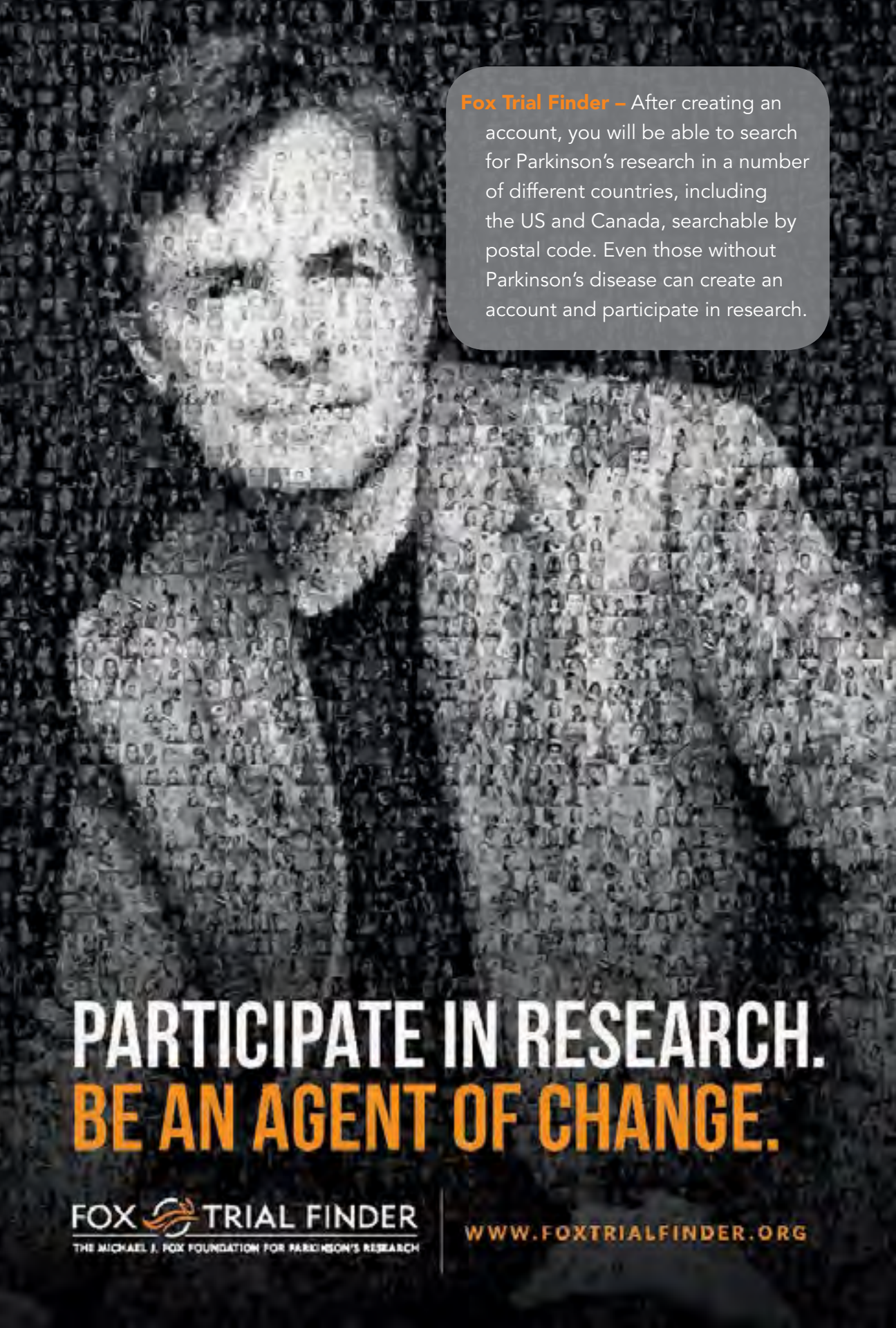
Health Canada's Clinical Trial Database – Acts as a searchable public database of ongoing clinical trials in Canada, largely involving pharmaceuticals and biological drugs. This site is not Parkinson's-specific, so you will have to search using the word "Parkinson's" in the search box in addition to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

FOX  **TRIAL FINDER**
THE MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH

WWW.FOXTRIALFINDER.ORG

6. WHAT NOT TO DO

Although the focus of this booklet has been on being proactive and the different strategies one can employ to help manage after receiving a diagnosis of YOPD, some participants also thought it was important to highlight specific things that you should not do after diagnosis.

On Making Changes

"You just found out that you got Parkinson's. Don't panic ... There is no need to rush into changing your life drastically. You already have to deal with uncertainty. So selling your house, resigning from your job, et cetera, will just make life more complicated ... I think it would probably be in everybody's best interest to not get ahead of yourself. Like, just deal with what you're dealing with now. If it's just a bit of trembling in your fingers, or you've got a stiff neck just deal with that."

Joella Kline

On Struggles

"Don't expect yourself to be optimistic all of the time ... Sometimes I get upset with myself after having a down day, but I have to recognize I'm only human and I'm going to have down days. Those down days are normal."

Suzanna Viles

"Don't beat yourself up. And I'm not quite sure what that means totally, but I think take your time, give yourself a break every once in a while. You don't have to be – not every little thing is a sign of bad things to come."

Patti Bradner

"Don't be hard on yourself as far as getting your life back together. It takes time, and it takes different amounts of time and different things that are going to make it right for people. It takes more time for some than others ... You have to give yourself time ... You need time to grieve and learning to cope with what you have ... It's not a death sentence, it's something you have to adapt to over time."

Shanna Mellins

And Most Importantly

"Don't underestimate yourself." Joella Kline

RESOURCES

Some Online Resources

The 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.parkinsonquebec.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>

TO USE

USA

- *American Parkinson Disease Association*
www.apdaparkinson.org
- *National Young Onset Center*
www.youngparkinsons.org
- *Davis Phinney Foundation for Parkinson's*
<http://www.davisphinneyfoundation.org/>
- *MedlinePlus*
<http://www.nlm.nih.gov/medlineplus/>
- *Michael J Fox Foundation for Parkinson's Research*
<https://www.michaeljfox.org>
- *National Institute of Neurologic Disorders & Stroke*
www.ninds.nih.gov
- *National Parkinson Foundation*
www.parkinson.org
- *Parkinson's Action Network*
www.parkinsonsaction.org
- *Parkinson's Disease Foundation*
www.pdf.org/

OTHER

Designing a Cure - <http://www.designingacure.com/>

European Parkinson's Disease Association - <http://www.epda.eu.com/en/>

Parkinson's UK - <http://www.parkinsons.org.uk/>

The Parkinson Hub - <http://www.theparkinsonhub.com/>

The Cure Parkinson's Trust - <http://www.cureparkinsons.org.uk/>

World Parkinson Congress - <http://www.worldpdcongress.org>

World Parkinson Disease Association - <http://www.wpda.org>

Daily Log for Medications, Meals & Exercise

NAME: _____

DATE: _____ (Month) _____ (Day) _____ (Year)

PAGE: _____ of _____

NOTE: It is not required 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.

Time of Day	Activity (Check One)			Description of Activity Describe the medication(s) taken and dosage(s), all food ingested, or the exercise completed at this time of day.	Did You Experience Unusual Symptoms or Side Effects After this Activity?		
	Meds	Meal	Exercise		Yes	No	
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	Only if Yes: Description of the specific symptoms or side effects that you encountered. <input type="checkbox"/> Dyskinesia <input type="checkbox"/> Dystonia <input type="checkbox"/> Freezing <input type="checkbox"/> "Off" Periods <input type="checkbox"/> Other: _____
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Dyskinesia <input type="checkbox"/> Dystonia <input type="checkbox"/> Freezing <input type="checkbox"/> "Off" Periods <input type="checkbox"/> Other: _____
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Dyskinesia <input type="checkbox"/> Dystonia <input type="checkbox"/> Freezing <input type="checkbox"/> "Off" Periods <input type="checkbox"/> Other: _____
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Dyskinesia <input type="checkbox"/> Dystonia <input type="checkbox"/> Freezing <input type="checkbox"/> "Off" Periods <input type="checkbox"/> Other: _____
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Dyskinesia <input type="checkbox"/> Dystonia <input type="checkbox"/> Freezing <input type="checkbox"/> "Off" Periods <input type="checkbox"/> Other: _____
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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Dyskinesia <input type="checkbox"/> Dystonia <input type="checkbox"/> Freezing <input type="checkbox"/> "Off" Periods <input type="checkbox"/> Other: _____

Questions for My Next Doctor's Appointment

NAME: _____
 DATE OF MY NEXT APPOINTMENT: _____ (Month) _____ (Day) _____ (Year)

NOTE: Given that your time with your physician is sometimes limited, try to rate the importance of each of your questions so that you ask the most important questions first.

#	Question for Doctor	Level of Importance to Me (Check One)		
		HIGH	MEDIUM	LOW
1		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Young-Onset Parkinson's Disease: Advice for Those Newly Diagnosed From Individuals Currently Living with YOPD (2nd Edition)

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