

**A Young Parkinson's woman's guide to pills, periods, pregnancy, parenthood, prevention, prognosis, and the power of a positive perspective (when diagnosed with an old man's disease).**



# **IN HER SHOES**

**Written by women who have walked that path.**





# Foreword

**What's the point of this little book? We like to think we've come a long way, young onset Parkinson's disease (YOPD), but the discrepancy in healthcare is yet another victim of the gender gap and one of the areas this little book hopes to address.**

**In some cases, authors of this booklet have been immersed in the Parkinson's community for the last few years - and not by choice. They are living with YOPD.**

James Parkinson observed his few subjects to later feature in his book *The Shaking Palsy* at a time when women were largely unseen and unheard. The suffragette movement was still a good hundred years in the future. The medical research world is still male-dominated – most of the mice are even male in Parkinson's research!

With YOPD, women face challenges on at least two fronts - age and gender. While more men are diagnosed with YOPD, with the notable exception of Japan, more women are being misdiagnosed with functional neuropathy or, worse still, labelled 'hypochondriac' and told it's all in their head.

Now, because Parkinson's knows no

boundaries, consider the international angle. Huge Kudos to the WPC and Eli, the woman at its helm, for supporting this project. There are many discrepancies and inequalities in nations desperate for levodopa and struggling with stigma. Most could not seem further removed from the classic illustration of an old white man with Parkinson's.

Different religions, cultures, diets, customs, lifestyle choices, and access to healthcare and education all play a part in levels of awareness, therapies available, and even the initial onset of the condition.

Considered 'the most complex neurological condition', Parkinson's is full of confusing and contrasting symptoms. A syndrome of many conditions and subcategories with symptoms constantly appearing and disappearing and side-effects of the medications masquerading as symptoms... what we learn in one study can often be conflicted in the next.

As the title of this booklet suggests, the

concise insights within these pages are based on personal learning experiences of YOPD women, a group side-lined more than most in the research. Topics covered include personalised medicine, periods, pills, and pregnancy.

The title's irony is that this constantly changing condition will probably result in any woman diagnosed having to trade in her favourite heels for sneakers.

This is by no means a definitive work; it's more a rallying cry for YOPD women to take charge of their condition, learn, teach, support, and share. It's a starting point. YOPD women of the world, we are passing you the baton and inviting you to join the race.

With love to the supportive YOPD sisterhood across the globe. Let's support each other!

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# Personalised medicine

There are many types of Parkinson's with wildly different symptoms, both motor and non-motor. Some types of Parkinson's are genetic. Those with a recognised gene at fault - called monogenic - are easily identified and tested for. In the YOPD world, that includes Parkin (PRKN; PARK2) and PINK1. DNA from a blood sample is generally used for testing and sequencing. DNA can also be extracted from a cheek swab and is more easily collected.

## **This time it's personal!**

A mix of genetic and environmental factors may cause other types of YOPD. Genetic variants are identified through targeted gene sequencing, exome sequencing (WES), or whole genome sequencing (WGS). Gene sequencing is now widespread and relatively cheap.

In the UK, the NHS recently introduced free sequencing to anyone diagnosed with YOPD under 50. To date, global Parkinson's sequencing has overwhelmingly concentrated on the elderly, white male Parkinson's population. While there is now a push to work with ethnically diverse populations to be more inclusive, women with YOPD are still overlooked.

Genetics offers the potential to find YOPD causes and subsequent cures and might lead to preventative therapy for the next generations. The younger the onset, the more likely genetic factors are involved.

Sadly, concerns about data security (genome discrimination) and what else they may find deters many people from having their DNA sequenced. Others don't want to feel responsible for passing Parkinson's onto their kids. Finally, others don't see the point of donating a genetic sample until there's a cure.



Only debate, discussion, and time will change this mindset. Before we fixate again on 'cure,' we must provide the



information for ‘cause.’ That’s why genome information is collected, stored, and sequenced, with access to the de-identified data provided to the global research community.

Personalised medicine is possible and achievable and will be built around symptoms and genetics.

Participants (or their parents in the case of infant sequencing) need to understand that the presence of a gene mutation only shows potential for disease; other factors may well come into play. Only by sharing this information and delving deeper will we understand the bigger picture.

*“It’s easy to spot a difference. When Spotlight YOPD was founded as the first dedicated charity for young onset, we knew that our community was different. And within that community, we knew women had their own experiences. It’s only when you chat with other young women with Parkinson’s that you realise how much you have in common.*

*Most Parkinson’s researchers are male, and most movement disorder specialists are male. Why are we so surprised that they don’t fully understand female hormones and how Parkinson’s impacts the menstrual cycle and vice versa?*

*I spent my first seven years post-diagnosis looking for a gynaecologist with some understanding of ‘this old man’s disease.’ I finally found one in Annelien, who came with the ultimate qualification of lived experience. (Annelien is one of the co-authors of this book.)*

*The first time I voiced my concerns and experience out loud was when I spoke at the Parkinson’s Eve event in 2019, the brainchild of another woman from the YOPD community. The audible murmur of ‘me too’ travelled across the room. Confirmation that within this rare cohort of this rare disease, the impact of our menstruation on our medication was widespread and not uncommon.*

*As co-creator of this little book, I hope our words will encourage greater deeds by YOPD women who follow in our footsteps.”*

Gaynor Edwards, CEO of Spotlight YOPD, United Kingdom

# Population

**The traditional image of Parkinson's stems from the line drawing by William Richard Gowers in *A Manual of Diseases of the Nervous System*, first published in 1886.**

The pen and ink sketch conveyed the classic Parkinson's posture and little else, except that the subject was clearly old, white and male. He appears to have been the preoccupation of the Parkinson's research community ever since.

We now know that Parkinson's does not discriminate and can impact people of all ages, races, and genders, although it's taking a while for the lab coats to redress the balance.

**Parkinson's does not discriminate. Recent data reports that 40% of those diagnosed are women.**

Recent data reports that 40% of affected individuals are women. Anecdotally, we know that many women struggle to secure a diagnosis, especially younger women who are often considered too young and too female; frankly too far removed from the line-drawing image of Parkinson's which most of us are familiar with.

Accurate figures for Parkinson's are

hard to substantiate because a diagnosis is hard to make. It's not unknown for those diagnosed to discover, often through genetic sequencing, that they have another form of Parkinsonism or a newly discovered rare genetic condition. Some may even present with side effects masquerading as symptoms; many are too similar for the patient or clinician to accurately identify the difference.

Subject to universal genome sequencing or, at least, a more reliable means of diagnosing Parkinson's, current estimates put the figure globally at 10 million individuals with Parkinson's - 2.7 million in China, 1 million in the US, 145,000 in the UK, and 120,000 in Spain.

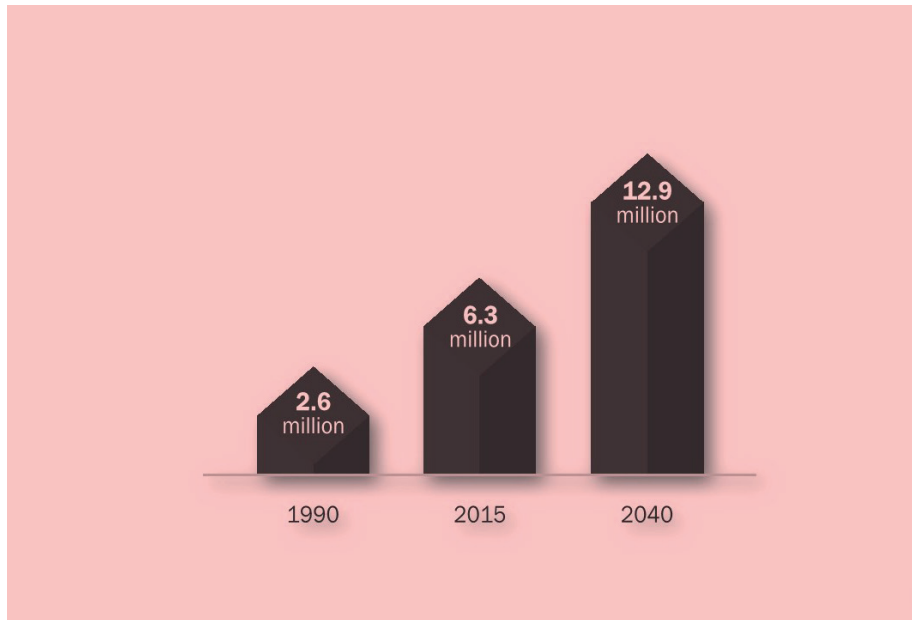
As the second most common neurodegenerative disease after Alzheimer's; Parkinson's often gets lumped together with Alzheimer's by the media, which is rarely helpful. Assumptions that anyone with either condition is elderly and cognitively challenged not only increase the chance of stigma but negatively impact an individual's ability to remain employed and earn a living.

In the US, employment lawyers recommend that those diagnosed do not go public for this reason.

Imagine being diagnosed with YOPD at 40 and trying to hide it for 10 – 20 years because people’s misunderstanding of

it could impact your ability to work or receive disability benefits. With estimates of YOPD ranging anywhere from 4-20% (and growing) of those with Parkinson’s, that’s a large part of the population being marginalized. We need to change that.

## **Parkinson’s is the world’s fastest growing brain disease.**



**“Sport is my #1 medicine. Not only does it have a great, positive effect on my physical abilities, but it also gives me such a powerful mental boost.”**

**“The fact that I am still able to run marathons makes me feel confident and in control. I would advise every person with Parkinson’s to move as much as they can.”**

# Physical Activity

Exercise benefits several motor challenges in Parkinson's, including gait, balance, flexibility and posture. It improves overall physical capacity, and reduces risk of falls. Growing evidence has also shown benefits over non-motor symptoms such as cognition, mood, constipation, and sleep quality.

Robust evidence shows that a sustained increase in overall regular physical

## **Exercise, boost your happy hormones, feel good both physically and mentally.**

activity levels in people with young Parkinson's was associated with a slower disease progression.

There are many exercise options, but the ones most recently studied in Parkinson's, include dance, aerobic exercise, Tai Chi, Qigong, Nordic walking, boxing, and aquatic exercise. Ping pong/table tennis, pickleball, golf, tennis, cycling, and soccer have also been reported as good exercise options.

Women often sacrifice their own needs for the demands of the family. They will prioritise running kids to after-school clubs rather than attending a dance

class - which would have physical, emotional and social benefits to the YOPD woman.



It's important for people living with YOPD to find a form of exercise they enjoy. This will keep them motivated. If they still have trouble getting started, they may choose to find an exercise group and do sports together. There are many Parkinson's exercise initiatives.

Doing sports will boost endorphins and dopamine, making people feel good physically, and mentally. This is especially important in women with YOPD who tend to be more likely to experience depression.

# Pills

Most people diagnosed will take medication to control their symptoms. While not a cure, medication can dramatically improve quality of life for those living with Parkinson's.

Happily, our medication knowledge is evolving. People may become discouraged when a medication doesn't work at first, but it's important to remember that it is often a case of trial and error to find the right combination of therapies. That combination will be unique to every individual.

**Our size, fat composition, and hormone fluctuations (from periods to menopause) can impact our response to medications.**

Historically, women were not included in clinical trials for medications. We are learning that our size, fat composition, and hormone fluctuations (from periods to menopause) can impact our response to medications. Therefore, discussing the effectiveness of medication and how it fluctuates with hormones is imperative.

At certain times life choices may require a change in medication - for example, when planning a family. It is possible to get pregnant with YOPD. If one is

considering pregnancy, they should consult with their care team to review and monitor medication intake during pregnancy and lactation. Within the YOPD community, there are many women who have had successful pregnancy, birth, and parenting experiences. A foetal/maternal specialist would be a useful addition to the care team.



It is critical to maintain regular healthcare screenings. Parkinson's and its treatments can impact bone density, melanoma risk, changes in sexual function and desire, increased migraines, and bladder infections.

# Periods

**Anecdotal evidence shows that Parkinson's medications may work differently - or not at all - during or before menstruation. This is not well documented in the scientific literature and many Parkinson's care teams are unaware of this issue.**

Many women report issues from a week before through to the first few days of their cycle. Some women have issues during ovulation. Symptoms are not managed well with medication, and some motor and non-motor symptoms may become prevalent. There are research surveys aiming to characterise these disruptive issues. Unsurprisingly, there is no agreed-upon treatment for YOPD women and periods. Some

women, if taking a form of levodopa, will take extra doses.

There are different philosophies and practices, and we recommend women with YOPD always communicate with their care team. Birth control is often recommended but there is a lack of data on how effective it is, with only anecdotal evidence. Many women have reported such issues.



# Partnered or single

YOPD may pose challenges for relationships. It's not just the person diagnosed living with Parkinson's. Care partners understandably worry. A person with YOPD may experience a shift in things that matter to them post diagnosis, their behaviour may change due to medication or simply due to these altered life values. They may become insecure about their looks and femininity. Parkinson's may also impact their sex life and change their libido.

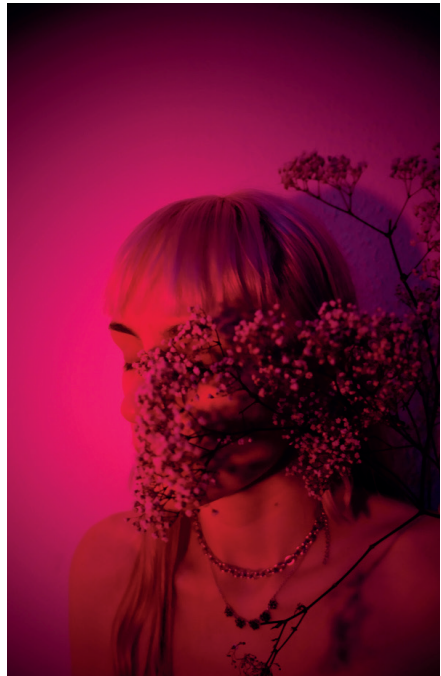


Keep the lines of communication open, consider seeking help from a therapist. An important conversation for YOPD women to have, may involve how they want to ask for and receive help and/or feedback.

Often partners will notice a symptom

**Keep the lines of communication open; seeking help from a therapist may be needed.**

before the person with Parkinson's will. Many find that setting aside a regular time to discuss Parkinson's with loved ones and health care team is a good strategy. There are tools to help guide discussions about Parkinson's. Some find it useful to join a YOPD support group or YOPD care partner support group. Individuals can ask their local Parkinson's organisation for help and local resources.





Communication tools can take many forms. Therapy or counselling with a trained professional can be helpful if someone is struggling with their diagnosis.

For those single and living with Parkinson's, having or developing a support network is essential. They likely already have this in place with family, friends, work colleagues, or faith community.

As with other parts of life, community is important. People who live the longest report having people they can rely on to help in times of need and have many

people they interact with regularly. There is often an increase in domestic violence toward women during pregnancy, disability, and periods of financial stress.

It's important for people with Parkinson's to communicate with their support network to be aware of any increased risk and seek help when needed.

We all feel alone at times, regardless of support. During these moments of darkness and loneliness, it's important to remember that there is an entire community of YOPD sisters that can empathise.

**We all feel alone  
at times,  
regardless of support.**

# Profession



After a diagnosis of YOPD, it may be difficult to maintain a career and keep working. A woman living with YOPD may struggle with symptoms, making it difficult to keep functioning at the same level they're used to.

They may struggle with their employer and/or colleagues, having difficulties in deciding to share or not to share their diagnosis, or having to process a negative reaction after telling others. This may have a big impact on how they feel at work.

It is possible that they may struggle with their own motivation because a shift can occur in what truly matters to them. Consequently, their career may not feel that important anymore.

**A woman living with YOPD may struggle in deciding to share or not to share their diagnosis with their employer.**

*"I feel that I am incredibly lucky to be a biology professor at a small, private college. I am very open with my diagnosis and have shifted my research from stem cells to women and Parkinson's. I have a network of faculty and student collaborators throughout the campus!"*

**Kristi LaMonica, USA**

*"Before my diagnosis, I was the director of midwifery in a large inner-city hospital. I spent long hours on call at the hospital delivering babies. With my diagnosis, I decided it was important to focus on my health and decided to leave the career I loved. Since that shift, my Act 2.0 has begun. I am now an author and advocate for those living with PD. I am truly blessed to have had the opportunity to pivot to find a fulfilling and meaningful path."*

**Kat Hill, USA**

*"As a movement disorder specialist (MDS), who treated over a thousand individuals with Parkinson's, I was keenly aware of the strengths and limitations in the treatment and diagnosis of the disease. Just as I was beginning to be cognizant of the possible gender differences in presentation and evolution particularly among those with YOPD, unbeknownst to me the same illness which had driven me to become a doctor had already begun to take root. As it began to develop and progress, my years of training, knowledge, and own personal experience as patient and caregiver confirmed that there is much more to this disease than we ever imagined, and gender does indeed play a role in how it presents and progresses. Hence, my work as an advocate and champion for women with PD began 16 years ago."*

**Maria L. De Leon (aka Parkinson's Diva), USA**

*"I was 37 when finally diagnosed with Young Onset Parkinson's. Looking back, I believe my first symptoms presented when I was just 10 years old. My mother was concerned at my distorted dystonic feet. I don't want the next generation to have to go through the same painful process. Every day I work to help other young patients in Japan understand this disorder. Over time I connected with some wonderful people, including my neurologist Dr. Hattori and other patient advocates across the world. The path I have taken has been hard, but it has brought many new encounters and much happiness."*

**Mie Maruyama, Japan**

# Pregnancy

**Getting pregnant with YOPD is possible. However, it is difficult to make a well-informed choice.**

The literature on pregnancy and YOPD is scarce. Many YOPD women are concerned before making the decision to start a family. For example, they may worry about whether their medication will harm their baby.

The use of Carbidopa/levodopa is most commonly advised for expectant YOPD mums with no adverse effects on newborns reported. Dopamine agonists may be safe but need more research. Amantadine is known to be harmful to a developing foetus and should be avoided. It's critical for women to communicate with their healthcare team about any medication they are taking.

YOPD women may not only worry about their baby but also their own health. Literature suggests that 50% of women experience worsening of Parkinson's symptoms during pregnancy and childbirth. There is no evidence on why 50% worsen and 50% do not. It may partly be explained by the group of women that completely stop their medication use because of fear of

harming their baby and consequently experience greater Parkinson's symptoms. According to the limited data, medication can be continued and stopping it will only result in poorer quality of life.

The course of Parkinson's symptoms after delivery and the impact of pregnancy and delivery on disease progression has not been reported.

Regarding medication and its effect on breastfeeding, there is also an overall lack of evidence about medication transmission and safety. Most women are advised not to breastfeed if taking Parkinson's medications. If they want to breastfeed, it is important for them to be aware that suboptimal dopamine may impact lactation. As with any decisions involving pregnancy and parenting, a careful assessment of risks and benefits should be made with the support of the healthcare team.

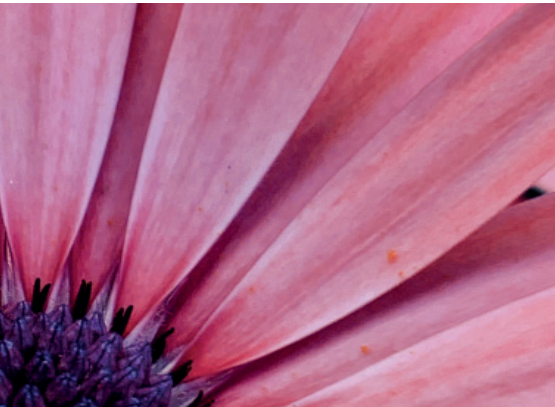


If a YOPD woman is considering pregnancy, they should talk to their healthcare team and reach out to their YOPD community. Together, everyone can share experiences and support one another.

**There is no research to indicate that Parkinson's impacts fertility.**

To close the gap in knowledge, a prospective worldwide registry for Parkinson's and pregnancy is being developed. This will change the future of YOPD and pregnancy.

To date, there is no research to indicate that Parkinson's impacts fertility. If there are no plans to have further children, it is important to initiate or continue a suitable birth control method.



Women pregnant with  
Parkinson's can register  
themselves on  
**[www.pregspark.com](http://www.pregspark.com)**.

YOPD community, please  
spread the word and help  
us collect data on as many  
pregnancies as possible.

Initiatives like this will allow  
YOPD women to make an  
informed choice and better  
prepare themselves!



*“From my own experience last year, having my fourth child but my first after being diagnosed with PD, pregnancy and Parkinson’s go well together. To decide to become pregnant felt risky, since the literature is scarce on this topic, and I just didn’t know what to expect. Most important to me, besides the potential risks for my baby, was whether disease progression would accelerate due to pregnancy. Being a gynaecologist, I dove into the literature but didn’t find any proper answers. This needs to change!*

*It has been my personal mission to build an International Pregnancy Registry for women all over the world living with Parkinson’s.*

*The registry was launched in 2023: [www.pregspark.com](http://www.pregspark.com). All pregnant women with Parkinson’s can register on this website.*

*Thankfully, I am back to my pre-pregnancy shape again, and physically fitter than before. For me it turned out great, and I am really enjoying my beautiful family. Something I wish for all wannabe YOPD mums.”*

**Annelien Oosterbaan, MD, PhD, The Netherlands**

*“After receiving a Parkinson’s diagnosis at the age of 32, I was concerned about getting pregnant and, even if I did, whether I would be able to carry the pregnancy given my health condition. Despite my Parkinson’s symptoms, I became pregnant, carried to term (my Parkinson’s symptoms improved significantly during this time), and gave birth to my baby. One lesson having Parkinson’s has taught me, among other things, is to embrace each day as it comes.”*

**Rachel Agwu, Nigeria**



# Parenthood

Many people with YOPD are actively parenting when their diagnosis is made. It can make the diagnosis more challenging begging the question, “How can I possibly care for my children and care for myself?” For single parents, this can be even more challenging, but it can be done. Here are some things to consider.

## **How can I possibly care for my children and care for myself?**

Embrace your community - family, friends, social support groups, faith communities, Parkinson's communities, and social services can all be helpful.

Simplifying and streamlining can also be a way to decrease energy output. People with YOPD may consider clumping together activities and decreasing the number of times they need to drive each day. They may let go of extra activities that do not add value to them or their family. They may consider hiring help.







# Pores for Thought

Many YOPD women notice that the skin around their face, through their hair, and across the back of their neck and shoulders is greasy or feels different. This is normal in Parkinson's. Approximately 60% of people with Parkinson's report this problem, but as Parkinson himself described the insidiousness of this disease, some are unaware when it started (Mastrolonardo et al., 2003).

The reason for this change in skin is due to an increase in sebum, a substance secreted from the sebaceous glands in the skin. Sebum production occurs everywhere in the body except the palms of the hands and soles of the feet, but it is more predominant on the face and upper trunk (Borda et al., 2015). This increase in sebum in Parkinson's is an early non-motor symptom (Ravn et al., 2017) and was first mentioned in 1927 (Krestin, D., 1927). If someone had skin problems that occurred before their diagnosis, or they visit a dermatology clinic after their diagnosis, it's important for them to talk to their physician about this, especially if long term care may be required.

Recently, research undertaken by the Barran Group at the University of Manchester has confirmed increased sebum to be a possible biomarker for

Parkinson's (Trivedi et al., 2019). Researchers are now developing a test for early diagnosis of Parkinson's using a non-invasive technique (Sarkar, D. 2022). It is a simple combination of a swab and a Q-tip from the face or upper back.

Most people know of the PKU (Phenylketonuria) test done shortly after a child is born, and although the Parkinson's test uses sebum instead of blood, it is a similar diagnostic technique. Most people will be surprised that the former test diagnostically screens up to 50 diseases in children. Further research will be undertaken to explore the inflammatory processes in Parkinson's, which Manchester University has already discovered, using other techniques within GCMS, LCMS, and TD-GC-MS. The simple swab technique will still be used for these samples. This could chart the individual progression of Parkinson's and will eventually lead to a personalised approach to treatment.

**Approximately 60% of people with Parkinson's report a change in skin. This is caused by an increase in sebum.**

# Podiatry

Gait changes are a hallmark of Parkinson's and can lead to foot issues. In fact, abnormal wear on the inside or outside of the shoes can be an early indicator of Parkinson's. Dystonia is common in those with YOPD. It can result in cramping and twisting of feet and hands due to involuntary muscle contractions. Dystonia can be managed with carbidopa/levodopa, Botox injections, and deep brain stimulation (DBS). Physical and/or occupational therapy can also be integral in managing dystonia.

Podiatrists can be important members of a care team. They can provide exercises to improve gait, along with custom insoles that can help with foot pain, gait, or even balance.



# Pelvis

Pelvic floor issues in YOPD can manifest as bowel, urinary, or sexual issues and, unfortunately, are not managed by carbidopa/levodopa. Bowel issues typically result in constipation by slowing the motility of the bowels. Constipation can be managed by increasing dietary fibre. Women with YOPD should always report if they are having constipation at their doctor's visits.

Urinary incontinence can be one of the most embarrassing symptoms of Parkinson's. There are two types: urge and stress. Stress is when you lift something, cough, or sneeze, and your bladder leaks. The urge to urinate is when you suddenly have to go, and you must go NOW. There are things you can do to help. First, there are plenty of incontinence products available. There are also drug therapies to treat overactive bladder. Consult a healthcare provider. In addition to drug therapies, they may seek referral to an urogynaecologist, urologist, or pelvic floor physical therapist - who specializes in treating pelvic floor issues.

Pelvic floor issues can also interfere with sexual intercourse by causing vaginal dryness or pain. It's essential for individuals to bring this up with their healthcare provider.

# Posture

Posture issues are linked to the rigidity and stiffness associated with Parkinson's. These issues can become more severe when medications wear OFF. Poor posture can lead to pain and loss of flexibility. It can also result in more falls.

To combat posture issues, PWR! and Lee Silverman Voice Therapy (LSVT) Big Initiative are examples of two exercise therapies that can be used under the direction of a certified practitioner. Being active and participating in any exercise program

helps maintain core strength and flexibility and increases stability. There are also devices that can be used to aid in maintaining posture. YOPD women should talk to their doctor to find a physical therapist, occupational therapist, or a certified personal trainer with movement disorder experience. It is important to maintain proper bone health, especially with Parkinson's and its treatments.

**Being a female with Parkinson's leads to an increased risk of osteoporosis and fracture.**



# Personality

**YOPD tends to come with a range of non-motor symptoms. Depression and anxiety are the most common mood-related non-motor symptoms in all people with Parkinson's.**

Some with depression have symptoms such as feeling sad or emotional for weeks. Others may feel off because their neurons aren't making the right connections. In both cases, the lack of dopamine may impact on the neurotransmitter serotonin, which is implicated in depression. There are treatments for depression that many living with Parkinson's use successfully.

Anxiety may be present with depression or on its own. With anxiety, one may feel agitated, nervous, worried, or panicked. Often, there is no defined trigger.

Depression and anxiety can be debilitating and leave people not feeling like themselves. If someone is in danger of harming themselves, they should seek emergency care immediately. They should also alert their care team about their symptoms, as these symptoms can often be managed through medication,

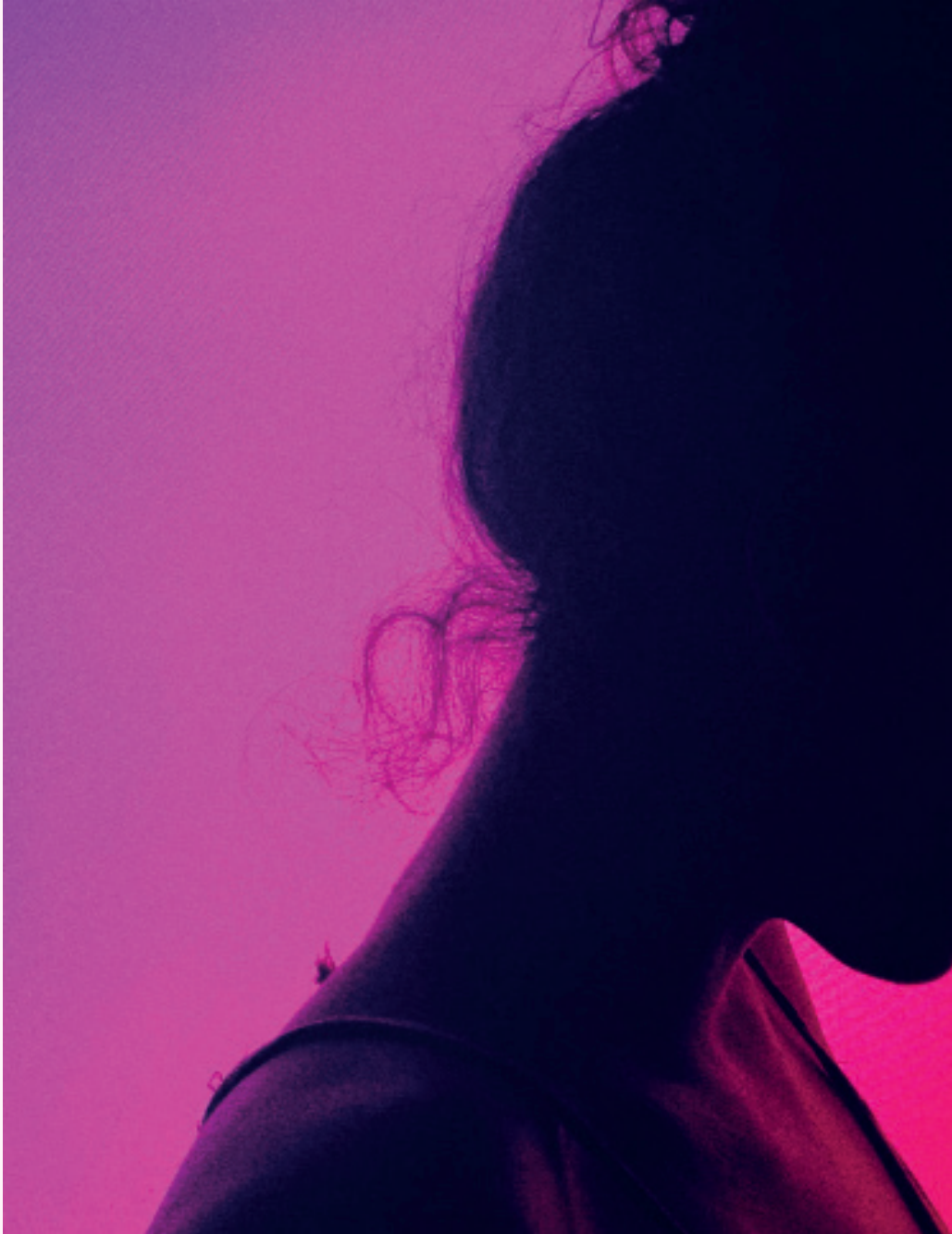
therapy, and taking time for self-care.

Apathy is another non-motor symptom often encountered. Apathy manifests itself as a lack of motivation and feeling like activities or chores have no meaning and aren't worth doing. One may not enjoy the activities they used to. They may still want to participate in life's events, but they don't have the drive to do so because of a lack of dopamine.



They may also experience facial masking, where one loses facial expressions. They may seem robotic or deadpan to others, which may be frustrating. Others may say that their personality has changed as well. It's critical to remember that nobody is alone on this journey, and there are tools available to help treat these symptoms.







# Psychosis

There are two types of Parkinson's psychosis. They present as either hallucinations or paranoid delusions.

People may experience hallucinations via sight, touch, taste, smell, and hearing. Most hallucinations are not troublesome to the person experiencing them but seem odd to those caring for them.

Delusions often present when people with Parkinson's become paranoid and believe others are out to get them. Delusions may also make people become intensely jealous and certain that their significant other is being unfaithful. Delusions usually occur in the presence of underlying dementia (which affects almost half of the Parkinson's population that has been living with Parkinson's for over ten years). Paranoid behaviours may be seen with various medication types, including amantadine and dopamine agonists.

It's essential for YOPD women to consult their physician if they experience any of these symptoms. Many treatments are available.

# Positivity

## **A positive attitude can help anyone shift the way they think.**

Evidence suggests that we can change how our brain is wired by teaching ourselves to find positivity.

Learning ways to keep thoughts from focusing on negativity is important. Learning ways to redirect thoughts can impact one mood. Focusing on what one 'can do', meditating, calling a friend, or exercising, can be ways to change the direction of thinking.



Martin Seligman is one of the leaders in positive psychology. His group shifted their research from looking at what went wrong to what people were doing when they were doing well. They found that people who had a regular gratitude practice were overall more positive. By writing down three things they're grateful for daily, participants increased their overall happiness and wellbeing by 25%.

Data show that keeping a gratitude journal for one week can increase well-being for six months (Seligman, 2011). We challenge all YOPD women to see what keeping a consistent gratitude practice can mean for them.

Another way people with YOPD stay positive is through community involvement. Many people with YOPD help maintain a positive mindset by playing an active part in advocating for change. Being of service to others can provide an opportunity to think of something other than a disease and find perspective in how others live.

Help and support are crucial to developing new therapies. Everyone has something to contribute!



# Participation

**We all have a critical part to play in both learning more about Parkinson's and how it impacts on women. This will only come about by participating in research and discussing our unique symptoms with our healthcare teams.**

**We must be part of the knowledge gathering and show up for opportunities to raise our voices.**

**Only we can be part of the solution.**

# Sources

## Chapter: Periods

- Subramanian, I., Mathur, S., Oosterbaan, A., Flanagan, R., Keener, A. M., & Moro, E. (2022). Unmet needs of women living with parkinson's disease: Gaps and controversies. *Movement Disorders*, 37(3), 444–455. <https://doi.org/10.1002/mds.28921>
- Michael J Fox Foundation and PD Avenger's survey series Experiences of Women Living with PD
- <https://davisphinneyfoundation.org/yopd-women-and-menstruation/>
- [www.mymovesmatter.com](http://www.mymovesmatter.com)

## Chapter: Pelvic Floor

- Links: DPF – Michele Spicka – Arun Mathur videos

## Chapter: Posture

- <https://www.lsvtglobal.com/LSVTBig>
- <https://pdmovementlab.com/blog/2017/9/12/posture-parkinsons>
- <https://davisphinneyfoundation.org/parkinsons-disease-and-posture/n>
- <https://abililife.com/>

## Chapter: Positivity

- Being Well with Chronic Illness, 2022 (Hill & Peate)
- <https://www.authenticchappiness.sas.upenn.edu/testcenter>

## Chapter: Participation

- Michael J Fox Foundation and PD Avenger's survey series Experiences of Women Living with PD. <https://foxinsight.michaeljfox.org/>
- Promoting Gender Inclusivity: A Questionnaire for Women's Health Factors in Parkinson's Disease. Rao, Shilpa C., et al. <https://doi.org/10.1002/mds.29020>
- Association of Women-Specific Health Factors in the Severity of Parkinson's Disease. Rao, Shilpa C., et al. <https://doi.org/10.1101/2022.10.03.22280671>

# Credits

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Translations in multiple languages available at **[www.yopdwomen.com](http://www.yopdwomen.com)**

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We would like to add a special thanks to Willemijn Oosterbaan for her help with the design and the Davis Phinney foundation for enabling the printing of this booklet.



**JOY MILNE**

“Shoes transform your body language and attitude, they lift you physically and emotionally.”  
(Christian Louboutin)

**KAT HILL**

“I can’t concentrate in flats”  
(Victoria Beckham)



**ANNELIEN OOSTERBAAN**

“Give a girl the right shoes, and she can conquer the world.”  
(Marilyn Monroe)



**JOSEFA DOMNIGOS**

“I still have my feet on the ground, I just wear better shoes.”  
(Oprah Winfrey)



**GAYNOR EDWARDS**

“A woman with good shoes is never ugly.”  
(Coco Chanel)



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**POLLY DAWKINS**

“I firmly believe that with the right footwear one can rule the world.”  
(Bette Midler)



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**KRISTI LAMONICA**

“I’m not afraid of heights, have you seen my shoes?”  
(Carrie Bradshaw)



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**MIE MARUYAMA**

“If your hair is done properly and you’re wearing good shoes, you can get away with anything.”  
(Iris Apfel)



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**MARIA DE LEON**

“You never take too much care over the choice of your shoes.”  
(Christian Dior)



## Welcome to the YOPD sisterhood.

Dear friend,

Though it may feel like it, you are not alone. There is a fantastic, welcoming, and supportive community of women with YOPD out there. We are here to support each other, starting with this booklet of everything we believe all YOPD women deserve to know at diagnosis.

When unfamiliar changes happen in our bodies, it can be tempting to stay isolated. However, giving up the social aspects of our lives can be lonely and add to feelings of anxiety and depression.

Getting out and staying social and connected to others is essential to living well and thriving with or without Parkinson's.

Many have found it helpful to be open about their diagnosis. Trying to hide symptoms takes energy and can cause undue stress. Stress can exacerbate Parkinson's symptoms. For others, it may be too stressful to share the diagnosis.

Whatever the situation, we hope every YOPD woman can find a level of acceptance with their diagnosis and stay engaged in their life.

You are not alone - many have walked your path before and are happy to guide and support you on your way.

With love X X

For more general information and downloads in multiple languages please visit:  
[www.YOPD.org](http://www.YOPD.org) and [www.yopdwomen.com](http://www.yopdwomen.com)

