PARKINSON'S, RELATIONSHIPS, AND SEXUALITY

Learn more about the effect of Parkinson's on relationships and sexuality, and what can help.

You are not alone. Find out how Parkinson Québec can empower you to take charge of your life.

PARKINSON QUÉBEC

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Parkinson's may affect your sexuality and your relationships whether you have Parkinson's yourself or are caring for someone who does.

This information is for you whether you're sexually active or not, and whether you're in a relationship or single.

This booklet covers, among other things, the challenges couples may face, starting a new relationship, and how the condition may affect their sex life, both physically and emotionally. Each section contains information and suggestions for ways to cope with problems that may arise.

At the end of the booklet, we've included websites you can consult for more information and support.

Contents

Contents

Note: The healthcare professionals mentioned in this booklet refer to nurses, physicians and medical specialists, pharmacists, physiotherapists, psychotherapists, psychologists, marriage and family therapists, and social workers.

HOW CAN PARKINSON'S AFFECT MY RELATIONSHIPS?

In this section:

- First reactions
- Expectations
- Emotional impact
- Changing roles

First reactions

How you handle the issues related to Parkinson's can have a big effect on your relationships. For example, how you and your partner react to a Parkinson's diagnosis can affect you emotionally.

Everyone reacts in their own way and can experience a range of emotions, including anger, frustration, denial, or guilt. You may even experience relief at finally knowing what's been causing your symptoms.

Learning to live with the diagnosis takes time. People affected by Parkinson's have told us how important it was to their relationship to allow time for this period of adjustment.

Expectations

Your expectations of Parkinson's may be very different from someone else's. Some people are more fearful and assume they will become disabled very quickly, while others barely expect Parkinson's to affect their lives.

If you're in a relationship, you and your partner may also have different expectations. Perhaps one of you is more optimistic than the other. One of you may like to talk about problems, while

the other prefers to reflect on them alone.

There's no right or wrong way to come to terms with a diagnosis. We encourage you to take the time to understand each other's points of view and to be as frank as possible. This can help to minimize differences and potential conflict.

Wherever possible:

- share your opinions without judging each other
- make sure you get as much accurate information about Parkinson's as you can, so your expectations are realistic and helpful
- share this information with the people in your life

To find out more about the different aspects of Parkinson's, check out **The Guide INFO PARKINSON**, or consult the resources listed at the end of this booklet.

Emotional impact

After a diagnosis of Parkinson's, some couples go through a period of mourning for the relationship they previously had. They need to come to terms with changes in their lifestyle, their personal identity, and their professional life.

If you have Parkinson's, your self-image may be affected. Certain symptoms, such as involuntary body movements, postural changes, or excess saliva, can make you feel self-conscious or embarrassed. Low self-esteem can also cause you to become withdrawn, which may affect your relationships.

When relationships are going well between partners and we feel positive about ourselves, it's easier to manage life's ups and downs. When they're not, even simple things can feel like a struggle.

You may find your relationship changes in ways you hadn't expected. Talking openly to each other can bring you closer as a couple. Some people may feel that they're dealing with these emotions on their own, and may feel isolated and resentful. If this sounds familiar, you may want to contact a psychologist, a marriage and family therapist or a social worker to help you through this challenging time.

See the end of this booklet for more information on available resources.

Changing roles

As the condition progresses, it's common for relationship roles and couple's dynamics to evolve. This can happen at any stage of Parkinson's. Any long-term condition is likely to have a significant impact on everyday life, even in the healthiest of relationships.

As Parkinson's progresses, you may find you and your partner take on the roles of care partner and cared-for. This can be difficult if your relationship was very different before – for example, if the cared-for person was used to being the main provider and decision-maker in the household, or if the care partner had an independent lifestyle.

Some couples find it hard to see each other as equal partners in these new roles. It may take time to adapt to this new type of relationship, which can still be fulfilling.

You could both try to:

- maintain a sense of independence; it is helpful to have time alone to do your own thing, and it is also important to do things together
- take any opportunity to reverse the caring role; for instance, the person with Parkinson's may continue to provide emotional or intellectual support
- find mutual activities, such as spending time together watching a film or socializing with friends, where you can be equals
- make a list of things you can continue to do together, or even new things you'd like to try
- keep communicating with each other, clearly and directly. Parkinson's can affect all types of communication – verbal, written, non-verbal (such as facial expressions), but it is important to keep these channels open as much as possible

To find out more about emotional impact, communication, and changing roles, you can consult sessions **5, 6, 8 et 9 of TAVIE™ in motion.**

HOW CAN STRESS, ANXIETY, AND DEPRESSION AFFECT MY RELATIONSHIPS?

Adapting to life with Parkinson's brings with it a certain amount of stress, whether you have the condition yourself or are caring for someone who does. Some people may experience feelings of depression. This can be due to Parkinson's itself or felt as a reaction to living with the condition.

In this section:

- Strategies to manage the emotional impact

Strategies to manage the emotional impact

You may find the following tips useful:

Don't hesitate to ask for support

The support of friends, family, and professionals can be very helpful. You can also consult the resources provided at the end of this booklet, or you can contact us **by email at communaute@parkinsonquebec.ca, or call the toll-free information and support line at 1 800 720-1307**

Relax

It's easier said than done... But it is helpful to relax by doing enjoyable and relaxing activities, such as taking a bath, going for a nature walk, reading a book, or just chatting with friends.

Treat yourself

Take every opportunity to treat yourself. It might be something as simple as enjoying a cup of coffee, listening to a new album, soaking your feet, or even a weekend getaway.

Start a journal

Some people find it helpful to write down their thoughts and feelings. Try to do this at a quiet time of the day when you won't be interrupted. It can be encouraging to look back, as the weeks go by, and see how much progress you've made.

Look after your physical health

Sometimes it can be tempting to eat comfort foods and spend a lot of time sitting on the sofa, but this won't necessarily help relieve your harmful emotions. Doing regular exercise and eating a healthy diet will benefit both your mind and body.

Talk, share

Not everyone is comfortable with talking, but sharing a conversation with others makes us feel less alone and allows us to connect with people, such as a trusted friend or a family member. If you're in a relationship, it's beneficial to talk to each other.

Let yourself cry

Some days, you will want to cry. It is important to allow yourself to do this, to acknowledge and express your emotions. When you're angry, you can let those feelings out too, as long as you can do so appropriately and respectfully. Keeping powerful feelings bottled up tends to make things worse and negatively affects the situation and your well-being.

Take time to laugh

It may be difficult to find things to laugh about sometimes, but when you laugh, your body releases feel-good chemicals. If you like watching funny TV series or comedies, or sharing jokes or funny stories with friends and family, we encourage you to keep on doing those things.

Click here to find out more about depression and anxiety

HOW CAN I IMPROVE MY RELATIONSHIP WITH MY PARTNER?

In this section:

- Ways to strengthen your relationship
- When a relationship ends

Ways to strengthen your relationship

The following strategies have been suggested by specialised professionals:

Accept differences of opinion

We're all unique, and differences of opinion are a part of life. Look upon arguments as a healthy part of life as a couple.

Present your arguments clearly and concisely

When you argue, make sure you are confronting the issue, not each other. Listen, be respectful, and try to find a shared solution.

Say sorry

Love doesn't mean never having to say you're sorry. We all make mistakes and get it wrong sometimes, so be ready to apologize.

Listen and learn

People change and grow over the years. Don't ever think you know your partner so well that you can predict what they're going to say.

Plan good quality time

It may be a cliché, but it is true – quality is more important than quantity. Take time to talk, laugh, chat, or just to be in a quiet space together.

Have shared goals

Another way to connect is to talk about and work towards common goals. It doesn't matter if that's planning a party, decorating a room, or saving for a holiday. The important thing is that you share the goal.

Spend time with other couples

It is easy to think you're the only couple with problems, but when you spend time with other couples, you'll see you're not alone. All relationships have their ups and downs.

Give each other the benefit of the doubt

Don't jump to conclusions about each other's behaviour or motivation. If you feel irritated about something, first check that what you're thinking is really what they meant. If it wasn't, then let it go. If it was, take time to stop what you're doing and discuss the problem.

Explore your senses

Exploring your senses – sight, touch, taste, etc. – is an activity you can share and enjoy.

For example, you can:

- laugh together – this is one of the best activities for bonding
- light scented candles or experiment with different fragrances of oils in an oil diffuser
- explore taste together by trying a range of foods
- listen to music

Tenderness, physical intimacy

Physical intimacy is a crucial part of many relationships. The slowness of movements may make it more difficult to be spontaneous. But touch is an essential part of being human, and you can experience this, whatever your physical condition. Touch has the power to soothe, support, and encourage, whether it's a peck on the cheek, a hug, or making love.

When a relationship ends

We've heard from people with Parkinson's whose relationships have broken down. The effects of Parkinson's and the demands it makes on a relationship are contributing factors. But there can be a lot of other reasons why a relationship may end, and often it isn't due to the condition alone.

If your relationship has ended, it is important to come to terms with what happened, even if this takes some time. It can be helpful to talk about it with friends or family, this can make you feel less isolated and give you a chance to stand back and gain some perspective. You could also consider talking to a family or marriage counsellor. Setting yourself goals or planning some projects can be helpful. Achieving one or more objectives can be a great confidence booster and a helpful reminder that you're moving on, even if on some days you may not feel like you are.

Some people have told us that a separation or divorce was a very difficult experience. Others, however, saw the end of their relationship as a change for the better. Whatever the circumstances, if your relationship does end, it can feel overwhelming, and you may worry about what the future holds. But it is important to remember that there are others going through the same experience and that there is support available to help you.

TO FIND HELP:

Ordre des psychologues du Québec
Toll-free line: 1 800 363-2644 | **www.ordrepsy.qc.ca**

Ordre des travailleurs sociaux et des thérapeutes conjugaux et familiaux du Québec
Toll-free line: 1 888 731-9420 | **www.otstcfq.org**

Ordre professionnel des sexologues du Québec
Toll-free line: 1 855 386-6777 | **www.opsq.org**

HOW CAN PARKINSON'S AFFECT SEXUALITY FOR MEN AND WOMEN?

Many people with Parkinson's experience sexual difficulties . This can be due to the physical effects of the condition on coordination and speed of movement, or emotional issues, such as low morale or depression. However, Parkinson's doesn't affect everybody's sexual functioning, and many people don't experience these types of problems.

Both men and women can experience difficulties with sex. Sex is an important part of life for many people, so any problem you encounter may have a big effect on your life. There are ways to resolve certain sexual problems or to explore intimacy in some other form.

Sexual problems can affect either the person with Parkinson's or their partner. Finding out one of you has a life-changing condition can change your view of your physical relationship. It may become less or even more important than before. You may feel you need to make the most of your time together, fearing the loss of your ability, or you may simply want to express your love for one another.

If you have Parkinson's, it can affect your sexual self-esteem. You may feel less attractive or desirable. If you're a care partner, you may worry you're being too demanding by wanting to have sex with your partner. Having new roles as care partner and cared-for may sometimes make it hard to feel like equal sexual partners.

These factors, as well as the impact of the condition and medication on the body, can affect sexual function.

Sexual relationships change over our lifetime, and most couples experience difficulties at some time or another.

Problems sometimes resolve on their own, or some couples may have to:

- adjust their sexual activities to take into account changes in their physical abilities
- redefine their expectations to fit with reality. Some couples may think it's a problem not to be enjoying regular sex, while others may be perfectly satisfied with a sensual caress once a month

If you've been in a relationship where sex has been good and you've both felt comfortable and confident talking about your desires and limitations, then it may be easier to face the challenges Parkinson's can bring. If this has been an awkward topic in the past, you may have to work harder to get over the hurdles. But it is worth trying – the increased openness and creativity required in your sex life may make it better than before.

WHAT FACTORS CAN CONTRIBUTE TO SEXUAL PROBLEMS?

In this section:

- Motor symptoms
- Fatigue
- Bowel and bladder problems
- Medications
- Hypersexuality
- Lowered sex drive
- Difficulties with sexual arousal
- Orgasm problems

Sexual problems can arise when something disrupts the partners' physical and emotional responses. Causes of sexual problems include reduced mobility problems, fatigue, and depression. These difficulties are common in people with and without Parkinson's, so it may not be easy to tell whether the problem is a result of your condition or not.

The physical ability to have sex is affected by the nervous system, so it's more common for people with neurological conditions, like Parkinson's, to experience problems.

Some Parkinson's symptoms may affect sexual activity. Let's look at these and consider what can be done to help improve these issues.

Motor symptoms

The motor symptoms of Parkinson's, such as stiffness, rigid muscles, and slow slowness of movement, may affect sexual activity. Making sure your Parkinson's medication is working effectively may help improve these symptoms. Speak to your doctor or Parkinson's care team. They may also be able to give you advice on sexual positions that may help you.

Fatigue

Fatigue can also be a symptom of Parkinson's. If it is an issue, try being intimate or having sex at a different time of day when you have more energy.

Bowel and bladder problems

Fear of incontinence may make you or your partner nervous about sexual activity.

If you experience urinary incontinence, certain medications or other treatments may be helpful. Using the toilet before intercourse may also help. For some people, using a catheter to help empty the bladder may be another alternative.

If you experience bowel incontinence, you may find dietary changes, an enema before intercourse, or other treatments helpful.

Whatever incontinence problem you're experiencing, talk it over with your doctor to explore alternatives.

Click here to find out more about bladder and bowel problems

The **Canadian Continence Foundation** can also provide information on this subject.

See the end of this booklet for more information on available resources.

Medications

Any medications you're taking should be reviewed for side effects that may affect sex. Some drugs for depression can cause a reduction in sexual desire, decreased sexual arousal, premature or delayed ejaculation, or inability to reach orgasm.

It's best to speak to your doctor or Parkinson's care team about the options available so you can continue to get the most benefit from your medication.

Hypersexuality

Some people who take certain types of Parkinson's medication known as dopamine agonists experience impulsive and compulsive behaviours. For a small number of people, other types of Parkinson's medications, in particular levodopa, have similar side effects.

Hypersexuality is a type of impulsive and compulsive behaviour, where someone is focused on sexual thoughts and their sexual impulses become more intense. These impulses might be felt at inappropriate times or towards people other than a partner. This can be distressing for the person and those around them. With hypersexuality, there's also a risk that someone will behave in a way that's socially unacceptable, or may even break the law.

This type of behaviour can have a big impact on the person affected and the people around them. It may be accompanied by sexual delusions and hallucinations, such as imagining that a partner is having an affair or thinking others are having sex when they're not.

If this side effect is mild, some couples may find they enjoy the extra sex. But for others it may become a difficult and distressing problem, particularly if the sexual desires are out of control and don't fit within the comfortable boundaries of the relationship.

If you're experiencing this behaviour, the first step is to talk to your doctor or Parkinson's care team. You may find it uncomfortable to talk to them about the difficulties you're having, but remember, they will have spoken to others with similar problems before, and everything you tell them will be confidential.

Sometimes people who display impulsive and compulsive behaviours may not realize they have this problem. If you notice your partner's sex drive has increased or their sexual behaviour has changed towards you or anyone else, it's important to discuss it with their doctor and pharmacist as soon as possible.

Impulsive and compulsive behaviours can usually be controlled and steps taken to address behavioural changes. In most cases, a medication change or adjustment can ease the problem. Some people may need more professional support, for example from a psychosexual therapist. At the end of this booklet, you'll find links related to professionals specialized in this matter.

To find out more about impulsive and compulsive behaviours related to Parkinson's, consult the professional resources related to sexuality listed at the end of this booklet, or click here to consult the health fact sheet "Impulse control disorders in Parkinson's disease".

Lowered sex drive

Some people with Parkinson's and their partners experience a lowered sex drive. This is more likely due to the psychological and emotional impact of diagnosis than as a direct result of the condition. General fatigue and depression, which are common in someone with Parkinson's, can also lower desire. Your family doctor or a specialist can help treat any depression or mood disorders you may experience. Also, there are many different things you can try to get in the mood for intimacy or sex.

Some of these suggestions may work for you:

- take a relaxing bath
- give or receive a sensual massage by candlelight
- do something more energetic or playful together to get you in the mood
- revive the spark by investing in new lingerie or sex toys, or by watching an arousing video or reading erotic stories to each other.

Whatever you do, agree beforehand that your goal is to get close and enjoy time spent together. The result may be sex, but it may not. Take the pressure off by investing your energy into creating a pleasant environment. Then, whatever the outcome, it will happen more naturally.

Difficulties with sexual arousal

Both men and women can struggle with becoming sexually aroused. This could be a side effect of Parkinson's medication or of the condition itself, or because of fatigue, stress, depression or low self-esteem.

The main way to overcome this is to try to relax. Before seeking treatment, try to rule out any emotional causes, such as stress or tensions in your relationship.

You may benefit from:

- changes in routine, such as having sex in the morning when you've got more energy, instead of in the evening
- an increase in stimulation, such as using a vibrator
- taking plenty of time to set the scene and get the mood right

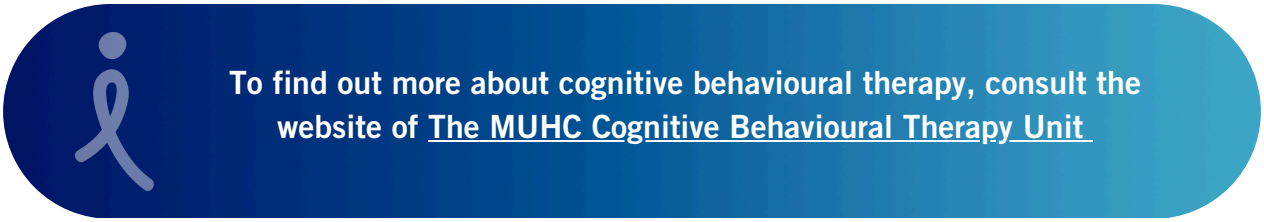
The more you can do to be sensual together, the better the chances of arousal happening naturally. It may be useful to consult a psychotherapist if you're experiencing a lack of sexual interest or desire.

Orgasm problems

Both men and women may experience reduced or absent orgasms.

Some men may experience problems with premature or delayed ejaculation.

Treatments such as cognitive behavioural therapy (CBT) may be helpful for this type of problem and for finding better ways to communicate sexually. For example, this therapy aims to positively modify negative beliefs and thoughts to make way for more soothing emotions and new behaviours.



If you have problems reaching orgasm the following suggestions might help:

Try to minimize any anxiety

If you worry about orgasm, it's more likely to happen too quickly or not happen at all. Spend

more time on general arousal and excitement. If you agree that it won't matter if one of you doesn't reach orgasm, you'll be able to enjoy your time together more.

Know what you enjoy

Masturbation can help you get to know what you find enjoyable. Give yourself enough time to explore what you find pleasurable without being disturbed. If you are feeling ashamed or embarrassed about what you're doing, it won't help you achieve orgasm; so try to relax into the sensations you experience.

Get to know each other

Take time to really get to know each other's bodies. Ask about the kind of stimulation your partner prefers. Try to fine-tune your technique so you're always giving the best experience possible. When you approach sex in a more relaxed and exploratory way, orgasm may follow more naturally.

Pelvic floor exercises

For some women, pelvic floor exercises may help increase awareness of pelvic floor contractions and improve pelvic tone, which can help with orgasms. These exercises can be a bit tricky or complicated, but a physiotherapist, nurse, or family doctor will be able to explain how to do them properly.

Ask for help

If problems persist, then speak to your doctor or Parkinson's care team. A change in medication could also make a difference.

WHAT SEXUAL PROBLEMS MAY AFFECT MEN?

It's important to remember that many sexual problems are common in men of all ages, whether they have Parkinson's or not. So the problems you might have aren't necessarily a result of your condition. There may be other causes, such as enlargement of the prostate gland. The prostate is a small gland the size of a walnut that surrounds the first part of the urethra, which carries urine from the bladder to the penis.

As men get older, the prostate around the neck of the bladder gradually gets bigger. This is normal in older men, but for some, it causes problems by blocking the flow of urine, which makes it difficult to empty the bladder. It can cause some men to experience the need to urinate more often, a difficulty in starting to urinate, a need to strain, or an urgent need to go to the toilet.

Medication may help reduce the size of the prostate, combined with healthy lifestyle changes. If medication hasn't worked, surgery may be recommended for moderate to severe symptoms of prostate enlargement.

If you begin to experience symptoms, you should talk to your family doctor, who can assess you and, if necessary, refer you to a urologist, a doctor specializing in problems relating to the bladder, kidneys, and male reproductive organs.

Andropause

As men age, their testosterone levels gradually decline over the decades. However, some men will experience a greater reduction than others as they age, which can have consequences in many aspects of their lives, including sexuality. Depending on the signs observed (e.g., loss of bone density, concentration, libido, etc.), appropriate assessment is required. If you're experiencing symptoms, discuss them with your doctor, who will be able to determine the assessment required and suggest lifestyle adjustments or treatment tailored to your health condition.

Erectile dysfunction

Research has shown one of the sexual problems that affects men is not being able to get aroused. When a man is struggling to get aroused, he'll find it difficult to get an erection. This is a common problem even in men who don't have Parkinson's, especially as they get older, or if

they have medical conditions such as high blood pressure or diabetes.

Some men may have difficulties getting an erection at all, while others get an erection, but then lose it too soon.

If you're having erectile problems, speak to your family doctor or a specialist. They'll ask about your response to stimulation, and when it is that problems happen, such as when you wake up in the morning or when you're with a partner.

This is because erectile problems may affect you in different ways at different times.

There's a range of options your family doctor or specialist may explore with you. These include:

Erectile dysfunction medications

Medication (e.g., Viagra, Cialis, Levitra) is one option for treating erectile problems. Research has shown that these treatments are safe for most men with Parkinson's. But first talk to your family doctor or specialist. There's a range of alternative drugs now available that work in different ways and are effective for producing an erection.

Self-injection or self-administration

There are medications that can be injected into the penis or inserted in the end of the penis to produce an erection. A man can be taught the technique, but initially it requires supervision by a doctor or other professional in the clinic that offers this treatment.

A vacuum pump device

Vacuum constriction device is an option for men who don't want to or are unable to take medication. This device can be put around the penis to produce an erection. Consult your doctor or pharmacist for advice before you buy one.

Surgery

Surgery to implant a penile prosthesis may be an option for men with erectile problems. It's normally a last resort, however.

WHAT SEXUAL PROBLEMS MAY AFFECT WOMEN?

With age, menopause, or other factors that affect their health, women may experience problems with vaginal lubrication, as well as reduced desire or orgasm.

Women may continue to enjoy sex even if their body no longer responds in the same way to sexual stimulation. However, it is important not to try penetration without arousal, as it can be painful. There are not many evidence-based treatment options for female sexual problems. However, there are certain options, such as hormonal treatments, psychosexual therapy, and treatments to reduce pain.

For some women, sex can be painful. You may also experience fewer sensations, a lack of sexual excitement, or insufficient lubrication when you have sex. Your family doctor or specialist may recommend trying anaesthetic gels, vaginal lubricants, or other methods to reduce pain.

It's important to remember that many sexual problems can be common in women of all ages, whether they have Parkinson's or not. This means that the problems you may have are not necessarily a result of your condition. There may be other causes, such as those listed below.

Menopause

Menopause is a time of life when many changes can occur, and it can have a major impact on many areas of a woman's life. Menopause can also affect vaginal lubrication and sexual sensation. If you're experiencing these symptoms and are of menopausal age, talk to your family doctor, who will be able to suggest treatments, including hormone replacement therapy (HRT), which is covered by the Régie de l'assurance-maladie du Québec.

Click here to find out more about hormone replacement therapy

Pelvic floor prolapse

Some women may experience prolapse of one or more pelvic organs, such as the bladder or uterus. This happens when organs have dropped out of their usual position, sometimes due to aging or after childbirth.

Lack of tone in pelvic floor muscles can increase this risk and have a negative effect on sexual function.

Pelvic floor prolapse can be corrected in a number of ways, such as a perineal and pelvic retraining exercise program, vaginal pessaries to support the vaginal walls and organs, or surgery. Talk to your healthcare professional about what options are available to you.

WHERE CAN I GO FOR INFORMATION AND SUPPORT?

Sexual relationships are an important part of life for many people. People of every age and physical ability can, and do, enjoy their sexuality, but it isn't always easy to talk about, as it is often a private part of life. If you're worried someone may laugh or disapprove, it can make it hard to talk about your sex life. But there are professionals you can turn to for advice and support.

In this section:

- Speaking to healthcare professionals
- Support for your partner
- Relationship counselling
- Psychological support and therapy
- At your appointment

Speaking to healthcare professionals

You may feel uncomfortable talking to a healthcare professional about the issues you're having, but remember, they will have spoken to many others with similar problems before. They'll take your particular needs into account when talking to you, including your attitude towards sex and cultural influences. All healthcare professionals are members of professional orders and bound

by strict privacy laws, and what you share with them will remain totally confidential.

If you find it difficult to talk about this subject, write out your questions, then ask them to the professional you're consulting or give them your list. You could also attend appointments with your partner, so you can discuss different aspects of the situation together. Ask your healthcare professional for literature, references, or trustworthy Internet sites that you can consult in your own time at home.

Support for your partner

Ideally, you should talk things through with your partner. This can sometimes be difficult, but it is essential for your partner to get the support they need too. Specialized healthcare professionals can counsel you as a couple or separately, if you don't feel you can talk about these things together.

Relationship counselling

If you've tried talking to each other about your relationship problems and you feel that you're not getting anywhere, couples therapy may help.

Couples therapy can help you see your problems from a different angle, improve your communication, and help you deal with any issues you're facing. Therapists can meet with the couple together or with each one separately, as some people prefer to talk through their feelings privately.

If you think this type of counselling might help, ask your family doctor or health care team if there are services available in your area.

You can also contact us by email at communaute@parkinsonquebec.ca, or call our toll-free information and support line at 1 800 720-1307 to help guide you in your process.

If you see a private therapist, make sure they're trained in the appropriate area – relationships, couples or individuals.

Psychological support and therapy

Counselling or psychotherapy can help some people talk more openly about relationship and sexual problems so they can make positive changes in their relationship. A therapist can explain the different types of support, the potential benefits of each, and then decide with you what areas you want to work on.

Cognitive behavioural therapy (CBT) is especially useful when a person's or couple's beliefs are contributing to the problem. Also, therapies that focus on the couple's relationship have better outcomes than approaches that only focus on problems with the physical aspects.

Sex therapists are specifically trained to consider the different aspects of sexuality, to understand the impact of medication and illness on sexuality, and to help bring about realistic changes. These therapists also have expertise in interpersonal relationships and can address practical, emotional, or relational problems. You can opt for individual or couples counselling.

Your doctor or care team can refer you to a therapist.

See the end of this booklet for more information on available resources.

At your appointment

When you meet with a specialist in sexual problems, the discussion about the difficulties you're facing may be combined with a clinical examination, if necessary.

If you've been experiencing sexual problems since the onset of your Parkinson's symptoms, this suggests they could be related. The professional will also look for other underlying causes, such as medication, heart disease, etc.

Most treatments for sexual problems are the same, regardless of whether the person has a neurological condition. Difficulties surrounding sex for people with neurological conditions are common, but complex. Your treatment should be tailored to your own situation, with the opportunity for education and counselling for you and your partner.

CONCLUSION

Sexuality is an integral part of your life. However, in the case of Parkinson's, you will have seen from reading this booklet that challenges can arise. Fortunately, various strategies and treatments exist to prevent and mitigate these difficulties and their impacts. We hope the information shared here will enable you to confidently seek help and support to maintain your well-being, pleasure, and the quality of your loving relationships.

The following pages present additional resources and support for other questions or specific needs you may have.

On the brink

I advance
I retreat
Resilience
Or twilight
(...)

On the brink
I love
I doubt
I think it over
And then I forget.

Lili Saint Laurent

Visit the YouTube channel of Piece of Mind Collective for a theatrical performance of the poem "On the brink".

Additional resources and support

Parkinson Québec

parkinsonquebec.ca

INFORMATION AND SUPPORT

free, confidential, and bilingual

1 800 720-1307, Monday to Friday, 8:30 a.m. to 4:30 p.m

communaute@parkinsonquebec.ca

While representing the community affected by Parkinson's, defending its rights and raising public awareness of the disease, Parkinson Québec and its regional partners offer information and listening services, conferences and training courses, as well as the opportunity to join support, self-help, and exercise groups.

On the Parkinson Québec website, you'll find valuable information on managing fatigue, anxiety, depression, constipation, urinary issues, and more. For further guidance, consult the **Guide Info Parkinson** and the Living Better with the Disease section, which also covers topics such as sexuality.

Additional resources and support

Consult the following resources developed by Parkinson Québec with the financial support of the Gouvernement du Québec through the Québec ami des aînés program.

TAVIE™ in Motion

You can watch videos on couples communication and role changes in sections 5, 6, 8, and 9.

Watch on YouTube

Advice from health professionals

You may find some interesting videos, particularly on posture, balance, and daily activities; these topics have an impact on sexuality.

Watch on YouTube

Inspiring testimonials

Shared by persons affected by Parkinson's, these thoughtful stories promote understanding and solidarity.

Watch on YouTube

Additional resources and support

DISCOVER OUR REGIONAL PARTNERS

Services near you or in your region

1. ABITIBI-TÉMISCAMINGUE
2. BAS SAINT-LAURENT
3. CENTRE-DU-QUÉBEC – MAURICIE
4. CAPITALE-NATIONALE CHAUDIÈRE-APPALACHES
5. CÔTE-NORD
6. ESTRIE
7. MONTRÉAL-LAVAL
8. OUTAOUAIS
9. SAGUENAY–LAC-SAINT-JEAN
10. MONTÉRÉGIE

Additional resources and support

PARKINSON CANADA

Toll-free line 1 800 565-3000 | **www.parkinson.ca**
On the website, consult, among others, the tabs: **About Parkinson's** and **Resources, Educational Publications**

Professional resources relating to sexuality

The professional orders mentioned in this booklet are listed below.
The various professional orders, which are responsible for protecting the public, publish information on services provided by health professionals in both the public and private health care sectors.

Some websites of professional orders may be useful to identify resources in your region and provide both information and appropriate tools.

COLLÈGE DES MÉDECINS DU QUÉBEC

Toll-free line 1 888 633-3246 | **www.cmq.org**

ORDRE DES INFIRMIÈRES ET INFIRMIERS DU QUÉBEC

Toll-free line 1 800 363-6048 | **www.oiiq.org**

ORDRE DES PHARMACIENS DU QUÉBEC

Toll-free line 1 800 363-0324 | **www.opq.org**

ORDRE PROFESSIONNEL DE LA PHYSIOTHÉRAPIE DU QUÉBEC

Toll-free line 1 800 361-2001 | **www.oppq.qc.ca**

ORDRE PROFESSIONNEL DES SEXOLOGUES DU QUÉBEC

Toll-free line 1 855 386-6777 | **www.opsq.org**

Additional resources and support

ORDRE DES PSYCHOLOGUES DU QUÉBEC

Toll-free line 1-800-363-2644 | **www.ordrepsy.qc.ca**

ORDRE DES TRAVAILLEURS SOCIAUX ET DES THÉRAPEUTES CONJUGAUX ET FAMILIAUX DU QUÉBEC

Toll-free line 1-888-731-9420 | **www.otstcfq.org**

Professional resources relating to bladder and bowel incontinence, and menopause

THE CANADIAN CONTINENCE FOUNDATION

Toll-free line 1 855 415-3917 | **www.canadiancontinence.ca**

ORDRE PROFESSIONNEL DE LA PHYSIOTHÉRAPIE DU QUÉBEC

www.oppq.qc.ca

In the search bar, enter **« incontinence »**.

You can also find a physiotherapist, in your area, specialized in bowel and bladder retraining: click on the "**Physiotherapy**" tab, then on the "**Find a professiona**l" button. In the "**Reason for consultation**" section, click on "**Incontinence**" in the drop-down menu.

THE MENOPAUSE FOUNDATION OF CANADA

menopausefoundationcanada.ca

Additional resources and support

ONLINE RESOURCES FROM HEALTHLINK BC, THE ALBERTA GOVERNMENT, AND ALBERTA HEALTH SERVICES

In this directory, you can access information of interest related to this booklet. For example, here are some downloadable health fact sheets that may be of interest to you.

Urinary incontinence

Urinary Incontinence in Men

Urinary Incontinence in Women

Vaginal pessaries - To treat urine leakage or abdominal organ descent

Fecal incontinence: Care instructions (including recommended exercices)

FEEDBACK

For any feedback about this booklet, please contact us by email at communaute@parkinsonquebec.ca, or call the toll-free information and support line at **1 800 720-1307.**

GLOSSARY

Impulsive behaviour
The tendency to act before thinking things through, without assuming the consequences of one's words or actions. Impulsive behaviour can be observed in rash decisions, confrontations with others (e.g., explosive anger, talking non-stop, violent gestures, etc.), excesses (e.g., sex, shopping, food, gaming, betting, time spent online, etc.) or risky behaviour (e.g., unprotected sex, dangerous driving, taking drugs or certain medications, etc.).

Compulsive behaviour
Persistent repetition of certain actions, despite the harmful consequences for the person and those close to them. The person feels compelled to repeat these actions in order to reduce their anxiety or obsessive thoughts (e.g., washing hands repeatedly, checking the door repeatedly for locks, adhering to an exaggerated routine, accumulating objects, repeating the same words over and over, etc.). The person may recognize that their thoughts and behaviours are illogical and exaggerated, yet feel unable to control them.

Pessary
Silicone object placed in the vagina to treat urine leakage or abdominal organ descent.

Pelvic floor
Muscle group located in the lower pelvis that supports the organs of the abdomen. It plays an important role during sexual relations, as well as in retaining urine, stool, and gas, and stabilizing the body's posture.

Pelvic floor prolapse
Descent of one or more organs located in the pelvis.

Cognitive behavioural therapy
Psychological approach that helps transform unhealthy thoughts into more helpful ones in order to better manage unpleasant emotions (e.g. fear, feelings of panic, discouragement, anger, etc.) as well as impulsive, compulsive or addictive behaviours (e.g. gambling, alcohol, drugs, medication, etc.).

Support the cause

Thanks to your donations, Parkinson Québec is able to carry on its mission and continue to improve the quality of life of thousands of people

Can you help us?

Making a donation is a very personal act, often spurred by the desire to support a cause or to express thanks.

For example, many donors to Parkinson Québec give to support research, while others give to support the development of our services.

Know that every donation is meaningful, you make a difference.

https://parkinsonquebec.ca/en/donate/

PARKINSON

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