

FACT SHEETS COLLECTION

SESSIONS 1 to 6

Adopt
strategies for better
living *together*
with Parkinson's

TAVIE
in **MOTION**
Treatment, Assistance,
Energy, Nurse Intervention,
and Education

**P A R
K I N
S O N**
QUÉBEC



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Introduction

TAVIE™ in motion fact's sheets are integrated into the different sessions. Each of them is accessible by clicking on the name of the document you wish to consult.

For ease of use, we have grouped together in this document the 12 downloadable and printable documents from sessions 1 to 6.

We encourage you to consult and share them with those around you. You will be better equipped with various strategies and tips.

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Session 1

Living as a couple with Parkinson's : Quite an experience!

How to maintain a relationship as a couple with respect to the changes related to Parkinson's

After a number of years of working, raising children, or supporting relatives, colleagues and friends, you share happy plans for retirement and dreams for both of you. However, the onset of Parkinson's is shaking up your life and bringing many questions.

Many couples mention that they have noticed certain changes related to Parkinson disease. And you, as a couple, you have surely experienced changes, small or large, following the diagnosis and over time with the disease. You are now invited to take a moment, together, to reflect on these changes.

For each of the following questions, rate the degree of change on a scale of 1 to 10.

As a couple, have you experienced any changes in your ability to act freely?

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Not at all

A great deal

Have you encountered estrangement in your relationship as a couple?

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Not at all

A great deal

Have you encountered any distance from people around you?

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Not at all

A great deal

Have you experienced a transformation of your roles in your relationship as a couple?

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Not at all

A great deal

Do you find it difficult to ask for help?

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Not at all

A great deal

Do you have trouble getting any help?

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Not at all

A great deal

Based on your answers, you notice that the left side of the scale from 1 to 10 reveals your strengths as a couple in developing your confidence to deal with current and future changes.

A score on the right side of the scale indicates that there may be adjustments to be made based on the changes you observe.

Fortunately, you are not alone. Other couples share a similar experience and have developed tips that may be helpful to you.

All sessions of TAVIE™ in motion aim to better prepare you for the present and future changes related to Parkinson's by drawing on the experience of other couples and in collaboration with your relatives and healthcare professionals.

Let's try to make a change?

Session 2

Preserving your health for a better quality of life together

Different strategies to preserve your health

Maintaining healthy eating habits

A healthy, well balanced and varied food intake helps maintain good health. The main challenge is to eat a variety of nutritious, high-energy foods at every meal and snack and to stay well hydrated while respecting certain limits if your health condition requires it, for example if you have heart or kidney problems. If you succeed in meeting this challenge, you will gain in energy, muscle strength, maintain a healthy weight, good intestinal elimination and even improve the effectiveness of certain anti-Parkinson drugs!

Do you know that some champion foods are not just for athletic teams?

Fruits (fresh, cooked), vegetables, cereals, whole grains, nuts (whole or ground) and olive oil are considered anti-aging and protective foods. Indeed, they provide several essential vitamins (A, B, C and E) and abundant fibre (prevention of constipation). These nutritious and energetic foods also protect your immune system and your brain. In addition, they facilitate digestion and improve the absorption and effectiveness of your medications. Take full advantage of these foods each and every day!

You may experience nausea with some medications. You may need to consider eating smaller meals and compensating with nutritious snacks.

The content of the plate is important, but the presentation of the food and the presence of other significant people at meals can be successful ways to stimulate your appetite and meet your nutritional needs.

Eat a variety of healthy foods each day

**Have plenty of
vegetables and fruits**

Eat protein foods

**Make water
your drink
of choice**



**Choose
whole grain
foods**

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In addition to the healthy plate pictured above, the Government of Canada website has a variety of information including the Food Guide available in various languages as well as tips on how to eat well, recipes and stay active. You can find and download these documents at: <https://food-guide.canada.ca/en/>

Maintaining an active lifestyle

Besides safeguarding your health and independence, physical and mental exercise helps to maintain your morale and quality of life over the years. Doing a variety of exercises every day gives you pleasure and increases your opportunities to get out of the house and see other couples who, like you, are looking to stay in shape and have fun in good company. The more physically and mentally active you are, the freer you feel to move and act as you wish.

Do you know that physical exercise can be a source of bonding and closeness?

Studies show that couples who engage in an exercise program together stay more active at home and between sessions. The majority report many benefits, including balance, flexibility and posture. Participants point out that the exercises were relaxing, energizing, entertaining and rejuvenating. Finally, they feel more efficient in their daily activities and note, to their great surprise, a closer relationship and a better complicity within their couple.

Do you know that physical and mental exercises are good antidotes to stress, anxiety and depression?

When you do physical and mental exercises then the amount of blood flow to the brain is increased, nourishing your nerve cells and strengthening them. Exercises, which help coordinate your hands and eyes, improve your brain's functioning, including memory and concentration.

Do you already do exercises?

Certain types of exercises have proven to improve the various motor and non-motor symptoms of Parkinson disease. These include Tai-Chi, yoga, dance (like tango), Nordic walking (with walking sticks), adapted boxing (in a controlled environment), singing, video and virtual reality games, etc.

The most common intellectual activities, such as Scrabble, Sudoku, strategy games, crossword puzzles, learning a new language or computer skills, reading, listening to music, artistic hobbies and using any strategy that exercises your brain, activate the brain chemistry responsible for, among other things, the development of your creativity and the regulation of your emotions.

In few words, these exercises are useful for couples because they facilitate problem solving and tend to provoke happiness.

Would you like to be part of an exercise group?

Several alternatives exist, such as an exercise group with the Parkinson's organization in your area, with the YMCA in your neighbourhood, with some community centres or recreation centres. In addition, on the Parkinson Québec Website, there are many interesting documents to consult and download at the following tabs:

<https://parkinsonquebec.ca/en/managing-parkinsons/physical-activities/>

Some online programmes are also available:

<https://cummingcentre.org/all-programs-classes/adapted-programs/parkinsons/>

Tips for saving your energy and securing the safety of your home

There are many tips to help you save energy. For example, alternating periods of activity and rest, and remembering only what is essential to do, can allow you to organize your daily life in a flexible way, adjusted to your strengths and needs. This way you save energy!

There are ways to organize your environment by making it more accessible and safe. You can also check what can be rearranged, for example, the lighting, the bathroom, the kitchen and your bedroom. Pay special attention to the floors and stairs.

By revising certain behaviour habits, such as avoiding unnecessary travel, and using a walking aid if necessary, and consulting an occupational therapist, that way you can take advantage of the energy you save and reinvest it in activities that are good for you.

- The organization APPUI has some suggestions for securing your home

<https://www.lappui.org/en/practical-advice/navigating-the-administrative-process/staying-at-home-moving-to-a-residence/preventing-falls-in-the-home/>

<https://www.lappui.org/en/practical-advice/understand-the-situation-of-the-person-i-am-caring-for/alzheimer-s-disease-and-other-neurocognitive-disorders/alzheimers-disease-and-safety-in-the-home-a-few-tips/>

And lastly, your community local services center as well as various health professionals (e.g. an occupational therapist, physiotherapist, nurse, etc.) can also provide you with more information and useful advice to maintain a good quality of life at home.

Session 3

Working together as a team to meet the difficulties encountered

Ways to recognize and to defuse unpleasant emotions

Do unpleasant emotions such as sadness, guilt or frustration overwhelm you and persist over time?

Recognizing and defusing these unpleasant emotions is a practical strategy to consider preserving your energy and quality of life together.

Like many couples who have adopted this strategy, you too can benefit from the unpleasant and persistent emotions associated with a situation. First, it is helpful to become aware of these emotions, learn to see them differently and defuse them.

In fact, when you look at them with a certain distance, these emotions weigh down your daily life, but they are also clear indications that a problem exists.

Moreover, because you cannot put up with these unpleasant emotions forever, they can become sources of motivation to set a goal, make changes and solve the problems they produce.

The following table provides some suggestions for questions that can help you recognize, defuse and effectively use unpleasant emotions.

Questions to use to effectively defuse any unpleasant emotions

① Which emotions do you feel more?	② What do these emotions mean?	③ What is behind these emotions?	④ Which beliefs or thoughts are feeding these emotions?
Feeling anxiety and fear?	Do you sense a threat or danger nearby?	What are you afraid of?	On what facts do you base these beliefs?
Feeling frustration and anger?	What are you hindered by?	What do you really want?	How can you spend more time together doing what you love as a couple?
Feeling sadness?	Are you experiencing a significant loss?	What have you lost?	Would there be win-win solutions for both of you?
Embarrassment?	Do you believe someone can see your limits or your flaws?	What can this person see?	If you have a limitation or make a mistake, is it that bad?
Do you feel guilty?	Do you feel responsible for something?	What do you regret?	What would another couple do in your place?
Feeling of helplessness?	Do you think you can control everything?	What do you want to be in control of? Is it realistic?	In what respect do you have to think that?

Table inspired and adapted from the work of Nezu, Nezu & D'Zurilla (2007), as well as Ducharme, Trudeau & Ward (2008)

By identifying the unpleasant emotions and trying to answer the questions suggested in the table, you will be more in a position to know what you want to change and solve as a difficulty or problem. And finally, the decrease in the intensity of these emotions will contribute to your well-being. It will also be a good indication that the difficulty or the problem is being resolved and that your goal is being achieved.

Reframing your thoughts

Are you facing a difficult situation?

We know that in life, some situations seem like steep hills. When a situation seems insurmountable, your thoughts and your way of seeing the situation influence your reactions. Unhelpful thoughts influence the way you interpret reality and can prevent you from moving forward.

The reframing: a winning strategy

Reframing is about shedding new light on things and transforming your way of thinking so that you can react differently. By changing the meaning given to a situation, you turn towards new perspectives, new solutions.

With reframing, you are invited to stop and think, to see the situation from a different angle and thus to regain your ability to act. The following images can be used to illustrate these different ways of seeing things: imagine wearing clear glasses instead of dark ones, or seeing the glass as half full instead of half empty. This new light helps you to take a more measured or even a more positive view in the face of a difficult situation.

Reframing steps

1. Stop
2. Think and see the situation from a different perspective
3. React in a more balanced and positive way to the situation

Successful reframing tactics suggested by couples

To take life one day at
a time, or one
moment at a time

To realize that no one
is to blame

To build on our
capabilities, strengths,
skills and interests

To look at the
positive or funny side
of a situation

To learn to live with what we
can't change

And for you, what are your
favourite reframing tactics?

The problem-solving approach

As a couple, you do problem solving on a daily basis, for example when renovating, planning an outing, buying a car or finding a service.

It is a process that allows you to make changes to a practical situation and to meet your individual and couple needs. The goal of this process is to find a win-win solution that works for both of you.

Here is an illustration of the process to help you solve a concrete issue or problem.



More details on the problem-solving approach...

1.	WHAT? What is the difficult situation or problem you want to improve?
2.	WHAT STRATEGIES have you tried it before?
3.	WHAT OBSTACLES you might encounter in this process and how to get around them?
4.	WHAT BENEFITS are possible for both of you as a result of solving the difficulty or problem?
5.	WHAT RESOURCES (personal and/or family and/or community) could help you?
6.	HOW TO DO IT? What concrete means can you use to facilitate your approach?
7.	WHEN TO DO THE IMPROVEMENT? When is the right time for you to start the process?

If the difficulty or problem is not resolved...

You are invited to re-assess two steps: **what are the resources** (step 5) and **how to do it** differently (step 6).

Problem solving is more effective if it is:

- put into practice regularly
- applied together and with realism
- combined with various solutions to find the one that really suits you.



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Session 4

**Be well-equipped with the
appropriate tools to know the
resources available to support
your needs**

Our ecomap

You are invited to draw up a portrait of your support network, i.e. your family and friends and the resources close to you, using a tool called the "Ecomap".

The purpose of this tool is to have an overall picture, as accurate as possible, of the people around you - or who could be mobilized - before expressing your support needs and requesting help.

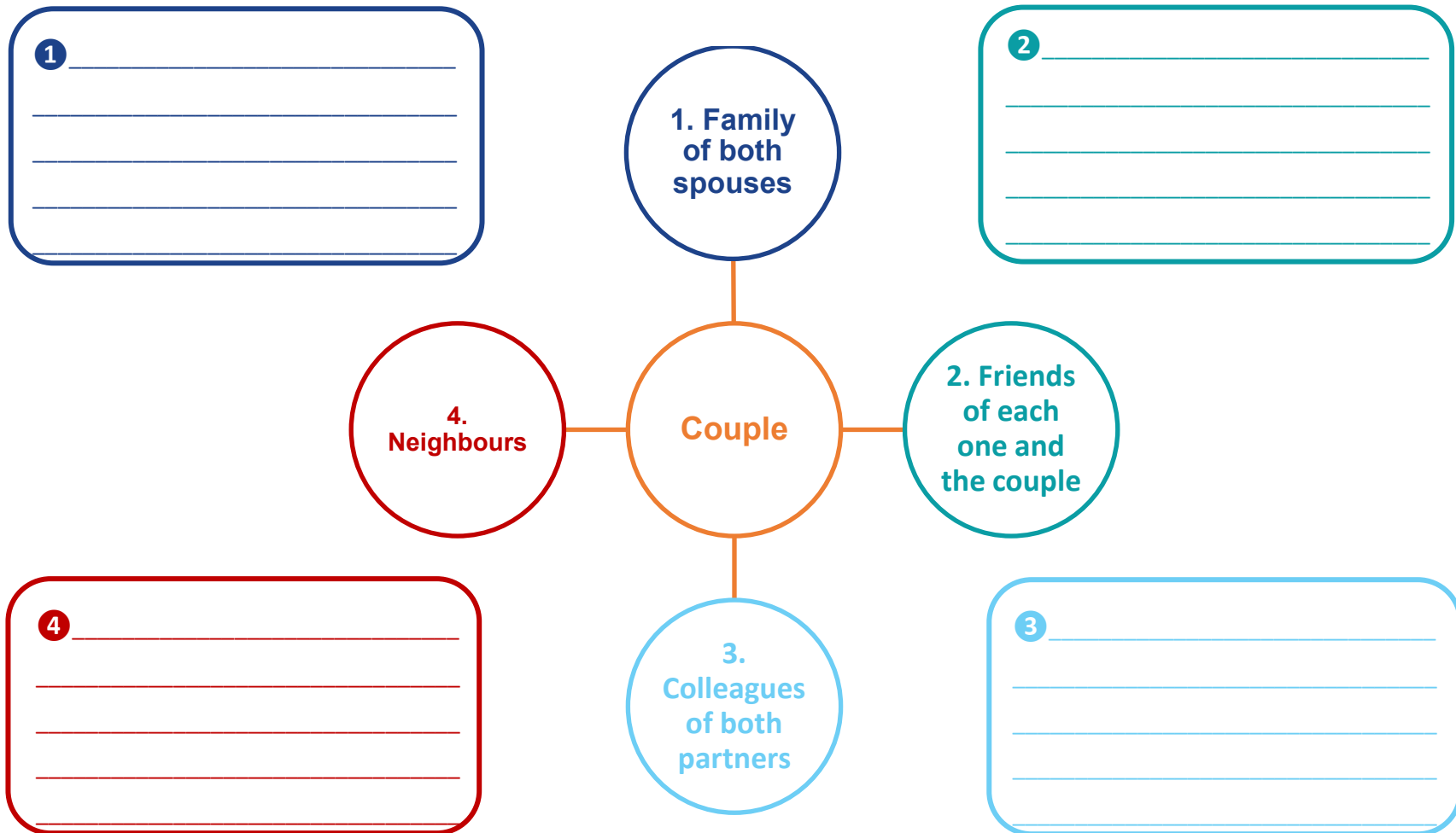
This ecomap allows you to identify your support network and also to consider whether there are other people who might be significant in a particular need or assistance situation.

This tool could be particularly useful if one of you is ever admitted to the hospital and in other everyday circumstances where you may need support and assistance.

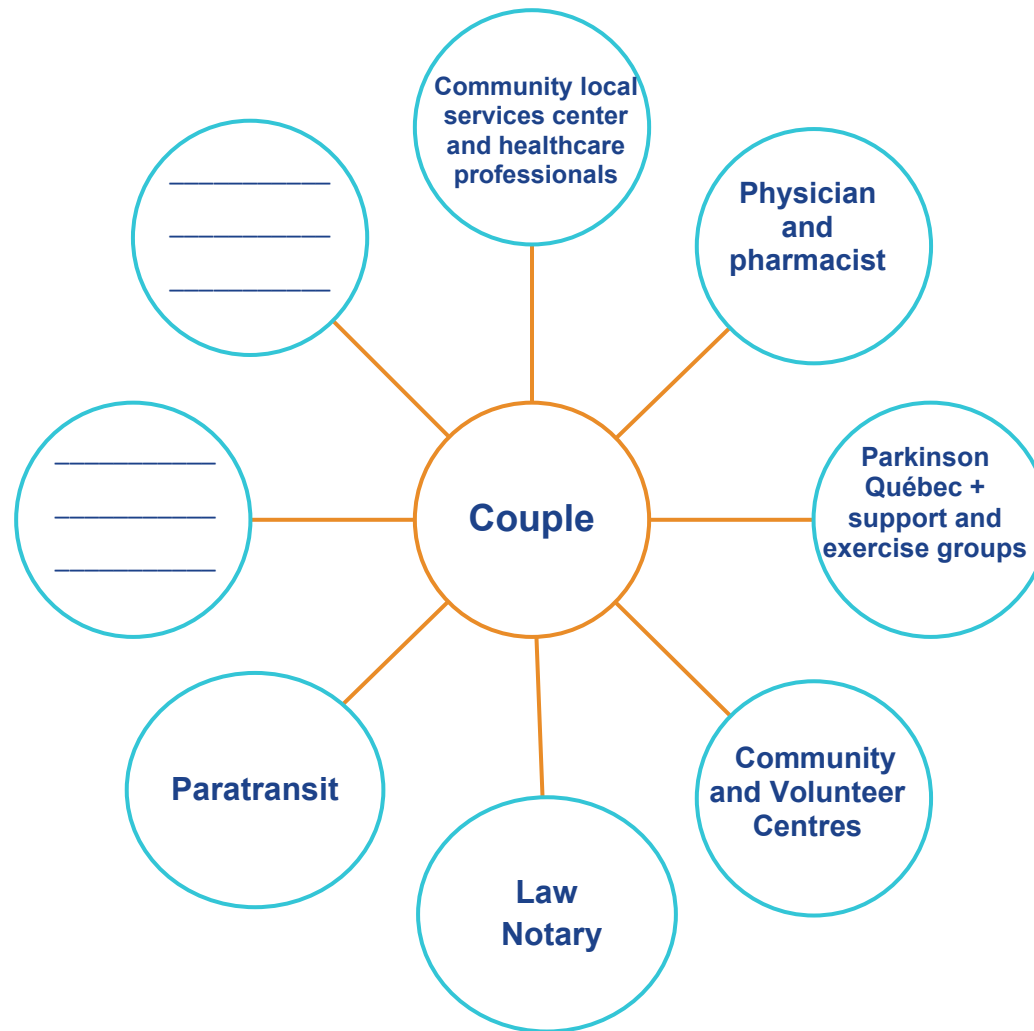


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Our environment: an example to be detailed



The resources in our community: a model to be completed



RESOURCES TO MEET THE DIFFERENT TYPES OF NEEDS

Responding to a need for information

There are many human and material resources you can call upon to respond to a need for information.

These may include health professionals such as medical doctors, nurses, pharmacists, occupational therapists, physiotherapists, speech therapists, nutritionists, social workers and kinesiologists, as well as legal professionals such as notary, lawyer and public curator.

The community local services center (CLSC in Québec), the local volunteer centre and government agencies may also be helpful.

You should not forget the other couples who live with Parkinson's and who have an enriching life experience. You can visit the Parkinson Quebec website or call to the information line to get information about support groups available near from your area.

<https://parkinsonquebec.ca/en/>

Books like [The Info Parkinson Guide](#), brochures, web interventions, and internet sites that are credible and recognized are a kind of library of information.

Finally, there is the "[Parkinson's disease](#)" brochure from the Québec Public Library Association which is updated annually and contains useful information. You can access this brochure and other thematic booklets by following the link below:

<https://bibliosante.ca/en/>

Responding to a need for physical and emotional support

There are **many people** around you who may be able to help if you need emotional or physical support. For example, your spouse, your children and grandchildren, your family and friends, a brother, a sister, your faithful friend, your colleague with whom you have an affinity, your neighbour who could be very receptive and willing to collaborate with you, or other couples who are going through the same situation as you.

The healthcare professionals at your **community local services center** and your local **in-home support services** are also an essential resource when physical support is needed.

Also at the emotional level, **a pet** can sometimes be a source of happiness and help you feel less alone.

You can also think of **activities that make you feel good**, that you enjoy and that are more relaxing. Even a walk in the nature is a good idea.

And for some, being part of a **support group** experiencing with Parkinson's and having a **spiritual life** can be valuable allies in meeting an emotional need.

Responding to a need for social activities

Despite the presence of Parkinson's, you may want to continue or have more recreational activities, hobbies and outings that you enjoy.

The value of engaging in these social activities is also to share time with people who have very similar interests to those of you.

With whom?

You may have social activities with several relatives, such as:

- your spouse
- your children
- your grandchildren
- your family
- a neighbour
- your long-time friends

Where?

There are many places to participate in these activities, such as:

- social clubs
- libraries
- cultural, sports, community or day centres
- on line activities

How do you do it?

You can also join exercise or walking groups, individualized trips or organized groups.

More suggestions?

Coffee shops, restaurants and community centres can also be great places to meet and chat over a snack, beverage or meal!

Responding to a need for material support

Your community local services center

If you need material support, you can make a request to your community local service centre to assess your situation and determine the care, services or assistance that would benefit you.

This assessment takes into account your abilities and resources. Co-operative services and private agencies listed at your community local services center can also play this role.

More resources

To meet your need for material support, there are also other resources:

- rehabilitation or volunteer action centres
- community agencies and organizations
- government agencies

They offer a variety of support programs, such as stickers along with disabled parking permits for people with mobility impairment, paratransit, or volunteer transportation for people with loss of independence, financial counselling and many other services.

You can also turn to pharmacies and adapted equipment stores as well as social economy co-ops for house cleaning, meals, respite, care, if needed.

For more information, visit:

Government of Quebec Guide

<https://www.quebec.ca/en/family-and-support-for-individuals/seniors/programs-services-for-seniors>

Parkinson Quebec's Financial Resources Guide

<https://parkinsonquebec.ca/en/living-with-parkinsons/employment-financial-resources/>

Practical tips to improve your chances of successfully request support

To improve your chances of success, here are some tips:

- ❑ When you call the office of an agency, an answering machine often directs you to a series of options before directing your call. Sometimes to avoid this situation, by immediately pressing the "0" button on your phone, you may be connected directly to an operator.
- ❑ Ask for and always record the full name, phone number, contact information and job title of the people you call. Write them down along with the date of the call, this information may be useful to you in the future.
- ❑ Ask for an email or business card from the people you meet, this contact information could be very useful at an unexpected time. Keep it in a safe and easy-to-reach place, do not hesitate to contact them again, if necessary.
- ❑ Asking for help when you feel the need shows that you care about your health and that of your loved one. Also, the people who are dear to you and those working in the health services, public or private, will understand more and more what it is like to live as a couple with Parkinson's. Dare to take a first step towards them to preserve your well-being and your quality of life.
- ❑ Don't hesitate to follow-up with the people working in the different resources. If they don't respond after a reasonable amount of time, contact them again until you get the information or service you need.

- ❑ If the person you are calling seems to be in a hurry, don't hesitate to say, "I see you don't have time to answer me right now. Is there a more appropriate time to speak with you? When is the best time to call?" If the worker cannot give you a satisfactory answer, politely ask if there is someone else you can talk to.
- ❑ Sometimes a person speaks to you in jargon, or in technical terms that are difficult to understand. If this is the case, advise him/her and ask him/her to repeat the information in different words. Resume what you have understood to prevent misunderstandings.
- ❑ Don't hesitate to ask professionals for pamphlets, books, writings or websites that you can consult at your leisure and reread as needed.
- ❑ Always keep a copy (paper or electronic) of completed documents and forms that you send to an agency for your records. This way, you won't have to start over if your application is lost or refused.
- ❑ Report accurately the signs (physical, emotional and others) that indicate that you will possibly need help in the future. This way, when you as a couple reach your limit, the professionals will be prepared and will take your request into consideration more quickly.
- ❑ Seek services before you are in a crisis or emergency situation. By being organized and prepared, you ensure that as a couple you remain in control of your decisions.
- ❑ There are other couples like you who have been through difficult situations and would be happy to share their time and tips with you, too. Their experience could be useful to you!

Session 5

Communicating more effectively together, with those around us and the health professionals

To better prepare medical appointments

Date of appointment: _____

Place of appointment: _____

Name of physician: _____

Name of pharmacist: _____

Name of community
local services center: _____

Prepare your medical appointment

List of changes, questions and issues of concerns

Overall health: _____

Physical symptoms: _____

Psychological symptoms: _____

Side effects of medications:
(if applicable) _____

Other information: _____

Bring your list of medications and the daily diary (e.g. ParkiTrack)

What we have learned from this medical appointment

The most relevant points for us are:

Date of next appointment: _____

Location of appointment: _____

Physician's name: _____

Do we have any particular follow-up to do before the next appointment?

<input type="checkbox"/> Yes. What?	
When?	
Where?	
With whom?	
<input type="checkbox"/> No	

Inspired and adapted from Parkinson Québec, 2016

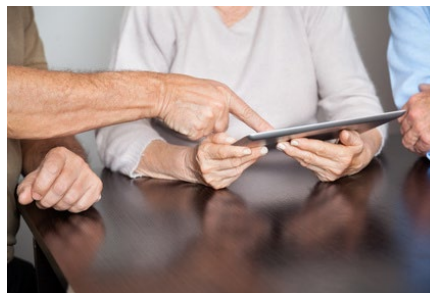
WHEN RELATIONSHIP AND COMMUNICATION RHYME WITH COOPERATION!¹

Introduction

Maintaining or improving communication, as well as the quality of their relationships, is an important concern for many couples during the course of Parkinson disease.

As a result, many couples, health care providers and researchers have become interested in effective ways to promote communication, bonding and harmonious functioning between partners. In order to refine or maintain your communication skills, you will find in the following pages various means resulting from their experience.

You may recognize ways of doing things that you are already using. This is good because you will know that you are on the right track! You'll also discover new ways to try out and evaluate the results. Usually, new things are difficult before they become simple and natural. As the old proverb says: one of the best ways of learning is doing.



¹ The following section presents different ways to help couples improve various aspects of communication and the quality of their relationships. It is based on testimonies from couples who have collaborated in the development of this helping intervention and from other couples encountered in the course of clinical activities. It is also based on the experiences and work of specialists in Parkinson disease, family health and communication. Free-stock pictures from Fotolia Image Bank.

Some tips to facilitate communication

Communicate clearly and directly

To maintain good communication, many couples living with Parkinson's stress that it is essential to speak clearly and directly with each other and with the person or people involved in the message.

«It's important to say what you're thinking and also to think about what you're saying. That way, a lot of misunderstandings can be avoided. »



«It's also important to allow time for the person with the disease to say what she/he has to say, to question, and to ask her/him to clarify if you didn't quite understand. I don't want to feel rushed or misunderstood or have someone speak for me. So, I make an effort to do that and to give her/him room. It just

takes a little more time, but that's okay. In retirement we have plenty of time! »

Adjust content of messages according to the audience

To make themselves understood, couples realize that it is often necessary to say the same thing using different words to their children, grandchildren and different health care providers. These couples adapt their language and information according to the age and development of the individuals, their emotional connection and the purpose of the information. According to these couples, simple and precise words that evoke images, sounds or a feeling are more easily understood and provoke more thought and action.



Communicate more effectively with health care professionals



To promote effective communication and mutual understanding with health care professionals, some couples systematized the way they explained their situation and asked questions during follow-up visits or phone calls. For example, they briefly explain: ***"What's on their mind right now? When is it***

happening? How is it going? Who or what is making it worse and making it better? What is most difficult? What would they like to change? What can be done now to improve that situation?" Some couples write this information down, using a diary, journal or computer, so that nothing is forgotten and everyone's time is optimized.

Getting out of dead-end situations

When a situation is at a standstill, couples find it helpful to **name what is going on** and change their vocabulary in order to get out of the dead-end situation and to discover liberating solutions. Rather than staying fixated on the **"why"** or the causes of a situation, they find it more productive to focus on the **"what"** - that is, the **consequences** the situation has on them and their relationship. This allows them to clarify their values and stay focused on their life goals rather than getting caught up in endless arguments.



"By having workable common plans, we make possible what is achievable."

Doing less of the same



A number of couples recognize that if what they're saying or doing is not working, they focus on doing something else and change their strategy to achieve their goal.

*"Changing tactics, **doing a little less of the same thing**, usually produces better results. There's no point in repeating what doesn't work. We look elsewhere for new solutions."*

How to put Parkinson disease in its proper place

There are times when Parkinson disease tends to take up too much room in some couples' lives, as well as in their conversations. Many couples therefore decide to **put the disease back in its proper place** and refuse to reduce their conversations to this single topic.

*"For us, what helps is **keeping in touch with daily life**, our family and all the **activities we love**. That's what gives purpose to our lives. Making the most of life's little and big pleasures, appreciating moments of calm and peace, and contemplating what's around us, this is what we try to occupy the majority of our time with."*



Preparing instead of hiding



Many of the communication difficulties that couples living with Parkinson disease experience have three common barriers: fear of disappointment, embarrassment about talking about a topic or showing weakness, and fear of losing the affection of others. It is normal to feel these emotions. However, couples report that over time it is helpful **to learn and practice how to calmly and simply tell people about things, instead of hiding them.**

"Rather than hiding a situation, symptom or illness, we quietly took the risk of talking about it and announcing it to our family, grandchildren, accountant, etc. A secret is hard to keep and at some point the discomfort becomes so great that instead of resolving the situation, it gets worse. So, after discussing it, we took the initiative. The first step was difficult of course. But it helped us to move forward and to take other steps more easily because people are a lot more receptive and understanding than you would imagine, you know, even at the bank or the pharmacy or the government."

"Plus, we didn't realize that our children and grandchildren were concerned. Knowing and understanding the disease and doing everything we could to stay healthy, reassured them. It calms a lot of unnecessary worries. People think we are brave!"

Expressing mutual feelings to each other

To cope with Parkinson disease, couples say how crucial it is **to give the same degree of consideration to each other's feelings.**

"It's very important to accept and allow everyone to express their fears, desires and needs. It allows us to understand each other and better adjust to changes when they come."

How to properly decode and interpret nonverbal communication

The quality of relationships and the feelings of couples are expressed through gestures, facial expressions, eye contact, touch, posture and the distance maintained between spouses, partners, with family and friends.

With Parkinson's, it is recognized that the person living with the disease is less able to express her/his emotions because of physical changes that are out of her/his control and beyond her/his efforts to correct. Also, some care partners express their feelings little or with difficulty because of their personality, their upbringing or emotional overload.



"It's important to be mindful of how the other person is feeling, because their facial features don't always go with how they really feel. It's like that with Parkinson's, it's better to find out instead of making a bad judgment or saying something hurtful. When I'm worried or stressed, I'm sometimes lost in my thoughts and other times I explode at the drop of a hat. I'm learning to breathe through my nose and put things into perspective. It's not always easy to stay Zen!"

Caring for yourself and other significant people

Maintaining a joyful spirit and regularly replenishing energy or doing stimulating activities help many couples remain satisfied, fulfilled and available to each other and their loved ones.

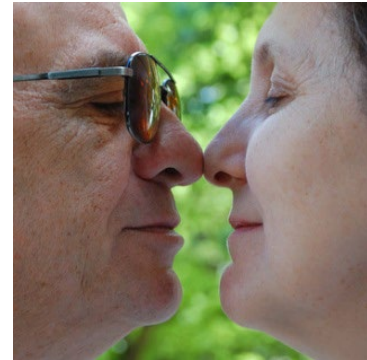


"To tackle difficult situations and stay in harmony, it's good to recharge and take care of ourselves to properly take care of each other and our family."

Cultivating moments of intimacy

Communicating and being in a relationship is also, according to many couples, enjoying a fulfilling sex life. Sharing moments of intimacy is for them a source of communion and pleasure. To do this, these couples emphasize that communication about this remains the key element in order to adapt to the normal changes associated with aging and the changes brought on by Parkinson's.

"My husband helps me a lot and considers me a woman in spite of everything. He tells me this from time to time. I still feel desirable and it's mutual."



"The longing is at its best when the medications are fully effective. It's also most beneficial when we feel good physically and emotionally."

"We have lessened the drama of Parkinson disease and its effects on our sexuality. Now, we see and undertake the situation differently. Foreplay, caresses and tenderness are more important. We are less concerned about performance! It's the quality of the moment that counts..."

"We talked with the nurse and the specialist about the concern we have regarding our sex life. Today, there are different ways to help couples like us, depending on the difficulty. It's not like the old days anymore!"

Maintaining harmonious relationships

And, when questioned about what works best to maintain harmonious relationships and cohesion between them, some of these couples reveal what they like best.



According to them, it takes:

"love and trust!"

"some mutual respect and complicity..."

"lots of cooperation, negotiation and compromise on both sides!" "to accept our shared responsibilities! It always takes two people to communicate, to argue, to resolve difficulties and to make up with each other..."

"humility to apologize and to repair a mistake..."

"humour, which is, being able to laugh at ourselves, at others, and at situations that are beyond us..."

"spiciness, some surprises, some creativity, and sometimes even some crazy things!"

"smiles and many grateful thank you. It's crazy how good those little paybacks feel!"

"courage, encouragement, understanding and gentleness. You can make a lot of mileage out of that."

"desire and wishing you could work out the kinks before you go to bed!"

AND FOR YOU, WHAT ARE YOUR FAVOURITE STRATEGIES FOR MAINTAINING GOOD COMMUNICATION AND HARMONIOUS RELATIONSHIPS?

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Session 6

Making role change adjustments

Take another person's place

When you face a time of change or a difficult situation, imagine that you are switching places with each other.

Adopt the other's position, roles and responsibilities. Consider their health and living conditions. Also consider the place that Parkinson's or another disease takes in her/his life.

If you were in her/his situation...

How do you think your partner feels about the changes in roles and responsibilities she/he is experiencing?

What are her/his greatest challenges in accomplishing her/his roles, tasks and activities?

What is the most difficult thing when I put myself in her/his shoes?

What is her/his greatest satisfaction at the end of each day?

What helps her/him the least?

What helps her/him the most?

Following this exercise, what most surprised you?

How did it feel to be in your partner's position?

What does this exercise tell you about your partner? How you feel about yourself? How about your relationship as a couple?

How might this be helpful, for instance, in times of stress?

When there are role, task, or activity adjustments, you are encouraged to repeat this exercise as often as necessary in order to anticipate and meet each person's needs on a regular basis, especially with Parkinson disease and its demands.

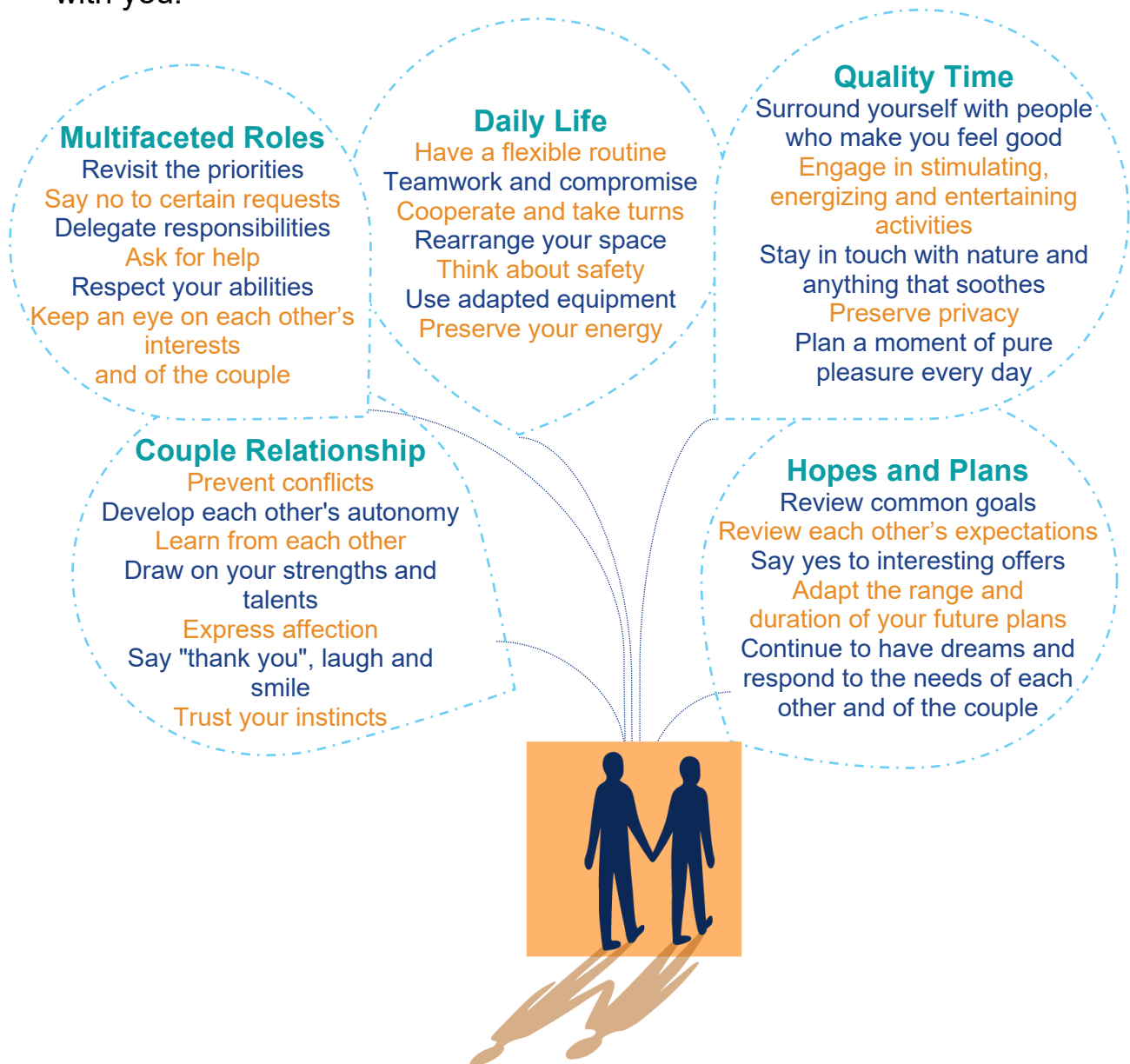
Feeling understood by each other, being complicit, cooperating and offering small gestures of appreciation are the sources of comfort and gratification. Many couples, like you, mention that putting themselves in each other's shoes helps to cope with the many changes and avoid many turbulent times...



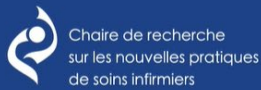
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Facilitate transitions and role adjustments

To facilitate the adjustment of roles with Parkinson disease, some couples living a very similar situation to your own offer different ways. They share their ideas and offer you to pick and choose what will make you and your partner feel better. Here are the suggestions they share with you:



A collaborative project



Chaire de recherche
sur les nouvelles pratiques
de soins infirmiers



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With the financial contribution of the
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