

TAVIE *in* **MOTION**

*Treatment, Assistance,
Virtual Nurse Intervention,
and Education*

WHEN RELATIONSHIP AND COMMUNICATION RHYME WITH COOPERATION!¹

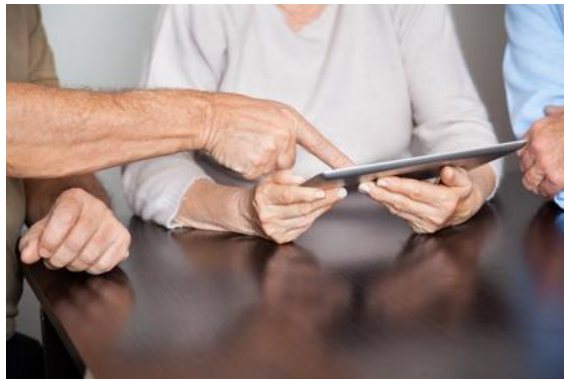
¹ The following section presents different ways to help couples improve various aspects of communication and the quality of their relationships. It is based on testimonies from couples who have collaborated in the development of this helping intervention and from other couples encountered in the course 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.

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's 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.



Some tips to facilitate the 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 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 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 keeping it going, 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's disease in its proper place

There are times when Parkinson's 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's 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'd 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's 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 and more easily 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.

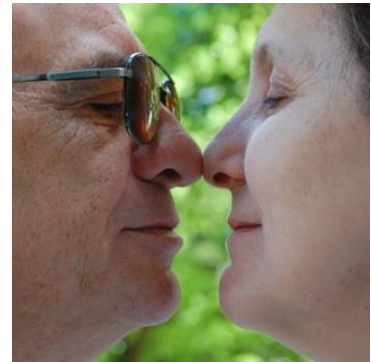


*"To tackle difficult situations and stay in harmony, it's good to **recharge and take care of ourselves to properly take care of each other and our family.**"*

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's 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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