

# Caring and sharing

Coping with the severe motor and non-motor symptoms of Parkinson's is a non-stop challenge. According to specialists **Gila Bronner** and **Orna Moore**, one of the first steps when dealing with these complicated issues is to understand how the disease affects communication and intimacy within personal relationships

“**W**hen my son visits with his children, I'm happy. Soon, however, the noise my grandchildren make while running around the house makes me nervous. My tremor gets worse and I have to leave the room. They think that I don't like their visits, but they are wrong. How can I tell them the real reason I am sad, when I can't even tell them about my Parkinson's?”

This is just one example of how Parkinson's can impact on the family relationships of people who live with the disease. Here's another:

“We recently told our five-year-old granddaughter about my disease. Last week, when she saw the tremor, she took the shaking hand and said: 'Parkinson! Parkinson! You are bad! Stop shaking!' Our eyes were filled with tears of excitement and happiness, and we felt we are not alone.”

Clearly, intimacy and communication are vital ingredients for a good life for people with Parkinson's (PWPs) and their families. But this is sometimes easier said than done. So what is intimacy and how can we communicate our feelings better?



**WHAT IS INTIMACY?**

Intimacy plays a central role in the human experience and doesn't only refer to sexual or erotic events. There is a basic need in everyone's life for intimacy – namely a need to belong, to be close to others and to be loved. This need may be satisfied within an intimate relationship (including friendships), dating relationships, spiritual relationships, and family and marital relationships. At the same time, each person will have different intimacy needs. Meanwhile, if you struggle with the demands of everyday life then this can negatively affect your intimacy needs, and if you are not open about this fact then your family members may not notice your problems, which could lead to other intimacy issues. One thing's for sure, however: Parkinson's often raises questions and concerns regarding relationships and intimacy.

**WHAT IS COMMUNICATION?**

Communication is the sharing of ideas, information and feelings – both verbally and non-verbally. It is the way we let other people know about our ideas and feelings. It is what you say, how and when you say it – but also what you *don't* say. It is your facial expression, gestures, posture and your vocal tones. Communication is the key to free and warm expression, caring and love, and is essential in maintaining a good relationship and a good quality of life. Good family communication involves being both an active listener and a thoughtful speaker. Different perceptions and expectations in the family can lead to confusion and frustration. Parkinson's has the potential to seriously affect communication and impact on family relationships.

**INTIMACY AND COMMUNICATION IN PARKINSON'S DISEASE**

Communication is the most effective way to deepen intimacy in relationships – in the family, with a spouse, with friends or when at work. *Every* aspect of life improves when we become better communicators. People who are open to sharing their feelings, thoughts and ideas without the fears of being misunderstood can achieve real intimacy in their relationships.

Yet this is where Parkinson's comes in. Dealing with any chronic illness demands communication. PWDs and their families often have numerous questions regarding the disease and its treatments – but they also need to intimately share their fears, thoughts and feelings. They need communication skills, which can be decreased due to the stressful and multi-dimensional environment that the disease creates.

Parkinson's can lead to emotional, family,



*“Parkinson's gives a 'second chance' – an opportunity to change behaviours that lead to open communication”*

social, financial and vocational dysfunction, and its psychosocial effects – the non-motor symptoms – may be more devastating and disabling than the motor symptoms. Since the disease's symptoms are often debilitating and unpredictable, couples may find their expectations for themselves and each other forced to change unexpectedly.

**IMPROVING INTIMATE COMMUNICATION IN THE FAMILY**

Maintaining intimate communication in a relationship will have a positive impact on the long-term effects of Parkinson's – especially at the time of diagnosis when PWDs and their families are forced to adapt to a future that includes a degenerative illness. On

the opposite page (see box) are a few steps and strategies that will help enable families that have to live with Parkinson's maintain intimate communication and feelings of closeness. People are not always used to disclosing feelings or sharing problems, but it must be acknowledged that Parkinson's gives a 'second chance' – an opportunity to change behaviours that lead to open communication with significant family members.

Intimate communication offers PWDs and their families a social network that provides strong emotional attachments and helps to fulfill a universal need of belonging and the need to be cared for. To experience intimacy, people must allow loved ones into their



mind, body, soul and heart. In short, good communication isn't something that just happens. But you can make it happen! ■

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## 10 STEPS TO IMPROVE INTIMATE COMMUNICATION IN THE FAMILY

### 1 SHARE WITH THE FAMILY

If people with Parkinson's (PWP) wish to adapt to changes that their disease creates then they have to share more feelings, thoughts, fears and difficulties. It is essential they keep their partners and family up to date on what's happening in all areas of their lives. For example, it is important to let them be familiar with the 'on-off' phenomenon, especially its manifestations in daily performances. It is recommended – for PWP as well as caregivers – to give loved ones practical tips on the best ways to help deal with these or other important situations.

### 2 BE HONEST WITHOUT ACCUSING

Sometimes PWP feel hurt, ignored or misunderstood. As a result, they may become angry and accusing – for example, if their children do not offer to take them to a family gathering. There could be reasons for this, such as not wanting the event to be too much of a burden for them. The decision could be the correct one, but it is also true that they should have consulted with the PWP. In these cases, it is recommended that PWP emphasise and make it clear to their loved ones that they prefer to discuss such cases in advance – so they have the opportunity to share decisions in an assertive way.

### 3 SET TOPICS FOR INTIMATE COMMUNICATION

PWP should focus on the main issues they wish to be aired. Lists of problems, challenges, ideas, feelings and requests are a good idea. The more important ones should be chosen and made the priority.

### 4 COMMUNICATE EFFECTIVELY

After choosing and planning the 'intimate talk', PWP should find the best person in their family to share it – and plan the best timing. For example, one of our PWP clients has pointed out that, for him, the afternoon hours are the best time to discuss important things, since he is active and feels at ease. He can talk loudly and clearly, and can be easily understood. He also said this is the best time for his wife as the house is quiet and she usually feels relaxed and welcomes their intimate discussions.

### 5 MEET EXPECTATIONS

One of the benefits of good intimate communication is that it leads to harmonised mutual expectations. It is important to share expectations, listen to one another, and to be realistic and clear. The key point here is to be considerate and empathetic.

### 6 BE FLEXIBLE

Parkinson's is progressive and surprising. Consequently, PWP might encounter unknown situations that demand family flexibility. Open communication regarding new feelings and concerns is vital, even if these issues have already been discussed in the past. Mutual responsibility is vital.

### 7 EXPRESS LOVE AND AFFECTION

It is well known that affection, expressions of appreciation and small gestures contribute to a better quality of life for PWP, spouses and their family. For example, the wife of a PWP said recently: "One of the main things that assist me is my husband's affection. In spite of the difficulties inflicted by his Parkinson's, he constantly compliments me. Even when he is exhausted he will caress me gently or make small gestures to express his love."

### 8 LISTEN AND BE EMPATHETIC

Simply listening, encouraging and being supportive is an empowering and essential act of intimate communication. And it's the responsibility of each and every family member to listen.

### 9 FIND A HOBBY TO ENJOY TOGETHER

Some families may find that doing things together contributes to their intimate communication. Good examples include playing games, going to the theatre and concerts or just walking together.

### 10 PLAN FOR A SHARED FUTURE

An optimistic way for PWP and their families to look at life is to focus on exciting and positive goals – and to share plans for the future. PWP should tell their families about their dreams, about the things they wish to accomplish, about their fears and expectations, and about their financial issues. Things discussed openly appear much less frightening.