



The
Inspiring Voices
of People
with Parkinson's

Wolfgang

“ I have discovered
inner resources ”

Foreword

Telling their stories in the next few pages are some inspiring people. Each has found their own special way of living with Parkinson's disease – a movement disorder which affects about 6 million people around the world.

Colleen, José Maria, Carola and Wolfgang have full rich lives, with families and friends who care about them. They run marathons, cycle over mountains, swim long distances, samba their way expertly around a dance floor! Yet their hands often shake, their limbs are stiff and heavy and their speech may be slurred. Sometimes they are frozen in a body that doesn't respond.

We have asked them to speak out about their Parkinson's disease, so that others can know more about a condition which is so often in the shadows. By talking about the reality of their symptoms and how they respond to the everyday challenges of their condition, they are helping to dispel some of the myths and misunderstandings that surround Parkinson's disease.

They show that Parkinson's disease doesn't just affect elderly people or individuals. It is diagnosed in younger adults too, and it affects wives and husbands, parents and children. That's why we've asked married couples, José Maria and Veronica, and Terry and Jean to tell us how they support each other, while living with Parkinson's disease.

Don't think the men and women in Parkinson's Voices are unusual. They are like thousands of other people with Parkinson's disease, who are refusing to let a loss of movement take the light out of their lives.



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Introducing

Parkinson's Voices



Parkinson's Voices is a new initiative from UCB which is raising awareness about Parkinson's disease and helping people affected by the condition to find out how their doctors, nurses, physical and other therapists can help them control their symptoms, improve their movement, and be more active.

Parkinson's is a condition that affects whole families, not just the individuals who are diagnosed with the disease. As their symptoms progress, people with Parkinson's disease can feel their role in the family becoming devalued if they cannot work or are unable to play a full part in bringing up children, and participating in family, sporting and social activities.

A conspiracy of secrecy often surrounds the diagnosis, as people hide their symptoms from employers, friends and even family members.

By improving public understanding and providing information and support for families, Parkinson's Voices aims to:

- Break down the barriers of silence that surround Parkinson's disease
- Encourage those living with Parkinson's to work with their medical team to improve their care
- Provide a forum where the hopes and needs of families can be heard.



When Colleen was diagnosed with Parkinson's disease in 2005, she decided to phone everyone in her address book and tell them. Then she took charge of her life, working with her doctors to find the treatment that suited her best, and continuing to do all the things in life that she enjoyed.

I remain blissfully happy

colleen

'My life is full and rich and I choose to make it that way. I still work, but I work for me, so I can be flexible and choose what I do on a daily basis. My team knows my situation. Being open and honest with them is the best way. Then they don't have to guess what to do – they know. I work with my health, not against it,' she says.

Colleen's symptoms of Parkinson's started with toes that bent strangely and a right foot that sometimes couldn't keep a shoe on. It was only when she froze in the street – unable to walk – that she went to her doctor. Extensive tests confirmed the diagnosis.

Finding the right treatment wasn't easy as some drugs made Colleen feel dizzy, sick and weak, and she lost a lot of weight.

'We found a better combination of medication, my balance returned, and I've regained some weight. Each day however, I fight through a wall of fatigue and overwhelming tiredness, but I am coping,' she says.

Colleen has plenty of support, and a new partner who is lover, friend and soulmate, and walks by her side as an equal. She is actively involved with her local community and, as she doesn't sleep well, writes, paints and cooks whenever it suits her:

'I am preparing for my future by learning to be comfortable in my own skin, developing my thinking so that I can be occupied in moments of non-movement. I hope to have the grace to dispel frustration.'

“ I am not afraid, I am open-minded, and I remain blissfully happy. ”



“ Parkinson’s is not a reason to give up. We all have so many potential resources in ourselves. But they are hidden and we have to search for them. ”

I have discovered inner resources wolfgang

There aren't many people who can say they have cycled over 15 Alpine passes, including the highest in Switzerland, Austria and Italy. But Wolfgang, diagnosed with Parkinson's disease 15 years ago, before he was 40, can say it!

'I don't recommend that everyone has to cross the Alps by bicycle, but I'd like to encourage everybody to define their own targets and challenges, and discover their own Alps,' he says.

For the first five years after his diagnosis, Wolfgang took his medication to control his symptoms, and went on raising his children with his wife, working, and living his life. It was only when he started having "freezing" attacks when he couldn't move properly that Wolfgang couldn't hide his Parkinson's disease any more.

'When I looked in the mirror I saw a man with hanging shoulders and

floppy muscles, so I decided to take more responsibility for my health. I started to run every morning and visited a fitness centre three times a week.'

With training, his muscles were rebuilt, his self-confidence was restored and many of his problems went away. He's always liked bike riding, but he started taking it more seriously, and found it worked like another medicine:

'When I ride my bike, I have to share narrow streets with motorised road users, so I must keep my balance and control my bike to avoid dangerous

situations. When walking and moving are difficult for me, I can still ride my bike. When my voice is affected by my "freezing," riding the bike can sometimes even make my speech better.'

Writing poetry also gave Wolfgang enormous satisfaction – to be able to express his feelings and thoughts about Parkinson's disease:

'Of course, I'd still prefer to be perfectly healthy. But it's true that having a life-changing illness can help people find the potential in themselves they'd never known was there. That was certainly true for me.'



I can still do my favourite things

josé maria

José Maria is training to swim across the port at Malaga – just as he did 40 years ago. Diagnosed with Parkinson's disease in 2004, José Maria believes that regular exercise is good for his mind as well as his body.

It was while José Maria was out walking with his wife Veronica in 2003 that he had his first symptoms of Parkinson's disease. He couldn't swing his left arm properly and had to work hard to make it move. The result was so forced that his wife, Veronica, thought he was waving at someone. As well as trembling in his left arm, José Maria was also having trouble walking, and sometimes his face was rigid.

By the time his son celebrated his first communion a year later,

José Maria felt too weak to help organise the party after the service and didn't even have the energy to talk to his guests. At work in the sales department of a large company, the travelling and driving were exhausting.

When José Maria was finally diagnosed with Parkinson's, his doctor reassured him that it is one of the most common brain disorders:

'I put myself in his hands with complete trust, knowing that he

will give me the best treatment for my symptoms to "live as normal a life as possible":

Medication helps to control José Maria's symptoms, and he has now retired from work. Instead, he runs the house as "budget officer" and "domestic manager":

"I accept that Parkinson's is a degenerative disease, but I am maintaining as normal a life as possible. Keeping up my exercise routine is essential to me physically, and it helps me to stay positive in my mind as well."



I am very proud of my husband veronica

When her husband, José Maria, took the diagnosis of Parkinson's disease in his stride, Veronica knew that she must be supportive and had to get over her initial despair.

'My task is not difficult as he is such a positive person. If he has a low point, we all pull together to help him get over it. We look at everything we have to be grateful about: our children, his hopes, our luck in living in such a beautiful city, and as we are believers, our faith in God,' Veronica explains.

At first, she and José Maria knew very little about Parkinson's, but they soon put that right by reading books and getting information on the Internet. Veronica watched her

husband's symptoms improve after a few months of taking his medication. As José Maria took more exercise, Veronica asked the neurologist whether her husband was trying to do too much. But she was advised to let him set his own limits.

'I am very proud of my husband and I have been very lucky in my life with him. His thirst for survival is admirable. I want to help him with everything, support him always and encourage him.'

“ Sometimes destiny deals us a blow but when one door closes, a window always opens. Let us be optimistic and appreciate what we have. ”

“ I try to live every day as consciously as possible, to enjoy the good times and the “here and now”, to be spontaneous, and to set myself small targets so that when a bad day comes, I know how to cope with it. My disease cannot yet be cured but I will not give up fighting.

”



I will not give up fighting carola

Carola always set herself ambitious targets, running marathons competitively, hiking and cycling in the mountains on holiday, and learning complex moves at advanced dance classes. But when she started to fall behind in her training, lost her coordination, and found her writing becoming illegible, she knew that something was very wrong. How would she continue her job as a dental hygienist if her hands were unsteady?

'The diagnosis of Parkinson's dealt me a hammer blow. Although I had long since had a foreboding, as my symptoms increasingly pointed towards Parkinson's, I had tried to shut out these thoughts, telling myself that it was something that happened to other people, not to me,' she recalls.

Once her medication started to work, Carola found that her life wasn't as restricted as she'd

expected. But the sudden death of her husband from a heart attack was a shocking new blow.

'A tough time lay ahead, but I found that I had an unexpected amount of resilience. I spent some time in a rehabilitation clinic to have my drugs adjusted so that I had "as much as necessary, but as little as possible"; Carola explains.

Being open about her Parkinson's disease to friends and family took

a great weight off her mind, and word got around her home town in Germany.

Carola still takes 10km runs through the forest, and Saturday is still dance night.



I talk about Parkinson's, not for sympathy but for understanding

terry

Since he took up marathon running in 1991, Terry has run 18 marathons and raised over £50,000 for Parkinson's disease.

'Some people get wrapped in cotton wool, others want to just get on with it. Parkinson's disease is very individual, and you just have to do what's right for you,' he says.

When Terry had his first symptoms of Parkinson's, he thought the tremor in his left arm was due to a trapped nerve. He was only 46, happily married to wife, Jean, with young children, and he believed that Parkinson's only affected elderly people. Even after he was diagnosed,

he thought there'd been a mistake, as his symptoms were mild:

'I tried to ignore the symptoms and I now realise that, like most people who are newly diagnosed with Parkinson's, I was in denial.'

Over the years, Terry's symptoms have progressed but continue to be largely well controlled by medication. Fine hand movements have become more difficult – writing, tying shoelaces, buttoning a shirt – and

Terry doesn't sleep well. But he stays active and doesn't let Parkinson's get in the way of family life and the other things he enjoys:

'I believe I have come a long way since 1987; from refusing to acknowledge Parkinson's disease, I now try to tell other people what it is like to live with a chronic neurological condition. Not for sympathy but for understanding.'



“ We have been married for 48 good years; we have a wonderful family and six grandchildren. I never consider that I am his carer. I am his wife and his friend as he is mine. ”

*I am his wife and his friend,
as he is mine.*

jean

In the 20 years since Jean's husband, Terry, was diagnosed with Parkinson's disease, she has had to become more self assured so that she can support him through difficult times.

I had always been quite shy and was happy to be a housewife and mother, while Terry worked in a job he loved. All that changed and I have had to become more assertive and have found strengths within myself which I did not know existed,' she explains.

When Terry was diagnosed with Parkinson's disease, Jean found it difficult to get the information she needed about the condition. She collected a pile of books from the library, and sat in her car trying to

understand what was happening to the man with whom she had built a happy, successful family life.

Little by little, Jean found the information she wanted. But she believes there is still a need for better information for people with Parkinson's disease, at all stages of their illness.

'Greater public awareness about Parkinson's is also needed, so that people understand that the disease does not just affect the elderly,' says Jean.

She believes that it helped Terry that their children were very young when he was diagnosed as he had to fight harder not to let his Parkinson's affect their lives. He was determined to play rugby, go to theme parks, swim and take part in all the children's activities along with other parents.

'Terry is, after all, still Terry who just happens to have Parkinson's,' she says.



Opportunity

By Wolfgang

“If every day
you lose a bit more,
of what yesterday you had,
despair is a bad counsellor;
for finding an outlook for tomorrow.

Only when we are prepared,
to think about things,
that used to be strange and unreal,
can we have an idea,
of what incredible potential hides in us all.

The art is to look for it in ourselves.

Everyone has the opportunity.”

About Parkinson's disease

Parkinson's disease affects over 6 million people around the world, 1 million of them in Europe.

It is the most common neurodegenerative disease in the elderly. But it can start much earlier, in people in their 30s and 40s.

The main symptoms of Parkinson's disease are tremor, stiffness and slowness of movement.

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