Positively Parkinson's

Symptoms and Diagnosis, Research and Treatment, Advice and Support

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Be gentle on yourself

Even when you've come to understand and accept Parkinson's, some days will be better than others. Feeling sad, discouraged, frustrated and apathetic is perfectly normal. Some days you feel so exhausted you think you'll never be able to do anything ever again. Be kind to yourself on days when you feel like this. Don't keep pushing yourself beyond your limits; go for a walk or some other gentle exercise, read a book or take quiet pleasure from talking to a friend.

Remember it is okay to talk about Parkinson's; explaining is not the same as complaining. And it's okay to ask for help, too. Being such an independent person, I always hated the thought of relying on others. Now it's time for me to learn to ask for help when I need it. It's not a matter of giving up and letting go, but of knowing when to share. I realise that in choosing not to ask for help I'm not allowing others to feel good by being useful. It's still okay to say no when you don't need help, but phrase it carefully; for example, 'No thanks. I value your help, but this time I can do it by myself.'

Dealing with a sense of loss is a big part of having Parkinson's – loss of health, career, ability, confidence, and sometimes even your relationship with your partner. Every one of these is a major loss, and we can't help but grieve for them. Elisabeth Kübler-Ross, who wrote the ground-breaking book *On Death and Dying*, identifies five stages of grief: denial, anger, bargaining, depression and acceptance. The loss of good health is like a small dying and is something to be grieved for. Unless we move through this process towards acceptance, we can remain angry and sorry for ourselves. If you are finding it hard to deal with mixed emotions as you come to terms with having Parkinson's, it might be worth seeking out the help of a therapist who specialises in grief counselling.

Dealing with a sense of loss

▶ *John was only 43 and was married with four children when he was diagnosed with Parkinson's. He was also one of the world's top athletes. In 1975 he broke the world record of 3 minutes 50 seconds for running a mile. He won gold in the 1500 metres at the 1976 Olympic Games in Montreal, and went on to become the first man to run one hundred sub-4 minute miles. In total, he won over 750 races, and competed for over 20 years internationally. At 43, John Walker was still winning races and in demand for sporting events around the world.*

And then John's Parkinson's was diagnosed. He had noticed symptoms about three years previously. His coordination hadn't seemed quite up to scratch; he'd had mood changes and felt a stiffness in his body that he'd not experienced before. He didn't know what was wrong, but knew there definitely was something wrong. His doctor suspected a brain tumour, and sent him to see a neurologist for a second opinion. Because of the seriousness of the consultation, his wife Helen went with him.

When they were finally told of the diagnosis, they couldn't believe it. Both felt shock and disbelief. How could this be? There was no history of Parkinson's in the family, and John was so fit. He knew nothing about Parkinson's. The impact was devastating. As John explains:

> I honestly don't know how I moved on from being depressed in the first few years. I think because my life was busy and a lot was still expected of me, I did not have time to dwell on myself. I had a young, busy family that I relied on a lot, and a business to help run. I told only a handful of people – obviously my family and a few close friends and work associates, and did not go public for several years. But then I had a phone call from a television presenter threatening to make it public. I had really wanted to do this in my own time, but was forced to make a statement to the press. The news of my illness quickly spread worldwide, and I tried to avoid the publicity as much as possible. I didn't want to be defined by having Parkinson's or be a martyr for the cause.
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> My wife and I had purchased a retail business selling equestrian equipment just before I was diagnosed. The business proved to be a constant in both our lives through the turmoil of those first years, and it has neither helped nor hindered my dealing with Parkinson's. It is just something we do as a day job.

As John came to grips with the change in his physical abilities and the brutal way that Parkinson's had ended his athletic career, he slowly began to feel he had the depression under control and began to take a new interest in the world. He was asked to stand for a local city council by a resigning member, a role he has now held for nearly ten years, and is more involved than ever.

He chairs the community development committee and has recently been able to employ his sporting hero image to establish funds and launch an initiative to get youth off the streets and onto the sports field. It is called the Find Your Field of Dreams Foundation and offers free after-school organised sports programmes and night-time sports at local parks. John hopes the foundation will become a *nurturing system for young athletes. In a recent television interview, John said he'd give back all of his medals for good health.*

Life goes on

Part of the acceptance of Parkinson's is the realisation that, even though the diagnosis has changed your life forever, you can still keep on doing the things you've always enjoyed with your partner, your family and your friends. Even if you feel unable to work full-time, you can work part-time, get involved in voluntary work, or just do things for sheer pleasure, like caring for children or grandchildren.

Think of all the things you'd still like to have a go at – writing, sculpting, photography. Don't be afraid to stretch yourself – if you want to hike one of the great tracks, do it; if you want to climb a mountain, do it; if you want to travel, do it. Don't let Parkinson's restrict your life.

You'll be surprised how your body can perform when stimulated by a trip, either at home or abroad. But don't be surprised by how long it may take to recover afterwards.

Managing travel

▶ *Judith is a life and business coach and frequently travels overseas. In every aspect of her life she utilises her strength and wisdom. Since diagnosis, she has taken up painting and is now a successful exhibiting artist. But her Parkinson's has not impaired her love of travel, and here she shares some of her travel experiences and tips.*

> I have just returned from three weeks overseas on a non-stop ride. We took a 12-hour flight from New Zealand to Los Angeles, had a two-hour stopover in Los Angeles and then flew on to Vancouver, which took another three hours. We stayed there for ten days, played golf twice, and then went up to Whistler for four days. I painted during the day, cooked dinner for six one night, and went out other nights.
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> Back in Vancouver we stayed with relatives and friends, and then were off to Baltimore via Chicago. We were delayed in Vancouver and were late arriving in Chicago. We had only 15 minutes to catch the plane to Baltimore – we made the flight, but our bags didn't. We had three days in Annapolis, then went on to New York for another three days. All this was topped off with a six-hour flight back to Los Angeles, and a 12-hour flight back to New Zealand.

How did I do it? I believe it was through determination and organisation and by staying calm enough to save energy. I planned very carefully in advance, checking out hotel accommodation, maps, weather and restaurants online. I joined every VIP scheme I could for rental cars and hotels. It cost nothing extra, yet we got priority service. I made sure I had enough money at all times for tips, and used porters where possible. We got upgrades wherever we could, and used airport cars instead of cabs for a flat-rate ride in rush hour.

During the trip I wore comfortable shoes with enough room for swollen feet, and I carried plasters in case of blisters. I used a saline nasal spray on flights to keep my nasal passages from drying out.

When you're travelling, don't be afraid to tell people you have Parkinson's. They love to help you when you have something like this, and will often offer you the best rooms and service, even if they are not quite sure what it is you have.

If you are travelling internationally remember to take your medication every four hours during the journey. Once you arrive at your final destination (a new time zone), adjust your medication to your normal schedule.

Setting new challenges

▶ *Judith had her travel schedule well sorted, but for Cathy it was a case of literally jumping in at the deep end when she heard about an Outward Bound adventure course for people with Parkinson's. Cathy decided to put herself to the test.*

It was the end of summer when I decided to test my survival rate on a week-long Outward Bound course. The first day I learned what was going to be the toughest part of the course – waking up in good humour at 5.30 every morning. What made it doubly hard was the lack of sleep because of the 'chainsaw orchestra' provided by my 14 snoring bunkroom mates. I think I showed enormous restraint in not throwing a few guided missiles during the night.

We were all Parkinson's battlers (I won't use the term 'Parkinson's sufferers' as it has too many negative connotations). We had Parkinson's with varying degrees of severity, and we'd gathered together for our own personal journey.

Cell phones, books and iPods were taken from us on arrival, thwarting any plans I may have had of a nice quiet interlude hiding in a corner to lick my wounds and feel solitary. They were ready for us and presented a punishing regime of daily physical and mental challenges to instil positive reinforcement and self-discipline, and take us out of our comfort zone.

I wondered how I would cope with these activities. I was not at all sporty. I had never been a 'runner', and avoided swimming in cold sea water, let alone at 6.30 a.m. The shakes I had abseiling down the cliffs were certainly not Parkinson's-induced! But as the week progressed I slowly realised that to survive here you didn't need to be sporty.

Team-building, especially morale-building, was the real focus; I came to see how it effectively blocked any thoughts of self-pity. We learned to trust one another and allow others to help us when we needed help. Through humour, a genuine concern for each other evolved.

We were given the tools to improve our self-confidence and keep pushing those boundary lines. At the same time, we were able to recognise our limitations and avoid becoming a danger to others in our group.

The result of attending this course was to be honest with myself and not use Parkinson's as an excuse for avoiding doing something I didn't want to do. I have even taken up running after discovering that I enjoy it and could benefit from it for the rest of the day.

I still smile when I recall our group on our day out sailing, sitting becalmed on our yacht in the rain, playing silly word games, and enduring the indignity of having a bucket of sea water chucked over our heads for an incorrect answer.

The 'chainsaw orchestra' I don't miss, but that week of challenges, that week of seeing us all push ourselves a little further each day, taught me a lot about myself and was an affirmation of what I could do with Parkinson's. I knew that I hadn't lost my zest for life, and that was a pretty special insight to take home.

Parkinson's can draw boundaries around us so that we decide there are things we can no longer do. We convince ourselves there's no point in going on a course like Outward Bound, or pushing ourselves in other ways, because we believe we couldn't do it anyway. We have a go because others bully us into it, and the first day we make tentative progress. Yet by the end, we know we can do much more, and that our life hasn't ended because we've been diagnosed with Parkinson's.