

On-line communities are not always positive, just as in families there are disagreements and fallings out. But overall the connection with others is helpful. Though I might smile at what I read on media sites I also appreciate the internet for the ease with which I can maintain close friendships across the world. I go to internet friends for specific support on tracking and medication management. I cannot find this support yet in my current circle of friends.

But my hope is not contained in social media alone. Recently I realised that pleasure and feeling hopeful are somehow connected. Last week I indulged in an evening of nostalgia, I went to hear the Seekers. Funny how I always thought those fresh faced young people with their easy listening music were from Britain. Not true. They are fellow antipodeans from over the way in the land of Australia.

The Seekers performed in the Hamilton Events Centre in New Zealand. Not quite the Royal Albert Hall in London, but it will do. There I was, surrounded by the aging citizens of my home town. I was astonished at how many were disabled in some way. On stage were the group, four people now in their seventies. Judith Durham, petite and fragile and recovering from a recent illness was guided to her place on the arm of a fellow Seeker. They sang all the well known songs from their early days and others new to me but with a certain familiarity. It was like the experience of being with old friends, the conversation content may differ but something about the conversation is known, the style of interactions, pauses, intonations, all so easy and reassuring. It was a happy event, an evening full of energy and joyful singing. I was left reflecting again on joy and hope, and how they are tied together. There it was the music lifting my spirits giving pleasure in the moment and a sense of hopefulness for the future.

I find hope in many places. It is there when I am sharing my life with others with Parkinson's whom I meet along the way. It is present when I see the work others do on my behalf to improve my circumstances and it is in activities that give me pleasure, for if I am joyful then it is easier to be hopeful.



NO LIMITS

Sheryl Jedlinski

Hope springs from refusing to allow PD to limit us.

Almost 17 years since I was diagnosed with Parkinson's disease, I have more reason than ever to be hopeful that I will live to see a cure. I say this because:

- A long-awaited vaccine that could potentially slow or even stop the progression of PD is showing positive results in phase one safety trials. It is the latest in a variety of new drug delivery methods being tested for improved PD therapy that would reduce the occurrence and severity of motor fluctuations and dyskinesia. This is in addition to the many promising new drugs already in the pipeline that will likely provide better symptomatic relief, slow disease progression, and ultimately cure PD.
- I have developed good rapport -- built on openness, trust, and good communication -- with my movement disorder specialist, Dr. Cindy Comella. We share in the decision making as she adjusts the dosage, timing, and combinations of medications to buy me more functional time. Studies show that patients with chronic illnesses who partner with their doctors are more likely to adhere to treatment plans and take prescribed medications, resulting in better symptomatic control and improved coping ability.
- I am in the best physical shape of my life, except for the fact that I have PD. A year into my diagnosis, I could barely lift a gallon of milk from the trunk of my car. The only hope of slowing my disease progression turned out to be something I had avoided at all costs my entire pre-Parkinson's life: exercise. Great. To live a better life I had to do what I hate most. Parkinson's is the disease that just keeps giving.
- I find inspiration and hope in friends who have battled their way back from the edge of the abyss: from surgeries that left them unable to walk or talk, from repeated falls, and from exhausting dyskinesia. If one of us can do it, we all can.



- Try new things, like joining a choir, or returning to college
- Rediscover your passion, gifts and talents and share these with others by volunteering. This builds self-esteem and provides a sense of belonging.
- Avoid people who make your life difficult.
- Recognize your limits and learn to say no.
- Accept help from others.
- Build fun into your life by allowing time for lunching and shopping with friends.
- Focus your resources on things that matter most.
- Read spiritual texts, and attend religious services.
- Join a support group or partake in individual or family counseling to get help coping.

“However bad life may seem, there is always something you can do, and succeed at,” says renowned astrophysicist Stephen Hawking. “While there's life, there's hope.”

- I transitioned from being a “poster child” for anxiety to an apprentice in optimism. Learning that optimists fare better than pessimists when faced with a health challenge, I committed to focusing on positive rather than negative thoughts, and to living in the moment. I had my work cut out for me, but I am living proof that over time, with patience and persistence, optimism can be learned.

Hope springs from refusing to give up or accept the limits of Parkinson's, and from believing that the next clinical trial we join or alternative therapy we try, may lead us to the cure. Just as we did not choose to have Parkinson's, we can choose not to allow it to keep us from living full and productive lives. As Parkinson's progresses over time, it imposes functional limitations that often require we alter our hopes and dreams, lifestyle, and employment. The key is learning to accept “a new yet ever changing normal.” Following are some coping strategies to help you maintain hope:

- Alleviate fear of the unknown by asking questions and learning as much as possible about PD and its probable course.
- Find new meaning in life
- Launch new careers and make new friends.

