

Hi John,

I read your very moving story about your friend and his dad having Parkinson's.

I am not a celebrity, a sports star, nor am I famous, but I am part of that almost invisible group of people affected by Parkinson's. I was diagnosed in 1999, 10 years ago, at age 42, I fall into the category called "Young Onset". I am inspired by Michael J Fox and others in the "celebrity" world and am thankful for the awareness they are creating about this devastating disease, but there is still so much more to it, than even they may never experience, just because they are celebrities.

In my non-celebrity world, I do not have the resources to get to the best doctors, therapies, home care. In my world, it takes 6-12 months to see a specialist, for a usually quick 20 minute check-up, an appointment where you'd better come with all your questions written down, as you try to understand, accept, and live with this disease.

In the rural areas, there is no specialist to see, and chances are your family doctor has general knowledge of many medical conditions, but isn't really an expert in any.

In my non-celebrity world, the career, the dreams, have gone by the wayside, to be replaced with disability payments as your income, marriages break up, friends disappear. Some of us do not have the "awesome love and support of a spouse and family", yet still have to manage the once easy tasks of living.

Things like getting groceries, making a meal, folding laundry, doing up buttons, tying your shoes, brushing your teeth, everything gets more difficult, even impossible at times. 60% of people with Parkinson's live with depression and anxiety, and this is not a situational depression, this is as much a symptom of the disease as the outward physical symptoms that occur. That in itself can be debilitating.

In my non-celebrity world, my heroes are regular people, just trying to hold on, knowing that what they were able to do yesterday, they may not be able to do today, or even ever again. They are not famous, but they are someone's parent, or grandparent, or neighbor or friend. These are people who are in for the fight of their life, for the rest of their lives.

Thanks for taking the time to understand,

Regards, Cindy Exton