

GIVEN and TAKEN

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By Failing to Prepare, You are Preparing to Fail - Benjamin Franklin

It has been a tough month for me, probably my toughest since the day I was told I had Parkinson's disease. We have lost one of our YOPD group members to suicide. This is my first loss, in this way, of someone so close, someone part of my circle of life. Our small group of 15 is now 14. We started out even smaller, at the time of my diagnosis but, right in line with the statistics, our group continues to grow.

I am going to call this woman Karen. Karen was diagnosed the year before I was and was a year older. We lost her too soon and I will never know why. We did talk about suicide, despair, and depression at our bi-monthly meetings but she never shared much on these topics. She seemed to be an optimist, a positive contributor, and a giver.

I have since found out that, in this past year, we have had three suicides in my local PD community plus a very publicized suicide by Robin Williams. I'm sure there have been many other similar losses in PD communities around the world.

I hear over and over again from other PwP's that PD would be easy to deal with if it truly was only a motor disease. We have known for some time now that there are common non- motor challenges that usually appear years before the motor deficits, depression being one of them. The scientists describe it as different from the depression experienced in the general population. Just living with Parkinson's can cause stress and sadness. However, PD depression can be caused by damage to areas in the brain that affect our mood. Anxiety often occurs with depression in Parkinson's. Some of us experience bursts of acute anxiety called panic attacks. Some of us worry excessively about everyday things that we cannot control. These can both be early signs of Parkinson's. Anxiety is also common during 'off' periods. I am talking about common and powerful symptoms that negatively affect the quality of life for those of us living with Parkinson's disease. It is very difficult to get out of the black hole of despair once it takes hold.

The good news here is that Parkinson's depression and anxiety are treatable. We need to share what we know about Parkinson's and depression with each other and with our physicians so they can find the best treatment options for us.

I have asked many PwP's what their greatest fear is. The common answer is that we are going to progress to a point of being in a corner sitting in a wheel chair, with our heads bobbing, drooling into the bib around our necks, and feeling completely hopeless. I don't believe this to be true. Healthcare has changed over the last decade and will continue to change. The baby boomers are not going to allow this to happen and frankly nursing homes are going to be a thing of the past. In fact the model has changed and new models are starting to be implemented in some areas in the global community. I also believe most of us are not going to get to that end stage. We are going to have our cure soon!

Time goes on and my Parkinson's disease progresses in its own way, slowly taking what it will from me. I realize that we who live with PD must prepare for our future. The reality is that we have an incurable neurodegenerative disease. We must gather up our clan and make a plan, preferably before we need it. We also need to gather our resources together and give to others in our community who are struggling with depression. We can't know who will need help next. You perhaps, or me. However, we can make sure that help is available for all of us where and when we need it.