

Nonverbal communication and Parkinson's

Catherine Oas



Once upon a time, I went to a local support group for people with Young Onset Parkinson's Disease shortly after my diagnosis, then second and finally third opinions (I was nothing if not thorough). I walked into a room and joined a club I really wanted no part of. Most of the people there

were men, with wives. Most were demonstrating the telltale signs of tremor, dystonia, and dyskinesia, bent posture, and a shuffling gait. I was 46, one of three single women with Parkinson's (my husband chose not to attend with me); the only one still employed, and played soccer three times a week. I had few motor symptoms and could still "pass". I looked at the flat expressions of the people with Parkinson's, and worse, their wives, and seriously wondered to myself, "When did these folks last get laid?" I did not return for another three years. By then, I was divorced, on partial disability, co-parenting my two daughters, and not so deeply into denial. I understood now what I had first taken for depression and lack of expression in the faces of these people with Parkinson's was in reality the very common "facial masking" and "reduced eye blink." The motor symptoms of PD which most of the public know about are but the tip of the PD iceberg. Most of the symptoms of PD, which have devastatingly negative impacts on the quality of our lives, lie under the ice cold waters. In 2002, the year I was diagnosed, the medical community knew very little about, much less discussed any of these issues with their patients.

I am a certified speech-language pathologist, and was aware of, diagnosed, and have treated children with "non-verbal communication disorders" since graduate school in 1978. We as speech pathologists force much needed attention on pre-literacy, vocabulary and word order skills. But the most important thing that we use language for is to communicate and interact with our world. Our species of *Homo sapiens* is a much socialized

degree of mammal. We need to connect with our social group in order to survive. We do this through communication. One study I read recently reports that we communicate with each other primarily through facial gestures and expressions. Tone of voice, speech rate, rhythm and emphasis convey another 38 percent; in fact, our words convey only 7% of our message. There has been insufficient research, in my opinion, regarding the difficulties people with Parkinson's have interacting with other humans. But it stands to reason, as dopamine affects every muscle movement within our control or out of our control. We now know that over time, PwPD develop a flat affect, smile less, at times even frown. Our voices tend to soften and we speak in a monotonous voice. We lose the ability to use inflection to make our voices sound more interesting and interested, we blink less, so look as though we are staring, and our voices can become harsh or hoarse. I find on hard days, it is all I can do to repeat myself. Talking, laughing, flirting, all require subtle facial movements which feel like too much work. So instead of forcing myself to get into the outside world, I stay home. This social isolation, even with social networks such as dating sites and Facebook, is not a good thing. I prefer texting over using the telephone or instant messaging, in part to hide from my Parkinson's disease.

So the effect on other people, and particularly our care partners, is potentially that their loved one with PD is depressed, unhappy, angry, and perhaps ungrateful for all that their partners do for them. I have heard from many friends or acquaintances that I need to smile more. It's not that I feel unhappy, although I continue to struggle with regulating my mood states, another symptom of Parkinson's. It's the "facial masking" which makes me look like 'grumpy face'; or the facial dyskinesia which result in a pulling down of the corners of my mouth. I don't intend to look mean, cruel, or tired. But when I catch myself in the mirror at times, I am shocked at how unapproachable I look.

Sometimes my voice roughens, as though I need to clear my throat. Sometimes it flattens, so people ask if I'm tired. Sometimes my voice becomes so soft that I find myself repeating everything I say, especially if I'm speaking to a person with a hearing problem. My spacing between words and my "verbal fasciculations" cause me to sound like I'm stuttering. Sometimes I gulp and swallow in the middle of a phrase. None of these are intentional, yet I do them anyway. And increasingly, over time, I am noticing gait changes: I stumble, stagger, and miss-step, which are behaviors one might see in a person who is inebriated, including slurred speech.

I have had to push through these (embarrassing, to me) behaviors to get out in public; to go to the gym,



dance classes, school events, and...even, out on dates. I know that if I hide, I negatively impact my quality of life. So I push it. Some days it's a push to get out of bed, to walk the dog, to go to the gym. And then, I see...how there are many people who show courage in the face of social isolation. There are people everywhere who deal with their "stuff". I'm only one of many, and you can always find people worse off...or better off than you.

A friend of mine from Canada gave her husband the choice to leave, or not, when she was diagnosed three years ago. He stayed, of course, and has become a better human for doing so. This doesn't always happen however, in fact, married women diagnosed with young onset Parkinson's disease do show higher divorce rates than average. Most people who are older, have been married longer and hold a broader perspective on marriage do stay together [1]. Some people cite the divorce rate to be 85 % [2]. This disease may not reduce your life expectancy [3] but it can deeply challenge your quality of life. If you do not have a solid marriage before your diagnosis, I suggest you start some marriage counseling. A diagnosis of Parkinson's disease will rock you to your core, especially if you are younger (as I was).

I am not an expert, but I believe that some dopamine agonists and other medications can affect your personality, sexuality and put a huge strain on a marriage. Work on your intimacy and ability to communicate, honestly. Sing, tell jokes, laugh and forgive each other for your perfect imperfections. Cuddle and kiss as much as you can. Go to support groups together, keep dating each other. And if you have an important discussion, turn off all competing background noise, including the television. Try not to multitask because this negatively impacts your memory that much more. Build some ritual in your life, whether cooking, reading or gardening together. Support your care partner in what interests them. And tell them DAILY how much you appreciate them in your life, through nonverbal or verbal means. Wear your tulip pin when out and about to increase community awareness and never never never give up.

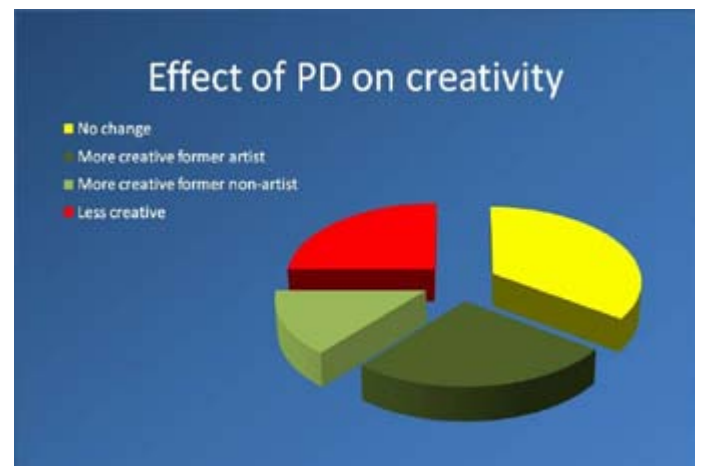
1. Neurotalk <http://neurotalk.psychcentral.com/>
2. PD Talk Radio, February 14, 2010, Rich and Kim Rozek
3. PDF website: March 9, 2009
<http://www.pdf./en/index>

Parkinson's & creativity: data from PM polls

Jon Stamford

Anecdotally, there is good reason to believe that Parkinson's or the drugs used to treat it cause an increase in creativity among people with Parkinson's. You only have to look at the number of poetry books written by patients to get a sense of the hidden talents unmasked by the condition. And I lose track of the number of times I have heard about Mr X or Mrs Y who have picked up a paintbrush and are now turning out paintings by the week.

But is it the condition or the drugs? Which causes us to turn into poets and painters? And how common is creativity as a side-effect?



To answer these questions we ran a series of polls on Parkinson's Movement asking about creativity, and all the circumstances surrounding creativity in patients. Firstly we asked whether patients had become more creative, less creative or found no difference due to their Parkinson's. 40% felt they had become more creative since the diagnosis while 25% felt that Parkinson's stifled creativity. Interestingly, of those whose creativity bloomed, around a third were not formerly artists.

