

“I have something to tell you”. Breaking the news of your diagnosis to friends

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'You have Parkinson's Disease.' These words, once uttered, change everything. Even though many PWP already 'know', or at least have deep suspicions about what ails them, these words uttered by the representative of the medical world confer patienthood. It is these words that make you ill: it is these words that legitimise your symptoms; it is these words that stamp you irrevocably with the label 'patient'. Words are transformative, and these words of diagnosis are poetry in the highest, purest sense: poetry is a word derived from the Greek *poieo*: to make.

And they say that words will never hurt you.

These words make a difference. Their utterance fundamentally shifts your worldview, your sense of self. They often represent concepts too damn big to be comprehended at once, and so they usher in a long process of soul-searching, adjustment and re-alignment.

So much for what these brutal, unforgiving words do for you. When the consultant who's uttered them a thousand times tells you, who will only hear them once, they mean one thing. But words are made to be repeated, and no sooner have you been told that you are irrevocably ill, than you realise you must turn the tables. It's now your turn: your turn to be the teller.



The thing about PD is that it makes a habit out of challenging you in new ways as a matter of course. It's not a disease that is predictable. It's a disease with attention deficit disorder. It's very similar to the way in which people respond when you tell them. I've had almost as many responses as I have had people to tell. The responses I've received have influenced the ways in which I subsequently tell people. I imagine you'll find the same thing.



The first people I told were expecting something, so weren't surprised: it was more confirmation, a name attached to a known problem, than a bolt out of the blue. The next set of people were those close, but unaware. They were told by my then wife and myself, usually with the caveat of 'we have some news', followed by an inability to grasp the nettle until too drunk to be overly coherent. The choice of the universal code for 'we're having a baby' as the introduction of the discussion was also perhaps unfortunate, as a look of embarrassed disappointment is perhaps not what you expect to see when you've told someone you have a progressive, degenerative, and incurable brain disease.

'You're very young', 'you don't look ill', 'it's only mild, then', 'er ...', 'sorry', 'oh my god!', 'you poor, poor man', 'you need to try ...', 'oh, what's that?', 'is that what that actor has', and so on. It starts off being hard to tell people, then often becomes hard not to comment on their reaction. As you get better at telling, at assessing when you ought to tell, it becomes easier. Sometimes you'll find yourself making a comment which only makes sense if people know. Then you begin to lose patience with people.

But remember this: when you tell somebody new, whoever they may be, they're merely one in a long line of people you've told. But for them, it's the first time you've told them. For them, you are the consultant. They will never look at you in the same way again. Give them a break.