

## *'The Parkinson's you can't see'*

Parkinson's; a condition by definition recognised by its overt presentation. You've got to see it to believe it right? The slowness of movement, the tremor, the rigidity, the instability. It's obvious right? You couldn't miss it even if you tried right? I guess folk just aren't trying hard enough...

Picture the scene. I'm walking, nay shuffling along the aisles of the local supermarket. I reach out for the same bran I've consumed ever since my mum went on a health kick in the '60s and threw out 'all of the sugar' which included my staple breakfast cereal, Sugar Frosted Flakes. It didn't last long, well except for the bran. My hands secure tightly around it as I steer it to my trolley. I turn slowly and unsteadily; like someone had pressed the slow motion button on the video of my life and given the camera a brisk shake for good measure. There are a few kids looking up at me, curious they ask if I'm doing the robot dance. I smile; at least I think I do. My friend Jean, a fellow Parkinson's sufferer says when she smiles no one can see it. Let's talk about Jean.

**Bradykinesia** [brad-i-ki-nee-zhuh] **n**: slowness of initiation of movement & progressive reduction in speed or amplitude during rapid alternating movements of body parts [1].

**Rigidity** [rij-id-i-tee] **n**: increased muscle tone present on passive movement of affected segment e.g. limb or neck. Two types identified in Parkinson's disease: Cogwheel: episodic resistance to passive movement. Leadpipe: Continuous resistance to passive movement present throughout entire range of motion [2].

I've known her since we were teenagers. As the oft used saying goes 'she was the life and soul of the party.' She was loud, eccentric, bubbly, and mischievous with a grin that could light a room although, that may partly be due to her blinding gnashers. Picture the scene. Jean's 60<sup>th</sup> birthday party with all of her family gathered. Sons, daughters, nephews, nieces, grandchildren and friends that outnumbered the lot. A joyous occasion with a smile on every single face but one; the birthday girl herself. Jean reiterated how happy she was, how much fun she was having..."you might want to tell your face that" blurted Derek; Jean's neighbour to whom subtly remained a foreign concept. I'm trying she muttered with sadness lacing the words that her face ignored. Jean reached for her jaw and tugged at the mask that would not dislodge. The face of Parkinson's but do you really see?

**Hypomimia** [hypo-meem-i-ah] **n**: Decreased facial expression due to limitation in the speed & coordination of facial muscle activity [3].

Every Tuesday afternoon is a day I meet others with Parkinson's at the local support group. We share our fears, our struggles, our ambitions, our goals. Greg holds the metaphorical mic although a real one wouldn't go amiss as we all strain to hear as he asks us to picture the scene. His grandson over in Australia is turning the big one-oh and Greg without fail sends him a birthday card every year. After grumbling about the postal charges in a barely audible tone unreflective of his ire he recalled how he'd written a paragraph of well wishes and silly jokes; his smile exuding a warmth

telling of his affection for his grandson. When he asked his wife to read it he told of her struggle to make out the words, they were too small or maybe it was her eyesight or maybe it was the bleeding ink... they eventually resorted to the use of a magnifying glass which revealed the text; it wasn't the bleeding ink.

**Hypophonia** [hahy-puh-foh-nee-uh] **n**: Reduced intensity & loudness of the voice due to reduced or defective coordination of laryngeal muscles [4].

**Micrographia** [Mahy-kruh-graf-ee-uh] **n**: Impairment of fine motor skill largely resulting in a decrease in amplitude of written material [5].

As we gather for a tea break, Catherine breathes a sigh of exhaustion. I look over and see the heaviness of her lids threatening to shut out the world. I rub her shoulder in sympathy and understanding. Picture the scene. Imagine dreading going to sleep knowing that what is to come is a night of undue exhaustion. As Catherine's head descends onto the pillow with the duvet pulled close, her attempts to drift off are rudely interrupted by a tingling in her legs. Her attempts to resist the itch in her legs are futile as she reaches down to scratch away the discomfort. She closes her eyes willing her brain to suspend its activities for the night but it's not soon after, that the urge to move her legs arises. Without her permission, her brain instructs her to lift her right leg off its resting place again and again with brief torturous respites in between. Her patience reaches its last resulting in her leaving the bed to hobble around the room in hope of alleviation. After repeating the process several times she eventually manages a few hours of the most unsatisfactory sleep. And repeat.

**Restless legs syndrome** [rest-lis legs sin-droh] **n**: Sensorimotor disorder characterised by an unpleasant and uncomfortable sensation in the legs accompanied by the urge to move them. Symptoms are worse in the evening/night and during periods of rest & inactivity. Unpleasant sensations relieved by movement and activity [6].

Later that day my sister Betty comes to visit; her husband Derek's Parkinson's has taken a turn for the worse filling me with a dread I work hard to suppress. A foreshadowing? A warning? A fate awaiting me? Picture the scene she says. She tells me she's been noticing something strange going on with Derek. He's been seeing things that aren't there. At first she didn't think much of it but then it began to happen more and more. A cat she says, he sees a golden furred cat passing by his armchair disappearing as quickly as it appeared but he swears blind he saw it. He knows it's not real she qualifies hesitantly; at least I think he does her voice quivering in doubt. She confides that the other day Derek asked her if she could see what he could see. She couldn't see what he could see.

**Hallucination** [huh-loo-suh-nay-shuh-n] **n**: A perception in the absence of an external stimulus. They are commonly of a visual nature in Parkinson's disease although hallucinations of other modalities (e.g. auditory) have been reported. Minor hallucinations can include: Presence hallucinations (vivid sensation of the presence of somebody), passage hallucinations (visions of a person, animal or indefinite object observed via the peripheral visual

fields) & illusions (misperception of actual stimuli) [7]. Insight can be variable however it is usually preserved amongst those experiencing minor hallucinations and those with preserved cognitive function. For the most part, hallucinations have been documented as being a consequence of dopaminergic treatment [8].

What has been described above features a selection of both visible and non visible manifestations of Parkinson's disease either as a result of underlying pathology or as a result of side effects of medication used to treat it. Those features which are objectively observed such as bradykinesia may not really be 'seen' and can easily be misattributed to 'ageing' or dismissed entirely. And then what of the loss of facial expression – a means of communication taken wholly for granted; paralysed. The nature of the flawed human is to judge and appraise someone by how they present before they're given a chance to truly present. Will those with hypomimia be given an opportunity to be seen for the warmth behind the non-existent smile? Will the tax office understand the tiny scrawl on the form as that of a man with Parkinson's? Sleep; the bedrock of human survival – to have it stolen so mercilessly night after night, do you see the weary eyes of that of Parkinsons? For some, visions so vivid unseen by others; "you're just seeing things" the common dismissal. Do you see their fear?

Open your eyes.

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