

JUGGLING SOUP

Presentation to Wealden Business Group

Wednesday, 11 April, 2024

INTRO.....

Thanks to WBG for opportunity to speak

Who I am.....

Journalist and PR man – clients SN, BT, British Beer and Pubs Association, Leeds Castle.

Joined WBG after I sold my agency, and supplied media relations and writing services to a number of WBG members. I was chairman of the group for a couple of years, and organiser of some of the annual charity fundraising dinners

I'd sort of packed up working during Covid, when one dull, midweek afternoon three years ago, I was slumped in front of the telly when I caught the tail end of an appeal from the charity Parkinson's UK.

It featured a guy endeavouring to have dinner in what appeared to be an earthquake, with food flying off the end of his fork as he vainly tried to control his shaking hand

An off-colour thought flashed through my head – good job he wasn't eating soup, as he would have ended up wearing it, with collateral damage to the carpet, walls, ceiling, and probably the cat as well.

It was also particularly inappropriate because on January 4th, 2022 I received the news from Dr Muhammad Chowdhury, a neurologist at Benenden Hospital, that I, too, had developed Parkinson's Disease.,

Like most people receiving a Parkinson's diagnosis, I had had some warning signs. For months I had experienced a deterioration in my walking (slightly dragging left leg), general mobility (sudden freezing on the spot), doing the buttons up on my shirt, getting in and out of bed (mountaineering would have been easier), and drooling (oh deep joy.....)

As the deterioration was becoming increasingly obvious, my wife Helen was covertly researching potential causes online, judiciously sorting the wise from the wacky, and she had come to the conclusion I was evincing the classic signs of Parkinson's.

On receiving confirmation from Dr Chowdhury I burst into tears, because my deepest, darkest fear was that it might be Motor Neurone Disease. At least Parkinson's was unlikely to shorten my life, I hadn't developed tremors (thus remaining capable of enjoying soup), and the sun would still come up in the morning.

I began doing my own research, discovering that Parkinson's Disease.....

- Is caused by a lack of the chemical dopamine in the brain, which controls many physical functions from walking to writing, memory to fatigue.
- Has symptoms which vary from person to person. Not everyone has tremors, muscle weakness or loss of balance, but instead may experience one or more of a whole suite of 40 different conditions ranging from the irritating to the depressing, disabling and downright embarrassing..

- Some of these are particularly nasty – such as losing the ability to speak and swallow – while others contemplate the possibility of life in a wheelchair. And Parkinson’s sufferers are six times more likely to fall prey to dementia than the rest of the population.
- Because the disease messes with your brain, there are some extraordinary side effects – such as developing compulsive habits leading to shoplifting, gambling, and even evincing inappropriate sexual behaviour. NOT I should emphasise, symptoms with which I am afflicted!!,
- It’s particularly hard for Young Onset Parkinsons’ sufferers, because the disease can strike at any time. You can imagine how those in their teens, twenties and thirties feel living with a disease which they know is only going to get worse as they go through life.
- Because the disease is progressive, and develops faster among some people than others.
- Nobody knows what causes it. The use of pesticides was thought to be one culprit, with a particular prevalence among the farming community, but this has not been confirmed. In 2023, scientists were increasingly looking at gut health as the likeliest source.
- It’s the fastest-growing neurological condition in the world with about 3 million sufferers. In the UK alone, around 145,000 people in the UK were living with the disease in 2020, and it is estimated that it will grow to 172,000 by 2030.

- There is no known cure, although research is going on all over the world.
- Is no respecter of age, race, gender or nationality. Among those who have received a diagnosis of Parkinson's are Billy Connolly, Jeremy Paxman, Ozzy Osbourne, Neil Diamond, Sir Ranulph Fiennes, Robin Williams and Linda Ronstadt. – and only a couple of weeks ago, one of the front men of pop duo Del Amitri.
- There is no known cure. Yet....

Here's what those coping with the disease have to say....

Billy Connolly "I have Parkinson's Disease, and I wish he would take it back. On the other hand, I can shake a mean Martini."

On the extreme side effects of inappropriate sexual behaviour and compulsive gambling "If you see a man in Las Vegas with a permanent erection, he's probably got Parkinson's".

Jeremy Paxman "I will not pretend that being diagnosed with an incurable brain disease is fun.....it isn't a fatal prognosis, but it sure as hell can make living a bit of a bugger".

Paul Mayhew-Archer (co-writer of 'The Vicar of Dibley' on two cases of Parkinson's being diagnosed every two hours in the UK) "...which means some people get told at three o'clock in the morning".

Michael J. Fox (*American actor, campaigner, and fundraiser for Parkinson's, still fighting and active after 30 years with the disease – his Michael J. Fox Foundation has raised an astonishing \$1 billion dollars for research into the disease – you may have seen him recently presenting an award at the BAFTAs*) He says “I don't have any choice about whether I have Parkinson's, but surrounding that non-choice is a million other choices I can make”.

Two habits which have helped me personally – intensive exercise for at least two and a half hours a week, partly at Tenterden Boxing Club under ex-Army PTI Tom Roach, and partly with local trainer Sarah Frow, whose life dedicated to fitness has not prevented her from becoming another of those living with Parkinson's.

And maintaining a sense of humour. For instance, my old journalist and PR mates are, as I fully expected, determined to cheer me up with some black humour over lengthy, liquid lunches. Many of them are facing their own health issues, so conversations tend to run along the lines of “I'll see your Parkinson's Disease, and raise you prostate cancer and a hip replacement”.

I've become a fan of the drolly-titled ‘Movers and Shakers’, the monthly podcast featuring six eminent people who have copped Parkinson's – ex-BBC science editor Rory Cellan-Jones, businesswoman Gillian Lacey-Solymar; broadcaster Mark Mardell, Jeremy Paxman, High Court judge Sir Nicholas Mostyn, and Paul Mayhew-Archer.

They meet each month in a Notting Hill pub, and discuss what it's like to be a Parky, focussing on topics such as exercise, carrying on work, the progress of new drugs, coping, Deep Brain Stimulation and the Holy Grail of a cure. Each episode is about half-an-hour long – and, without exception – takes a positive, and often humorous, view on the disease. It's a brilliant and motivating listen, and has just won the national Podcast of the Year title.

So I continue to follow their creed of facing up to all the bloody symptoms with pragmatism and humour.

For instance, I couldn't help giggling helplessly when one night I bent down to re-tie one of my shoelaces, and slid slowly to the floor. It happened in the gents' loo at Ronnie Scott's club in London, so I was confronted by a row of blokes' backsides at the urinals. Fortunately, one chap spotted me on the floor, and hauled me to my feet. All I could do was thank him, weakly adding: "Bloody Parkinson's", just in case he thought I'd had too much to drink.

However, there has been one local development which is really exciting, and of direct relevance to Parkies living in Kent.

Earlier, I referred to Sarah Frow, one of my trainers.

And here she is.....

If I can be perfectly frank, neither Sarah or I seek any sympathy from family, friends or acquaintances.

What we would like to ask of you today is some financial support for the Canterbury centre – it's incredible that the NHS does not fund the Canterbury centre in any meaningful way, so we have to raise money wherever we can.

If WBG as an organisation, or individual members whose businesses have corporate social responsibility programmes, can offer some support financially, it would be of great benefit to an awful lot of people battling this dreadful disease, many of them living locally in Tenterden and Ashford.

So thank you for listening – tomorrow is World Parkinson's Day, the annual profile- and fundraising event across the world, so just by listening to myself and Sarah together we've all achieved a contribution to the profile-raising – and hopefully fundraising as well.

Finally, if one day you see me in the High Street lying flat on my back – give us a hand will you!

Questions.....

