the need for innovation in parkinson's disease

When, at the age of 27, I walked into the waiting room of a Neurology Department of a west London hospital, I wondered what on earth I had in common with the other people in that room. Some of them shook, some of them seemed to be frozen like statues and others moved around wildly; their limbs seemingly in a state of perpetual convulsion. All of them were a good forty years my senior. Half an hour later having been diagnosed with Parkinson's, it was as if someone had pushed the fast forward button on my life and walking back through the waiting room I realized that I now had an affinity with the people in that room. I had become one of them. Thirty minutes had become forty years.

Parkinson's is perceived as an old person's illness. The perception is that the biggest issue faced by those who have it, is not being able to carry cups of tea without spillage. The reality is about as far removed from this as it could possibly be.

When you are diagnosed with Parkinson's, life changes beyond all recognition. Initially, the problems faced are more of a psychological nature; you perceive that you have suddenly become the Parkinson's stereotype and that others perceive you in the same way. Of course, in reality, there is no such metamorphosis overnight, it usually takes a considerable number of years before the full range of symptoms manifest themselves. It is then that the real horror of the condition reveals itself.

Socially, Parkinson's is a very visible disease and yet to society it seems to be invisible – no-one talks about it. It is, to many, a private misery. No- one ever mentions becoming frozen in one position overnight and the ongoing sleeplessness. No one ever talks about the side-effects of the complex medication regime, which can be as extreme as the Parkinson's symptoms themselves. No one ever talks about being imprisoned in your own body. And no-one ever talks about the psychological challenges that face people who live with this chronic condition. Parkinson's removes control. It destroys natural movement. It can be painful. Parkinson's challenges everything in life that is taken for granted. There is no respite.

In the past year my Parkinson's medication, L-dopa, and I have both celebrated our 40th birthdays. In some respects, I suppose that I am lucky that for the last 13 years, I have been able to swallow varying amounts of this drug everyday. It is fantastic. Without it I would not enjoy my life. Despite this, I do not celebrate its 40th anniversary because, in that time, there has been nothing to even come close to replacing it. It has remained the so-called 'gold standard' treatment for my illness.

How can this be when every week we hear stories in the media of new therapies, even potential cures for this chronic neurological condition?

The truth is that pioneering new treatments for Parkinson's have become more of a breeding ground for breakdowns than breakthroughs and for the past five years, I have been involved with The Cure Parkinson's Trust in trying to think of ways to improve a situation which is in desperate need of action.

The current system of bringing new treatments to market is almost totally reliant on biotech and pharmaceutical companies whose first responsibility has to be to their shareholders, otherwise there would be no investment in this sector at all.

Despite this, these industries are charged with the responsibility of taking basic science and delivering it through an extremely costly, highly risky and prohibitively long regulatory and clinical trial process to ensure safety and efficacy for all new products. The likelihood of taking any product out of basic science and translating it into something for use in the clinic is slim. At best, only one in ten products which reach a Phase I trial actually make it onto the market. There is, therefore, an understandable reluctance to pioneer new products and a propensity towards adapting existing products rather than investing heavily in new science which is high risk and hugely expensive.

Ultimately it is the patients who suffer from these imperfections in the market and the shortage of the development of new treatments.

A further by-product of this lack of control is that pharmaceutical products which do reach the market tend to be disproportionately expensive compared to the real cost of manufacture. This stems again from the totally commercial nature of the development process. Given the frightening statistics on the future burden of healthcare for chronic conditions such as Parkinson's, it seems likely that this situation will become unsustainable. National Health organisations such as the one in the UK will not be able to maintain the standard of care to which they aspire unless other methods and strategies for drug development are generated. In other countries the system would be far worse, increasing the polarisation of access to medicine between rich and poor.

The three principal stakeholders in the drug development process are the patient, the pharmaceutical industry and the state - which exercises control over the entire process through regulation, legislation e.g. patents and distribution. Each of these parties have different priorities all of which are positively influenced by innovation; patients feel better, pharma company profits increase and the costs to the state will be reduced dramatically if the new therapies are disease-modifying in nature.

It seems obvious therefore that the duty of encouraging innovation should be a collective responsibility between all three stakeholders. An organisation which pulled the expertise and interests of these stakeholders could act as a hub through which exciting new products could be provided. These prospective treatments

could have a structured plan for their development and the resource to accelerate the process. The hub could also provide much needed governance to early stage drug development, making it more risk averse, quicker, cheaper and generally more focussed and effective.

Above all else a culture of teamwork would be created by this new structure. Organisationally, it would sit mid-way between the commercial and public sectors; commercially run but with the profits being reinvested into the business thus retaining its charitable, moral and ethical status. The goal would be to deliver therapies to a stage where the three critical precursors to medical progress would be satisfied; therapeutic benefit, value to the state both in terms of cost and benefit and commercial viability.

In this way, therapeutic benefit to patients would be the principal focus but without compromising the required outputs of state and industry.

There is sufficient evidence to suggest that there is science out there to make a real impact on the lives of people living with Parkinson's – not just in the future – but now! Structural change to the system is needed to convert this science into tangible treatments and such change can be achieved to the advantage of all of those involved in the process – not just the patients.

The Cure Parkinson's Trust is planning to harness the expertise and energy within the Parkinson's community to effect this change and should be able to report progress made at The World Parkinson's Congress in Glasgow in October (28th September to 1st October 2010).

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