

MICHAEL J. FOX & THE "GIFT" OF PARKINSON'S DISEASE



BY JOHN GATT-RUTTER

Three years ago at the age of 65, I was diagnosed with Parkinson's Disease, the shaking palsy, more familiarly known as Parky's. I have just read Michael J. Fox's 2002 autobiography, *Lucky Man*. For those who haven't read the book, it revolves around the author's

experience of Parkinson's, diagnosed, in his case, at the much earlier age of 38.

Fox's book presents Parkinson's as a gift which saved him from the vortex of a life as a self-engrossed celebrity, submerged in inauthenticity and booze, wallowing in the fun-house of the Hollywood entertainment industry. The ten years following that diagnosis, Fox writes, have been "the best ten years of my life – not in spite of my illness, but because of it." He goes on to tell us: "I am no longer the person described in the first few pages ...," and "I am forever grateful for that." That's why he calls himself a lucky man.

Fox's book is thus an implicit challenge to the reader to embrace any incurable and inexorably degenerative condition as an enhancement to our humanity, rather than a curtailment of it. That's a big ask, and the stakes are raised by the ringing epigraph to the book – a quotation from Henry David Thoreau, which reads: "In accumulating property for ourselves or our posterity, in founding a family or a state, or acquiring fame, even, we are mortal; but in dealing with truth we are immortal, and need fear no change nor accident."

This quintessentially humanistic affirmation invokes that most elusive of values – truth – from the perspective of our own mortality and immortality. An existential choice – a change of life-style and values, a personal transformation – embraced in view of mortality and immortality is presented as a truth claim, and *Lucky Man* comes across quite clearly as a conversion narrative – one of the classical paradigms of autobiography, and thus as a double success story – the central paradigm of autobiography: the story of a man who first achieved fame as an actor, and then transcended that achievement by renouncing self-indulgence and becoming a model husband and father, an outstanding advocate on

behalf of the Parkinson's community, and the author of first one best-selling autobiography and now, earlier this year, of a second autobiographical work, punningly titled *Always Looking up: The Adventures of an Incurable Optimist*. And all without wholly giving up his role in the world of film and television as actor and director, while the shaking palsy steadily extends its sway over his body.

Michael J. Fox as a Parkinson's Everyman? Someone with whom every Parkinson's bearer can empathize? Someone whose experience of life and of Parkinson's the non-Parkinsonian reader can vicariously share?

The answer is clearly both yes and no. Yes, the engagingly comic and disarmingly unassuming personality is ever present in *Lucky Man*, busily crafting little tales within larger tales within the master-narrative which is his encounter with Parkinson's, the mysterious antagonist which could strike any of us. Fox shares the experience with us in many vivid moments, the first being the mesmeric memory which opens the book with the little finger of his left hand moving, unbidden, all on its own as Fox emerges one morning from a beery slumber; another being that recounted in *Always Looking Up* of his apparently obscene groping to get his wallet out of his hip pocket with that uncontrollable tremor in his hand.

The bravura of his narrative is the petty cash of Fox's major investment in 'coming out' as a Parkinson's bearer, no longer hiding his condition from himself or the world, coming to terms with the insidious antagonist not only as an individual, but making common cause with Parkinsonians generally, and even more broadly with bearers of other disabling conditions in their shared interest in resourcing the search for a cure and mounting the political campaign to sanction the use of stem cells in that research. Here too, then, the answer is yes: Fox conscripts his dynamic individuality into the collective interest.

Fox also gives us in *Lucky Man* a lively layman's exposition of what the shaking palsy is, its physiology and pathology and the pharmacy and neurosurgery for treating it, and he reports on his encounters with doctors, neurologists, psychiatrists. In all these ways, Fox, while focussing on his own particular story, relates it to a paradigm involving all bearers of Parkinson's disease and thus approaches the model which has come to be called auto-ethnography – that is, the

description of a social group of which the author is himself or herself a member, and thus a participant observer.

If these are ways, then, in which Fox presents himself as one of us in his struggle with Parkinson's, first as a lucky man and then as an incurable optimist, there are ways in which he is clearly *not* your average Parkinsonian Everyman, who may be far less lucky and less incurably optimistic. Fox's celebrity status with its attendant privileged social networks and financial resources, puts him well above the average. His fortunate family situation is likewise an advantage that not every Parkinsonian will enjoy. Those deprived of such resources, and faced with the prospect of diminishing returns and an eventual negative balance in their own lives, or of imposing a crippling burden on those dearest to them, may, of course, be tempted by an exit strategy.

This negative calculus may be repressed or tacitly implied in Fox's *Lucky Man* and *Always Looking Up*, but it is squarely faced in another autobiography that coincidentally appeared in the same year as Fox's *Lucky Man*. This is more sombrely titled *A Life Shaken: My Encounter with Parkinson's Disease*, though its author, Joel Havemann, is not much less lucky than Fox. Havemann was diagnosed with Parkinson's at a relatively early age, though not as early as Fox. He was then a senior editor at *The Los Angeles Times*, and, like Fox, was able to continue in his prestigious career for several years after diagnosis, being in fact appointed European editor in Brussels for three years, and, like Fox, enjoyed a warm and supportive family life.

Here is how Havemann sums up his reckoning with the shaking palsy: "At first, I denied my fate. Now, thanks largely to preparing this book, I accept it for what it is – a life on the downward slide. What I don't accept is this: that such a life is no life at all. To accept that would be to quit living."

And he returns to the topic: "Parkinson's wins if it makes me focus on the long term – and give up. I set challenging short-term goals (finishing each chapter of this book provided a dozen of them) and strive to achieve them. I think not about what lies ahead for me but what awaits Anne, Margaret, and William, and now Evelyn and Audrey [his children and grandchildren]. Their future is my future. Their healthy bodies are my body. I live to enjoy their living."

He goes on to ask, but not answer, a rhetorical question: "What if I had no children, no Judy?" And he considers the alternative downside: "I worry about the burden I might place on them if I become incapacitated for a long period of time but refuse to die... I don't want them to sacrifice their best years for my worst."

In lieu of answering the unanswerable, he ends the book with his declaration of faith, providing the uplift indispensable to the writing of biography and autobiography, which is always in some sense celebratory, a testimony to survival: "Admiration for humanity. Reverence for nature. Love of family. These are my core beliefs. These

are my religion. This I have learned from my disease. Parkinson's, do your worst. You can't rob me of that."

Life itself can be seen as a death sentence, and the diagnosis of a degenerative condition like Parkinson's serves to spell that out more concretely, and to concentrate the mind. Face the negatives, but focus on the positives, and live life as fully as possible – this unoriginal but hard-earned wisdom is the central message of both Fox and Havemann. Both claim to have reconstituted and fortified themselves as a result of that diagnosis, and to have done so largely through the autobiographical enterprise. The project and the act and the effort of writing is itself for them a chunk of positive living.

It is also offered as a service to others and with others. Does this mean that others with Parkinson's would also benefit from writing their own life story? Certainly, identifying positives and combating negatives through writing ourselves is worth trying. And we can certainly benefit from reading Fox's and Havemann's stories – published autobiographies mediate between individual and collective experience. We can be beguiled and fortified by the struggle of other selves against the Other which is in themselves – and in us.

As for me, would my own Parkinsonian narrative be therapy or trauma? The question is redundant as such a narrative does not exist. Perhaps I am too old, compared to Fox and Havemann. My narratives have already played out. My major trauma came when I jettisoned most of my research material upon my retirement as an academic. It felt like throwing my life away. Or perhaps my shaking palsy is too new, having been diagnosed only three years ago, as compared to the decade intervening between diagnosis and autobiography for Fox and Havemann. Or perhaps I have lost my innocence as a life writer, having been involved academically with written lives for four decades.

Or perhaps "I" am playing hide and seek with "me". Parky's came to me as no epiphany of conversion, more as the writing on the wall, a confirmation of what, in theory, I already knew, but a nasty surprise nonetheless, attended by a marked decline of volitional energy and of mental energy and agility. Family problems limit the positives, but some positives are still there. I still have a life to live, and so have my children. Who knows what life story might still be in the making for me? 🌀

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FURTHER READING

Couser, G. Thomas – *Recovering Bodies: Illness, Disability and Life Writing*, The University of Wisconsin Press, 1997.
Fox, Michael J. – *Lucky Man: A Memoir*, Bantam, 2002.
Fox, Michael J. – *Always Looking Up: The Adventures of an Incurable Optimist*, Ebury Press, 2009.
Havemann, Joel – *A Life Shaken: My Encounter with Parkinson's Disease*, Johns Hopkins University Press, 2002.