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## A Half-century of Awakenings

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Fifty years have passed since the 1973 publication of *Awakenings*, a remarkable book by a remarkable author, Oliver Sacks.<sup>1</sup> At the time he wrote it, Sacks was a newly minted neurologist and, approaching age forty, struggling to find his place in the world. By chance, he sought work at a hospital in New York that housed patients who, decades earlier, contracted encephalitis lethargica. First encountered in Vienna in 1916, the epidemic of this mysterious malady (also known as von Economo disease) spread worldwide over the following decade, killing thousands young and old. Survivors developed lasting neurological impairments including Parkinsonism and catatonic states<sup>2,3</sup>. For decades afterwards, hundreds of victims remained in chronic care wards. As recounted in *Awakenings* and in a later autobiographical memoir<sup>4</sup>, Sacks was fascinated by the aftermath of this disorder. He was equally intrigued as to how his patients might respond to levodopa, a novel treatment recently developed for Parkinson disease. Previously, a few English post-encephalitic patients had shown improvements with levodopa<sup>5</sup>. Sacks initiated a small placebo-controlled trial and, after encountering promising results, began to treat other post-encephalitic survivors. While the extraordinary pharmacological outcomes he encountered might have been sufficient material for a good tale, Sacks envisioned a far more encompassing project for his book.

Having immersed himself in learning all he could about his post-encephalitic patients, Sacks then devoted months to write their stories. The result was a collection of twenty case reports together with details about their levodopa experiences. Each of these detailed vignettes went beyond the usual content of a neurological history, chronicling each patient's early years, personality, and aspirations for levodopa treatment. Much of the book is devoted to describing levodopa's almost metaphysical prowess at unlocking frozen minds and bodies - "the uncanny lifting of blockage and the return of ease, of grace, of joy and delight and resolve." [Weschler<sup>6</sup>, p. 88]. The dramatic motor and behavioral improvements after treatment give *Awakenings* its special appeal. While today the routine clinical practice of administering levodopa can be unremarkable, in 1969 this experience seemed much like witnessing magic. For Sacks,

these therapeutic ventures provided him with fascinating insights into how dopamine fuels the brain. Though the clinical results could be exhilarating, he also came to recognize the less fortunate outcomes that commonly occurred with the drug. That levodopa did not enhance cognition eventually became evident to him.

Beyond the sensational descriptions of levodopa in action, readers of *Awakenings* fell under the spell of the author's storytelling as they became familiar with the lives of the twenty patients he described. Readers became privy to the unique doctor-patient relationship Sacks fostered; how he befriended his patients and agonized over their disabilities is a driving force of *Awakenings*. Along with his own day-by-day observations, he recorded words his patients used to describe their interactions with levodopa. The reader gets to share Sacks' amazement as levodopa-treated patients returned to decades-old interests and skills of their youth. Patients previously immobile abruptly became animated, leaping up to stroll about and even dance. Tunes were banged out on the ward's piano. Smiles returned to previously masked faces; excited conversations and independent functioning became the new norm.

Despite the high points of this dramatic treatment, the drug-induced rescue from the grip of post-encephalitic Parkinsonism could be inconsistent. For some patients, the benefits of levodopa became increasingly irregular or eventually overshadowed by unforeseen adverse effects. Even skillful adjustment of this powerful drug sometimes gave capricious results or worse. Side effects, among them tics, ballism, oculogyric crises, and behavioral aberrations (irresistible pacing, emotional instability, sexual acting-out, and hallucinations) were common and devastated the wellbeing of some patients. In general, post-encephalitic Parkinsonism proved to be far more difficult to manage than management of Parkinson disease today<sup>2,3</sup>. The phrase carved over the entryway to Sacks' chronic care hospital ('Home for the Incurable' [Weschler<sup>6</sup>, p. 91]) was an apt metaphor framing the bittersweet experience of levodopa. For Sacks, stress and burnout from his devotion to work also weighed heavily on him:

“...one of the main things that made it possible to live with what might otherwise be unbearable therapeutic pressures is that ultimately, as I say, I'm a naturalist before I'm a doctor. I didn't enter medicine for ... Freud talks about the 'lie of salvation,'” he continued, “and this business of feeling myself a naturalist in the landscape of postencephalitics enabled me to work amid atrocious affliction and insoluble therapeutic dilemmas.” [Weschler<sup>6</sup>, p. 90].

Shortly after its publication, the neurological community gave *Awakenings* scant recognition [Sacks<sup>4</sup>, p. 205] though it quickly became popular among a diverse readership. Praise from the literary world included the British poet W.H. Auden and the novelist Doris Lessing. With its fame and mystique spreading, *Awakenings* received a prestigious British literary award, the 1974 Hawthornden Prize for "imaginative literature." The book also left its mark elsewhere on the cultural landscape. It inspired a theatrical adaptation in 1982 by Harold Pinter (a one-act play titled *A Kind of Alaska*<sup>7</sup>) as well as an opera<sup>8</sup> and a ballet<sup>9</sup>. Hollywood took note of the book and transformed it into an acclaimed 1993 film of the same name. The cinematic treatment of *Awakenings* stayed close to the book's themes, presenting to a wide audience a realistic and compassionate portrayal of Sacks and his patients.

For many readers, *Awakenings* was the entrée into the author's vibrant personality and erudition. His Oxford education and an insatiable love of books left Sacks well versed with writings of the world's thinkers. As a result, *Awakenings* abounds with ideas and images. In explaining his writing process, Sacks later noted that "it seems to me that I discover my thoughts through the act of writing, *in* the act of writing." [Sacks<sup>4</sup>, p.180]. Almost every page was dosed liberally with literary citations, personal comments, and footnotes. This wealth of words presented a major editorial challenge [Sacks<sup>4</sup>, p. 195]. Pages of footnotes needed to be expunged for the book to meet its publication deadline. Readers may have been perplexed by its frequent run-on sentences, a writing style that proved Sacks wasn't influenced by Hemingway. Sacks later confessed that "...I never use one adjective if six seem to me better and, in their cumulative effect, more incisive" [Sacks<sup>4</sup>, p. 190]. Towards the end of the book, in a section titled Perspectives (*Awakenings*, *Tribulation*, and *Accommodations*), his writing drifts away from a focus on the patients and their treatment and becomes broadly philosophical. But the abundant musings and literary analogies – quotes from Nietzsche, Donne, Auden, Proust, and many others - only add to the work's charm. Despite the considerable efforts initially expended to create *Awakenings*, Sacks revised the book twice, in 1976 and 1998.

*Awakenings* was notable for how thoroughly it conveyed its author's compassion for the thwarted lives of people under his care. Not everyone viewed his efforts as beneficent, however. Since they divulged highly personal information, the intimate portraits of his patients engendered controversy. While Sacks claimed that he wrote their stories with good intentions, it is uncertain if all patients authorized these invasions of their privacy. Riffing on the title of Sacks' book *The Man Who Mistook His Wife for a Hat*<sup>11</sup>, the British disability rights activist Tom Shakespeare tartly described Sacks as "a man who mistook his patients for a literary career."<sup>12</sup> Other criticism came from Leonard Cassuto, who likened the popularization of disabling neurological maladies to "freak show" entertainment<sup>13</sup>. In later writings, Sacks acknowledged

these concerns, commenting on his challenges at navigating the space between compassionate accounts in the case histories and the glorification of human oddity.

As extraordinary as was the story of levodopa and post-encephalitic Parkinsonism, the publication of *Awakenings* exerted a broader influence, one that was transformative for the literature of neurology. In subsequent years, a new genre of writing emerged. This was especially evident in the prolific literary career of Sacks, whose inquiring mind traveled widely into many realms of brain science and human experience. Around that time, other eminent neuroscientists also turned to general audiences for sharing neurological insights – examples are works by Antonio Damasio<sup>13</sup>, Harold Klawans<sup>14</sup>, and Michael Gazzaniga<sup>15</sup>. Leading neurological journals started to add sections reflecting human perspectives on brain disease and the interface between physician and patient. For example, starting in 2001, *Neurology* has offered articles highlighted as “Humanities in Neurology” and described as:

“...stories, essays, and poems that draw on the personal experience of the writer, and provide insights into themselves, their patients, and human relationships. It is about who our patients are and who we are. As we look into the hearts and souls of our patients, some of us will be inspired to describe and define their responses to illnesses.” [American Academy of Neurology, author instructions in *Neurology Journals*, *Neurology Journals Author Center*. 1.2 Non-research articles, Humanities in Neurology].

Another influence that can be tied to writings by Sacks was an evolution in the identity of neurology as a professional calling. Long after its 1973 publication, *Awakenings* continues to be popular among medical trainees. It has inspired career choices -- my own path as a Parkinson disease clinician and researcher, for example -- and other colleagues have concurred. One clue to the impact of Sacks’ writings comes from a study of personal statements submitted by medical students seeking neurology residency training. In a word search analysis of their applications, a frequent citation was “Oliver Sacks”<sup>16</sup>. Sacks was sometimes regarded as merely a popularizer of neurological topics, though his writings and inquiries became the impetus for scholarly pursuits by others. The British neurologist and writer Andrew Lees commented on his considerable influence at bridging neurology and the humanities:

Neurophilics transfixed by the connections between brain science and culture regard him as their leader. His writing has also inspired and fertilized the work of a wide array of scientists researching subjects ranging from the mechanics of visual and auditory perception to the workings of memory and consciousness itself. [Lees<sup>17</sup>, p. 3826].

As a classic for the knowledge and perspective it conveys, *Awakenings* has a well-earned place on the bookshelf next to James Parkinson's 1817 *Essay on the Shaking Palsy*<sup>18</sup>. Perhaps its neighbor should be Alexander Luria's *The Mind of a Mnemonist*<sup>19</sup>, an enthralling in-depth neurological case history that inspired Sacks to write *Awakenings* [Sacks<sup>4</sup>, p. 179]. *Awakenings* has other legacies. Beyond its value as literature, it also informed readers with a warning that a mysterious illness rapidly arising and spreading through the world could have devastating consequences. In the opening section of the book, Sacks researched several past instances of epidemic encephalitic disorders, each followed by Parkinsonism (the last one in the 1880s). Fortunately, since the 1920s, there have been only rare sporadic cases<sup>20,21</sup>. Nevertheless, the continuing mystery of encephalitis lethargica challenges neurologists to be on the lookout for future recurrences.

Another takeaway message from *Awakenings* was a call for caution against unbridled optimism in the face of medical breakthroughs like levodopa, especially if such thinking hobbles the path to objective assessments. Sacks offered a balanced view of the drug, highlighting both its miraculous effects and its imperfections. At the time, this opinion was disconcerting to the neurology community until others encountered and reported similar adverse effects. In the final section of *Awakenings* entitled "Perspectives", Sacks summarized what physicians need to recognize and what his patients taught him:

One must allow the possibility of an almost limitless repertoire of functional reorganizations and accommodations of all types, from cellular, chemical, and hormonal levels to the organization of the self – the "will to get well." One sees again and again, not merely in the context of L-DOPA and Parkinsonism, but in cancer, tuberculosis, neurosis – *all* diseases – remarkable, unexpected, and "inexplicable resolutions, at times when it seems that everything is lost. One must allow - with surprise, with delight - that such things happen, and that they can happen to patients with L-DOPA as well [Sacks<sup>4</sup>, p. 228]

Now a half century after publication, *Awakenings* still offers messages resonant with our times. It continues to inspire explorations and a focus upon neurology's human stories and insights.

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