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Awakenings Revisited

Cover Page Footnote

This talk was presented at Sacred Heart University on October 30, 1991 as part of a lecture series sponsored by the Center for Performing Arts. In his talk, Dr. Sacks refers to two films: a 1974 documentary showing some of the patients described in his book, and the feature film *Awakenings* (1990), directed by Penny Marshall and starring Robert De Niro and Robin Williams.

OLIVER SACKS

*Awakenings Revisited**

First of all I want to express my pleasure at being here, I'm always driving through Connecticut, and I think this is the first time I've stopped on the way and I am very glad that I did. I want to thank my neighbor, Kristen Wenzel. We both live on City Island. She is nautical and I am a swimmer. She first suggested that I come here and then Dr. Cernera was kind enough to formalize the invitation and Ed Malin has arranged everything, so I am deeply grateful to them and to all of you who have made it possible for me to come here.

I feel a little odd in this auditorium which has recently featured *The Doll's House* and an Arthur Miller play. I feel you need a stage of people, and there's only one of me. But I will try to people it for you with the extraordinary patients whom I have worked with over the years. It's a very special position and a very great privilege being a physician because people give you their stories and their lives and you get a view of human nature that you can't get any other way. In 1966 I came to a hospital in the Bronx called Mount Carmel. There I encountered, as I walked into the lobby, large numbers of patients, many of whom were frozen in extraordinary positions which they held for hours on end, like statues. There were some eighty of these sentient-statues there at Mount Carmel. I had never seen any patients like these. I had not imagined that such patients could exist. And I didn't know how sentient they were. I didn't know what was going on inside, and whether, indeed, there was an inside.

I wondered what was the story with these patients. I learned that most of them had been in the hospital since 1920, that indeed

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the hospital had been opened in 1920 for these patients, as had other

hospitals all around the world. And these patients were the first victims of a strange disease, the sleeping sickness or *encephalitis lethargica* which was then rampaging and epidemic all around the world. Now I had vaguely heard of this epidemic and I had occasionally seen in the out-patients someone with Parkinsonism or some relatively mild sequellae of the sleeping sickness. But I had no idea until I went to Mount Carmel of the enormous range of the epidemic and the profundity of its later effects, some of which are illustrated in the film clips I would like to show you tonight.

I've sometimes been accused of romancing disease or presenting a romantic picture and I know these are very grim films, but it's important for you to see how grim this illness actually could be. The epidemic rampaged until 1927 and then it disappeared. No cases of epidemic sleeping sickness have been seen since then. There was an enormous amount of medical and public interest in this illness in the 1920s. There were newspaper headlines, there were thousands of medical articles and monographs. But by the mid-1930s this attention and interest had practically vanished. The patients hadn't vanished. Many hundreds of thousands of patients were put into chronic hospitals and asylums and special communities and colonies all over the world. There their fate was very much to be forgotten and often to be abandoned by their families. My introduction to such patients was originally a hospital in London, which was an old fever hospital covering seventy acres, and originally twenty thousand patients were in this hospital. It was a whole post-encephalitic town.

Physiologically all sorts of changes happened with the patients. In the early days some of them had been rather hyperactive and had twitches and tics, somewhat like people with Tourette's Syndrome. But then a great slow, sluggish wave, not of sleep, but of something like trance, catatonia, came over them, and they sunk into a state of profound immobility, as can be seen in the film clips I will now show.

I think one is very struck even with these shots by the extreme immobility of the face and at the same time the look of intelligence and personality which is there. The immobility of these patients was extraordinary and this was not only a physical immobility, but a mental immobility as well. Often the stream of thought and the stream of consciousness had been stopped or splintered in these patients. I should give you an example of this with one such patient who later

did very well, but occasionally had sudden reversals to this state. On one occasion we had a flood up in the ward where I worked, and this was traced to the bathroom where this patient was found up to her armpits in water. I touched her and she jumped and said "My God, what happened?" and I said "Well, you tell me." She said she had started the water and there was about an inch of water in the bath and then I touched her. In other words, she had been frozen at that instant, at that perceptual instant when there was an inch of water in the bath, while in reality the water went up to the top and overflowed. This sort of freezing of perception and freezing of consciousness probably doesn't occur like this in any other illness and it is very difficult to imagine.

But sometimes patients could come out of the freezing. Sometimes the patient would sneeze suddenly and the sneeze would mobilize them and then they could talk and move for thirty seconds and then they would freeze up again. In those thirty seconds you might see what an alive and real person there was and how intact. But then the doors would close again and they would freeze up. There were certain other things which could unfreeze these patients for a little while. Typically, although they couldn't initiate any activities, they could respond. They could respond sometimes to a thrown ball, they could respond to music, they could sometimes respond to other people. And therefore it was crucial to *call* to these patients to get them to respond, because otherwise they would be sunk in an abyss.

I would like to show a scene of these patients playing ball, and then a film clip which shows Lola in slow motion. This bit of film was taken at a hundred frames per second, and you're seeing there a Parkinsonian tremor in slow motion and a very fixed expression. But then nearly in a hundredth of a second, as you see, she changes from being Parkinsonian to being very animated. A change like this is too sudden to be a process in the nervous system. What really happens in something like this is that the Parkinsonism is bypassed and the person is called into the mode of play or the mode of art.

One play on words which I rather like has to do with the word "art." The opposite of art used to be "inart," which then became "inert," and these patients showed profound inertia. Many of them in fact complain of inertia. They may say that they feel wooden or robotic, but in the act of play or art they suddenly come alive.

Well, in 1966 then, one could play ball with these patients, one could see them briefly animated, but there was no way of awakening them for more than a few seconds. They were obviously intense, vital individuals who had been shut in by this disease. And they seemed quite hopeless, and they felt hopeless and they felt abandoned.

Early in 1967, a new medication was announced for patients with ordinary Parkinson's disease, a medication called L-DOPA. Many of these patients were very alert and they heard about this. Leonard L. heard about it. He called the man who devised this medication, Cotsias, "the chemical messiah." And since the medication, L-DOPA, alters a chemical in the brain called dopamine — dopamine is necessary for movement, the movement of the mind, movement of the body — Leonard called dopamine "resurrectamine." This will give you some idea of the desperate yearning and the ironic detachment combined, with which many of these patients looked forward to something or other.

Now, perhaps I could, perhaps I should have given L-DOPA as soon as I heard of it in 1967. I didn't. I waited two years. There were two reasons why I hesitated. One reason was that these were not patients with ordinary Parkinson's disease; they had a much more complex disease and many of them had been very explosive when they were younger. Von Economo, who described this illness, spoke of these patients as extinct volcanos, but I didn't think the volcanos were extinct. I thought they were dormant and I didn't know what would happen if they came to. The other thing was that these patients had been "out of the world" and not up-dated in many many decades. I didn't know what they were like inside and I didn't know what it would mean to come to, if they did come to, in a world not their own.

So because of these doubts I hesitated. But the patients were deteriorating, some of them were dying, and I thought I mustn't hold things up because of my own doubts. I am sure some of you later are going to ask questions about informed consent, although that was not a term which we used in the 1960s. In March of 1969, then, I gave L-DOPA to Leonard L. and shortly after that to several other patients. I'll show you a little film clip in a moment. I hadn't really believed that anything would happen and I was startled out of my wits when it did happen, especially with some patients like Lola. This was a patient who showed no warming up period whatever. We gradually increased

the dose and saw nothing. Then at a particular critical level, this previously motionless, speechless woman suddenly got up, shot down the corridor, and burst into conversation with the nurses. There is one point in the feature film where the nurses burst in, where one of the nurses says "It's a fucking miracle." This was exactly the sort of event which produced that. Lola had also been rather apathetic for many decades. She would have food put into her mouth and didn't care what it was. But now she became very animated: she said she wanted a steak, well done.

There was an instant, wonderful sort of animal and sensuous animation with these patients. Suddenly they could breathe, they could move, colors were brighter, there was just a great delight in being alive and being able to move and talk. This first feeling of awakening was a miracle feeling and indeed was very close to a sort of resurrection. It wasn't just an individual feeling but it was a communal feeling, and although we didn't have fifteen patients coming to in one night, in the somewhat Hollywood way you see in the movie, yet there were eighty patients who were awakened over three weeks. This was pretty dramatic and the whole hospital was agog.

Let's see the next strip. [What follows is the narration from this section of the film.]

Lola who was unable to swallow solid food and was threatened with starvation. She was given the medication first in May 1969 in the hope of keeping her alive. It did much more than that. Lola had been transfixed in a state of extreme, really in a state of infinite Parkinsonism. Her change, her awakening, occurred in seconds, and she jumped out of the chair and she flew down the passage and burst into conversation and it was an incredible scene and I would doubt my own memory if it were not supported by everyone else's memory and of course by our accounts and films which we took at the time. The most dramatic awakening came in July with Sylvie. After thirty-five years in hospitals, frozen and inert, she regained the enthusiasm for life which had

deserted her forty years before. But something in her manner was strange. Sacks noted in his diary, "Is it possible that Sylvie has in fact never moved on from the past?" She was in a marvelous mood for a while and she was talking away, singing and dancing, but almost everything she said and did had reference to 1926 or before. She referred to figures who were topical at that time. Some of her mannerisms, some of her slang, was of a sort which had been obsolete for 40 years. She was, so to speak, a flapper who had come to life.

During the summer months the patients came back to life. Their childish gaiety and enthusiasm shattered the hospital routine.

The summer of 1969 was full of excitement, full of elation. Some of the patients, as you see, sometimes had deformities or contractures of limbs and of course these couldn't be reversed. But other patients became very active and began going out of the hospital and taking public transport. I think many of them could have gone home at that time had they had homes to go to, but remember these were people who had been on the whole separated from their families and friends for forty or more years. But with some of the patients, and especially Sylvie, whom you saw there, there was this feeling that they had awakened in an anachronistic fashion. Sylvie talked and behaved, as I say, like a flapper, as if she were still in the 1920s. I asked her some questions to see what her orientation was, and she was a very quick woman: she said, "Look, I can give you the date of Pearl Harbor, I can give you the date of Kennedy's assassination." She said "I've registered it all, but none of it seems real. I know it's 1969, but I feel it's 1926. I know I'm 64, but I feel I'm 21. I've been a spectator for the last 43 years."

Sometimes people with depression or people with schizoid withdrawals may have some feeling of being a spectator and not a participator in the world. But here there's an organic basis of a very profound sort. In some sense, these patients with post-encephalitic illness who may be absolutely immobile mentally and perceptually as well as motorically, may indeed not update; they may not have a

stream of experience in the way in which the rest of us do. Occasional things, like Kennedy's assassination or whatever, will have a sudden flash bulb effect. And they will know about that but they may not have any sense of *personal* history. So with Sylvie and some others, they were indeed survivors or relics of the past who had found themselves animated, and they knew this very well and they didn't always like it. Sylvie didn't like it. She said "I don't like your world, all this television trash. None of it has any meaning for me. Everything and everyone which had meaning for me has gone, went long ago." She had ten days of this strange nostalgic excitement and then she suddenly went back into the trance-like state that she had been in before and neither giving her L-DOPA nor anything else could move her from it.

I should say, however, that the summer on the whole was a very good summer. It wasn't a good summer for Sylvie: she was in trouble within 10 days. For most of the patients it was a very good summer. One only started to see side effects and the medication going wrong later in the year. Really then, there were two sorts of problems. One was a sort of existential problem, an identity problem of being animated into a world which is not one's own. And the other has to do with a physiological problem that probably something like 99% of the dopamine systems in the brain have been destroyed and if you give L-DOPA you are demanding that the remaining 1% do everything and it can't sustain this. With this on the one hand the patients started to relapse into Parkinsonism and catatonia and on the other hand to develop all sorts of bizarre movements and passions.

I'm going to talk about the feature film in a moment, but as those of you who've seen it know, in a way the movie confines itself to the summer and the fall of 1969, to the resurrection and then the disaster which seemed to overtake so many of these patients. In reality most of the patients were able to get through this terrible period. Sylvie didn't, and also Leonard L., and in a way which may be somewhat unfair, it is these two patients who have been seized on for dramatic portrayal, Sylvie in Harold Pinter's play, *A Kind of Alaska*, and Leonard L., of course, in the movie. But most of the patients were able to make some sort of accommodation. Their nervous systems became better able to handle the L-DOPA and they would have many good hours a day. It also became very clear that this wasn't just a matter of chemistry, it

wasn't just a matter of giving someone a drug, but of the sort of life which could be found or created for these patients. The things which mattered intensely to all of us – meaning, structure, freedom, spaciousness, relationships, work, play – these were exactly the things which were crucial for these patients and which could stabilize them if they were possible.

I remember this very much with one patient, who was a former shoemaker and cobbler, who had initially done beautifully on L-DOPA and then started fluctuating wildly, as a lot of the patients did, between frenetic states and catatonic states, and he continued doing that until we set up a shoemaker's last and bench and suggested that he return to his original occupation. When he did this he became physiologically stabilized and he stayed that way for another ten years, in fact until his death. Experiences or experiments like this which seem so far out I think all the while cast light on what everyone needs; they cast light on the universal human condition.

I kept, as I always keep, a diary, a record, about these patients, partly because so much was happening and partly because I have to write to clarify my own thoughts. But I think also I had some thought of telling their stories. They themselves were very conscious both of how cruelly they had been forgotten but also of how extraordinary and important their situation was. They often said to me, again and again, "Tell our story or it'll never be known." So I told their story and I published it in 1973, basically the story of twenty of these patients. A documentary was made the same year and the clips you've seen come from that.

I didn't know whom I was addressing when I wrote the book or when the documentary was made. I never have in my mind a clear distinction between my profession and the public. I wrote for anyone who was interested and anyone who would be moved. There was an unexpectedly deep and wide movement and a creative one as well. Many playwrights became interested in the theme, and as I've mentioned already, Harold Pinter wrote a beautiful play about one of these patients. I think having had Ibsen and Arthur Miller here in this auditorium last week, you might have that Harold Pinter play as well.

In 1979 I got approached by Hollywood, who were interested in making a film. Actually I never go to the films, or very rarely, and I didn't think too much about it. I said, well, OK, and then in fact

nothing happened for seven years, and so I thought it had been OK to say OK. In 1986 a scriptwriter came and visited the hospital and some of the patients. In 1987 a script came, and it worried me intensely. It especially worried me because it contained a character called Dr. Sacks. I didn't want to be a character myself. I said the story is about them, it's their story. In 1988 I met Penny Marshall. She came to the hospital and saw the patients. We spent hours talking in the botanic garden. Penny herself was born in the Bronx, and liked the idea of a film situated in the Bronx. And then in 1989, the actors came on board.

Robert De Niro is extremely shy. And although you see me gabbing now, I'm also rather shy, and I think had Penny not been there, De Niro and I would have sat in complete silence and not exchanged a single word. The first thing he said was that he had been looking through tapes of *Rain Man* and would I like to talk about some of the differences between autism and the post-encephalitic syndromes. I certainly think *Rain Man*, and the critical and commercial success of *Rain Man*, was something that made what might have been before an unpalatable subject a possible one.

A month after this, I met Robin Williams. I was rather cautious of meeting Robin Williams. It was one thing for the patient to be portrayed, and I was very intent that De Niro should see a lot of patients and should get it right. I was fascinated to see his observation of the patients, which was so minute. It was a sort of observation which was silent and absorptive. I took him to see one patient, the one who largely became a model for him in the film. At one point this patient said, "This freezing I have, I have seven sorts of freezing. Let me explain." De Niro said "No don't, I'll stay the weekend." And he spent the next forty-eight hours nonstop with this patient, seeing him night and day, seeing him awake, inside, outside.

I didn't like the idea that I was going to be observed by Robin Williams. But fortunately he didn't seem to be observing me. We spent a lot of time together, we went for drives together, we talked about things, we saw patients, we hung out together. I kept thinking, "Well, when is the observation going to begin?" But by that time of course it had been completed. I knew it was completed because he started to get more and more like me. One isn't normally conscious of one's gestures. I have become conscious; in fact I've really had to give up all

my gestures. Most people say I'm imitating Robin Williams. But we'd be talking together and I would be in one of my sort of clumsy, idiosyncratic postures and he would be in exactly the same, not imitating but sort of automatic. This mimesis went very, very deep. He didn't simply have my gestures, the way I adjust my spectacles or had these sudden micro-panics in losing things, but he seemed to have acquired my interests, my prejudices, my memories, and my hopes. And it was really very extraordinary, like having a sort of instant twin, or rather an instant twin for a younger part of myself, as you can see from those films. Although the patients had not aged that much, and somehow been preserved by their post-encephalitic stupor, I think I have aged a great deal and it was both nice and not so nice, having my younger self re-created like this.

It was a relief to both of us when I said we mustn't use my name: don't call the doctor Sacks, think of another name beginning with S. I think this allowed a sort of detachment and allowed him to go on and create the figure of a doctor who was not a literal reconstruction of myself but had some aspects of me and many aspects of Robin. I'm half sorry that Robin was so serious in his presentation. Between the scenes we had the most incredible im-provisations, and also he and De Niro would swap roles so that he would become the patient and De Niro would become the doctor.

I spent a lot of time with the actors and going to rehearsals, and I was very intent on producing a very authentic point of departure. It was very extraordinary teaching the actors how to be Parkinsonian. This is somehow the reverse of what doctors usually do: normally you have to teach people how to be healthy and here I was teaching people how to be sick, how to shake, how to festinate, how to drool. Penny didn't like the drooling, so I'm afraid there is no drooling in the final film, although I think drooling is a great neurological accomplishment. It's well worth learning.

I got sort of spooked again and again by De Niro because he played with such conviction and such verisimilitude that I kept thinking he had Parkinsonism. I kept thinking he was getting it. There were many times when I thought there had been a sudden neurological disaster on the set and that the chief actor had in fact been struck with the reality of the illness of which he was trying to present the illusion. And even when I knew it was only acting, even

then, I wasn't quite certain and wondered whether acting of this intensity and this conviction could actually produce Parkinsonism. These may be absurd thoughts, but this is what happens when a neurologist gets on a film set. And one saw with De Niro and with many of the actors often how the persona they were acting, even the neurological changes, would persist for hours when they weren't on the set. A lot of the "patients" went off the set with their necks in strange positions, and with De Niro I noticed that his foot was curled up for almost the entire three months of the filming. Sometimes at dinner he would talk very strangely and one would realize that it wasn't him talking, it was Leonard L. I think the way in which a whole personality can be incorporated like this is quite extraordinary and I'm a little scared of method acting. I don't know how far it can go. I hope De Niro never plays a murderer or a suicide.

I was told a story that once Dustin Hoffman was going to London to play an exhausted man. He arrived in London very exhausted having stayed up the previous five nights and Lawrence Oliver expostulated with him. He said, "My dear boy, you don't have to be exhausted, you must just play exhausted." But somehow the line between playing and being seems very ambiguous and at times almost ominous. One of the nicest scenes I think was when Lillian, who was a very vivid, funny patient, a spokesperson in the documentary and still alive, came to the set. The actors were amazed when they saw her. They had been in this Hollywood world, this world of scripts, and Lillian was real, she was a real post-encephalitic and they wanted to touch her, to ground themselves. They were in awe, and they said "What are you doing in 1990? We thought it was all over in 1969." She said "Not for this one." She did a scene with De Niro. She herself was in the sort of catatonic position that so many of these patients are in so much of the time, and he came in slightly nervously – it is unusual for him to be nervous – and took up this position, and then she gave a very quick critical glance at him. I wondered what she was thinking. Then she gave me a tiny thumbs up sign: he's OK, he's got it, he understands.

I think the level of understanding was very real. The film has got its fictions, and quite a lot of them, but it is also full of beautiful authentic things, from the ball-playing scene, which as you see for yourself is taken straight from the documentary, and the

post-encephalitic card game, to the patterns on the floor, to the responses to music, and although it has been a bit softened and sweetened and stereotyped in some ways, I think it is also full of real power. Lillian liked the film very much. The only negative comment which she expressed to me was, "They cut us both out of it!" Her scene wasn't in, nor was my scene. I was actually a Father Christmas in a sequence which was not used. In the original film, which was five and a half hours long, there was a second awakening and it was rather powerful. At the end of the second awakening Leonard throws the L-DOPA into the East River. Penny hesitated for quite a while between different endings. (At one point the film had six alternative endings.) It's easy for me: I just write footnotes. But for the film you are only allowed one ending.

Anyhow, I think I had a deep satisfied feeling when the movie came out, that somehow the patients' wish many years before – "Tell our story or it'll never be known" – has been posthumously granted. Now I've already talked much too long, so I hope now we can talk together. Thanks very much.