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## Interview: Michael J. Fox discusses his acting, his experience with Parkinson's disease and his new book "Lucky Man"

April 30, 2002 from **Fresh Air**

TERRY GROSS, host: This is FRESH AIR. I'm Terry Gross.

When Michael J. Fox was diagnosed with Parkinson's disease in 1991, his doctors said he'd probably be able to continue acting for another 10 years. That was about right. In the spring of 2000, Fox's symptoms progressed to the point where he had to give up his leading role on the sitcom "Spin City." After keeping his illness a secret for many years, he writes about it in his new memoir, "Lucky Man," which is at the top of the best-seller list.

Fox became a star in his early 20s with the success of the sitcom "Family Ties." Some of his best-known movies are "Back to the Future," "Teen Wolf" and "The Secret of My Success."

The symptoms of Parkinson's include rigidity, shuffling, tremors, lack of balance and diminished motor control. The intensity of Fox's symptoms varies. He's given several interviews for his new book. I asked him what he does when he gets symptomatic during an interview.

Mr. MICHAEL J. FOX (Actor; Author, "Lucky Man"): Well, actually, I've been erring on the side of caution--I think 'erring' is actually the right word--in that I've been medicating perhaps too much, in the sense that a lot of times the symptoms that people see in some of these interviews that have been on are actually dyskinesia, which is a reaction to the medication. Because if I were purely symptomatic with Parkinson's symptoms, a lot of times speaking is difficult. There's a kind of a cluttering of speech and it's very difficult to sit still, to sit in one place. You know, the symptoms are different, so I'd rather kind of suffer the symptoms of dyskinesia, which is this kind of, you know, what I call Axl Rose singing "Paradise City." You know, this kind of weaving and this kind of continuous thing is much preferable, actually, than pure Parkinson's symptoms. So that's what I generally do. And, you know, it's kind of like shooting a mosquito with an elephant gun, but that's the approach I take.

So I haven't had any, you know, problems with pure Parkinson's symptoms in any of these interviews, because I'll tend to just make sure that I have enough Sinemet in my system and, in some cases, too much. But to me, it's preferable. It's not representative of what I'm like in my everyday life. I get a lot of people with Parkinson's coming up to me saying, 'You take too much medication.' I say, 'Well, you sit across from Larry King and see if you want to tempt it.'

GROSS: So I know you have comparatively good and comparatively bad days. Is today a good day or a bad day?

Mr. FOX: I have good and bad days 10 times a day.

GROSS: Right.

Mr. FOX: So, you know, right now this is a good moment in a fairly good day. I feel pretty good today. And this is pretty mellow and comfortable, so I'm pretty good. And I'm flopping around a little bit like a fish in a boat today, but there's nobody here to see me. I'm just in a little sound studio, so it's great.

GROSS: That's the nice thing about radio. When did you first realize...

Mr. FOX: Yeah.

GROSS: ...there was something wrong?

Mr. FOX: Well, I woke up one morning. I was down in Gainesville, Florida, and I was doing a film called "Doc Hollywood," and it was a Tuesday morning, which means the night before I was probably in the bar watching "Monday Night Football" with all the crew. And so I woke up the next day a little fuzzy-headed, to put it mildly, and I noticed that the pinkie on my left hand was twitching uncontrollably and just, you know--it was a curiosity as much as anything else. I just was fascinated by it, 'cause I couldn't stop it, no matter how I tried to restrict it or--you know, I couldn't will it away. And actually, I would physically hold it, but as soon as I released it, it would start up again.

And I consulted with a neurologist down there, who said that it was probably an injury to my ulna or my funny bone. I went down that track very quickly in thinking that it was something physiological. And it was a year later that, with some other rapidly building symptoms--you know, rigidity on my left side and some slowness and some other things, in addition to the escalating tremor, which had by then gone into my hand and into my arm--that was when, a full year later, that the neurologist finally gave me a definitive diagnosis.

GROSS: Yeah. As you mention in your book, Parkinson's is very rare for people under 50, and it's usually people even older than that who get it. And you say that the first literature you were given had an elderly couple on the beach at sunset, and there you were in your 20s.

Mr. FOX: Yeah. I remember the pamphlet. I can't remember what the medication was. And there was this elderly couple strolling on the beach, and there was a seagull above their heads, and they both looked really happy. I say in the book that it

was hard to tell which one had the incurable neurological disease, because they both looked great and pretty pleased with things. And there was a seagull flying overhead and he looked good, too. I wanted to hit him with a rock. And it just was very hard for me to process the whole thing. It just made very little sense to me.

I found that, you know, looking back on it, I took the news very passively and very--you know, I just kind of sat there and I didn't have a big explosive reaction, because it was literally like somebody telling you you may have just discovered your parents were martians, you know? It just didn't compute.

GROSS: Now you say that about three other people who you used to work with when you were in your teens and you did a Canadian TV show--this was in 1977--that three other people who worked on that show also had early-onset Parkinson's disease. What do you make of that?

Mr. FOX: Yeah. I've since learned that they did. And, you know, it's being investigated as a cluster, and it certainly sounds like a cluster. You know, and clusters exist with other diseases and in other situations, and they're usually associated with something environmental or a sick building or that kind of thing. It could be viral, which is the hypothesis, or at least the theory, of the investigating doctor up there--researcher up there in Canada.

I don't know. I mean, it could certainly be a cluster. It could also quite possibly be coincidence. You know, I'm concerned for my co-workers, but from a personal point of view, it's not something that I'm, you know, devoting a lot of time or energy into in the sense that 'Oh, this is the answer.' I've kind of moved beyond this being a personal thing, as strange as that might sound. And so I'm interested in clusters in general and I'm interested in things like biomarkers and genetic predisposition and issues like that, but not, you know, wholly on a personal level and not to the extent that I want to put aside a lot of those things to focus on this, you know, one event.

GROSS: After your diagnosis, you decided to tell only families and selected friends and associates. What were your fears of what would happen if everybody found out?

Mr. FOX: My experience with the celebrity and with certain, you know, elements of that made me very distrustful of letting anything out that--I wanted to process it myself first, or at least I wanted to ignore it myself first and then, in time, process it. But I just didn't want to put it into the machinery and have it kind of processed publicly and have, you know, the tabloids have a run at it and let other people have a run at it and come up with opinions and conclusions when I was, you know, still kind of flailing. So I was very distrustful of letting it out there. And also, you know, I didn't really articulate it this way early on, but I eventually did, you know, because I was involved in comedy. I thought, you know, if people know that I'm ill, would they be able to laugh at what I do? You know, I say in the book, 'Can you laugh at a sick person without feeling like an asshole?' You know, it was a concern of mine.

So a lot of these things were in my mind. And, you know, who among us, you know, walks down the street and leads with, 'Hi, I've got a boil on my ass,' you know?

GROSS: Right. Right.

Mr. FOX: We keep these things to ourselves.

GROSS: Well, the comedy thing--especially if there's physical comedy involved where, you know, part of the joke is that you walk into a wall or something like that...

Mr. FOX: Right.

GROSS: Yeah.

Mr. FOX: Yeah, exactly. It's--and that was a difficult thing, you know? It was--one of the nice things about having written this book is it was a really nice transition for me from going from a craft where I relied on a good deal of physicality and a good deal of mastery over, you know, making my body do things that were, you know, kind of bizarre and athletically demanding in some cases, to a place where I couldn't do that anymore, but instead was able to basically lock myself up for 14 months and write a book.

GROSS: Right.

Mr. FOX: And it was nice to have made that transition, at least for myself.

GROSS: When you were telling selected friends and family that you had Parkinson's, were you confident that people would keep the secret, or did you have to go around worrying, 'What if somebody leaks it?'

Mr. FOX: No. I'm lucky that I think the quality of the friends that I had and my family--and especially with them having gone through, you know, four or five years of what I call the fun house--you know, having been in the public eye, that at that point I was pretty confident in the discretion of those that I had chosen to talk to about it. And they were all pretty great. So it was--you know, it's kind of funny. I was so good at keeping the secret from so many people that it shouldn't have been a surprise to me that I was equally good at keeping the secret from myself. And that was really, you know, what I was most...

GROSS: What do you mean by that, by keeping it from yourself?

Mr. FOX: Well, you know, I just--I would constantly--somehow, you know, I would not deal with it as a fact. I would deal with it as something that was negotiable. Because in so much of my life I'd been able to negotiate--you know, kind of dealing with acting and dealing with things where it's about impression and it's about 'If I can make it look a certain way, then that's really what it is, for all intents and purposes.' But when you have this constant reality, this, you know, implacable fact of the disease--you know, it took me a long time to get to that. And so almost, in a way, by keeping it from other people I could, in effect, keep it a secret from myself. And that probably goes to the core of your original question about why keep it a secret. It was like the less people knew, the less people that could bring it up to me; and the less people that brought it up to me, the less I had to really deal with it.

GROSS: My guest is Michael J. Fox. His new memoir is called "Lucky Man." We'll talk more after a break. This is FRESH AIR.

(Soundbite of music)

GROSS: My guest is Michael J. Fox. He has a new memoir called "Lucky Man."

It was after you were diagnosed that you got the job on "Spin City." How did you decide who to tell about it? Like, did you tell Gary David Goldberg, the creator of the show, who had also created "Family Ties"?

Mr. FOX: Yeah, I did. Well, I went into it--by that point I was kind of--had gone over the curve of acceptance and had done a lot of work on my own with understanding and accepting the disease. And so when I went into it, you know, I specifically picked the people that I worked with and also the forum. And, you know, the idea of doing a sitcom again, doing it in New York, being near my family, kind of setting the schedule, and for the first time making sure that everybody that I worked with was aware, in the tightest inner circle--you know, my production partners and network and whatnot--knew what I was dealing with and had accepted the possibility there might be a problem down the line; certainly not in the short term. And that was a great relief to me and it was very liberating.

GROSS: Everybody was confident that you could do it.

Mr. FOX: Well, they were willing to take a bet. You know, it seemed like a good pony. It was one of those things where the pony might go lame in a while, but we think he can make it down the home stretch. So...

GROSS: So at what point did you have symptoms that you had to disguise during shoots?

Mr. FOX: Well, I think before I ever--right from the beginning, in the sense that even something as small as a trembling hand is something that--you know, you find yourself putting your hand in your pocket. Or you can interrupt symptoms, at least with Parkinson's early on, by, you know, manipulating props and putting your hand in your pocket, leaning against a wall. Any kind of break in the circuit causes a pause in the tremor. And then as time went on and I was doing the show, when it started to get more kind of global in my body, and so the three or four body parts would be going at the same time, and it kind of got to where I had to be more than just a sleight-of-hand artist and almost a contortionist. You know, that's when I really started to consider, you know, moving on.

GROSS: You describe Parkinson's as being about resting tremors. If you're resting, the tremor starts, but if you move, it temporarily stops the tremor. So you say if you, say, picked up a cup or picked up a pencil, it would stop the tremor. And so you did that a lot while you were shooting "Spin City."

Mr. FOX: Right.

GROSS: Do you think it ever gave you the look of being fidgety or having a certain nervous energy in the show because you were doing things like that?

Mr. FOX: Well, I think that it's so long been a part of my persona that it was kind of seamless, in a way. You know, in fact, I say in the book, you know, talking about the inverse kind of outward physical deterioration and inward emotional and personal development that I couldn't really be still until I could no longer keep still. You know, it's this great irony that by the time that I had kind of an inner calm, I was so outwardly frantic, and I get very used to the fact that--you know, I tell people all the time, 'Body language lies. Don't make any assumptions based on what you see my body doing or the way I may look, you know, as to whether I'm nervous or agitated or excited. There's a complete separation between the two.'

But in performing--no, like I said, just I would incorporate it into everything I did. You can see a lot of times if you watch those old tapes, I'll be leaning against a desk or I'll be picking up a prop. And as I said, by then, you know, it surprised me how few people noticed it. I had a thing that I showed my son very early on that he could--if he saw my hand shaking, he could grab my thumb and give it a twist, and if he counted to five and did it again he would, in fact, stop it from ever trembling, 'cause that's about the period of time that it takes. And, you know, I'll never forget teaching him that. And then at one point he did it for a while and thought it was great that he could do this every time, and then when he realized that it would start up again, he kind of looked at me like, 'Oh, my God, what have I gotten myself into?' And I said, 'No, you don't have to do this all the time; you know, just if you want to.'

But yeah, it was an interesting thing, so that whatever I appeared to be doing at any given time, I was really doing something else. I was constantly doing the math and constantly figuring out, you know, what my options were when that next tremor would come, so that I--you know, how it was going to get to something that could disrupt it.

GROSS: Were you in on what the final script of "Spin City," the final episode that you starred in, would be like and how your character would be written out?

Mr. FOX: Yeah. The actual device that was used was something that the writers came up with, but as we got into the nuts and bolts of doing the show, I got more involved and actually took, you know, pen to paper, just in terms of trying to integrate some of the things that I was feeling and anticipate some of the things that the audience might feel.

GROSS: Why don't you describe what the premise of that final episode was.

Mr. FOX: Boy, if memory serves, I think my character took the fall for an apparent connection between City Hall and organized crime, and he realized he had to take the hit for the mayor. And that's something that, you know, he felt--Mike Flaherty felt, you know, fell within his job description, so he did it. And he was aware that that meant that he would have to City Hall and leave politics for a time. And so the last part of the show was really this kind of prolonged goodbye.

GROSS: What were your thoughts about how to best promote your departure from the series, you know, like a very special "Spin City" kind of thing?

Mr. FOX: Well, you know, the thing is, yeah, I'd always said that. I said it early on, too, when we were talking about what kind of show we wanted to do, and that if you ever read in TV Guide, 'A very special "Spin City,"' you could, with my permission,

come up and hit me in the head with a frying pan. That was never, you know, my intention. But at a certain point, you know, the network kind of does what they do, and they're going to promote it the way they're going to promote it.

But, you know, I'd also experienced this disconnection that I'd had, you know, that I'd always kind of rationalized away previously between myself and an audience that had come to know me over the years. And earlier on in my career, it'd been much more convenient and it seemed to me to make much more sense to say, 'Well, in a way, this is this, you know, kind of business thing that's been transacted, and I go out and do what I do, and people watch it or don't watch it and buy the product that's advertised or don't,' and, you know, it just seemed much safer to look at it that way.

But once I had disclosed my diagnosis, the depth and the sincerity of the connection that I felt with people that approached me and that watched the programs and wrote to me and called and whatnot and supported our foundation and our efforts just seemed so real that I felt that in the last show, I had to in some way address that and be respectful of it. And, you know, then how the network, through their promotion, may kind of up that a notch or not really was beyond my control, but I did feel very overwhelmed in a good way by the response and wanted to honor it. So that kind of went into it.

GROSS: I want to quote something that you write in your memoir about acting. You say, "Actors don't become actors because they're brimming with self-confidence. For those of us lucky enough to become professional performers, the uncertainty about who we really are only increases. For many actors, this self-doubt is like a worm eating away at you and growing incongruously in direct proportion to your level of success. No matter how great the acceptance, adulation and accumulation of wealth, gnawing at you always is the deep-seated belief that you're a fake, a phony." Is that what you were experiencing as you became like more famous, that you were experiencing less self-confidence and...

Mr. FOX: Yeah. I write that earlier in the book. And then I think later in the book, I kind of expand that in a way, in the sense that for most of us, the first word probably that we learn and understand is 'no.' And in a lot of ways, you know, 'no' describes home to us in a way. You know, it defines boundaries. And all of a sudden, you're in this place where you hear nothing but 'yes,' and you, in turn, say nothing but 'yes.' And I don't mean this by way of complaint. In fact, when I talk about celebrity, I try to step back from it and become somewhat detached. Because, you know, there's a lot about it that's fun.

But it is strange and it's strange to, you know, realize that you're doing something and you're doing it as well as you can, but really what is it in the fullness of human endeavor that is so spectacular about this? And you're torn because you love the cars and you love the girls, you know, that never would give you the time of day that are, all of a sudden, you know, very available to you, and all these great things are happening to a 22-year-old. And at the same time, too, you're thinking, 'This is strange. You know, someone's going to come and knock on the door and say, you know, "This is all over. You know, go back to Canada and don't take any of the stuff with you."' So there's this feeling that, yeah, there's no way that you can deserve this.

GROSS: My guest is Michael J. Fox. His new memoir is called "Lucky Man." We'll talk more after a break. This is FRESH AIR.

(Soundbite of music)

GROSS: Michael J. Fox is my guest. He has a new memoir called "Lucky Man."

You say in your book that you've gone back and you've watched old tapes and older movies that you made. Do you notice symptoms or tremors that you didn't realize were symptoms at the time?

Mr. FOX: Yeah. I can see it now, even with old "Family Ties" episodes that was, you know, four or five years before I was diagnosed. And they say that by the time the first symptoms are present, as much as 80 percent of the dopamine-producing cells in your brain are already dead or dying. So the great likelihood was that I did have cell death occurring during that time. And, you know, I can see a weakness on the left side or certain things that I was doing, you know, obviously not consciously, but I can see an interruption in the rhythm on my left side and other things in some of that old work. So, you know, the brain is an amazing machine, both in the way that it works and in the way that it breaks down. You know, it's fascinating from that point of view, and I've actually gotten to a point where I can be fairly detached about it.

GROSS: You say in your book that when you got sick, you eventually gave up drinking. Had drinking been verging on a real problem for you?

Mr. FOX: Well, you know, in the '80s when I was younger, as I said, you know, when we were talking about that feeling that someone was going to come and knock on the door and take it all away, and so my kind of loosely thought-out theory was that I'll be drunk when they get there and, you know, not so much that I drank when I was working and in those kind of situations, because that was fantasy enough for me that I was actually doing that for a living. But on the other time, I wanted to distract myself from the possibility that, as I said, perhaps it was undeserved or perhaps it was going to end. But by the time I got married, that had really calmed down a lot.

And then shortly on the heels of getting married, of course, came the diagnosis. And then drinking--well, again, not rising to the level that would be dramatically dysfunctional. I certainly recognized that I was using it, you know, more as a means of escape and more as a means of self-medication, not looking at what my new reality was. And when that hit a point where it was obviously disrupting my family and breaking down the communication that I had with them about my health and other issues, then I just knew that it was time to stop it. And really stopping it, although not immediate, the next phase was not immediate, it certainly led to my being able to really look at my diagnosis and accept it and move on.

GROSS: Do you think that dealing with the tremors of Parkinson's has made you more of a self-conscious person, and were you self-conscious before that?

Mr. FOX: Well, actually, now it's actually really terrific because, you know, vanity goes out the window. I mean, if you're talking about self-conscious in the sense of how one appears to others and one's awareness of how they appear to others, you know, it's so apart from how I feel and perceive myself that I think about it very little now. I think about dealing with symptoms in public more on the level of how will it help me to function and accomplish the things that I want to accomplish? In other words, if I'm in a situation where I need to communicate, will I be able to communicate? Or if I have to perform some physical task, you know, whether it was with my children or something else, will I be able to do it? In terms of how will I appear, well, that

might have been the major concern earlier on. It's little or no concern now.

I write in the book about being at a public function where I was clearly symptomatic and demonstrably tremoring and twitching, and a lot of people were looking at me and I was aware that they were looking at me. Yet it didn't concern me. And then at some point, the lights went down, and a concert began, and I was happy that once the lights went down, actually my medication kicked in, and I smoothed out and I was really relieved and pleased that I would be relatively symptom-free to enjoy the music. And that really represented a 180-degree turn for me in that I wanted to be symptom-free for me to be able to enjoy what I wanted to enjoy, as opposed to wanting to be symptom-free to create an appearance that I was healthy or at least create an illusion that I was healthy. So it changed a great deal.

GROSS: Michael J. Fox, thank you very much for talking with us.

Mr. FOX: My pleasure. Thank you.

GROSS: Michael J. Fox's new memoir is called "Lucky Man." He chairs the Michael J. Fox Foundation for Parkinson's Disease.

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GROSS: I'm Terry Gross.

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GROSS: On the next FRESH AIR, author Carol Shields discusses her life, her work and her diagnosis of stage IV breast cancer. She won a Pulitzer Prize for her book "The Stone Diaries," which was also a best seller. Her new book, "Unless," was written after she was diagnosed with cancer. I'm Terry Gross. Join us for the next FRESH AIR.

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