

The Great Drug Debate

Parkinson's flap spotlights balance between symptoms and side effects

BY DAN HURLEY

When conservative talk-radio host Rush Limbaugh accused actor Michael J. Fox of either acting or intentionally going off his prescribed medications to exaggerate his Parkinson's symptoms for a political TV commercial, patients and their families reacted with a few choice words.

But Parkinson's specialists take another view of the flap. Think of it, they say, as a "teachable moment"—an opportunity for the public, patients, family members, and even health professionals to deepen their understanding of Parkinson's and how challenging it is to balance the effects of the disease with the side effects of the medications taken to treat it.

"People don't understand what Parkinson's is like, and how quickly patients can go from moving normally to abnormally, sometimes without warning," says Oksana Suchowersky, M.D., director of the Calgary Movement Disorders Program. "I've had many patients accused of malingering, putting it on. Sometimes it's really hard to explain that they're not acting. It's a matter of educating people to better understand this challenging disease."

Even staff members at nursing homes sometimes think, as Limbaugh apparently did, that a Parkinson's patient is acting, says Rajesh Pahwa, M.D., director of the Parkinson's Disease Center of Excellence at the University of Kansas Medical Center. "One minute the patient is walking around, and the next minute the medication wears off and he can't even go to the bathroom," Dr. Pahwa says. "A nurse might feel the patient is making it up. It's a common misperception."

In the TV commercial which first aired during the opening game of the World Series, Fox spoke in support of Claire McCaskill, the Missouri Democratic candidate for the Senate who



Michael J. Fox's dyskinesias made his TV commercial newsworthy for medical as well as political reasons.

opposes President Bush's restrictions on embryonic stem cell research. Once known for his boyish charm in movies and TV sitcoms, the actor swayed and writhed in the 30-second commercial—classic signs of the side effects that all too often bedevil patients taking levodopa, the primary medication used to relieve Parkinson's symptoms.

Two days later, Limbaugh said on his syndicated radio show, "This is really shameless of Michael J. Fox. Either he didn't take his medication or he's acting, one of the two. He is an actor, after all. He is exaggerating the effects of the disease. He's moving all around and shaking, and it's purely an act." Later, upon learning that Fox had been exhibiting the exact same symptoms in other settings, Limbaugh apologized but insisted that Fox was still using his illness to "shill" for McCaskill (who went on to a narrow victory).

In an interview with "CBS Evening

News," Fox set the record straight on what was causing the involuntary jerky movements known as dyskinesias. "The irony is that I was *too* medicated," he told anchor Katie Couric. But, he added, "At this point now, if I didn't take medication, I wouldn't be able to speak. I'd have a mask face and I wouldn't be able to speak and I'd lock up and freeze and not be able to move. So there's no time I'm not medicated. It's just a matter of titrating the medication to make sure it works as best it can."

That's precisely the problem that leaves so many Parkinson's patients feeling stuck between a rock and a hard place. One challenge for patients, families, and caregivers seeking to find the "sweet spot" between dyskinesia and immobility is to learn to distinguish between the symptoms caused by the disease and those caused by the medication.

"Very often patients and families get mixed up about which is which," says

Michael J. Fox's real-life TV drama showed the **balancing act** endured by many Parkinson's patients.

William J. Weiner, M.D., director of the Parkinson's Disease and Movement Disorders Center at the University of Maryland School of Medicine. "The distinguishing factor is that the tremor caused by Parkinson's is a rhythmic,

back-and-forth movement, and the dyskinesia caused by levodopa is more of a writhing, twisting movement."

While dyskinesia is rarely a problem in the earliest stages of the illness, Dr. Weiner says, at least half of Parkinson's patients experience it within five or six years after the initial diagnosis. And the percentage keeps climbing to include nearly all patients as the years go by. At that point, adds Dr. Weiner, "it's very often trial and error, trying to figure out how one should use the medicines to make symptoms better this way or better that way. Even very slight changes, half a pill, can sometimes throw a patient one way or another."

To complicate matters, the drug can wear off too soon. "We call it the wearing-off phenomenon," says Stanley Fahn, M.D., director of the Center for Parkinson's Disease and Other Movement Disorders at Columbia University Medical Center in New York City. "Some people will walk into a restaurant and they're fine; you can't even tell they have Parkinson's. By the end of the meal, the medicine stops working and they can't even get out of the chair to walk out of the restaurant. These are real problems and people hate it."

That's why it is particularly important to work closely with a neurologist who specializes in Parkinson's.

"For some patients, it's almost impossible to find that line between enough medication and a little too much," says Roger L. Albin, M.D., co-director of

the Movement Disorders Clinic at the University of Michigan Health System. "There are a lot of medications and alternatives, and that's where being under the care of a competent physician makes a big difference. We spend

a lot of time on medication adjustment. It takes a lot of commitment on the part of patients to try different things and to work with their physicians to get the best they can out of what's available. But the effort is worth it."

Even early in the disease's progression, before dyskinesia becomes a problem, it's important to diligently take medications as prescribed. "If you pro-

vide the medications consistently early on," Dr. Pahwa says, "then down the road dyskinesia may not be as severe or may take longer to start."

Until science comes up with a better treatment for the disease, patients will have to keep balancing the symptoms against the side effects. "On any given day," Fox told CBS News, "I have a thousand different things I can feel. I go through a million cycles." NN

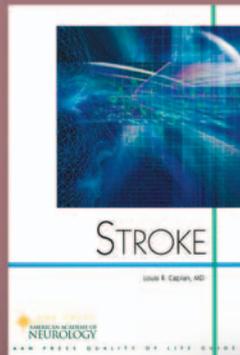
Dan Hurley is an author whose medical articles have appeared in Men's Health, Psychology Today, and The New York Times.

 For more information about Parkinson's disease, see **RESOURCE CENTRAL** on page 46.

A PROACTIVE APPROACH to Managing Stroke

Stroke

By Louis R. Caplan, MD



"Dr. Caplan's clinical insights and closeness to the human condition make the book useful and interesting. His direct writing style makes it easy to read and the reader can easily comprehend what otherwise seems so mysterious."

—Walter J. Koroshetz, MD,
Department of Neurology, Harvard Medical School

#201703 / \$19.95 List Price

 AAN PRESS
AMERICAN ACADEMY OF
NEUROLOGY

ORDER ONLINE: www.aan.com/store
ORDER BY PHONE: (800) 879-1960
INTERNATIONAL: (651) 695-2717

Shipping charges and sales tax may apply.