



**MS Learn Online
Feature Presentation
Progressive MS: Diagnosis
Paul O'Connor, MD**

Tracey>> Hi I'm Tracey Kimball

Tom>> And I'm Tom Kimball, welcome to MS Learn Online. One of the most fascinating aspects of MS is that it presents itself in so many different ways. The majority of people with MS have relapsing remitting MS.

Tracey>> But many have what is known as a progressive MS, and that's the subject of this two part series featuring Dr. Paul O'Connor, from the University of Toronto.

Tom>> In this first program, Dr. O'Connor talks to medical correspondent Rick Somers about the role MRI's play in the diagnosis and management of progressive MS.

Tracey >> He begins by giving us an overview of the different courses that MS can take.

Tom>> Lets watch.

>>**Paul O'Connor:** So, there are four different types of MS, based on how your clinical symptoms and signs evolve over time. Eighty-five percent of all new MS patients are diagnosed with what's called relapsing-remitting MS. And so the attacks themselves are the relapses; the improvements are remissions. Hence, the name relapsing-remitting MS. So, that's the first type and that's the first of four.

Now, after many years -- and it varies between patients -- 10 to 20 years, relapsing-remitting MS patients may transition into what's called secondary progressive MS. So, that's the second type I wanted to mention. In that phase of the disease, attacks are less common and there's a slow increase in neurologic disability.

In terms of secondary-progressive MS, there is a similar process of looking retrospectively to clarify the onset of this phase of the illness. And by that I mean patients with relapsing-remitting MS have their attacks followed by improvement, partial or complete, and they're rolling along through time. And eventually they begin to notice that not only are they recovering incompletely from attacks, but even when they're not having attacks there seems to be a slow worsening of certain functions. The main functions are walking, in terms of leg strength and coordination of walking, and arm function, in terms of coordination. So, handwriting and doing buttons. Fine motor activities in general.

It's at that point the discussion with a neurologist may occur as to what's happening to me? Why do I seem to be getting worse, even in the absence of relapses. And it's at that point a determination of the presence of secondary progressive MS can be made. But, again, very often one can look back several months or even longer to when this tendency had actually started.

Now, some MS patients worsen slowly right from the beginning of their disease. These patients are usually a little older, middle aged, generally, 40, 50, and when the disability worsens slowly right from the beginning, we call it primary-progressive MS. So, that's the third type.

Primary-progressive MS is notable for the fact that it's got kind of this insidious onset; it sort of creeps up on you. One day you may notice that you're not running as well as you used to, or at the end of a long walk one of your legs is starting to drag. You don't think anything of it, but six months later, a year later, you notice, boy, that leg is dragging a lot these days, and not only when I go on long walks. And you take yourself off to your physician and quite often at the beginning the diagnosis is missed. But at some point somewhere along the line, someone will think, well, maybe this is a neurological problem and refer you to a neurologist.

And at that point, if a diagnostic workup is performed with a proper history and neurological exam, followed by testing, such as an MRI of the brain and perhaps a spinal fluid exam, a diagnosis of primary-progressive MS can be made. But the really interesting aspect of this type of MS is that typically patients will say that in retrospect, they've had symptoms for a year or two, or even longer.

And a rare subtype of MS is what we call progressive-relapsing MS, and in that type of MS you have worsening right from the beginning with superimposed attacks every now and then.

But, again, the most common type of MS for the start of the disease is relapsing remitting disease affecting 85%, and 15% are primary progressive or progressive relapsing.

>>**Rick Somers:** Boy, you know what? You describing the course is exactly what I have and am going through, like a textbook, you know, on that textbook case.

>>**Paul O'Connor:** Of relapsing-remitting that's transitioned to secondary- progressive?

>>**Rick Somers:** Yes, absolutely. And it's frustrating, because at times I'm in with my doctors and we'll do these tests and, "Oh, you seem great." What I want is my doctor to sit on my shoulder for a day and come with me, and walk up the stairs at the subway and see me trying to get across the street, and living life out there and seeing what it's really --

>>**Paul O'Connor:** No, it's difficult. And I think in an office visit you can get only a rough and undersized idea of how disabling MS is for the patient.

>>**Rick Somers:** Absolutely.

>>**Paul O'Connor:** It tends to understate how bad things are.

>>**Rick Somers:** Using an MRI as your primary diagnostic, I'm assuming, what can you tell from looking at an initial MRI, as far as where a person may be on this chart?

>>**Paul O'Connor:** Well, you can't really tell. So, I think that's an important point. When you look at an MRI, you cannot tell whether that patient has relapsing-remitting MS, secondary-progressive disease, primary-progressive disease, because these disease subtypes that I've discussed are based on the evolution of their clinical symptoms and signs. They're not based on how the MRI looks.

>>**Rick Somers:** If a person continues, how often should they be getting MRI's?

>>**Paul O'Connor:** So, the frequency with which you should have repeat MRI scans is very controversial and variable. For example, if you're stable, it's arguable that you do not need to have repeat MRI

scans done. On the other hand, if your neurologist suggests that there is some diagnosis other than MS that's emerging, you need to have an MRI done promptly.

If you are on a disease-modifying therapy and it looks like that therapy is not working for you clinically, then that's an indication to do a repeat MRI, to see what's going on. But there is no single or simple rule about how frequently MRIs should be repeated.

MRI is an excellent diagnostic tool in MS, but it might interest you to know it's not a validated tool for following patients.

>>**Rick Somers:** And that's because?

>>**Paul O'Connor:** Because the studies to show validation have not been performed or, alternatively, it's not that useful in the long-term management of an MS patient as compared to their clinical symptom and sign evolution.

>>**Rick Somers:** So, you mean to tell me that looking at MRIs, you could look at two patients' MRIs side-by-side, one chock full of lesions, one with not so many lesions, implying that the one chock full might be a progressive and the one not so busy might be a relapsing-remitting, but that's not necessarily the case.

>>**Paul O'Connor:** Correct. That's not the case. In fact, an aphorism that we use at our MS clinic is that when you look at a patient's MRI, you have absolutely no idea how they are going to look clinically to you. And there is actually statistically a poor correlation between findings on clinical examination and findings on the MRI.

Now, the MRI is an excellent diagnostic tool, no question about that. It's also very useful for giving us a window on the biology of the disease. But it is not the gold standard of how a patient is doing.

The gold standard of how a patient is doing is how they are doing clinically, symptoms and signs.

So, I just want to say one last thing about MRI is, I do feel that it gives us some idea about patient prognosis. And so it is useful in determining therapeutic choices at times, or in helping us to make the decision about whether or not a patient ought to go on therapy.

The point I wanted to stress with you, though, is that there is no single formula that dictates how frequently MRIs should be repeated. You may know that in various parts of the world, parts of the developed world, MRIs are not done on a repeat basis; they're done to make a diagnosis and then the patient is followed clinically. And in other parts of the world, principally parts of the world where MRI scanners are more available, they're used more frequently.

>>**Rick Somers:** Do you see any common characteristics of people who are diagnosed as being progressive MS patients?

>>**Paul O'Connor:** Well, those patients usually are a little older, so instead of being in their twenties and thirties are usually in their forties and fifties. They usually are having progressive stiffness and weakness of their legs. They usually have some incoordination of their arms. And they often have an attack of optic neuritis somewhere in the past.

But in a word, progressive patients tend to be middle-aged; relapsing-remitting tend to be young. And the cutoff between youth and middle age, as we all know, is about 40.

>>**Rick Somers:** That's a subject for a whole 'nother debate, and we could probably spend another 10 minutes, if not a lot more on that.

I want to thank you for your time, Dr. Paul O'Connor. We really appreciate you sharing your expertise and your insights with us. Thanks.

>>Paul O'Connor: My great pleasure.

Tracey>> I could really relate to Rick's comment about wishing his doctor could just sit on his shoulder for a day to better understand his symptoms. I feel the same way sometimes.

Tom>> Well maybe the next best thing would be for me to help track some of your symptoms. That way, at your next appointment, we could better explain to your doctor your most troubling issues.

Tracey >> That's a great idea. The more accurately I can tell my doctor what's happening, the better chance I have of managing my MS.

Tom>> Yes and in the next episode Rick and Dr O'Connor will talk about treatment options ... what's currently available and what may be down the road for dealing with the different progressive courses. As always, thanks for joining us.