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EDUCATIONAL SUPPLEMENT #16

When Should Parkinson’s Disease Patients Go To The Emergency Room?

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I am occasionally called by an emergency room (ER) physician to be informed that Mr. Smith is being evaluated for “freezing” or increased tremors or some other aspect of his Parkinson’s disease (PD), and asked what would I advise. Usually I advise the ER doctors to tell the patient to call me the next day and get him out of the ER before anything bad happens.

A number of times I’ve heard the same story ,”I went to the ER last week because PD got so bad I couldn’t stand it anymore! And what did they do in the emergency room? They kept me waiting six hours, did a chest x-ray, brain CT scan, cardiogram and a bunch of urine and blood tests and sent me home. And you know they didn't know anything about Parkinson's disease! They never heard of dyskinesias, of "off" periods or even some of my drugs."

It's not the ER's fault. Let's look at the role of the patient, family and perhaps us PD doctors in the situation.

A trip to the ER may be useful for evaluating anything except PD. Never go to the ER because your PD is worse! You should go if you think you have an infection making the PD worse, or if you fell and are worried about a broken bone or a blood clot in the brain, but if you have bad PD problems that you've been working on with your neurologist and some time when the doctor is unavailable and PD takes a sudden turn for the worse, I will guarantee that you will be lucky if you leave the ER with only a few hours and a few tablespoons of blood lost.

ER doctors do not know much about PD. The better ones will tell you this and advise you to call your PD doctor the next day. Sometimes patients are admitted to their local hospital where their PD specialists may not be able to see them. Then someone who meets them once for 20-30 minutes alters everything that it took you three years to get into place.

Now I don't mean to imply that one should never go to the ER, but I do mean that you should never go because your PD is worse without talking to your PD doctor first. Let me provide some scenarios because it is sometimes not so straightforward.

Basically , PD patients are relatively stable over weeks at a time. By this I mean "good" patients who reliably respond to the medications stay that way, perhaps developing mildly increased scuffing or tremor or dyskinesias. Patients with moderate to severe fluctuating remain fluctuating no matter how we adjust medications. If we're lucky an adjustment will add one good hour and if we're unlucky we may lose an hour. Some days are good, some days are bad. The parameters of these changes are generally well known but change slowly over time. A person with only two good "on" hours per day may panic if there's a day without any "good" time and will experience it as a terrible, excruciatingly bad day. But in the context of the illness it really was only a little worse, 14 hours "off" increased to 16 hours "off." Of course the patient and family report that "two hours "on" went to zero," hence a complete loss of function. While this is certainly cause for grief and concern, it's not cause for alarm and all the brain CT scans and blood tests are not going to teach the ER doctors any new tricks your PD doctor doesn't already know and probably has already tried.

There is no doubt that living with PD is frustrating for the patient, the caregivers and anyone else involved. No matter how many times a patient has been through an "off" to an "on" period, there is rarely a complete sense of confidence that the bad time will end. There's always a little fear that this "off" will never end and this fear, of course, makes the "off" more severe and last longer. And for many patients the "on's" and "off's" are very unpredictable, making the frustration even worse. For the patient who has only small amounts of "on" time, each "on" moment is golden, so that a loss of one hour of independent mobility is a true calamity. Sometimes the frustration just boils up over the top and neither the patient nor the caregiver can take it anymore. Frequently the caregiver panics because the patient, "their responsibility" has gone downhill and there must be something the caregiver can do to fix it. Sometimes it's the patient, overcome by fear that the "on" will never happen, seeks immediate relief, as if the ER can supply a balm, like they do so easily for treating pain. Unfortunately there's no narcotic equivalent for PD.There's no magic or the patient would be on it.

When a patient whose PD has been stable suddenly deteriorates, then reasons other than the PD itself must be suspected. Mild pneumonia, stress, severe constipation, bladder infection, and sometimes other, more serious, non-neurologic problems may exacerbate the PD problems. The same is true for problems of memory, thinking and sleepiness. Sudden, persistent declines in concentration and memory usually indicate either an "occult" (hidden) medical problem such as an infection or thyroid dysfunction, or a medication related problem.

Too often the ER doctors diagnose "stroke" even when there's nothing to suggest this condition. They hear the words, "suddenly got worse" and the only thing ER doctors know that causes sudden neurologic worsening is stroke, so the patients get a CT scan and an unnecessary stay in the hospital. And the hospital is the last place you want to be if you have problems with Parkinson's disease.(See Educational Supplement No.5 on the hspitalization of the PD patient.)They disrupt your medication schedule, interrupt your sleep, and interfere with your exercise routines. Remember how many medication adjustments you've been through. Add one drug, subtract another, play with the schedule by a half hour, front or back load a dose of L-dopa, try physical therapy. It's unreasonable to expect an ER doctor even at the best medical centers in the country to know you or your PD better than your own doctor. No ER has a neurologist working in it. Certainly none has PD experts unless the ER doctor happens to have a family member with advanced PD. It doesn't make sense to expect a doctor who specializes in the common ER problems to know anything about PD. The ER is not a good place to get a second opinion on PD management.

Problems with PD? Call your doctor. Problems with thinking, memory, concentration, hallucinations or strange behavior? Call your PD doctor. Needless wastes of time, body fluids and money along with potential harm can be avoided with a call to the doctor who knows your PD best. Keep in mind that your doctor or a covering physician is always available but not instantly so. If you are experiencing a possible emergency then it is reasonable to expect a quick response if you let the secretary know it's urgent. However, going to an ER because the doctor didn't call back in an hour is not wise.

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