Is there more I can do to manage my myasthenia gravis? A NetWellness column

By Plain Dealer guest columnist
January 06, 2010, 8:15AM

Question: I was recently diagnosed with myasthenia gravis. I have been experiencing muscle weakness and have had double vision and drooping eyelids. I have been working with a neurologist, but I want to make sure I am doing everything I can for my disease. What kinds of questions should I be asking my doctor? What can I do on my own to help myself?

Answer: First of all, I want to commend you for being such a motivated and involved patient. Getting the best healthcare is a team -- you and your doctor -- effort. Here are a few things you should discuss with your neurologist:

Safety first

It's important to have a good understanding of what are serious symptoms in myasthenia gravis and how you should deal with them. For example, difficulty breathing may represent a life-threatening change in the disease.

Ask your doctor about concerning symptoms and what you should do if you have such symptoms. This means that you should have a rapid way of contacting your neurologist 24/7/365 and also have her/him give you instructions as to when to call "911".

Treatment risk/benefits and severity of disease

This week's NetWellness column is authored by Dr. John G. Quinlan, a professor in the Department of Neurology at the...
Understanding the benefits and risks of a treatment plan is the foundation of a collaborative doctor-patient relationship.

Often, myasthenia gravis interferes with your ability to work and manage other family obligations. By explaining how the disease prevents you from doing important things in your life and what risks you are willing to take to correct those disabilities, you and your doctor can develop a treatment plan personalized to your lifestyle, goals and disease severity.

Exercise

Ask your neurologist how much exercise you should be doing. The amount varies depending on how well your myasthenia gravis is controlled and what treatments are being used.

Diet

Some treatments that we use in myasthenia gravis, such as prednisone, have a strong tendency to cause weight gain and diabetes. Ask your doctor about the best diet. You may wish to make an appointment with a dietitian.

Keep being an involved patient and don't forget to be good to yourself. Get plenty of rest, eat a balanced diet, maintain a positive attitude and remember -- you are the most important member of the team.