

Living with Lambert-Eaton Myasthenic Syndrome

You have been diagnosed with Lambert-Eaton Myasthenic Syndrome or LEMS. This leaflet will give you and your family some more information about LEMS, what you can expect and the medicines used to treat it.

What is LEMS and how did I get it?

LEMS is an autoimmune disorder; this means that the antibodies that normally help you to fight infections have started to attack different parts of your body. In LEMS, these antibodies attack the ends of the nerves at your muscles and stop them from releasing acetylcholine, a messenger that tells your muscles what to do.

There are two different types of LEMS:

- About half of people have a cancer, the majority of whom have “small cell” lung cancer (which mainly happens in people who smoke). In this type of LEMS the antibodies start by attacking the cancer and then get “confused” and attack the nerves as well. This type usually starts when you are over 50 years old
- In other people, there is no tumour and this type of LEMS usually starts after the age of 40 but it can start in children under 10. Doctors are not sure why the antibodies start to attack the nerves in this type of LEMS

What are the symptoms of LEMS?

The main symptom of LEMS is weakness in your muscles, the legs feel heavy (almost like walking through water) and it can affect your arms. Very often, there are also problems with “automatic” bodily functions; this can cause dry mouth or constipation.

Sometimes (but not as often) it can also affect the muscles that help you talk, chew and swallow.

How did the doctor diagnose LEMS?

The doctor checked if you have LEMS by looking for specific neuromuscular changes in a test called electromyography (EMG). This is when the nerves are stimulated electrically and the nerve impulses are measured in the muscles. A blood test for the antibodies may also have been used to check for LEMS.

As LEMS can be caused by a cancer, the doctor will check for lung cancer, especially in people who have smoked. When they check for cancer, the LEMS can often be a valuable early warning of the cancer.

How do you treat LEMS?

Treatments for LEMS work in one of three ways:

- A.** They reduce the number of antibodies - if there are fewer antibodies to attack your nerves, your muscles will work better
- *Intravenous immunoglobulin* - mops up a lot of the antibodies
 - *Plasmapheresis* - a process where the blood is filtered to remove the antibodies
 - *Corticosteroids, cyclosporine or azathioprine* - used to suppress the immune system
 - *Monoclonal antibodies* - eliminate some of the cells which produce antibodies
- B.** They increase the number of nerve impulses received by the muscle
- *Cholinesterase inhibitors* - make the nerve impulse break down more slowly so more of the signal generated reaches the muscle
- C.** They increase the number of nerve impulses sent by making sure that more acetylcholine is released
- *Aminopyridines* - cause more acetylcholine to be released and so increase the number of nerve impulses



Try not to let it take over your life

Your LEMS may be with you for many years, but treatments are improving all the time and the current treatments can help to bring LEMS under good enough control so that you can have a reasonably normal life.



Your doctor will decide, along with you, what is the most appropriate treatment for you.

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