

*FREQUENTLY ASKED QUESTIONS ABOUT...***Preparing for a Visit with the Neurologist**

Receiving a diagnosis of ataxia can make you feel as if you are losing control of your life. One way to feel more in control is to take an active role in your health care. Becoming informed is an important way to achieve that goal. Choosing a physician to supervise your overall health care is essential. It is worth the time and effort it takes for you and your doctor to build a relationship of openness, caring and mutual respect. Such a relationship can be a powerful factor in your own physical and emotional well-being.

This fact sheet is to assist you in having productive appointments with your physician so that you can feel and function better with ataxia.

Your role during your medical appointment is to provide information about your health, health history, medications, and symptoms honestly and concisely. The following recommendations were made by neurologists who see patients with ataxia. Using these suggestions can make your appointment with the neurologist a more beneficial experience.

PRIOR TO THE APPOINTMENT:

- Bring the name and address of the doctor who you want to receive a copy of the medical report following your visit (such as a primary care physician).
- Bring a record of all your test results. Include the actual images of any MRIs and/or CTs of the brain and spine, preferably on a CD if possible. It is particularly important to bring the reports from any genetic testing you may have had. This prevents the necessity and expense of having tests repeated and allows your doctor to confirm any findings from your previous evaluations. If possible, provide all written records to your doctor's office a few weeks in advance of your appointment (e.g., by fax or by mail) but remember to still bring copies with you in case the ones you sent are not available at the time of your visit.
- Bring a complete list of all the medications with the dosages as well as any vitamins or supplements that you are currently taking. In addition bring a list of medications, vitamins or supplements that you have tried and are no longer taking. People are understandably reluctant to talk about this, but if you

are using illicit drugs, it is important to tell your doctor.

- Bring an accurate and complete family medical history with specific walking or other coordination problems that family members may have had or currently have. Prior to the appointment, ask family members about medical conditions that exist in your biological family. Include grandparents, parents, aunts, uncles, siblings, cousins. Ataxia is often a hereditary disease and this information is helpful for the physician. If there are other diseases or conditions that run in the family (neurological or otherwise) include those too as it may be useful.

If the neurologist who you will be seeing is not familiar with ataxia, **Evaluation and Management of Ataxic Disorders: An Overview for Physicians** by Susan L. Perlman, MD from the National Ataxia Foundation. "This book is intended to inform and guide family practice and other physicians who may be caring for patients with ataxic symptoms or who have been diagnosed with ataxia." Available at www.ataxia.org.

DURING THE APPOINTMENT:

- Be prepared to answer the following questions: How and when did the ataxia symptoms come on? How have the symptoms changed? What activities are you finding difficult to do? What makes the symptoms better? What makes the symptoms worse? Be as specific as possible. It may help to make a list you and your doctor can refer to.
- Select the top three symptoms or problems that are the most severe that you want discussed during the appointment. Your neurologist may ask specific questions about those symptoms. Stay focused, listening closely and carefully so that you can answer his/her questions accurately.
- Describe other medical conditions that you may have, and any allergies or adverse reactions that you have had to medications.

Be sure you understand what the doctor has discussed with you. Ask for clarification; do not leave the doctor's office confused. If necessary, bring a relative or friend who can write the information down.

FOLLOWING THE APPOINTMENT:

- Make appointments immediately for any follow-up tests, therapy or other orders. In some cases, doctor’s orders can expire within a certain time frame, so it is important to make these follow-up appointments immediately.
- Confirm that your primary care physician received the report of your neurologist visit.
- Fill medication prescriptions immediately and begin taking them as prescribed, reporting any troublesome side effects immediately.
- Call the doctor’s office if you have forgotten or are confused about anything that was discussed or prescribed. Do not wait until the next visit.
- Learn as much as you can about your disease. Find and use only reputable and accurate sources for information. The following websites have reliable information on ataxia:

 The National Ataxia Foundation: www.ataxia.org
 National Organization for Rare Diseases:
www.rarediseases.org
 The Movement Disorder Society:
www.movementdisorders.org
 National Institute of Neurological Disorders and Stroke: www.ninds.nih.gov
 National Center for Biotechnology Information:
www.ncbi.nlm.nih.gov
- Consider joining an ataxia support group which can offer companionship and information for people coping with either the hereditary or sporadic types of ataxia and the challenges that accompany those disorders. The National Ataxia Foundation has a listing of known ataxia support groups at www.ataxia.org

RECOMMENDED READING:

AfterShock: What to Do When the Doctor Gives You – or Someone You Love – a Devastating Diagnosis by Jessie Gruman, PhD. When faced with a devastating diagnosis people must quickly understand the prognosis and often must choose from several treatment options – all while still in shock. Social psychologist Jessie Gruman offers a practical, ten-stage approach to making clearheaded, informed decisions. Jessie Gruman’s website:
<http://www.aftershockbook.com/>

Living With Ataxia: An Information and Resource Guide by Martha A. Nance, MD, for the National Ataxia Foundation. The message of this book is that living a good life is an entirely reasonable aspiration even with ataxia. The book is packed with practical information for everyday living, and it points the way to many useful resources. Available at www.ataxia.org

DEFINITIONS:

MRI - Magnetic resonance imaging is a noninvasive medical test that helps physicians diagnose and treat medical conditions. MRI uses a powerful magnetic field, radio frequency pulses and a computer to produce detailed pictures of organs, soft tissues, bone and virtually all other internal body structures. MRI does not use ionizing radiation (x-rays).

CT scan - Computerized tomography or just CT is an X-ray technique that produces images of your body that visualize internal structures in cross section rather than the overlapping images typically produced by conventional X-ray exams.

Genetic testing is a special type of blood test which examines your genetic material, or DNA, for heritable changes that can cause disease. Abnormal results can identify a specific form of ataxia with you and your family. It is recommended you receive special counseling from your doctor or a professional trained in such testing so that you understand what is being tested and what the results mean. Examples of genetic testing include tests for the common spinocerebellar ataxias (e.g., SCA1, SCA2, SCA3, etc.) and Friedreich ataxia.

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