Working with YOUR DOCTOR

CARLOS (CENTER), DIAGNOSED IN 2001

National
Multiple Sclerosis
Society

The relationship you have with the doctor who helps you manage your MS is very different from the traditional doctor-patient relationship with which we are generally familiar. For most common illnesses, one or two visits to the doctor are sufficient to identify the problem, receive a prescription for medication, and get well.

Because MS is a chronic disease that requires continuing treatment and monitoring, you and your doctor are likely to have an ongoing relationship — working together in an effort to manage symptoms, slow disease progression, prevent complications, and maximize your quality of life. In addition, the physician will likely be your link to other healthcare professionals that may be involved in your care. Therefore, it is important to develop an effective working relationship with your MS doctor. This chapter covers ways to build or improve this relationship and make visits to the doctor as comfortable and productive as possible.

How people feel about going to the doctor

Let's start by talking about some of the feelings people have when they seek treatment for their MS. Initially, many people feel quite hesitant to go to the doctor for their MS symptoms. On the one hand, they want an explanation for the problems they are having; on the other, they are afraid that they won't like what they are going to hear. Looking for answers when there is no cure can make people feel anxious, angry and confused.

In addition, many people feel anxious or uncomfortable in the doctor's office simply because they are afraid they won't remember to mention all of their various questions and concerns, or that there won't be time for them. They may also be unsure which of their problems are related to MS and which are not.

People who are working mostly with their general practitioner or other non-MS specialist may be concerned that the doctor is unfamiliar with specific MS problems or their treatments. The combination of all these feelings can make it very difficult to hear and remember everything that the doctor says.

Developing a good working relationship

It is best to start by finding a doctor who has experience working with people who have MS. If your insurance plan allows you to choose your own physician, you can contact the National MS Society at 1-800-344-4867 for names of MS specialists in your area. If you are required to choose a primary care physician (PCP) within your health plan, check with your health insurance or with your neurologist. Find out from your health plan what the requirements and procedures are for seeing specialists if your PCP is not particularly familiar with MS.

Making the most of your visits to the doctor

Be prepared

If you are going to an MS doctor for the first time — particularly if you have been referred by another physician or you are seeking a second opinion — you may be asked to send your medical records ahead of time or bring them with you to the first visit. In either case, ensuring that the doctor has these records is an important first step to a productive and informative first visit. When requesting your medical records from other doctors, ask for office progress notes or hospital discharge notes, as well as all blood test results, spinal tap results, evoked potential tests and MRI results. If you have already had an MRI of the brain and/or spinal cord, bring or send a disc or film of the MRI images. It is also a good idea to call the office well ahead of the visit to confirm that they have received the requested records.

If the doctor sends a medical history form for you to complete, do your best to complete it ahead of the visit. If a form is not sent to you ahead of time, you may be asked to provide the information when you arrive to the office. Have the following information available: 1) List of your medications (including dose and how often it is taken), including any over-the-counter medicines, vitamins, food supplements or alternative therapies you are taking; 2) List of any drug, food or environmental allergies; 3) Past medical history, including surgeries; 4) Family medical history (mother father, siblings and grandparents); 5) Names and phone numbers of other physicians involved in your care.

> “What kind of information can I take to my doctor to make the best use of our time together?”

During this initial visit, the doctor will ask you the reason for your visit and the history of the problem leading up to the present time, so it is a good idea to make a list of the various symptoms you have had and the approximate dates when they started.

Rona (left), diagnosed in 1986

Because follow-up visits are generally much shorter, you can make best use of the limited time with the doctor by coming prepared with a list of your most pressing issues, including any new or worsening symptoms you have experienced, reactions to medicines or difficulties taking medicines, and any family or work issues that are on your mind. Keep an up-to-date list of allergies, medications and supplements.

You might even want to start a simple health diary for yourself — a notebook in which you keep brief notes about fluctuations in symptoms, your response to medications or their side effects, and factors such as heat, time of day or stress that seem to influence the way you feel. This is useful information for your doctor and will help you identify ways to manage your MS more comfortably. Your doctor may not have time to read the daily entries in your health diary, but the information you record will help you be organized and prepared for your visit.

Don't worry if you don't know whether a particular problem is MS-related or not; it is the doctor's job to sort out the problems and either recommend treatments or refer you to a specialist for additional care. As you become more familiar with your MS, you can determine more easily whether a problem is MS-related.

If you have specific questions you want to ask the doctor, be sure to write them down. People have a tendency to forget one or more questions and then remember them as soon as they get home. If you aren't sure how to prioritize your questions, ask, the Society's **Questions to Ask Your Healthcare Team Worksheet** may be a helpful place to start. Find the worksheet at **nationalMSsociety.org/KIP** or in this KIP book if you received it by mail.

Some people "don't want to complain" and are therefore reluctant to mention the various symptoms they have been experiencing. However, a successful doctor-patient relationship depends on good communication. The doctor needs to know what kinds of problems you have been having — even if you are not experiencing a particular symptom on the day of your visit — in order to be able to suggest possible ways to treat or manage those problems. Talking about symptoms isn't "complaining;" it's providing the doctor with vital information.

It is equally important to let your doctor know if you are having difficulty following the recommended treatment plan. If you haven't been able to take your medications regularly or follow other recommended management strategies, sharing that information openly will help the doctor revise the treatment plan to better meet your needs.

Bring someone with you

If you find that you have difficulty concentrating or remembering everything that the doctor says to you, you might want to bring a family member or friend who can be an "extra set of ears" or take notes. The person could come in for the entire visit or wait outside if there is something you wish to discuss privately with the doctor.

Take responsibility for knowing about your disease

In order for you to be an active and effective partner in your healthcare, you need to become educated about MS. Knowledge about the disease is even more essential if you are working with a physician who is not an MS specialist. There are a number of easy-to-read, up-to-date books written for individuals with MS and their family members. If you read or hear about a particular MS treatment that your doctor has not mentioned to you, you can bring in a relevant book or news article and ask the doctor if that treatment would be appropriate for you. If, at any time, you feel that the physician is unable to answer your MS-related questions, you should feel free to ask for a referral to a neurologist or other MS specialist.

Schedule regular appointments

See your MS physician regularly even if you are not having an exacerbation or experiencing new symptoms. Periodic neurologic examinations provide the doctor with the information that he or she needs to monitor your condition, recommend new treatments and prevent unnecessary complications. These visits also provide an opportunity for you to ask questions and for the doctor to evaluate your overall well-being. MS specialists are aware of the potential impact of MS on various aspects of everyday living, including family life and employment, and can alert you to helpful resources if the need arises. If the doctor you are seeing for your MS sees no value in periodic visits, or says that “there is nothing to do for MS except learn to live with it,” it is time to look for another physician.

Don’t be bashful

MS can cause a wide variety of symptoms, including some that are less visible and perhaps more difficult to discuss than others. People with MS are sometimes reluctant to talk about bladder or bowel difficulties, changes in sexual function, or problems with thinking and memory. Unfortunately, there are still many doctors who do not routinely ask their patients about these issues, thus leading the patients to believe that they shouldn’t bring them up either. Bowel and bladder, sexual, and cognitive changes are relatively common in MS and can occur at any point over the course of the illness. Fortunately, there are a variety of interventions to deal with them, and prompt attention to symptoms in these areas can help to make them more manageable and less upsetting. All of these topics are discussed in the chapter on **Treating Yourself Well**.

If you are experiencing any of these problems, the information provided in this book will help you to discuss them with your doctor. If you find that your doctor is not comfortable discussing any of these issues with you, or indicates that there is nothing to do about them, you should feel free to look for another physician with whom to discuss them. The National MS Society can refer you to MS specialists in your area.

Dealing with emergencies

Fortunately, there are very few instances in which a new MS symptom is a true emergency. Initially, however, every new symptom will feel like an emergency to you.

The doctor knows that you are anxious about your disease and will try to help you gradually become more comfortable with the symptoms you are having.

> "Every new symptom is frightening to me, but I hesitate to call my doctor. How can I tell when something is an emergency?"

Communicate with your doctor about any new symptoms, but try to exercise some judgment about when to make the call. There is seldom a new symptom related to MS that requires middle-of-the-night attention. Feel free to ask your doctor when and how it is best to communicate your questions or concerns — and what time of day your phone calls are likely to be answered.

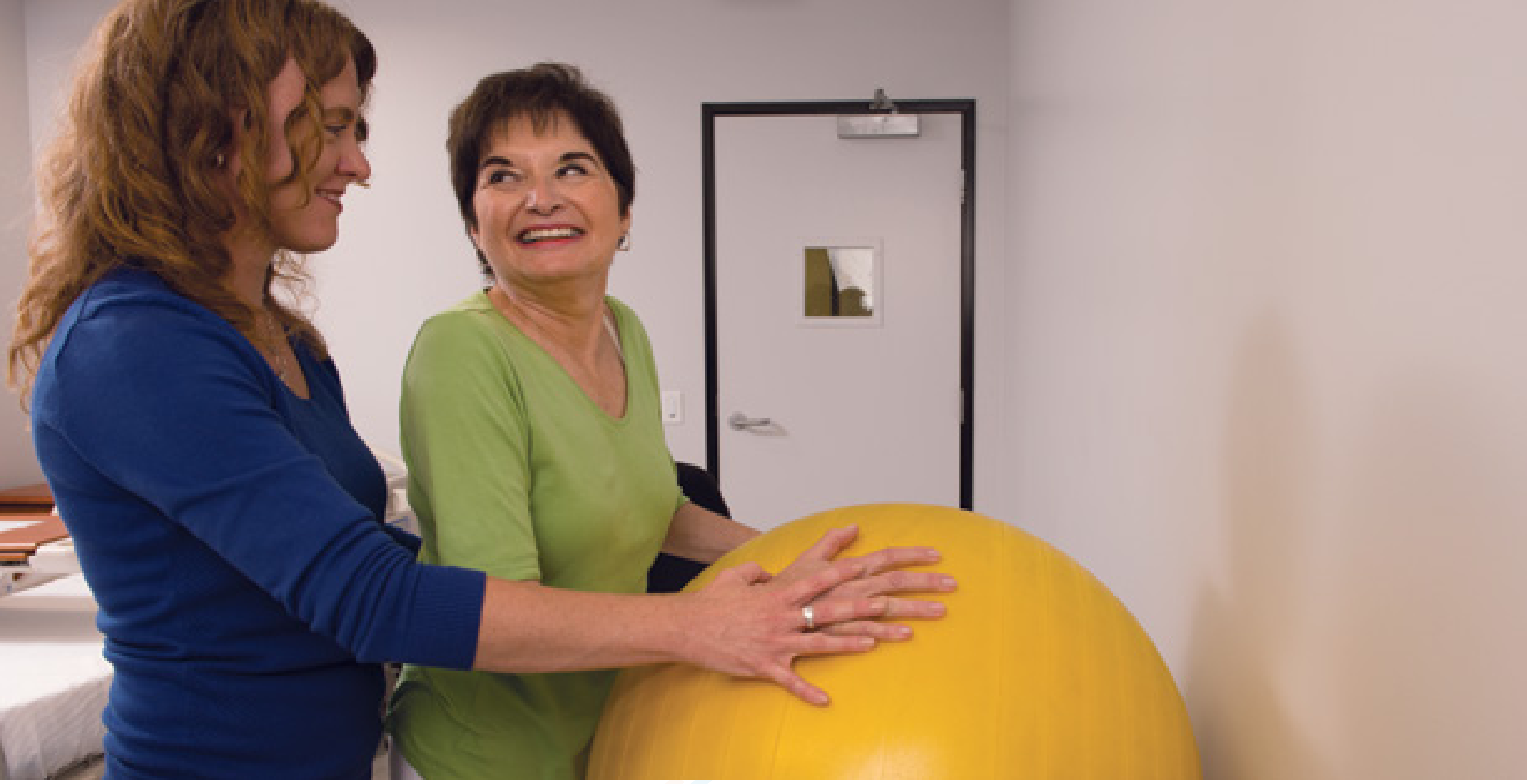
Drug reactions can be quite frightening. Being knowledgeable about the medications you are taking will help you recognize if you are having a reaction to one of them. Pharmacists will discuss side effects and risks of any medication and have written information that describes the purpose of the drug, dosing, side effects and risks.

Drug reference books that are relatively inexpensive and easy to understand are available at all local bookstores. If you are experiencing what you feel to be a life-threatening emergency, your best strategy is to call 911. Your doctor can be informed of the emergency once you are safe and stable in the emergency department or hospital.

Many managed care programs offer 24-hour telephone hotlines with nurses available to answer questions. This is a good route to take if you need to find out whether a symptom or problem you are having is a true emergency; the nurse can provide reassurance and tell you whether or not you require immediate medical attention.

Who are the health professionals involved in MS care?

At various points along the way, your physician may refer you to other specialists for a consultation or treatment. If you receive your MS care at an MS treatment center, you may see these specialists in the same location; otherwise, your doctor will provide a referral to someone in the community. The National MS Society may be able



Rona (right), diagnosed in 1986

to give you the names of practitioners in each of these disciplines that have particular expertise in MS.

- **Neurologist** — A physician who specializes in the diagnosis and treatment of conditions related to the nervous system.

Some people receive their primary MS care from their family doctor and are referred to a neurologist only for confirmation of the diagnosis and specific treatment issues; others receive their ongoing MS care from the neurologist. While all neurologists are trained in the diagnosis and management of diseases affecting the nervous system, there are some who specialize in the care of people with MS. If at all possible, it is recommended that you consult, at least occasionally, with an MS-specialist neurologist to ensure that you are getting the most up-to-date information about MS treatments.

- **Neuropsychologist** — A psychologist with specialized training in the evaluation and treatment of cognitive functions.
- **Nurse** — The nurse often acts in a management and patient education role, teaching self-care skills and providing ongoing support for the treatment. The nurse provides a link between physicians and other healthcare professionals and people with MS, their families and the community. Some nurses are also licensed to prescribe medications.

- **Occupational therapist (OT)** — A rehabilitation specialist who helps people maintain the everyday skills that are essential for independent living and that allow for productivity at home and at work. The OT works with people on: upper body strength, movement and coordination; the use of assistive technology to enhance accessibility and independent living; fatigue management through energy conservation, work simplification and stress management; and compensatory strategies for impairments in thinking, sensation and vision.
- **Physiatrist** — A physician who specializes in the rehabilitation of physical impairments.
- **Physical therapist (PT)** — A rehabilitation specialist whose goal is to evaluate and improve movement and function, with particular emphasis on physical mobility, balance, posture, and fatigue and pain management. The PT helps people meet the mobility and functional challenges in their family, work and social lives while accommodating the physical changes brought about by the disease.
- **Speech/language pathologist (SLP)** — A rehabilitation specialist who diagnoses and treats speech and swallowing disorders. A person with MS may be referred to a speech/language pathologist for help with either or both of these problems. Because of their expertise with speech and language difficulties, SLPs may also provide cognitive remediation for individuals with cognitive impairment.
- **Psychologists, social workers, counselors** — Mental health professionals who help people with MS and their family members learn how to manage the stress and emotional challenges of adapting to the intrusion of MS in their lives.
- **Urologist** — A physician who specializes in the branch of medicine (urology) concerned with the anatomy, physiology, disorders and care of the male and female urinary tract, as well as the male genital tract.

While you may never need these types of specialty care, it can be comforting to know that there are a variety of health professionals available to help you manage whatever types of problems may arise.

A word about insurance

The world of insurance has gotten increasingly complex in the last several years. If you haven't already done so, it would be well worth your while to familiarize yourself with your insurance plan, particularly concerning what access you have to specialty care in the event that you need it.

The National MS Society can answer questions about health insurance coverage and direct you to additional information or consultation if you are in need of it.

Things to think about

- It is crucial for you to feel comfortable with your doctor so that you can be an active partner in your health care. Recent changes in healthcare policies have made this truer now than ever before. Effective teamwork is the key to successful management of MS.
- Regular visits with your MS provider are important. Try to prepare for the visit ahead of time so it is productive and informative for you.
- New symptoms can be worrisome, so inform your doctor about them. Discuss the optimal methods for communication with your doctor so that your questions and concerns are addressed and any worry or anxiety is minimized.
- As you work to establish a comfortable, collaborative relationship with your MS doctor, be sure to pay adequate attention to your general health and wellness. People with MS have the same need for exercise, a healthy diet and regular medical screenings as everyone else.
- Nurses, physical therapists, psychologists and other healthcare professionals can be valuable resources for people living with MS. Become knowledgeable about all your resource options.
- If you haven't done so already, familiarize yourself with the coverage provided by your health insurance plan. Find out about your plan's appeals process in the event that coverage is denied for a particular type of treatment or medication.

Resources

Thousands of resources, pieces of information and shared experiences about MS are available in print and on the internet. Some of the information you come across may be strictly experiential, anecdotal, unsupported or even inaccurate. Always consider the source; ask your healthcare provider or the National MS Society to help you identify credible resources.

From the National MS Society

For answers to questions about MS and its management, contact the National MS Society at 1-800-344-4867 or visit **nationalMSsociety.org** or the following topic-specific pages:

- **nationalMSsociety.org/docvisit**
- **nationalMSsociety.org/insurance**
- **nationalMSsociety.org/symptoms**
- **nationalMSsociety.org/KIPdocs**

The Society produces many other resources about various aspects of MS. These resources are available online or call 1-800-344-4867 to request.

- **nationalMSsociety.org/educationalvideos** (also at youtube.com/nationalMSsociety)
- **nationalMSsociety.org/brochures** (or see the Catalog of Informational Resources mailed with this book if you received it by mail)

Books

Books may be available at bookstores and/or online booksellers.

- Ettinger AB, Weisbrot DM. **The Essential Patient Handbook** (2004). (NY:DemosHealth)
- Kalb R (ed.). **Multiple Sclerosis: A Guide for Families** (3rd ed.) (2006). (NY:DemosHealth)
- Kalb R (ed.). **Multiple Sclerosis: The Questions You Have; The Answers You Need** (5th ed.) (2012). (NY:DemosHealth)
- Kalb R, Giesser B, Costello K. **Multiple Sclerosis for Dummies** (2nd Ed.) (2012). (NJ:Wiley)

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The National MS Society's mission is for people affected by MS to live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides services designed to help people with MS and their families move their lives forward.

The National Multiple Sclerosis Society ("Society") is proud to be a source of information on multiple sclerosis related topics. The information provided is based on professional advice, published experience, and expert opinion, but does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney.

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Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your healthcare professional and contacting the National MS Society at **nationalMSsociety.org** or 1-800-344-4867.

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