



**Title:** It's About Team Work – It's About Communication: Coordinating with Your Healthcare Team

**Date:** March 4, 2008

**Time:** 8:00 PM, Eastern Standard Time (GMT-5:00 New York)

Check your time zone 7:00 PM, Central Standard Time (GMT-6:00 Chicago)

6:00 PM, Mountain Standard Time (GMT-7:00 Phoenix)

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**Link to the Webinar:** <https://wemove.webex.com/wemove/onstage/g.php?d=552891260&t=a>  
Click on the link above or copy and paste it into the address bar of your Web browser. For detailed instructions, please see the next page.

**Password:** tigger

### **WHAT IS A WEBINAR?**

A Webinar is a web-based seminar that includes visual (slides) and audio (lecture) portions that you can see and hear.

### **WHAT DO I NEED TO TAKE PART IN THE WEBINAR?**

To have the best experience, you will need a computer that is hooked up to a high-speed Internet connection. If you don't have a computer or don't want to watch the slide presentation, please use the toll-free number that is listed on the next page and call to listen to the audio portion of the Webinar.

### **HOW DO I TAKE PART IN THE WEBINAR IF I AM USING MY COMPUTER?**

1. Please be sure to allow plenty of time to complete the log-in process. Depending on what programs are running on your computer and the speed of your Internet connection, this process may take from 5 to 30 minutes to complete.
2. Before the meeting's start time, copy and paste or type this address into the address line of your Web browser: <https://wemove.webex.com/wemove/onstage/g.php?d=552891260&t=a>
3. Enter only your first name, your email address, and the meeting password (the password is **tigger**), and then click *Join Now*.
4. You will now be in the meeting room. Turn up the volume on your computer's speakers and sit back and enjoy the program. You're now taking part in the WE MOVE Webinar!

### **I CAN'T GET THE LINK TO WORK. DO YOU HAVE ANOTHER WAY TO CONNECT TO THE WEBINAR?**

If you are unable use the link provided above, go to [www.webex.com](http://www.webex.com) and click the *Attend Meeting* tab on the upper right-hand corner of your screen. Enter the meeting number **552 891 260** and click *Join Meeting*. On the next screen that comes up, type in **tigger** in the password field.

### **WHAT IF I DON'T HAVE A COMPUTER OR I DON'T HAVE SPEAKERS ON MY COMPUTER?**

If you are unable to access the Internet or can't hear sound from your computer, you can call **toll-free** from the US or Canada: **866-469-3239**. When you are asked for the meeting number, enter 552 891 260. When you are asked for the ID number, press the # symbol.

### **WHAT IS THE FORMAT FOR THE WEBINAR?**

If you are connected with your computer, your screen will have two parts. The main window, on the left-hand side of the screen, will have the slides that will be used to give the lecture. Another box on the right-hand side will have a list of all of the people who are attending the Webinar and a smaller box in which you can type your questions. Staff members from WE MOVE will be watching for questions. We will copy these questions and make a list to give to Dr. Gaebler-Spira and Ms. Panko-Reis during the third part of the webinar.

### **WHAT WILL HAPPEN DURING THE WEBINAR?**

1. The first part is a faculty presentation: *It's About Team Work – It's About Communication: Coordinating with Your Healthcare Team*
2. During the second part of the Webinar, Dr. Gaebler-Spira and Ms. Panko-Reis will answer questions that people sent in when registering for the Webinar.
3. After answering the preregistered questions, Dr. Gaebler-Spira and Ms. Panko-Reis will answer the questions that people submit into the chat window during the Webinar.

### **FOLLOW-UP INFORMATION**

Many people signed up to take part in this Webinar, and many submitted questions during the registration process. During the Webinar, Dr. Gaebler-Spira and Ms. Panko-Reis will try to answer all of the preregistered questions that are about communicating with your healthcare team and coordinating care. If your question is not answered, please go to the WE MOVE Discussion Forum at [www.wemove.org](http://www.wemove.org) and click on the *Discussion* tab located at the top of the page. Once you have registered to take part in the forums, you can post your questions in the *Patient – Physician Communication: Maximizing Your Care* Forum and interact with others who have similar concerns.

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***It's About Team Work – It's About Communication  
Coordinating with Your Healthcare Team***

**M**ost movement disorders are chronic, long-lasting conditions that can be challenging to manage over time. Finding the best treatment usually means taking an active role in managing the condition. To make important decisions, you need to be informed about your condition, able to understand the information that you have, and then make healthcare choices that support improvement in your symptoms. Patients who work with their healthcare providers in a process called collaborative care, share in decision making, and assume self-management of their chronic diseases are more likely to have **improved health outcomes.**

**Shared decision making**

**S**hared decision making is a process by which doctors and patients consider available information about the medical problem in question, including treatment options and consequences, and then consider how these fit with the patient's preferences for health states and health outcomes.

Shared decision making is a partnership in which patients and their medical professionals make healthcare choices. This includes the medical professional taking into consideration the patient's preferences as well as presenting to the patient the best available evidence about treatment or

- doctor alone
- doctor led & patient acknowledgement (sought or offered)
- doctor led & patient agreement (sought or offered)
- doctor led & patient views/opinion (sought or offered)
- shared equally
- patient led & doctor views/opinion (sought or offered)
- patient led & doctor agreement (sought or offered)
- patient led & doctor acknowledgement (sought or offered)
- patient alone

*Degree of sharing. Reprinted with permission from Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. Patient Education and Counseling 2006;60:301-312.*

test options, including potential benefits and harms. Shared decision making results in patients being able to integrate all of the information that they receive about their movement disorder or treatment, increasing the person's perceived confidence and ability to perform a set of behaviors. This is called self-efficacy. People's level of self-efficacy has been shown to predict their ability to follow through on a course of action.

Collaborative care for chronic disease includes shared decision making but goes even further to integrate patients into more activities. Collaborative care takes place when patients and doctors work out mutually agreed upon goals, have a good working relationship, and understand each others' roles and responsibilities in that care. When patients and doctors identify a specific problem and work together to set realistic goals and plans, achieving the goals is more likely to be possible.

Studies have shown that **health and day-to-day functioning improve when patients exert more control** in the interactions with their physicians. However, this isn't a role that is comfortable for all people. Some people simply do not want to assume a greater role in managing their health, in general, or in managing the symptoms of their movement disorder. Others may be intimidated about speaking up and expressing their preferences for treatment, perhaps feeling that "the doctor knows best." It is important for doctors to recognize and respect patients' wishes in this circumstance; however, doctors also need to be aware of aspects of their own behavior that may undermine a patient's desire to partake in collaborative care. Whatever their level of comfort in participating in treatment decisions, it is important that patients have the opportunity, encouragement, and support to participate to the degree that they are able.

In most office visits, the doctor does most of the talking and the patient responds to questions, reinforcing the

## Two Perspectives of the Same Medical Condition

Doctor	Person with the condition
Diagnosis of condition	Pain
Compliance with treatment	Symptoms
Change in lifestyle	Problems with functioning Struggles with lifestyle changes

traditional passive role of patients. Their points of reference are quite different.

However, the healthcare system in the US is changing and, during their training, physicians are learning about how to better communicate with their patients. The classic scheme of the physician obtaining the patient's past medical history, performing a physical exam, obtaining laboratory and other tests, arriving at a diagnosis, and prescribing treatment is outdated. People are more educated and more aware of their own medical needs, and a major shift is occurring in the patient-physician relationship.

So, what does this mean for you? To be actively involved in your care requires a willingness to **assume responsibility not only for your personal health, but for the achievement of the goals** that you establish with your doctor. It means that you will seek to become health literate, actively identify accurate and timely information related to your disorder, and prepare for your appointment with your doctor to maximize the time you spend together.

# Health Literacy

To have adequate health literacy means that you are able to read and understand the instructions on medication labels appointment reminders, brochures, consent forms, and other written materials and follow through with the instructions.

However, health literacy is not simply being able to read. To have adequate health literacy skills means that you are able to see, read, hear, listen, analyze, and make decisions—all within an unfamiliar and often stress-filled environment—and then apply that information to your unique healthcare situation to make it better. Being health literate is a two-way street. In addition to understanding what you are told, you also need to be able to express yourself clearly when speaking with your healthcare professionals. You need to be able to ask questions when you don't understand instructions. And, you need to be able to make decisions based on discussions with your healthcare professionals. It might sound simple, but it is not easy to do.

You also must possess several other skills to be fully health literate. A key skill includes the ability to evaluate information, including confirming the trustworthiness and quality of the material. And, if that information is available only on the Internet, computer skills are necessary to access that information. To be fully health literate also means that with the help of your healthcare professionals, you are able to weigh the benefits and risks to you of each treatment option and understand the results of any blood tests or other tests. In addition, adequate health literacy requires that you are able to physically navigate the often complex healthcare system. That means that you are able to get to the doctor's office or hospital and get around once you're there. Finally, on your doctor's instructions, you have enough understanding to take your medications in the way they were prescribed. Keep in mind that the more medications you take, and the more complicated your dosing schedule, the more likely it is that you will make a medication error.

Your level of education is a major factor that impacts your level of health literacy, but other issues also play a role. If you are older, have a chronic mental or physical illness, or have a first language that is not English, you are more likely to have a lower level of health literacy. Even if you are completely able to function on a day-to-day basis at home, your ability to process new and unfamiliar information may not be as good when you are in the stressful environment of a doctor's office. Inadequate health literacy and poor communication can create obstacles at many points along the path of correct diagnosis and the best treatment for people with a movement disorder.

## Be Prepared when You Go to Your Next Doctor's Appointment

**M**any people find it very difficult to process information when they go to a doctor. This can happen for any number of reasons, but it's often related to the amount of stress that you're under—visiting a doctor's office can be a very stressful experience. Perhaps your doctor has just given you a life-changing diagnosis, and your brain simply can't process anything once the diagnosis is given. Or, maybe it's more of a routine visit, but you are trying so hard to remember all of your questions and take in the answers that your stress levels rise and you, again, can't absorb all of the new information. It can also happen because your doctor is speaking a foreign language—medical speak! When doctors and patients don't share a common language, the information exchanged is less than ideal—you may not understand anything that's being told to you or even the questions that your doctor is asking. What can you do to remedy the situation during your next doctor's appointment? Being prepared will go a long way toward helping you to relax and get the most out of your visit.

### Preparing for Your Appointment

#### *Care Notebook*

**I**n an ideal world, all medical care is provided through a medical home that coordinates your care among a variety of providers and keeps all of your records—whether electronic or paper—in one place. A medical home is a concept developed in pediatrics to ensure continuous care that is coordinated and

sensitive to families' needs. However, if your care is not provided this way—and, for most of us, that is the case—creating a *Care Notebook* will help you to organize your medical information, saving your time and avoiding hassles. (For more information on care notebooks, see the appendix beginning on page 9.) We've also highlighted a few other things that you can do, in addition to keeping a *Care Notebook*, to help you to prepare for a doctor's appointment.

Between appointments or for a few weeks before a new appointment, write down any questions that you might have. On the evening before your appointment, decide which questions are most important. Your doctor may have time to discuss only a few of your questions, and you want to make sure that you ask the most important ones first.

Be prepared to answer these questions

- What is your main concern?
- What do you think it is?
- How is it affecting your
  - Quality of life?
  - Ability to work?
  - Ability to perform your regular activities around the house?
  - Ability to participate in recreational or leisure activities?

Bring a list of all of the medications that you take. Include in this list any prescription drugs and over-the-counter medicines, herbal products, or vitamins that you are taking. Be sure to include the dose of each medication or product and how often you take it. Even if you only take these items occasionally, it's important for your doctor to know the

names of all of these medicines, supplements, and vitamins.

It will also help to make your appointment go more smoothly if you have a list of your symptoms and a list of anything that makes the symptoms better or worse. Try to give this some thought ahead of time so that you can spend your office visit discussing your important items rather than trying to think. Also, let your doctor know if you have had any laboratory tests or imaging studies done since your last appointment and whether you are being treated by other doctors for other medical conditions.

Have a friend or relative come with you to the appointment to serve as an extra set of ears or your advocate. Sometimes, in the stress of an office visit, you may not remember clearly what the doctor told you about your medical condition or about any treatments or recommendations. Having someone else there to listen and even write down the answers to your questions may be very helpful.

### *At the Appointment*

When your doctor tells you for the first time that you have a movement disorder, you will likely want to ask a few key questions.

- What is the diagnosis and what does it mean as far as my overall health?
- What can I do today about any health challenges that this diagnosis entails?
- What are the next steps?

## **What is a Medical Home?**

**T**he concept of a patient-centered medical home came about in pediatrics for the care of children with special care needs. According to the American Academy of Pediatrics, in this “hub,” doctors and staff provide accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective care. They collect and share information with parents about best care practices. A practice-based care coordinator supports the children and family, and clinicians take extra steps to coordinate care with specialists and therapists.

Various organizations are now proposing that this concept be incorporated into the care of the 133 million American adults who have chronic medical conditions. The adult medical home model includes a continuous relationship with a personal physician caring for the whole person, with insurance of coordination with specialists and other healthcare providers.

This type of care requires mutual trust and respect between the patient and physician, as well as shared decision making, and results in improved communication. Key features of the ideal medical home model include

- Access to care and information
- Continuity of care
- Point-of-care services
- Information systems
- Practice management
- Team-based care
- Quality and safety

- <sup>2</sup> Is there an urgent need to make treatment decisions today?
- How do we decide on a course of action?

It's human nature to want to appear to be competent, but if you don't understand something your doctor is telling you, **keep asking questions and talking until you do understand.** Doctors often overestimate the health literacy levels of their patients. In fact, the more educated you are, the less likely the doctor will be to explain things to you—and, just because you have a PhD in nuclear physics, doesn't mean that you can understand medical terms or words that your doctor uses in unfamiliar ways.

Every time your doctor gives you a new prescription, make sure that you understand the what, why, and how of the medication. If you need additional information, your pharmacist may be very helpful in answering these questions as well.

- What is the name of this medicine?
- Why am I taking it?
- What times of day should I take it?
- How long should I keep taking it?
- Should I take it with or without food?
- Are there any side effects?
- What should I do if I have side effects?

By the way, don't wait until the doctor is headed out the door to bring up the fact that you have a list of questions. Be aware that some of your questions may be answered during the visit anyway, so they don't have to be the first item of discussion. But, don't wait too long—

most of us are aware of the time crunch of office visits, so bring up the most important questions first!

### **Conclusion**

People need specific skills to take care of their own medical conditions. They must have the problem-solving skills, the decision support, and the confidence to take the on day-to-day management of their own care.

Researchers have shown that teaching people with chronic diseases to self-manage their disease can result in

- Increased ability to take medications properly
- Increased functioning
- Improved health-related status
- Reduced pain
- Reduced healthcare costs
- Fewer hospitalizations
- Reduced stress and emotional distress related to the condition

Being an active participant in your care, working with your healthcare professionals in a collaborative environment, having accurate, up-to-date information about your movement disorder from a reliable source, and assuming responsibility for managing your medical information in a *Care Notebook*, will all help you to manage your health and your movement disorder. For further reading and links to available material, please visit [wemove.org](http://wemove.org) and see the list of resources provided for you.

## Resources

### *Care Notebooks*

- [A parent-partner guide](#)
- [My Child's Life Care Notebook and Organizer](#)
- [A Care Notebook from the Children's Hospital and Regional Medical Center, Seattle, Washington](#)

### *Decision-making tools*

[Ottawa Personal Decision Guide](#)

### *Further reading*

Ainsworth-Vaughn N. *Claiming Power in Doctor-Patient Talk*. Oxford: Oxford University Press; 1998.

Gruman J. *Aftershock: What to Do When the Doctor Gives You—or Someone You Love—a Devastating Diagnosis*. New York: Walker & Co.; 2007.

Heritage J, Maynard DW, eds. *Communication in Medical Care: Interaction Between Primary Care Physicians and Patients*. Cambridge: Cambridge Press; 2006.

Institute of Medicine. Available at: Health Literacy: A Prescription to End Confusion; 2004. <http://www.iom.edu/CMS/3775/3827/19723.aspx>.

Roter DL, Hall JA. *Doctors Talking with Patients/Patients Talking with Doctors: Improving Communication in Medical Visits, Second Edition*. Portsmouth: Heineman-Prager Paperback; 2006.

## Care Notebooks

**A** *Care Notebook* serves as a central place to organize all of your healthcare information. Using a Care Notebook will make it easier for you to find and share important information with people who are part of your healthcare team. You can use your Care Notebook to

- Prepare for appointments
- Keep track of changes in your medications or treatments
- File lab or x-ray results or other test reports
- List contact information for key people on your healthcare team
- Compile information that you download from Internet searches, brochures, and other sources of information and support
- Record your immunizations
- Note any allergies or adverse reactions to medications or foods
- Share information with family members and all members of your healthcare team

The following tips may make it easier for you to create and use your new Care Notebook.

- Most people find it easiest to use a three-ring binder to create their *Care Notebooks*. You may also want to buy a three-hole punch that slips into the rings of the binder. By keeping the punch handy, you can avoid the hassle of dealing with loose material. When you receive a report or other information, simply punch the holes on the spot and slip the new material into the notebook. Other people prefer to store their material in an accordion file, so use whatever method works best for you.

- Use dividers to separate the material in your *Care Notebook*. You can create the dividers in any way that is helpful to you. You may wish to include a few plastic sheets to insert information that can't be punched.
- When you first put together your *Care Notebook*, you will likely want to spend some time creating a medical history. Make note of any operations or hospitalizations as well as other helpful information on your current medical conditions.
- Include blank pages in a special section of your notebook for questions where you can jot down questions for upcoming appointments. Make sure to leave space so that you or your advocate can write down the doctor's responses to those questions.
- Keep your *Care Notebook* in an easily accessible spot. Make sure that a family member or other caregiver can locate your Notebook in an emergency and knows to bring it to the clinic or hospital
- Bring your *Care Notebook* to all medical appointments.

You will want to create a *Care Notebook* that is specific to you and your medical conditions. Insert the pages that are most important to you. Here is a list of our suggestions for pages to start you off.

#### Contact information for

- You and other family members
- Caregivers
- Emergency contacts
- Hospital
- Healthcare providers
- Therapists
- Pharmacy
- Insurance company or even a copy of your insurance card
- Special transportation
- Equipment providers

#### Diary pages to track

- Medication effects
- Sleep
- Activities

#### An appointment log that includes

- Who the appointment is with
- The reason for the appointment
- The results of the appointment
- Any follow-up action that you need to take

#### A medication log that includes

- Name of the medication, including any brand or generic names
- Date the medication was first prescribed
- Who prescribed the medication
- The dose
- How often or when you take it
- The way you take it
  - With or without food
  - By mouth, injected, or some other route
- Date the medication was stopped and why

#### Highlight pages for

- Treatment results
- Hospitalizations

#### Questions for upcoming appointments

#### Test results

#### Calendar