

# EFFECTIVE COLLABORATION WITH YOUR NEUROLOGIST AND CARE TEAM

### WHY SELF-ADVOCACY MATTERS

Living with multiple sclerosis (MS) can bring with it waves of emotions: anxiety, frustration, and feelings of being overwhelmed, among others. But you're not alone. Your neurologist and care team are there to help treat your disease and manage symptoms – and collaborate with you along your journey to help you live your life as fully as possible with MS.

#### YOUR VOICE MATTERS

It's important to be an active partner in discussions with your neurologist and care team, sharing your needs, wishes and what you value – especially when living with a chronic, unpredictable and highly individualized disease like MS. This tool has been created to help you have these discussions.

#### SHARED DECISION-MAKING

Learning about MS and staying informed helps you have those conversations and make decisions you feel are right for you – powering your sense of control of your future. Seek out information from trusted resources and don't hesitate to ask your neurologist and care team for insights and guidance.

#### CONSIDER YOUR GOALS

Whether you're newly diagnosed or have been living with MS for some time, it's important to consider your goals in terms of your lifestyle now and in the future, including family life and planning, social activities, recreation and career – and discuss them with your neurologist and care team. Re-visit them regularly to help ensure your care and treatment continue to align with your evolving needs and expectations.

#### MAKE THE MOST OF YOUR APPOINTMENTS

Be sure to ask your clinic what information they'll need from you at your first appointment, such as your medical history. For ongoing appointments, it's good to be prepared with:

- A summary of physical and cognitive symptoms experienced since your last visit;
- Notes on how closely you've followed your treatment regimen; and
- Any changes to your overall health, including mental health, and any new medications.



#### THE IMPORTANCE OF SYMPTOM TRACKING

Tracking your symptoms over time helps your neurologist assess your MS. Become well connected to your body, noting changes – no matter how small you may think they are. Don't be afraid to discuss changes you may feel shy about sharing, such as sexual health, mood or bladder issues. **Your MS Questionnaire** can help you summarize your symptoms for your regular appointments.

#### MAKE A LIST

Note your questions and concerns, including those related to your care and your current treatment, as well as any MS-related work or family issues. Be sure to prioritize them and remember that MS clinic nurses can answer many of them if time with your neurologist is limited. Some questions you may want to consider include:

#### DIAGNOSIS

- What type of MS do I have and how does it differ from other types?
- Is my MS considered active or inactive?
- How do we know if my MS is progressing?

#### SYMPTOMS

- What symptoms might I experience?
- What is a relapse and how do I know if I'm having one?
- When and how do I report symptoms I may be experiencing?
- How are symptoms treated? What can I do to help manage them?

#### TREATMENT

- What are the goals of treatment and how best can we work together toward achieving them?
- What are my options and their potential benefits for my type or stage of MS?
- How are they administered and how might they affect my lifestyle and routine?
- What are the possible side effects and how are they managed?
- Whom do I contact if I experience side effects?
- How will I know if my medication is working?
- If it is working, should I stay on it or switch to something that may be better for me at this point or in the future?

#### SELF-CARE

- What can I do in terms of self-care to help manage symptoms and stress?
- What mental health supports are available if I'm having trouble coping with my MS?
- What healthy lifestyle approaches can I take that may positively impact my disease?
- Is there anything else I can be doing to optimize my journey with MS?

## **TRUSTED FRIENDS AND FAMILY**

Consider bringing a family member or trusted friend to appointments. They can often also share insights with your care team and can help take notes as you focus on the discussion. They may also want to learn more about MS and how they can best support you.

## **ADDITIONAL CARE AND SUPPORT**

MS is a complex disease and at points may be addressed by a variety of healthcare professionals, such as physical or occupational therapists, physiatrists, or mental health experts. Speak to your care team if you feel you need additional resources or support. And if you feel you are not being understood or heard, share your concerns with your care team and ask about available options to improve your experience.

## **YOU ARE NOT ALONE**

While you are your own best advocate, you may find it helpful to connect with others also living with MS who can offer support and encouragement and can share their learned experience in navigating MS care and treatment. The MS Society of Canada is also an invaluable source of peer support and networking.

## **YOU (AND YOUR TEAM) GOT THIS!**

Learning about MS and finding your voice can be as much of a journey as the disease itself. Know that resources are there to support you and answer questions, and a team and a community are with you!



## **CLINIC APPOINTMENT WORKSHEET**

### **1 MY GOALS**

### **2 MY CONCERNS**

### **3 MY EXPERIENCE WITH MY MS AND CURRENT TREATMENT** Remember to complete **Your MS Questionnaire** and bring it with you to your next appointment.

### **4 MY MEDICATIONS** Include any supplements and over-the-counter medicines you may be taking.

### **5 MY QUESTIONS** (in order of priority)

**For more information and resources for people living with MS, visit [MyRules.ca](https://myrules.ca)**