Questions for Your Loved Ones Healthcare Team

Now that your loved one has been diagnosed with MS, you may have a lot of questions for his or her healthcare providers. Let your loved one know you would like to go along on some or all of the visits to the physician, and perhaps ask questions of your own in addition to any that he or she may plan to ask. Remember, no question is too small or too big, but time with the doctor is limited, so work with your loved one to prioritize all your questions. Use the questions below as a starting point to help you think about the specific questions you may want to ask the healthcare team.

Taking First Steps

☐ Why did my loved one get MS?
☐ Is MS fatal?
☐ Why are his or her symptoms so different from those of some other people I know?
☐ What are the different disease courses? Will the course of my loved one’s MS change over time? How will we know?
☐ How will we know when we should call the neurologist?
☐ What tests need to be repeated on a regular basis?
☐ How often do you recommend an MRI and a neurologic exam?
☐ Is it important to test vitamin D levels? Other vitamin levels? What needs to be done if any of these levels are too high or too low?
☐ If my loved one is seeing you on a regular basis, are regular visits with the primary care physician also necessary?

Disease-Modifying Treatments

☐ What is the goal of starting treatment at this time?
☐ What are the risks of not starting treatment at this time? Do disease modifying therapies make people feel better?
☐ Do disease modifying therapies improve symptoms?
☐ How will we know if the medication is working?
☐ Will my loved one need to stay on this medication forever?
☐ What is the risk of stopping therapy?
☐ What are the side effects of the disease-modifying medication he or she is taking?
☐ What is the best way to manage the side effects of this medication?
What are the long-term risks associated with this medication?

What type of monitoring is required with this medication?

Can the disease-modifying medication be changed if the side effects aren’t manageable?

Can the medication be changed if this one doesn’t control the disease as much as we want it to?

What can I do to support my loved one’s treatment plan?

Treating Yourself Well (Symptoms and Wellness)

What are the common symptoms of MS?

How do I know if what my loved one is experiencing is an MS symptom or something else?

How will we recognize an MS relapse?

Will the symptoms go away? Stay the same? Get worse?

How can we determine if one or the other of us is experiencing depression rather than just feeling down or blue?

Are there medications that can help with symptoms? Are there other strategies?

Is exercise good for my loved one?

How often should he or she exercise?

Is there a specific type of exercise that’s better for people with MS?

How can I help my loved one stay motivated?

Is there a diet that is recommended for MS?

I’ve read online about a lot of different supplements. How do we know if the information is reliable?

I’ve read online about (FILL IN THE BLANK). Should my loved one try it?

Employment and Financial Security

How will my loved one’s diagnosis impact his or her employment?

Should I disclose to friends, family, coworkers, my employer about my loved one’s MS?

What if I need to miss work to care for my loved one? Are there any protections for me?

Maintaining Healthy Relationships Family

Will our children get MS?

Should we tell our kids about my loved one’s diagnosis?

How do I talk to my kids about the diagnosis?

Will MS affect our ability to be intimate?

Will MS affect our ability to do things as a family?

My loved one can no longer do (insert activity). How do we cope with that? Is there another way to do that activity or a different activity we could do?

My loved one is trying to protect me by not telling me everything. How do I encourage him or her to maintain communication?
Roles in our family are shifting and our partnership is changing. How do we manage changing roles so that everyone feels like they're contributing and no one feels overwhelmed?

I feel guilty if I take time for myself – how can I balance my loved one’s needs and my own?

Resources

- What resources are available for family members?
- What resources are available to help kids understand MS?
- What resources are available to help me connect with other family members of people with MS?

Additional Questions You Want To Ask

For more resources and connection to information and other people and families living with MS, visit nationalMSsociety.org/resources.