

Questions to ask your doctor.

When we see the doctor, taking a list of questions with us is often helpful. We are often anxious and forget to ask questions, so having a list is a good idea. Our communication with the doctor is critical to our diagnosis and care. As the doctor gets their information from us, the better organized we are, the more we can tell the doctor what our symptoms are.

Experience shows us that many people who have IBM are initially misdiagnosed and that, on average, it takes five years to arrive at a correct diagnosis of IBM.

First:

List ALL medications you have been on in the past five years.

List doctors you have seen in the past five years and why you saw them.

Make a list of any tests you have already had.

There are two crucial phases we need to look at:

What is wrong? (What is the **diagnosis**?).

What can I do about it? (What **treatment** is recommended?)

Diagnosis.

There are several essential steps involved here.

You must write a detailed list of what you feel is wrong with you.

What are YOUR symptoms?

List each and describe it in detail – what is different from before?

Give examples: “My legs seem weak; I can’t get up the steps the way I think I should.” Do you have pain? Do you have muscle cramps? Have your muscles changed shape?

For each symptom:

When did it seem to start?

Does it seem to “go up and down?” When is it worse?

Are there things that you do that make it better or worse?

Differential Diagnosis.

The doctor will say what he thinks is wrong. They will also suggest what else it could be. This is called a differential diagnosis – “I think it is the appendix, but it COULD also be the gall bladder.” The doctor will order tests and examine you until they feel confident, saying, “Yes, this is what I think it is.”

This is done in two important ways:

- One: Tests are done to show you HAVE a condition.
- Two: Tests may be done to help RULE OUT a condition.

Tests.

The doctor will likely order several tests.

In many cases, a diagnosis of a muscle disorder includes a muscle biopsy.

“The results are back.”

What does the doctor think it is, and why?

Ask the doctor to write down the diagnosis so there is no confusion.

It may be appropriate to ask for a follow-up appointment in a month. Go home, “let your diagnosis sink in.” Learn the basic information about your diagnosis. Return in a month and ask any questions that you have.

Is it okay to question the doctor about the diagnosis?

When you take your car to a mechanic who says you need a new transmission for \$2000, you ask him why.

“But I don’t want to insult the doctor!” No, but asking good questions that apply to your case should not upset your doctor – your doctor should not mind answering a few essential questions.

What should I ask about?

What are MY symptoms that make YOU feel that I have this diagnosis?

Does MY PATTERN of weakness fit this diagnosis?

Given that these are rare disorders, are there more tests that can be done to confirm my diagnosis?

A second opinion:

Some doctors will have never seen a patient with IBM.

Should I see a doctor specializing in IBM or a special clinic?

Please don’t feel you are insulting your doctor; it is VERY common for second and even third opinions in cases of rare disorders, like IBM.

Ongoing Diagnosis:

Diagnosis continues as time goes on. Over time, symptoms may change and further support the diagnosis or suggest something different. As treatments are tried, your response may further support the diagnosis or suggest something different. If the treatment does not work as anticipated, perhaps the first diagnosis is wrong. So, a person's diagnosis is always open to review.

IBM is a complex disorder, and new information about it is constantly coming out. We must be confident that we have an up-to-date, accurate diagnosis. This is especially true with muscle disorders.

Treatments:

Note: No treatment is recognized as effective for IBM. Based on their experience and opinions, doctors may TRY medications with IBM patients. However, this is a clinical judgment where possible benefits must be weighed against potential side effects.

If the doctor suggests a medication, ask why this one.

Are there side effects, and how might they affect me?

What experience does the doctor have using this medication with IBM patients?

Ask about exercise. It is increasingly recognized that a specialized exercise program may be helpful for IBM patients. A physiotherapist may design an appropriate specialized, ongoing exercise program for you.

Get advice from your doctor before you take vitamins or other health supplements.