

Asking Your Doctor Questions.

 ibmmyositis.com/list.htm

Inclusion Body Myositis (IBM).

Site presented by Bill Tillier

When we see the Doctor it is often helpful to take a list with us. Often, we are anxious and we forget to ask questions, so having a list is a good idea. Also, as the Doctor gets his or her information from us, the better organized we are, the more clearly we can tell the Doctor what our symptoms are. Our communication with the Doctor is a critical part of our diagnosis and care.

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 do I need?)

Diagnosis.

There are several important steps here:

You need to write out a detailed list of what is wrong:

- What are YOUR symptoms?
 - List each one and describe it in detail - what is different?
 - Give examples: "My legs seem weak, I can't get up the steps the way I think I should"
 - Is it hot? Is it painful? Is it sore? Does it cramp? Is it red? Has it changed its shape or feel?
- For each symptom:
 - When did it seem to start?
 - Does it seem to "go up and down?"
 - When is it worst?
 - Are there other things that you do that make it better or worse?
- Also:
 - Make a list of ALL of the medications you have been on in the past three years.
 - Make a list of any Doctors you have seen in the past five years and why you saw them.
 - Make a list of any tests you have already had.

Differential Diagnosis.

The Doctor will say what he thinks is wrong. He 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 he or she feels confident in 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 are done to show you DON'T have something else (example: check dystrophin level to rule out Becker's muscular dystrophy).

Tests.

The Doctor will likely order several tests on your muscles.

One important test is a muscle biopsy. You may have to ask for a muscle biopsy. Why? Because the test is more expensive and more complicated and YOU may not like having it done. A Doctor freezes your muscle (often in the leg) makes a small incision and removes some muscle for study (about the size of a sugarcube). Your leg (or arm) will be pretty sore for a few days.

I believe that in many cases, a diagnosis of a muscle disorder includes a muscle biopsy.

"The Results are back"

When all of the results come back there are several important questions:

-What does the Doctor think it is and why?

Again, in my layman's opinion, I feel it is important to ask for a follow-up appointment in a month, go home and learn about your diagnosis. Return in a month and ask any questions that you have.

Why ask the Doctor why?

-When you take your car to the mechanic and he says you need a new transmission for \$2000 you ask him why, right?

-"But I don't want to insult the Doctor!" No, but asking good questions that apply to your case, should not upset your Doctor - if it does, this may be a different problem.

What should I ask about?

-What is wrong? [Specific diagnosis] O.K.:

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

-Does MY pattern of weakness fit this diagnosis?

-What does MY biopsy show? Are the findings consistent with this diagnosis?

What tests were done to rule things out?

-Were protein studies done? Which? What do they show? (if they are O.K., it should rule out other problems).

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

--They may not want to do more tests: "We can't do every test there is" and "It is too expensive." We are asking for a few very specific tests to confirm a very rare disorder - this does not seem unreasonable.

Second opinions:

- Many Doctors will never have seen a patient with your diagnosis:
 - Ask: Do you know of a Doctor who specializes in this diagnosis who I should see?
 - Don't feel you are insulting your Doctor, it is VERY common for second and even third opinions in cases of rare disorders.

Ongoing Diagnosis:

-Diagnosis continues on as time goes on. Over time, symptoms may change and may become more clear. As treatments are tried, diagnosis is refined. If the treatment does not work as anticipated, perhaps the diagnosis was wrong to begin with. So, a person's diagnosis is always somewhat open to review.

-"I've already been diagnosed." Yes, but this is a complex disorder and new information is coming out on it everyday. Experience shows us that many people are misdiagnosed and if we are considering going onto "harsh" medications that have serious side effects, then we need to be as certain as we can be 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 sIBM (as of 2017). Research does not generally support the use of ANY of the medications available today. Based upon their experience and opinions, doctors may TRY medications with IBM patients however, this is a clinical judgment where any 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 patients?
 - Given the poor research results for the various medications that have been tried, is it appropriate for me to choose not to be medicated at this time?

Ask about other treatments:

- Physiotherapy? A physiotherapist may design a specialized, ongoing exercise program for you. Ask if you can be a "rehabilitation" patient (you may be able to pay a lower monthly fee for access to machines rather than pay per visit).
- Seek advice from your Doctor before you take vitamins and other health supplements.

.

.