What to Ask Your Doctor at Your First Multiple Myeloma Appointment

If you've just been diagnosed with multiple myeloma, your head is probably swimming. For most of us, myeloma is a disease we haven't heard of before. It doesn't seem fair, but early in your diagnosis, you will be asked to make important decisions about your care. After you get the official diagnosis, you need to come to your appointment prepared with important questions.

We suggest bringing this checklist to your visit and asking the following questions:

Making sure a myeloma specialist is part of your care

1. How many myeloma patients do you treat annually?

Note: If your doctor is treating less than 50 myeloma patients per year, find a myeloma specialist in our directory: https://healthtree.org/myeloma/community/directory or get a telemedicine visit with one to confirm your diagnosis. Data shows that with the help of a myeloma specialist, you could live 2-5 years longer.

Understanding your Diagnosis

2. What is my actual diagnosis?
   - MGUS
   - Smoldering Myeloma
   - Active Multiple Myeloma
   - Plasma Cell Leukemia

3. What R-ISS Stage of myeloma do I have?
   - Stage I
   - Stage II
   - Stage III

4. Do I have any of the following?
   - Low albumin
   - High LDH
   - High beta-2 microglobulin

5. Which subtype of myeloma do I have?

6. What genetic characteristics do I have?
   (You can ask your doctor to mark the ones that are positive)
   - Gain 1q21 or amp1q21
   - Deletion (1p)
   - Deletion (17p)
   - Deletion (13q) / monosomy (13)
   - Deletion (16q)
   - t(4;14)
   - t(6;14)
   - t(11;14)
   - t(12;14)
   - t(14;16)
   - t(14;20)
   - Trisomies
     Specify: __________
   - Tetrasomies
     Specify: __________

7. Do I have standard-risk or high-risk myeloma?
   - Standard
   - High
Understanding your Treatment Options

8 What tests will I have performed before starting treatment?
- Biopsy
- FISH test
- Cytogenetics
- Flow cytometry
- Beta 2 microglobulin
- LDH
- Albumin
- Serum protein electrophoresis
- Free light chains

9 Am I eligible for a stem cell transplant?
- Yes
- No
  Why?

10 What are my treatment options?

11 What are some side effects to be expected with this treatment?

12 How are the treatments administered?
- Intravenous
- By mouth
- Injection

13 Can other medications, supplements, or vitamins interfere with my myeloma treatment?

14 How will I know if I am responding to the treatment?

15 What will happen if I don’t respond to the first treatment option?

16 When should I consider joining a clinical trial?