

QUESTIONS TO ASK ABOUT YOUR MDS

This is a list of commonly asked questions you may use in your MDS diagnosis and treatment journey.

Frequently, patients may get overwhelmed by the information provided by the treatment team and may not think of specific questions during consultations or clinic visits. This is perfectly normal as these visits are often stressful, with complex disease and treatment related information. Having this list will help you prepare for your visit and may help you better understand your diagnosis, treatment options, and strategies for wellness.

This list was compiled by MDS patient groups in collaboration with clinicians.^{1,2} This list has been updated by the MDS Foundation Nurse Leadership Board. Not all questions may apply to your unique MDS journey.

DIAGNOSED WITH MDS

- Are you sure I have the diagnosis of MDS?
- Can you explain what MDS is?
Is it a form of cancer?
- Can I get a copy of the reports from my blood and bone marrow tests?
- What type of MDS do I have?
- Are there stages in MDS?
- Which risk group does my MDS fall into (IPSS-R)?
- What is the prognosis for my survival?
- What factors could affect my prognosis or treatment options?
- Where can I get information about MDS?
- Are there MDS support groups available?
- Who can I see to get a second opinion?

DECIDING ON AN MDS PHYSICIAN

Support groups and MDS experts recommend seeking an opinion from an MDS expert when it comes to rare blood cancers like MDS, as not all hematologists are MDS specialists. This can be particularly helpful to gain access to clinical trials.

- Are you part of a multidisciplinary team or do you have access to a recognized MDS expert?
- Can you suggest an MDS Center of Excellence?

DECIDING ON A TREATMENT PLAN

- Which treatment, if any, do you recommend, and why?
- What would happen if I do not receive treatment?
- How is the treatment given? How often is it given? How long does each treatment take?
- What are the risks or side effects of the treatments that you recommend? How long are they likely to last?
- Will treatment affect my daily activities?
- How will I know that treatment is working?
- How and when will you re-assess my MDS disease?
- Am I a candidate for a bone marrow transplant?

CLINICAL TRIALS

- Am I a candidate for a clinical trial?
- What are the advantages or disadvantages of participating in a clinical trial?
- Are there any clinical trials I should consider now?
- Is travel required?
- Am I able to travel by plane, both domestically and internationally?
- Will I have additional responsibilities or additional doctor visits if I participate in a clinical trial?

WHILE ON TREATMENT

Once treatment begins, you'll need to know what to expect, how you can manage your health, and how your response to treatment will be evaluated.

- How will we know if the treatment is working?
- What type of follow-up will I need during treatment?
- Is there anything I can do to help manage side effects?
- What symptoms or side effects should I tell you about right away?
- How can I reach a healthcare professional with knowledge of MDS on nights, holidays, or weekends?
- Are there any food restrictions or dietary changes I need to make?
- Should I exercise? What type of exercise is recommended?
- What would my options be if this treatment isn't working?

OTHER SUPPORT

- Can you suggest a mental healthcare professional?
- What other support services do you recommend for me and my caregivers?

VISIT RECOMMENDATIONS

- Take a pen and paper or use your smart phone or tablet to take notes
- Bring a family member/caregiver to all of your visits, have them take notes. With the permission of your physician, you may be able to record the visit.
- Ask about team members that can provide additional information about your diagnosis or treatment plan. These may be Advanced Practitioners, Nurses, Social Workers, Nutritionists, or other health care professionals.
- Explore resources in the Building Blocks of Hope®. (www.mds-foundation.org/bboh/)

References:

¹ Completed by French MDS experts in France, Leukaemia Foundation of Australia, Melbourne, Australia, CCM - Connaître et Combattre les Myélodysplasies, Paris, France. <https://www.ncbi.nlm.nih.gov/pubmed/25850728>

² Original article from MDS UK Patient Support Group, June 2019

