

Making the most of your consultation

MDS Question prompt List

This is a helpful list of questions, which you can use at any point in your MDS journey - from diagnosis to various forms of treatment, including clinical trials.

Frequently, patients do not think of specific questions until after the consultation is over or until they read specific information booklets. This is perfectly normal as consultations are tense times, where your mind can go 'blank'. Using such a list may help to cover all topics you need to be aware of.

Most of this list was compiled by patient groups, working in conjunction with researchers, to help MDS patients gain greater control over the flow of information in consultations. You can read more about this work 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>

We adapted the list for Canada and added a few comments - to facilitate the discussion with your hematologist.

Just diagnosed with MDS

- How sure are you about the diagnosis of MDS?
- Can you explain what MDS is? How is it different from leukemia?
- Do I need any other tests before we can decide on treatment? e.g. cytogenetic testing, a gene mutation profile.
- Can you explain the types of tests to me?
- Do I need to see any other types of doctors?
- What type of MDS do I have?
- Which risk group does my MDS fall into (IPSS-R)?
- How might this affect my prognosis and treatment options?
- Are there other factors that could affect my outlook or treatment options?
- Can I have a print out of my blood results?
- Where can I get information about MDS, what support groups are there?
- Am I able to travel by plane, both within Canada and internationally?

When deciding on a treatment plan

Support groups and MDS experts do recommend an additional opinion when it comes to rarer blood cancers like MDS, as not all hematologists can be MDS specialists. This can also be helpful to gain access to a wider range of clinical trials.

- How much experience do you have treating MDS?
- Are you part of a multidisciplinary team (MDT) or do you have access to an MDT with access to a recognised MDS expert?
- Should I get a second opinion before starting treatment?
- Can you suggest a doctor or Centre of Excellence?
- What treatment choices do I have?
- Do we need to treat the MDS right away?

- Which treatment, if any, do you recommend, and why?
- What should I do to be ready for treatment?
- How long will treatment last? What will it be like? Where will it be done?
- 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?
- What is the outlook for my survival?

Clinical Trials

- Are there any clinical trials I ought to be aware of before deciding on a standard treatment?
- What travelling is involved? I am, (or I am not) able to travel far for a clinical trial.
- Will I be treated any differently if I enrol in a trial?

During and after treatment

Once treatment begins, you'll need to know what to expect and what to look for. Not all of these questions may apply to you, but getting answers to the ones that do may be helpful

- How will we know if the treatment is working?
- What type of follow-up will I need during and after 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 health professional with knowledge of MDS on nights, holidays, or weekends?
- Do I need to change what I eat during treatment?
- Are there any limits on what I can do?
- Should I exercise? What should I do, and how often?
- What would my options be if the treatment isn't working?

Other support

Can you suggest a mental health professional I can see if I (or my spouse/partner) start to feel overwhelmed, depressed, or distressed? Where can I find more information and support?

Top tips

- Take a pen and paper and write your questions down.
- With the permission of your physician, you can sometimes electronically record the consultation, if you feel you cannot take all the information down.
- We recommend you attend most consultations with a family member or friend, as it can be difficult to remember all that is said in a conversation.
- When necessary, a health professional may also be available to go through the main aspects of the consultation again with you.