

Questions to ask your healthcare team about MDS/CMML

Going to medical appointments can be stressful and it's normal to get a little overwhelmed by some of the complex disease and treatment information given.

Having a pre-prepared list of questions can help you prepare for your visit and get the most out of your appointments.



Getting prepared for your appointment

- Take a pen and notebook to make notes
- With the permission of your clinician you may be able to record your visit (on your phone or another appropriate device.)
- Try and bring a family member or caregiver with you who can help you take notes and be another pair of ears.
- Print this list and take it with you to your appointment or note down some of the questions from the list below. There may be other questions you would like to add, and some you already have answers to, but it's a useful checklist.

Diagnosis of MDS/CMML

- How common is my MDS? How many people get it?
- Is my MDS a cancer?
- What increases the risk of developing MDS?
- Are other members of my family at risk of developing MDS?
- What is anaemia?

Tests

- Do I need any further tests?
- What will more tests tell us?
- Are the tests performed here?
- Will I need a bone marrow biopsy?
- When will I get the results?
- How will I get the results (over the phone, at the next appointment, etc.)?
- Can you explain my pathology report (laboratory test results) to me?
- What follow-up tests will I need, and how often will I need them?

Prognosis and evolution

- How bad is this MDS?
- How high is the risk that my illness will develop into leukaemia?
- What symptoms will the MDS cause?
- Will the treatment cure the MDS or just control it and manage symptoms?
- How long do people with my type of MDS usually live?
- Is the treatment going to improve my chances of longer survival?
- How likely is it that the treatment will improve my symptoms?

- Is it worth going through treatment?
- Will the treatment or illness reduce my sexual drive?
- Is there anything that I can do to help myself? e.g. diet, work, exercise?
- If I get new symptoms or side effects or existing ones worsen, what should I do?

Treatment options

- Is it necessary to have treatment right now?
- Do I have a choice of treatments?
- What are the pros and cons of each treatment option?
- What can I expect if I decide not to have treatment?
- How much time do I have to think about this?
- What is your opinion about the best treatment for me?
- Will I need chemotherapy?
- Will I need a bone marrow transplant?
- Will I need any additional treatment after this?

Treatment plan

- What is the treatment schedule, e.g., how many treatments will I have, how often, and for how long will I have treatment?
- Where will I have the treatment?
- Do I need someone to come with me?
- What are the dos and don'ts while having treatment?
- What are the side effects?
- Will I lose my hair?
- Are there long-term side effects from the treatment?

Clinical trials

- What are clinical trials?
- Are there any clinical trials that might be relevant for me?
- Will I be treated any differently if I enrol in a trial?

The team

- Who will be coordinating my overall treatment and follow-up care?
- Whom should I call with questions or concerns during non-business hours?

Support

- Where can I find more information about my MDS? E.g., its treatment, or clinical trials?
- Are there any complementary therapies that you believe may be helpful?
- Are there any complementary therapies that would be bad for me?
- Is there someone I can talk to who has been through this treatment?
- Are there services/support groups that can help me and my family deal with this illness?
- Will I be able to work, exercise, and perform my usual activities?
- Will I be able to eat as usual?
- Can you recommend a social worker to help me find support services?