

Myelodysplastic syndrome

Your guide to best cancer care



About this guide

Being told you have or could have myelodysplastic syndrome (MDS) can be overwhelming. A lot can happen quickly, and you might have many questions. This resource can help to guide you, your family and friends through this experience.

Information and support

For more information about MDS, visit the Leukaemia Foundation website www.leukaemia.org.au/MDS.

Cancer Council: For information and support, call **13 11 20** to talk to an experienced health professional or visit www.cancer.org.au.

Leukaemia Foundation: To speak with an experienced health professional who can provide you with disease-specific information, answer questions, talk through concerns and connect you to blood cancer support groups call **1800 620 420** or visit www.leukaemia.org.au. The team can also help with practical concerns such as accommodation close to treatment, transport to appointments and financial assistance.

More information is available in the 'Resource' section of the optimal care pathway for MDS www.cancer.org.au/OCP.

Translating and Interpreting Service (TIS): If you need a translator, call TIS on **13 14 50** or visit www.tisnational.gov.au.

Initial tests and referrals

Symptoms

Your general practitioner (GP) or other primary care physician will do a check-up to see if they can find out what is making you unwell. They will ask about any symptoms you might be having such as persistent tiredness and fatigue, weakness,

shortness of breath with minimal exercise, easy bruising, a rash of small red dots, mouth ulcers, and recurring infections, especially chest infections.

Initial tests you may have

Physical examination. This is to check for signs and symptoms of MDS.

Blood test. A sample of your blood is collected and sent to a laboratory for testing.

Referrals

If your GP thinks you may have MDS, you will be referred to a haematologist or medical oncologist (specialist) at a public hospital or in private practice for more tests. Haematologists are doctors highly trained in conditions that affect blood and bone marrow.



It can help to have a family member, carer or friend attend appointments with you.



Let your doctor know what is most important to you in a specialist (e.g. that they specialise in MDS, cost, location, bedside manner, expertise).



Timeframes

The timing of your specialist appointment will depend on the initial results of tests performed by your GP. For most people an appointment **within four weeks is appropriate**. If you require urgent referral, your appointment should happen **within two weeks**.

If you can't get an appointment within these timeframes, follow up with your GP.



Ask your GP to recommend trusted sources of information and support – you can share these with your family and friends too.



Talk to your GP/specialist about how to manage other health conditions you may have during your blood cancer treatment and let them know if you have any concerns.



Questions you might want to ask

- Are there any symptoms that I should watch out for while I am waiting for my appointment to see a specialist?
- Can I choose the specialist I see?
- What emotional and mental health support services are available and how do I access them?
- Can I choose whether I go to a public or private hospital?
- What are the differences of being treated in the public versus private system?



It's a good idea to keep a written diary or digital record of treatment details and appointments with your GP and specialists. You can ask permission to record your appointments. It's also helpful to bring a list of questions and ask for a written treatment plan.



Don't ignore new signs and symptoms. Alert your GP or specialist. Trust yourself. It's OKAY to be persistent.

Travel to access tests, treatment and care

You may have to travel to see a specialist, undergo tests or access treatment, especially if you live in a rural or regional area. In some cases you may have to leave home for an extended period of time. Accommodation and transportation support services are available and it is encouraged to have family support with you whilst you undergo treatment.

Mental health and emotional wellbeing

A blood cancer diagnosis can affect your mental and emotional wellbeing. Patient support organisations, your GP or another health professional (e.g. a psychologist or social worker) can help you process your diagnosis and develop strategies to cope. They can help you access a mental health treatment plan if required.

Diagnosis and treatment planning

Your haematologist/specialist will do more tests to see if you have MDS, to check how advanced it is and to help determine the best treatment for you.

An MDS diagnosis is confirmed by a **bone marrow biopsy**. A small sample of bone marrow is taken from the back of your hip/pelvic bone under local anaesthetic and, in some cases, under light sedation. The samples are sent to a laboratory for examination to see if there is any blood cancer detectable and in some instances for further specialised testing.



Timeframes

You should generally have results back **within two weeks**. Other specialised tests may take longer.



Questions you might want to ask

- What is MDS and where can I find more information about it?
- What tests will I need and why?
- Will my follow-up appointments be face-to-face or by tele/videohealth or a combination?
- What's my prognosis?
- How much will appointments and tests cost and how much will I have to pay myself?
- Can I choose where I have treatment?
- Will I need to start treatment straightaway?
- How long will treatment last?
- Can I choose the type of treatment available for me?
- Is there information that I can share with my family or friends?
- What support services are available to me?
- Do my family members need to be tested?

Treatment

Your specialist will talk to you about your treatment options for MDS. You may be treated by a team of experts, and you may need more than one treatment type to get the best results. The team will work with you and your family or carer to plan your treatment.

You may have one or a combination of these treatments:

- **Supportive therapies.** Required by all people with MDS, these therapies help keep your organs functioning properly and may include things like transfusions of red blood cells and platelets and treatments to help prevent infections.
- **Chemotherapy.** Drugs are used to kill cancer cells and stop the cancer growing.
- **Targeted therapy.** This uses drugs to attack specific features of cancer cells and stop the cancer growing.
- **Immunotherapy.** This is a type of cancer treatment that helps the body's immune system fight the cancer.
- **Allogeneic bone marrow transplant.** This replaces the blood-forming cells that have been destroyed during intensive chemotherapy or radiotherapy. Stem cells are collected from the blood of a suitable donor. These stem cells are cells that help the body grow new healthy blood cells. When your chemotherapy is finished, the stem cells that were collected are injected into your bloodstream through a drip into a vein. This is only used in rare cases and will not be the first treatment used.

For more information visit www.cancer.org.au/cancer-information/treatment.

Supportive care (treatment or services that support you through a cancer experience) are also available, often delivered through a multidisciplinary team that may include nurses, pharmacists, psychologists, physiotherapists and dietitians.



Timeframes

By evaluating your symptoms and test results, your specialist will determine when treatment should start. Treatment for MDS will generally start **within six weeks**. If you're a candidate for a stem cell transplant you should be referred to a bone marrow transplant specialist as soon as possible.

Clinical trials

Your specialist may recommend participating in a clinical trial (or you can ask if you are eligible for any clinical trials). Clinical trials often provide access to promising new treatments that are not yet available to the general public. Many people with cancer are now living longer, with a better quality of life, because of clinical trials.

For more information visit www.australiancancertrials.gov.au or <https://anzchog.org/clinical-trials-research/clinical-trial-initiatives/>, or search the Australian New Zealand Clinical Trials Registry www.anzctr.org.au.

Complementary therapies and other medications

Speak to your healthcare team about any dietary supplements, vitamins, herbal remedies and other medications that you use or would like to use, including prescription and over-the-counter medicines (e.g. paracetamol or ibuprofen). Some medicines and complementary therapies might not work well with your treatment.

Fertility and sexual health

Blood cancer and blood cancer treatment may cause fertility problems. This will depend on age, the type of blood cancer and the treatment received. If this is relevant, get advice from your treating team about contraception before, during and after treatment. Discuss having children whilst undergoing treatment and the need for a referral to a fertility specialist and options for fertility preservation before starting treatment. Diagnosis and treatment may affect your sex life or overall sexual health. For support and, if necessary, referral to counselling services, contact the Leukaemia Foundation on **1800 620 420** or visit www.leukaemia.org.au and type 'Relationships and sex' in the search bar.



You can ask for more time to think about your treatment options.



You can ask your GP for a referral to another specialist for a second opinion.



Questions you might want to ask

- What treatment do you recommend and why?
- Are there alternatives?
- What will happen if I don't have treatment?
- How long will I need to be on treatment?
- What will treatment cost and how much of the cost will I have to pay myself?
- What activities/exercise will help me during and after treatment?
- Is there any specific diet I should follow or foods or drink to avoid during treatment?
- How will the treatment affect my day-to-day life and can I still work?
- Who is in my treatment team and who is the main contact person if I have any questions or feel unwell?
- What side effects could I have from treatment and how should I manage them?
- Will treatment affect my ability to have children and, if yes, what options should I consider?



Decisions about cost

You may have to pay for some appointments, tests, medications, accommodation, travel or parking.

Speak with your GP, specialist or private health insurer (if you have one) to understand what is covered and what your out-of-pocket costs may be.

If you have concerns about costs, talk to your healthcare team or a social worker about:

- being bulk-billed or treated in the public system
- help with accommodation and/or transport during treatment
- the possible financial impact of your treatment and financial support schemes you may be able to access
- how your treatment might affect your ability to work.

For more information about costs, call the Cancer Council on **13 11 20** or visit www.cancer.org.au/support-and-services/practical-and-financial-assistance. You can also contact the Leukaemia Foundation on **1800 620 420** or visit www.leukaemia.org.au/how-we-can-help/practical-support-services.

Care after initial treatment

Treatments for MDS are generally not curative so you will need ongoing support, treatment and specialist care.

Transitioning to shared care models of treatment and a survivorship care plan

In some cases you may need ongoing hospital-based care. In other cases, a shared follow-up care arrangement with your GP may be appropriate. Your specialist and healthcare team will work with you to make a plan for you and your GP. This plan will explain:

- who your main contact person is
- how often you should have check-ups and what tests this will include
- understanding and dealing with the potential side effects of treatment
- how to look after your overall health and wellbeing
- what healthcare and community support services are available to you and how to access them.

For more information visit www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment.



Questions you might want to ask

- Who should I contact if I'm feeling unwell?
- What can I do to be as healthy as possible?
- Where can I get more help?

Living with relapsed or progressive disease

MDS is often incurable and will come back (relapsed disease) or may develop into another cancer (progressive disease).

Treatment will depend on the extent of how far the cancer has progressed, how fast-growing it might be, the symptoms you are experiencing and what your preferences are.

Options may include:

- participating in a clinical trial where you may try a new treatment
- treatment for MDS that has developed into acute myeloid leukaemia.



Questions you might want to ask

- What are my treatment options?
- What are the chances that the treatment will work this time?
- Is there a clinical trial available?
- What financial, practical or emotional support is available?

Advance care planning

Your GP or healthcare team may talk with you, your family and carer about your future treatment and medical needs.

Advance care directive

Sometimes known as a living will, an advance care directive is a legally binding document that you prepare to let your family and medical team know about the treatment and care you might want or not want in case you become too unwell to make those decisions yourself. For more information visit www.advancecareplanning.org.au.

Symptom and palliative care management

Palliative care can help you to live as well as you can including managing pain and symptoms, psychosocial support and assistance in identifying care goals. This care may be at home, in a hospital or at another location you choose. Your specialist may refer you to palliative care services, but this doesn't always mean end-of-life care. Today people can be referred to these services much earlier if they're living with blood cancer or if their blood cancer returns.

Speak to your GP or haematologist/specialist or visit www.palliativecare.org.au.

Making treatment decisions

You may decide not to have treatment at all, or to only have some treatment to reduce pain and discomfort. You can always change your mind about your treatment. Just talk to your specialist. For more information visit www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment.



Questions you might want to ask

- What can be done to reduce my symptoms?
- What extra support can I get if my family and friends care for me at home?
- Can you help me to talk to my family about what is happening?
- What range of palliative care services are available for me?
- What support is available for my family or carer?
- Can I be referred to a community support service?

Disclaimer: Always consult your doctor about matters that affect your health. This guide is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities. While all care is taken to ensure accuracy at the time of publication, Leukemia Foundation and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided above.

Published in July 2022.

This resource is based on information from the optimal care pathway for people with myelodysplastic syndromes (1st edition), available at www.cancer.org.au/OCP.