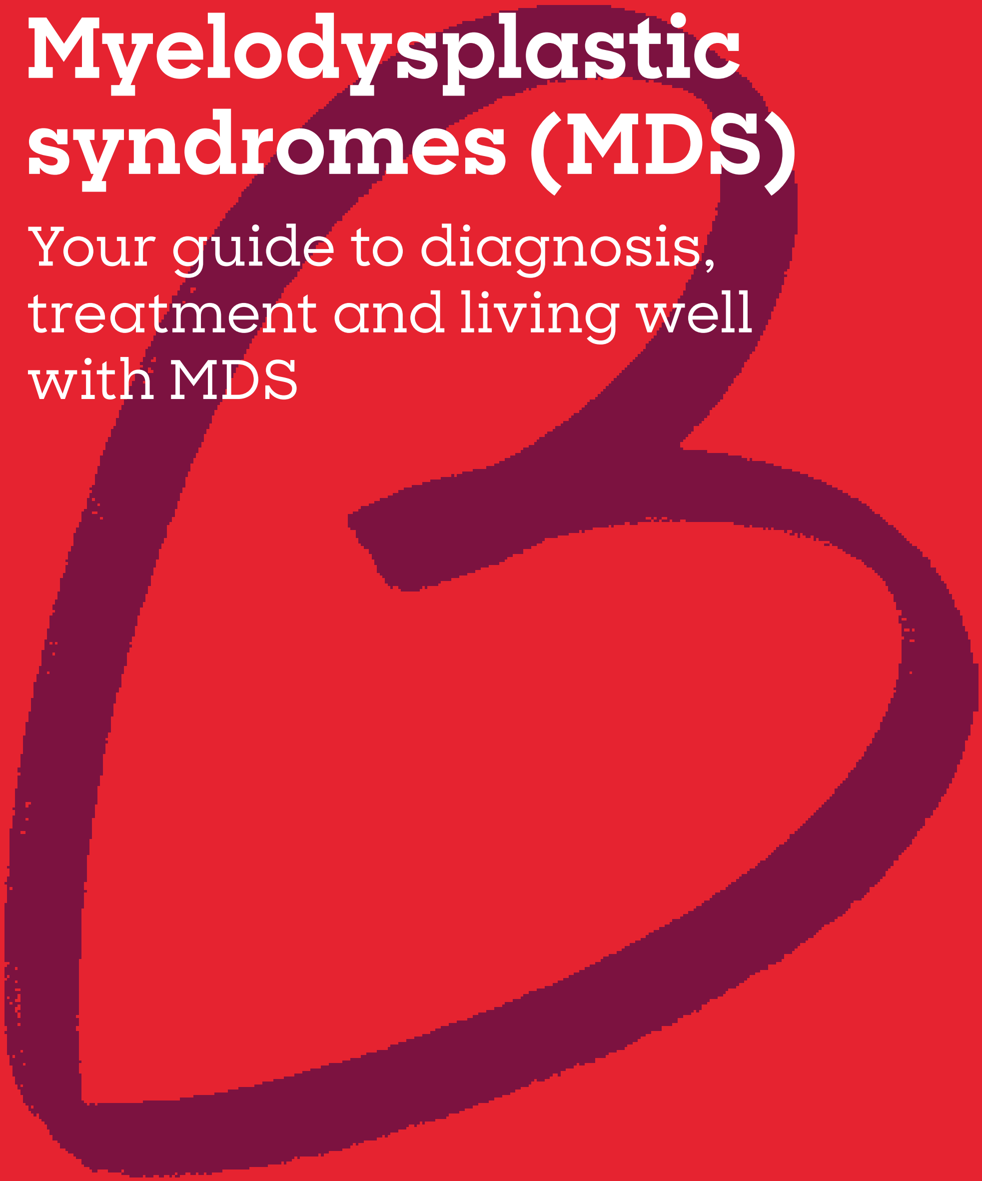
Myelodysplastic syndromes (MDS)

Your guide to diagnosis, treatment and living well with MDS



Blood
cancer
UK

Need to talk?

Contact the Blood Cancer UK Support Service with questions or worries about your diagnosis, family, work, mental health, the future.

Call free on **0808 2080 888**
(Monday: 10am to 7pm, Tuesday to Friday: 10am to 4pm and Saturday and Sunday: 10am to 1pm)
Email **support@bloodcancer.org.uk**
Visit **bloodcancer.org.uk**
Talk to others **bloodcancer.org.uk/our-forum**
Order this booklet in print **bloodcancer.org.uk/our-booklets**

We're the UK's specialist blood cancer charity, supporting anyone affected by any blood cancer. Family and friends can contact us for support too.

My diagnosis and care

Ask your doctor or nurse to help you fill in this page about you, your diagnosis and key contacts:

My diagnosis is:

....

My hospital number is: ....

My NHS number is: ....

My main point of contact (key worker) is:

Name: ....

Role: ....

Phone no: ....

Email: ....

You should be given a key worker. Ask if you're not sure who this is, or call us.

My consultant's name is:

....

Haematology ward/clinic: ....

Phone no: ....

If I need medical help outside normal hours, I can call:

Name of service: ....

Phone no: ....

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Finding out you have MDS

If you've been diagnosed with MDS, this booklet is for you.

MDS is a type of blood cancer where your body doesn't make enough healthy blood cells. For most people, getting a diagnosis of MDS will come as a shock. And it can be scary to hear you have a type of cancer.

We have written this booklet with people who know what it's like to live with MDS. It aims to give you the basics, so you understand a bit more about what having MDS might mean for you.

Don't feel you have to read it all at once. Keep it handy so you can come back to it when you're ready. You could also show it to others to help them understand.

You can order more free copies for your family and friends from **bloodcancer.org.uk/our-booklets**

> **The doctor explained what MDS was, but I was too shocked to take it in. I found reading about it, and contacting charities like Blood Cancer UK, helped me understand the diagnosis.**
> Tony, diagnosed with MDS in 2020

Is it normal to feel how I'm feeling?

People have different experiences of diagnosis. Some people are diagnosed with MDS after a routine blood test, so they may not have known there was anything wrong. Others may have had health problems for some time and struggled to get answers.

No matter what your experience of diagnosis has been, the news can be life-changing and a lot to get used to. People talk about feeling stunned, sad, angry, scared, numb...and it can change from minute to minute. So whatever you're feeling right now is normal. And you're not alone.

There are around 40,000 people diagnosed with blood cancer every year in the UK, and around 2,150 of them have MDS. So there are other people who will understand what you're going through. You might find it helpful to connect with some of them on our online forum at **bloodcancer.org.uk/our-forum**

> **Finding the Blood Cancer UK Forum, and the welcome I got on there, was hugely important to me. I met other people who really understood what I was going through.**
> Peter, diagnosed with MDS in 2017

The next steps

It's useful to know what will happen next after you've been diagnosed, but it can be hard to take in what your doctor or nurse has told you. Don't be afraid to ask questions and ask them to go over things again. In the meantime:

1. **You should be given contact details of a key worker**, your main point of contact in the hospital team. Usually, this is a clinical nurse specialist (CNS). Ask who your key worker is so you can contact them if you have questions.

2. **You may have more tests** to find out more about the MDS, whether you need treatment straight away, and what treatment will work best for you. Ask your hospital team what the tests are for and if you're likely to have them again.

3. **Your hospital team will explain your treatment plan** or how you will be monitored if you don't need treatment yet. Ask any questions you like, including how the treatment or your symptoms will affect everyday things like driving, working, housework and gardening. It's also OK to ask for another appointment. Most people need more than one to take it all in.

Some people don't feel confident about talking to their hospital team at first. If you find this difficult, contact our Support Service who can give you tips on how to build a relationship with your team.

Checklist of things you can do

Here are some practical things you can do to make life a bit easier in these early days:

☐ Contact our Support Service to talk through your diagnosis and what comes next.

☐ Try not to google – the information can be out of date, misleading and unnecessarily worrying.

☐ Put all your appointments in a diary or calendar so you know what's coming up.

☐ Decide how you will get to face-to-face appointments and consider taking someone with you if you can.

☐ Get a folder so you can keep medical letters and health information in one place.

☐ Keep a list of questions to ask at your next appointment or to email to your CNS (see page 13 for suggestions).

☐ Choose books, magazines, podcasts or videos to give you something to do if you have to go to hospital.

☐ If you need to, think about who could help you with things like shopping, cooking, gardening, housework, childcare or caring for someone else.

☐ Follow general advice on healthy eating and ask your hospital team about ways to stay active.

If you need to talk

If you want to talk about what your diagnosis means, how you’re feeling or what to do next, contact our Support Service free on **0808 2080 888** or **support@bloodcancer.org.uk** and tell us that you’ve just been diagnosed with MDS.

Or talk to people who’ve been where you are now on our online community forum: **bloodcancer.org.uk/our-forum**

Telling people about your diagnosis

When they hear your news, most people will be supportive and offer help. But here are some tips if you have to handle some more difficult reactions:

- **If people get upset** – Acknowledge their feelings, and let them know how you feel too. If you end up having a cry together, that's fine!
- **If people don't know what to say or say nothing** – Next time you see them, bring up the subject so they know it isn't something they need to avoid. Then move the conversation on to other things.
- **If people say unhelpful things** – Point them to the Blood Cancer UK website or give them a copy of this booklet so they'll understand more about what it's like living with MDS.

Don't be afraid to tell people how you want to be treated. Most people just want others to behave as normal.

It's perfectly OK to let people know when you want to talk about your health, and when you would rather talk about other things.

Telling children

The first thing is to decide whether you want to say anything. You may decide that the children you're close to don't need to know right away. Or you may think it's better to explain what's happening. That may depend on their age, the relationship you have with them, how you're feeling and whether your diagnosis is likely to affect their routine.

Many people say it's best to be as honest as you can. Children of different ages can react in different ways, but our Support Service can recommend some age-appropriate resources to help you.

There's a story on our website from Simone, about how she told her family, including children, that she had blood cancer: **bloodcancer.org.uk/simone**

Other people with blood cancer will share their experiences with you at **bloodcancer.org.uk/our-forum**

> **I didn't tell my family right away. But once I told them, it felt like therapy. I'd been holding this big burden inside, so it was such a relief to let my loved ones know.**
> Kal, diagnosed with MDS in 2019

Telling your workplace

You don’t have to tell your employer about your diagnosis, but you might want to, even if you don’t need treatment.

Telling them means you can discuss adjustments to help you deal with MDS symptoms such as tiredness (fatigue). See page 76 for some examples of adjustments that might help you carry on working, and information about your rights as someone with cancer.

You might also benefit from a workplace risk assessment, as you’re likely to be at risk from infections like covid-19 or flu.

If you want other people at work to know about your diagnosis, you can ask your line manager or HR team to tell work colleagues. Or tell them yourself, it’s your choice. Your employer can’t tell anyone without your permission.

> **If your employer knows what you’re going through, you may feel more comfortable in telling them when you need a day off, or when you need time to rest.**
> Peter, diagnosed with MDS in 2017

Questions to ask after your diagnosis:

It can be hard in the early days to know what questions to ask your hospital team, so here are some suggestions. There's also space to write your own on pages 85 to 87.

Questions about MDS:

- Can you explain what type of MDS I have?
- How is my type of MDS likely to affect me?
- You mentioned [any medical term]. What does that mean?

Questions about tests:

- Will I need more tests?
- What are the tests for?
- Where will I have the tests?
- How will I get the results?

Questions about treatment:

- Do I need treatment?
- If I need treatment, when is that likely to start?
- What kind of treatment will I have?
- What is the aim of treatment?
- If I don't need treatment, what happens next?

Understanding MDS

Many people find it helps them feel more in control to learn about what MDS is and how it can affect them.

People often talk about having to learn a whole new language when they're diagnosed with MDS. Different people have different feelings about how much they want to research and read up on their condition, and that's a personal choice. But most would agree there are some things it's good to know from the start.

Knowing more about MDS can also make you feel more confident about asking questions so you can get more out of your appointments.

This chapter gives you a very brief summary of what MDS is, the effect it can have on the body and how it can develop.

> **It can be really hard to think of questions when you're first diagnosed and you know nothing about MDS. It's OK to take some time to process the news, and then ask for another appointment.**
>
> Ally, diagnosed with MDS in 2008

What is MDS?

MDS stands for myelodysplastic syndromes. It is a type of blood cancer where your bone marrow does not work properly and makes faulty blood cells. Bone marrow is the spongy tissue inside some of our bones where blood cells are made.

You might hear MDS called myelodysplasia. Myelo means bone marrow and dysplasia means abnormal cells.

There are several different types of MDS. Your doctor can explain what type of MDS you have and how it's likely to affect you. You can also read about the different types of MDS on our website at **bloodcancer.org.uk/mds-types**

Blood cells and MDS

All blood cells start from special cells in the bone marrow called stem cells. In healthy bone marrow, the stem cells develop into immature cells called blasts, before turning into mature blood cells.

The three main types of mature blood cell are:

- red blood cells that carry oxygen around the body
- white blood cells that fight infections
- platelets that prevent bleeding.

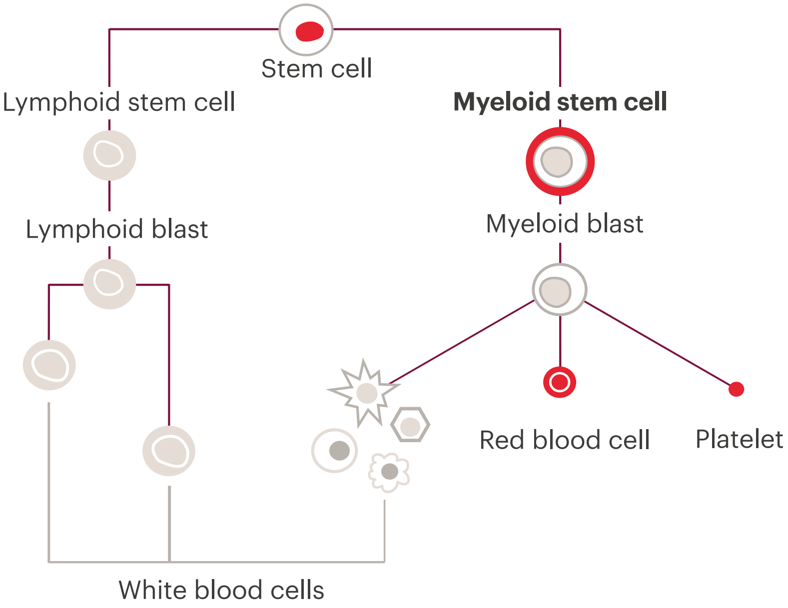
Once blood cells are fully grown, they are released into the bloodstream to do their jobs in the body.

There are two types of blood stem cell: myeloid stem cells and lymphoid stem cells. When you have MDS, some of your myeloid stem cells don't develop properly into healthy blood cells. Instead, they stay at the immature blast stage or develop into abnormal blood cells that don't work the way they should.

This means you don't have all the healthy blood cells you need in your bloodstream. This is what causes the symptoms of MDS.

Your hospital team will regularly check your blood counts (the number of each type of blood cell in your blood). You can read more about blood counts on pages 25 to 26.

How stem cells grow into blood cells:



How does MDS affect the body?

The effect MDS has on your body depends on which types of blood cells are reduced and by how much. Some people with MDS only have low levels of one type of blood cell. Others might have low levels of two or all three types of blood cell.

Anaemia

Anaemia is the medical name for a low level of red blood cells. It's a common symptom of MDS, and can make you feel weak and tired (fatigue), breathless or dizzy.

Infections

Having a low number of healthy white blood cells in your blood can make you more likely to get infections. It can also make it harder for your body to fight infections. Infections can get serious quickly, so it's important to know the signs of an infection so you can get treatment. See page 69.

Bruising and bleeding

If you have a low number of healthy platelets in your bloodstream, this can make you bruise and bleed easily. You might notice you have frequent nose bleeds or bleeding gums. If you have periods, they may be heavier and last longer than usual.

Managing symptoms

You might not have any symptoms when you are diagnosed with MDS. But let your hospital team know if you notice any symptoms, even if you're not sure if they're related to the MDS. There are effective treatments to help.

Kal

How did you feel when you were diagnosed with MDS?

“When the doctor started talking about myelodysplastic syndrome, and saying it was a form of blood cancer, it felt like she must be talking about someone else, not me. I thought if I had cancer I’d feel more ill, not just tired.”

Read Kal’s story at **bloodcancer.org.uk/kal** or call us and we’ll post it to you.

What does the future look like?

After you’ve been diagnosed with MDS, you may want to know more about your prognosis – what’s likely to happen in the future.

MDS can sometimes be cured with a stem cell transplant. But this treatment is not suitable for everybody as it can have serious side effects. For most people MDS cannot be cured, but it can be controlled and often improved with treatment.

How does MDS progress over time?

The way MDS develops over time is different for each person. For some people, MDS develops very slowly and stays the same for many years. For others, it develops much faster and can make them very ill, as more blood cells are affected over time.

Sometimes, MDS can turn into a fast-growing type of blood cancer called acute myeloid leukaemia (AML). For some people with MDS, the risk of developing AML is very low, while for others the risk is higher. Overall, for every 10 people with MDS, seven or eight will never develop AML, and two or three will.

Nobody can know exactly what will happen for you as an individual, but your doctor will do their best to predict how the MDS is likely to develop. The main way they do this is by working out your MDS risk group.

MDS risk groups

Your doctor might explain you have lower risk or higher risk MDS. Or they might go into more detail and talk to you about your MDS risk group. The system many doctors use to work out risk splits people with MDS into five risk groups: very low, low, intermediate, high and very high.

Your doctor works out which group you are in by looking at:

- your blood count results
- the number of immature cells (blasts) in your bone marrow
- the genetic test results from your bone marrow.

Some doctors have also started using a newer system, which uses more detailed genetic information. The risk groups in this system are similar to the ones above, but the ‘intermediate’ group has been replaced by two groups called ’moderate low’ and ’moderate high’.

The level of risk describes how slowly or quickly the MDS might develop, and the risk of it turning into AML.

Your doctor can explain which risk group you are in, and how this affects your treatment and prognosis.

Leukaemia Care and MDS UK Patient Support Group have a booklet about MDS with more detail about the sub-types of MDS and the different risk groups. See page 81 for their contact details.

Asking about prognosis

If you want to know about your prognosis, your medical team are the best people to ask. They know you and your individual situation. Your prognosis will be affected by things that are unrelated to the MDS, including your age and general level of fitness.

You could ask questions like:

- What is my MDS risk group, and what does this mean?
- How likely is it that the MDS can be cured?
- What is the best outcome I can expect?
- I want to plan for an important event in the future (for example a wedding or a grandchild being born). Do you think I will be able to be there?

If you look up statistics, be aware these are often not explained fully and can be misleading. Many people find statistics unhelpful, but if you do want to look at them, you should always discuss them with your doctor, who can explain what they mean for you.

> **Remember what you read online can't tell you what will happen to you as an individual. Every person is different, and the statistics you read online do not necessarily apply to you.**
> Peter, diagnosed with MDS in 2017

If you want to know more

You can read more about MDS prognosis and risk groups at **bloodcancer.org.uk/mds-prognosis**

Leukaemia Care and MDS UK Patient Support Group have a booklet with more detail on how doctors calculate risk scores and survival averages, if you want to know this. See page 81 for contact details.

If you read something about prognosis that worries you, contact our Support Service to talk it through.

Tests you may have

Doctors use tests to help them diagnose MDS, work out your risk group and decide on the best treatment. You'll also have tests to monitor the MDS and check how well any treatment is working.

Blood tests

You'll have regular blood tests to check if the MDS, or the treatment, is affecting your healthy blood cells. You may also have blood tests to check your general health.

Bone marrow biopsy

A bone marrow biopsy means removing samples from your bone marrow to look at under a microscope. You've probably had one already, to confirm the diagnosis of MDS. Sometimes your doctor might ask you to have more bone marrow biopsies to see how the MDS is responding to treatment.

> **I've had two bone marrow biopsies. The teams doing them were very helpful and caring, explained everything that was going on and minimised any pain as much as possible.**
>
> Tony, diagnosed with MDS in 2020

Understanding your test results

These are some of the terms you might hear when talking to your hospital team about your test results.

Blood counts

A blood count means the number of each type of blood cell in your blood. MDS usually causes at least one of your blood counts to be lower than normal. You might hear your doctor mention cytopenias – this is the medical name for low blood counts.

If you're healthy, your blood counts will usually be within the ranges we mention below. But healthy blood counts can vary depending on your sex, age and ethnicity. For example, people of African Caribbean heritage have slightly lower blood counts than people who are white. Ask your medical team what your blood test results and numbers mean, because they know what's normal for you.

The most useful blood counts to know about for MDS are:

Haemoglobin (Hb) – This is a substance found in red blood cells that carries oxygen around the body. In someone healthy, this level can range from 115 to 180 (measured in grams per litre).

Platelets – These cells help the blood to clot, to prevent uncontrolled bleeding. In someone healthy, the level of platelets can range from 150 to 400 (measured in billion cells per litre).

White blood cells – This count measures the total number of all the different types of white blood cell in your blood. In someone healthy, this level can range from 4 to 11 (measured in billion cells per litre).

Neutrophils – Neutrophils are an important type of white blood cell that help to fight infections. For a healthy person, the level can range from 2 to 7.5 (measured in billion cells per litre).

Blasts

Blasts are very young blood cells. They are normally found in the bone marrow, where they grow into mature blood cells, before moving into the bloodstream to do their jobs in the body – see page 17.

In some types of MDS, the body makes too many blasts and they don't develop properly into mature blood cells. These faulty blasts can build up in the bone marrow and blood.

Your doctor might use blood tests and bone marrow biopsies to measure how many blasts you have. If the number of blasts increases, this could be a sign that the MDS is progressing.

Genetic test results

Your doctor will arrange for your bone marrow sample to be tested for genetic changes in your blood cells. This can give important information about how the MDS might progress and which treatments to use. Your doctor will explain what the results mean.

More information

You can read more about blood tests and bone marrow biopsies at:
bloodcancer.org.uk/tests

Waiting for test results can be a worrying time. If you have any questions, or just want someone to talk to, contact our Support Service free on
0808 2080 888 or
support@bloodcancer.org.uk

If you don’t need treatment

Because MDS is often slow growing, many people don't need treatment straight away. Some people don't need any treatment for many years.

If your doctor doesn't think you need treatment for MDS, you'll go on watch and wait. This means you'll have regular check-ups to monitor the MDS.

You may also hear this approach called watchful waiting or active monitoring. Some people think active monitoring is a better description because it makes it clearer that your doctor is actively involved in your care, even if you don't need treatment.

It can be hard to find out you have blood cancer but won't be having treatment right now. This chapter aims to answer key questions and help you manage your physical and emotional health while you're on watch and wait.

> **It's always in the background, but I don't let it dominate my life. I'm still active, I still cycle, walk and play golf. I get tired, but I have a good quality of life.**
> Tony, diagnosed with MDS in 2020

Why am I waiting for treatment?

Your doctor might recommend watch and wait if you have lower risk MDS and you have few or no worrying symptoms. Saving treatment for later is safe in this situation and means the treatment will have more impact if you need it later. You'll also avoid potential treatment side effects for as long as possible.

But being on watch and wait can be tough emotionally. It might feel strange to be told you have blood cancer but don't need treatment. It can be hard to explain to others, and people often say their anxiety level rises as their next check-up comes nearer.

We have printed information to help you understand watch and wait and explain it to others. You can order or download this from **bloodcancer.org.uk/watch-wait-booklets**

If you feel anxious

Talk to your doctor or nurse if you feel anxious about being on watch and wait. They may be able to reassure you about some of your concerns. They can also refer you for counselling or other professional support, which many people find helpful.

The chapter on living well with MDS (see page 60) has more information and tips on looking after your emotional and physical health.

What will happen at my check-ups?

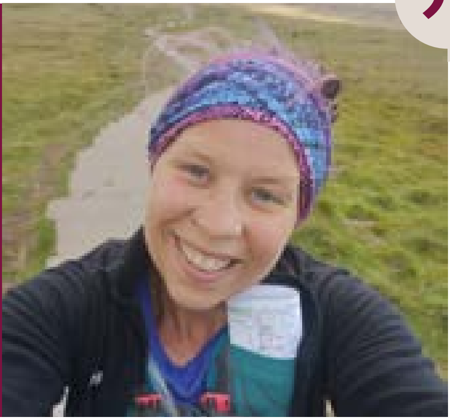
Your check-ups will involve blood tests, which may be done at the hospital or at your GP surgery. A nurse or other healthcare professional will take some blood and send it to a laboratory to check the numbers of each type of blood cell.

A nurse or doctor will also ask you if you have any symptoms, like tiredness, feeling breathless, bruising or bleeding easily. Make sure you tell them about any changes in your symptoms, and any worries you have.

It's getting more common now to discuss your test results by phone or video call, which many people find convenient. But you can ask to have your appointments face to face if you prefer.

Ask your doctor or nurse who you should contact if you have any concerns in between appointments. There's space to write their contact details at the front of this booklet.

> **You know your body best, so trust your instincts. If you've had a change in how you're feeling between blood tests, like feeling more tired or getting more bruises, then contact your hospital team.**
>
> Emma, diagnosed with MDS in 2011



Waiting for your test results

It's natural to think or worry about test results before you get them. Here are some tips for managing this:

- **Distract yourself** – Get engrossed in an activity you enjoy, something that's achievable but needs a bit of mental or physical effort, or both. This might be a DIY or craft project, an exercise programme, gardening or reading.

- **Unwind and relax** – If you find it difficult to concentrate, something that needs less effort might work better, like watching TV shows or films, reading magazines or chatting to friends about other things. Anything that will take your mind off your worries for a period of time will help.

- **Say your worries out loud** – You might prefer the more direct approach of talking through the possible outcomes of your test results and your feelings about them. Expressing your worries out loud can often help you manage them.

- **Techniques for managing anxiety** – If you've experienced anxiety in the past, you may already know some self-help techniques you can use. If not, or you need a reminder about different things to try, you'll find a range of ideas at **bloodcancer.org.uk/mind-emotions**

Anxiety around waiting for test results is a common topic of conversation for people who call our Support Service. Contact us if you want to talk things through.

Will I need treatment in the future?

Many people stay on watch and wait for years without needing any treatment. You won't start treatment until your doctor thinks it's the right time.

Each time you have a check-up, your doctor will be looking for signs that show whether the MDS is progressing and needs treatment. They will look for changes in your blood test results, like your blood counts going down.

They will also want to know if you are having any symptoms. Low blood counts on their own don't always need treatment. But if you have low blood counts and are also having symptoms this could be a sign you need to start treatment.

Keep a record of how you feel

Many people find it helpful to note down how they've been feeling in a symptom diary. This helps you notice if anything changes and makes it easier to report any symptoms to your doctor.

It's important to tell your doctor if anything changes. It doesn't always mean the MDS is progressing – your doctor will look at a range of things before deciding whether you need treatment.

Coping with your feelings

It's natural to have mixed feelings about being on watch and wait. On the one hand, it's good that you don't need treatment. With a few adjustments, you should be able to carry on with life as before.

On the other hand, it's hard to take in, and explain to others, that you have cancer but aren't being treated for it. And waiting for test results or looking out for new symptoms can cause a rollercoaster of anxiety.

Managing difficult feelings

Some people talk about feeling like a 'fake' cancer patient. Others say they feel they're not in control, because they don't know if and when they'll need treatment.

There are things you can do to manage these difficult feelings. You'll find a checklist of simple things to do to protect your mental health on pages 63 to 65 and more things to try at **bloodcancer.org.uk/mind-emotions**

It can help to read how other people with blood cancer cope with being on watch and wait. You can read Kate's story on our website at **bloodcancer.org.uk/kate** or call us and we'll post you a copy.

More information

You'll find more information at
bloodcancer.org.uk/watch-and-wait

We also have printed information to help you understand watch and wait and explain it to others. You can order or download our free factsheets from **bloodcancer.org.uk/watch-wait-booklets** or by calling **0808 2080 888**.

You can get support from other people on watch and wait at **bloodcancer.org.uk/forum**

Questions to ask about watch and wait

It's a good idea to write down questions for your hospital team or GP. Many people say their mind sometimes goes blank when they're in an appointment, and they don't get the answers they need.

Here are some suggestions for questions to ask about watch and wait, or you can write your own at the end of this booklet:

- Why don't I need treatment?
- When will I need treatment?
- How often will I have check-ups?
- What are the check-ups for?
- What tests I will I have?
- How long will it take to get the results?
- What symptoms should I look out for?
- Who's responsible for my care?
- Who can I contact if I'm worried or feel ill?

> **I used to come out of appointments and realise the doctor hadn't answered my questions. So now I always go with a list of questions and a pen and paper to write down the answers.**
> Ally, diagnosed with MDS in 2008

Finding out about treatment

If you're on watch and wait, you may not want to find out about treatments for MDS just yet. If so, save the next chapter on treatment for another time.

For now, the most important thing is to be aware that if the time comes, there's a range of effective treatments for MDS and more are being developed all the time.

If you do want to know more about what's involved in treating MDS, the next chapter will give you a general overview. When you're ready, you'll find detailed information about the latest treatments for MDS at **bloodcancer.org.uk/mds-treatment**

MDS treatment

The treatment you need will depend on the type of MDS you have, your MDS risk group and your general health

MDS can be very different from one person to another, and people's experiences of treatment can vary a lot too.

Some people just need treatment to manage their symptoms, while others need treatment that aims to control or get rid of the MDS.

This chapter tells you about the different treatment options for MDS. You'll also find information about treatment side effects.

We asked people with blood cancer for their advice on how to cope during treatment. You can read their tips in this chapter as well.

> **Once I knew what treatment I needed I was on autopilot. I was so focused on preparing myself for the chemo and stem cell transplant. I treated it almost like a work project!**
>
> Kal, diagnosed with MDS in 2019

Your treatment team

Your treatment will be planned and managed by a team of doctors, nurses and other healthcare professionals who specialise in blood cancer.

- **As MDS is rare, not all hospitals have a doctor who specialises in it.** If your doctor is not an expert in MDS themselves, they might discuss your case with a specialist from another hospital.

- **Some people find it helpful to see an MDS specialist for an extra opinion**. You can ask your current hospital doctor or GP to refer you if you'd like this. The charity MDS UK Patient Support Group (see page 81 for contact details) has a list of MDS specialists and can give advice about asking for a referral.

- **If you need a stem cell transplant or want to take part in a clinical trial** your doctor might refer you to a different hospital that specialises in this treatment.

> **I was really nervous about asking for a second opinion, but my doctor was fine about it. Now my care is shared between the MDS specialist and my local hospital.**
> Tony, diagnosed with MDS in 2020

What treatment will I have?

If you need treatment, your doctor will talk to you about your treatment options and make a treatment plan with you.

Each person with MDS is different, so not everyone will have the same treatment. Ask your hospital team if you're not sure what treatment you're having, so you can read the right pages in this chapter.

These are the main types of treatment for MDS:

- **Supportive care** – These are treatments that don't target MDS itself but manage the symptoms. Most people with MDS will need supportive care at some point. See pages 42 to 44.

- **Intensive treatment** – This gives the best chance of getting rid of the MDS completely, but it means having strong treatment that can cause lots of side effects, so isn't right for everyone. See pages 46 to 50.

- **Non-intensive treatment** – These are gentler treatments that don't get rid of the MDS, but aim to slow its progress for as long as possible. See pages 52 to 53.

No matter what type of treatment you're having, you'll find information about clinical trials, treatment side effects and questions to ask about treatment at the end of this chapter.

Supportive care

These treatments don't target the MDS itself. Instead, the aim is to control the symptoms of MDS so you can have a better quality of life. Some people with MDS just have supportive care, while others have supportive care along with other types of treatment.

Growth factors

Growth factors are drugs that encourage your bone marrow to make more blood cells. There are different types of growth factors which can increase different types of blood cell.

You usually have growth factors as injections under the skin on your tummy, thigh or upper arm. A doctor or nurse can teach you or a family member to do the injections. Or they can arrange for a district nurse to visit you at home to give them.

> **Ask your hospital team anything you want to know about your treatment. It's their job to make sure you have all the information you need to make decisions about your treatment.**
> Ally, diagnosed with MDS in 2008

Blood transfusions

Many people with MDS need blood transfusions to increase their numbers of healthy blood cells.

There are two types of blood transfusion to treat MDS symptoms:

- **Red blood cell transfusions:** Your doctor might recommend these if your red blood cell count is low and you have symptoms of anaemia like tiredness and breathlessness.

- **Platelet transfusions:** Your doctor might recommend you have a platelet transfusion if your level of platelets is too low and you have bleeding.

  You can read more about blood transfusions on our website at **bloodcancer.org.uk/transfusions**

> “**I found it quite surreal, knowing that someone else’s blood was going into my body. But I really appreciated the transfusions when I needed them, as I felt so much better afterwards.**
>
> Emma, diagnosed with MDS in 2011

Treatment for infections

Having MDS can put you at more risk of getting infections, because the condition and some of the treatments affect your immune system. If you get an infection it can become serious quickly, so it's very important to get treatment fast.

The treatment you have will depend on the type of infection, but could include:

- antibiotics – to treat bacterial infections
- antivirals – to treat infections caused by a virus
- antifungals – for fungal infections

See pages 68 to 69 for more information about infection risk and signs to look out for.

Drugs to prevent infections

If your doctor feels you are at especially high risk of getting an infection, they might prescribe you antibiotics, antivirals or antifungals as a precaution, to prevent infections. This is called prophylaxis.

Drugs to manage iron levels

Red blood cell transfusions contain a lot of iron. If you need frequent transfusions, you may have a build-up of iron in your body.

If too much iron builds up over a long time, this could cause health problems later in life. Your hospital team will monitor your iron levels and can prescribe medicines to reduce them if needed.

Ally

How has learning about MDS helped you?

"When I got the diagnosis of MDS I'd never even heard of it. Learning about it from booklets like this one gave me the confidence to ask my doctor questions."

Read Ally's story at **bloodcancer.org.uk/ally** or call us and we'll post it to you.

Intensive treatment

The aim of intensive treatment is to get rid of the MDS, so your bone marrow can work normally again. It usually means having intensive chemotherapy followed by a stem cell transplant.

Intensive treatment can be tough on the body and cause a lot of side effects. So your doctor will only recommend it if they think you are fit enough to cope with the treatment, and the benefits outweigh the risks.

Intensive chemotherapy

Intensive chemotherapy means using high doses of cell-killing drugs to destroy as many MDS cells as possible. It’s often used to get your body ready for a stem cell transplant, although a small number of people with MDS have intensive chemotherapy on its own.

You’ll have one or more cycles of intensive chemotherapy in hospital. Each cycle is made up of about five to ten days of treatment, followed by three or more weeks for your healthy blood cells to grow back.

When your healthy blood cells have recovered, you’ll have tests to check for MDS cells. If no MDS cells can be seen under a microscope, then you are in remission.

Once you’re in remission, you may go on to have a stem cell transplant (page 48). If you’re not having a stem cell transplant, you may have more chemotherapy to keep you in remission for as long as possible.

More information

To find out more about the drugs you might have during intensive chemotherapy, go to: **bloodcancer.org.uk/mds-treatment**

We have information about research being done to keep improving treatments and find new ones: **bloodcancer.org.uk/research**

Stem cell transplant

Stem cells are very young blood cells, which can grow into new healthy blood cells in your body. A stem cell transplant for MDS involves replacing your stem cells with healthy ones from someone else (a donor). This is called an allogeneic stem cell transplant or an allograft.

You'll have treatment first to get your bone marrow and immune system ready to accept the stem cells. Usually this means having chemotherapy.

When your body is ready, the stem cells will be put into your bloodstream using a tube that goes into a vein. They then travel to your bone marrow and begin growing into new blood cells.

You will need to spend a few weeks in hospital so the staff can take good care of you until you are well enough to go home.

A transplant is an intensive treatment that can have serious complications. So they are only recommended for people who are fit enough, and when the possible benefits outweigh the risks.

Although a transplant carries a lot of risks, it is also the treatment with the best chance of curing MDS. For more information about stem cell transplants you can order our free booklet from **bloodcancer.org.uk/our-booklets**

Emma

What helped you cope while having treatment in hospital?

“It’s always been really important to me to stay as active as I can when I’m in hospital. I think if you just lay in bed all the time, it can make you feel more ill. So I used to take things in with me to help me do gentle exercise in my room, like a yoga mat and resistance bands.”

Read Emma’s story at **bloodcancer.org.uk/emma-mds** or call us and we’ll post you a copy.

Tips for a better hospital stay

If you're in hospital for several weeks, you might at times feel lonely, vulnerable, frustrated or even bored. Other people with blood cancer find these things helpful:

- Moving around your hospital room each day if you can. Even just walking and standing will be good for you.
- Notepad and pen, to write down any questions for your doctor, or to plan your visitors.
- Drawings or cards from children – they brighten up your room, but they also give children something positive to do.
- Being honest about whether you want visitors – sometimes you might not feel like it, and that's fine.
- Home-cooked food – but check with your medical team.
- Keeping a diary to track your progress.
- Photographs of happy memories, family or friends.
- Eye mask and ear plugs – helpful for sleeping at hospital.
- Chosen person to get medical updates – give your medical team permission to give updates to a close family member or friend. Sometimes you might not remember everything.

Supporting someone through treatment

We have information, practical tips and stories about supporting someone through blood cancer treatment on our website at **bloodcancer.org.uk/friends-family**

If you don’t use the internet, call us and we’ll post what you need.

Non-intensive treatment

If you are not fit or well enough to have intensive treatment, or if you choose not to have it, there are non-intensive treatments available.

These treatments aim to control the MDS as much as possible, without causing as many side effects that could harm you more. Non-intensive treatment is often a better option for people who are more frail, or whose general level of fitness would make it difficult to tolerate strong treatment.

Non-intensive treatments can’t cure the MDS, but they can often keep it under control for a long time.

These treatments are gentler than intensive treatments, and aim to give you the best possible quality of life. Most of them can be taken at home or as an outpatient.

If you're having non-intensive treatment, you’ll have regular checks with your hospital team. You’ll also have blood tests to monitor how the treatment is working.

You might need other treatments to keep you as well as possible and manage your symptoms. This is called supportive care. You can read more about these treatments on pages 42 to 44.

Which drugs will I have for non-intensive treatment?

Not everyone's MDS is the same. There are different types of MDS, and different drugs work for different types.

Some people have their treatment as part of a clinical trial. This offers the chance to try newer treatments being looked at for MDS – see page 54.

Many people on non-intensive treatment have a type of low-dose chemotherapy, which is usually given by injection as an outpatient. Other medicines called targeted drugs and immunosuppressive drugs are sometimes used for people with specific types of MDS.

Your treatment will be tailored to your personal situation, usually with the aim that you can spend as much time outside of the hospital as possible. Ask your hospital team if you have any questions about the treatment they recommend.

Research into new MDS treatments is happening now, so information about treatments can change. For the most up-to-date information on MDS treatment, visit **bloodcancer.org.uk/MDS-treatment** or call us.

Clinical trials

A clinical trial is a research study involving people. Clinical trials help researchers develop new treatments for blood cancer and improve existing ones.

If there is a clinical trial available, your doctor might suggest you join it. You can also ask your hospital team if there are any clinical trials that are relevant to you. This could include trials being run at a different hospital.

Taking part in a clinical trial has benefits, like the chance to have a new treatment that might not be available otherwise. You'll be very closely monitored and have detailed follow-up. But it does come with uncertainties, so it's up to you whether you take part.

If you don't want to be in a trial, or there isn't a suitable trial running, you'll be given the best standard care that's right for you.

> **I research things online so I can keep up-to-date with anything that's new with MDS. I stick to sources I can trust, and if I find anything I think might be relevant to me I discuss it with my doctor.**
> Ally, diagnosed with MDS
> in 2008

Find out more

We have more information about clinical trials on our website. We also have a clinical trials support service that offers individual support to find suitable clinical trials and explain what's involved.

Find out more at **bloodcancer.org.uk/clinical-trials**

Side effects of MDS treatment

The treatment you have for MDS may cause unwanted side effects. Some side effects are more common than others, but everyone reacts differently, even if they are having the same treatment.

Your hospital team can tell you what to expect from your treatment, including any possible side effects. If you do get side effects, there are medicines and self-help tips that can make a big difference. Your doctor may also be able to adjust your treatment to reduce side effects.

We have lots of information about common side effects and things that can help on our website at **bloodcancer.org.uk/side-effects**

It can also be helpful to share experiences and tips with other people. You can do this on our online forum at **bloodcancer.org.uk/our-forum**

> **I found it really helpful to talk to other people who'd had their own experience of cancer. Because if you're feeling rubbish, just to be able to talk to somebody who understands is amazing.**
> Peter, diagnosed with MDS in 2017

Protecting your fertility

Some MDS treatments can affect your ability to have children. If you are planning to have children in the future, or just want to keep your options open, tell your hospital team. It may be possible to freeze eggs, embryos, ovarian tissue or sperm, to use when you're ready.

You can find out more about blood cancer treatment and fertility at **bloodcancer.org.uk/fertility**

Kerry talks about having fertility preservation before her blood cancer treatment at **bloodcancer.org.uk/kerry**

Talk to us

Being told your fertility is likely to be affected can be a hard thing to hear. It may also be a difficult subject to discuss with a partner or close family.

If you would like to talk things through, contact our Support Service. We're here to listen and help you get the support and information you need. Call us free on **0808 2080 888** or email **support@bloodcancer.org.uk**

Questions to ask about treatment

Whether you have supportive care, intensive or non-intensive treatment, here are some questions you could ask your medical team.

- What treatment do you recommend and why?
- What is the aim of my treatment?
- How will the treatment affect my daily life?
- Will I need to go into hospital for the treatment?
- What side effects should I expect from this treatment?
- Are there any long-term effects of the treatment?
- Will the treatment affect my fertility?
- What’s the best outcome I can hope for?
- Is there a clinical trial I can join?
- If I don’t want this treatment, what are my other options?
- When I’m at home, how can I look after myself?
- Are you an MDS specialist, or have you discussed my treatment with one?

Key things to know about treatment

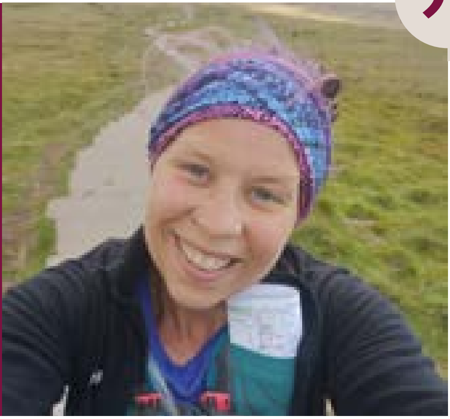
Your treatment will be managed by a medical team who are specialists in blood cancer.

- **You should be given a named key contact, usually a clinical nurse specialist (CNS),** and a phone number or email in case you have any questions or worries. If you don’t know yours, ask your team.

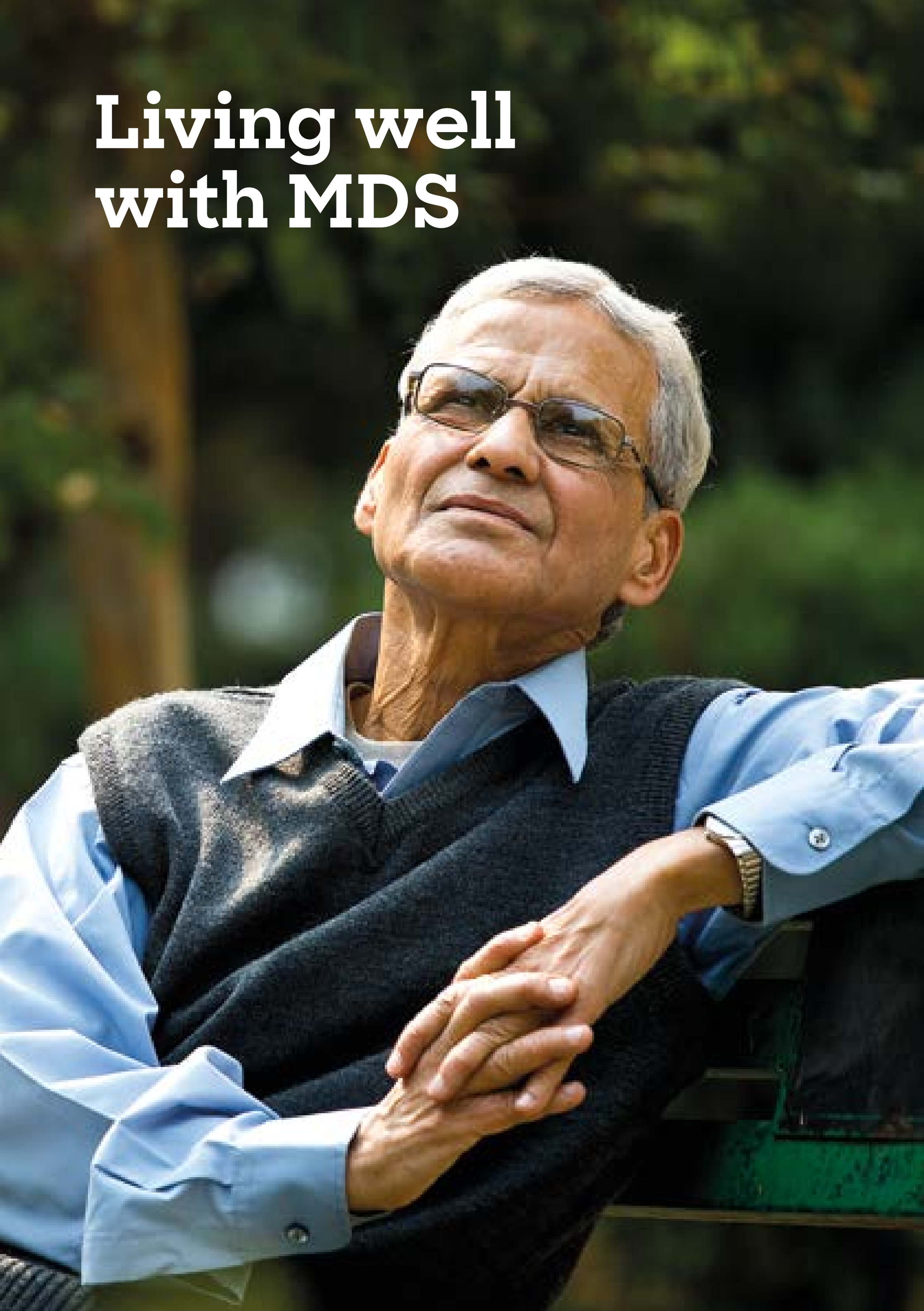
- **Your doctor or CNS might mention a multi-displinary team (MDT).** This is a team of healthcare professionals who will meet regularly to plan your treatment. Your doctor or CNS can update you on what’s been discussed after the MDT meetings.

- **You can contact us for help preparing for appointments or talking to your medical team** – this is something we talk to people about a lot. If you don’t feel confident talking to your medical team, contact our Support Service.

> **I’ve built up a relationship with my hospital team over the years. I’ve got the email addresses for my CNS’s and I email them when I have questions.**
> Emma, diagnosed with
> MDS in 2011



Living well with MDS



Having MDS doesn’t have to stop you being you and living life to the full.

We’ve talked to people with MDS to get their thoughts on what has helped them cope with their diagnosis and continue to enjoy life.

This chapter covers:

- What can I do to help myself?
- Checklist: 10 things that can help
- Changing your thinking
- Staying safe
- Keeping active
- Eating well
- Managing fatigue (tiredness)
- How to help your family and friends
- Working when you have MDS
- Help with money
- Places to get support

> **I don’t waste time anymore. I used to lounge around at the weekend. Now I’m always wanting to do things, whether it’s just taking the dog out or making pancakes on a Saturday morning.**
>
> Peter, diagnosed with MDS in 2017

What can I do to help myself?

Looking after your physical and mental health is important. When we say mental health, we just mean how you feel about your daily life and what's happening.

Everyone reacts differently to their diagnosis. Some people feel sadness, fear, guilt or anger. Many find themselves asking, "Why me?"

Some people don't have strong emotions or are able to accept the diagnosis quite quickly. Others feel shocked, or like it isn't really happening.

Whatever you're feeling is normal. For now, it's just important to take care of yourself in any way that works for you. The next few pages have some ideas to try.

> **I've joined every group going, just to get some support and to find people that understand what I'm going through. I've found it really helpful and I hope I can help others too.**
>
> Kal, diagnosed with MDS in 2019

Checklist: 10 things that can help

This section is about small, simple things you can do that can make a big difference. These are all things that have helped other people with blood cancer at different times.

1. **Focus on the here and now** – Focusing on the present moment can help if you feel overwhelmed. Try focusing on your breathing for a minute, or engaging your senses (listen to the sounds around you, feel the texture of something in your hands, or simply look at the objects around you and notice their shapes and colours). Exercises like this can help calm you if you feel stressed, and you can do them anywhere.

2. **Give yourself time to absorb and ask questions** – You don't have to learn everything at once. Take time to read information, write down all your questions, and then take them to your hospital team, GP or our Support Service.

3. **Listen to your body** – If you're tired, the housework can wait, and most plans can be changed. You're going through a lot, so it's OK to say no to people and take time out. People will understand. If you're having a good day, going on a walk or doing some exercise can help. Do what feels right for you and take it one day at a time.

4. **Keep up your hobbies, or start a new one** – Anything you enjoy and which keeps your mind occupied can give you a break and lift your mood. A hobby can be something you find relaxing, or something that motivates you. Getting engrossed in something that requires some mental or physical effort can help. Gardening, DIY, drawing or crafting can take you out of your head.

5. **Have goals or a focus** – Goals can keep you going, provide motivation, and help you feel positive. While there is a lot you can't control, try to think about the things you can. Whether it's planning the next place you want to visit as soon as you're able, having mini goals for each day, or simply keeping a photograph of someone special to look at – find something that can motivate you to get through this.

6. **Keep a diary or log** – Record your goals, things you've achieved, things that have helped you, and how you're feeling each day. It can be helpful and motivating to look back at how far you've come.

7. **Try to stay active** – Physical activity can help you sleep better, release feel-good hormones and help manage stress, anxiety and depression. Even a five-minute walk can help you feel better. Exercise also helps by giving you something to focus on and brings a sense of achievement. Ask your hospital team what's safe for you.

8. **Keep connecting with other people** – While it's OK to say no when you don't feel like seeing people, it's also important not to withdraw too much. Seeing or talking to other people about things that are not related to blood cancer can really help to lift your mood.

9. **Talk to someone** – Trying to keep things to yourself can add extra pressure and make things harder. Talking about things can make them feel more normal and less scary, even when that thing is blood cancer. Be open with close friends and family if you can – many people say this is their biggest support. Or contact our Support Service and talk to us – we are here to talk about anything that's bothering you.

10. **Keep doing things that make you smile** – People say it's important to carry on as much as you can with the things you enjoy, and that life should not stop because of MDS. There might be some things you can't do right now but try to focus on the things you can.

There are more tools on our website to help you try some of these practical tips, including some videos to help you relax, at **bloodcancer.org.uk/mind-emotions**

If you don't use the internet, call us and we can send you some resources.

Changing your thinking

Many people say that staying positive is really important for coping with blood cancer. This doesn't mean being positive all the time – everyone has bad days and it's important to accept these and not put pressure on yourself to be fine all the time. But sometimes just looking at something differently or changing what you focus on can help.

Our thoughts affect our feelings. So while it's difficult to change feelings (emotions) directly, changing our thought patterns can actually change how we feel about things.

You can spot unhelpful thoughts because they are often very unbalanced (things are either all good or all bad) or catastrophic (worst-case scenarios). Sometimes these thoughts don't relate to what your hospital team or GP has actually told you – that's completely understandable, but it is possible to turn these thoughts around.

> **I felt like I was failing at first when I couldn't do all the things I used to do. Counselling really helped me to focus instead on the things I can still do, and find creative ways around the more challenging tasks.**
> Peter, diagnosed with MDS in 2017

Thinking about things differently can change your outlook to a more balanced and positive one.

Examples of balanced thinking:

It might be hard, but I have coped with challenges in life before, and I can find a way to cope with this.

My hospital team said there was a good chance of treatment working for a long time.

Life will be different, but there are still things I can enjoy. There are good things in my life, and I can focus on these.

If I feel lonely, I know there are people out there who understand. I can contact Blood Cancer UK.

Rather than dwelling on things I can't change, I'm going to concentrate on what I can control, like keeping active.

Staying safe

Reducing the risk of infections

MDS and its treatment can put you at higher risk from infections. Infections can get worse quickly and turn into a dangerous condition called sepsis. But if you act fast, they can be treated before they become serious.

Here are four key things to do:

- **Ask your medical team about vaccinations** – they will usually recommend you have flu and covid vaccines, and possibly a pneumonia jab.

- **Find out who you can contact urgently** (and out of hours) if you think you have an infection. Write the number somewhere you can easily find it.

- **Make sure you know the symptoms of infection** (see the next page) and call your emergency contact number straight away if you have any of these symptoms.

- **Share this information with your family and friends** so they know what to look out for too.

You should also follow general advice about lowering your risk of infection. This includes washing your hands frequently, staying away from anyone who is unwell and storing and cooking food safely.

Check with your hospital team about your own level of risk and what you should do to protect yourself.

Symptoms of an infection

These are common symptoms of an infection, but tell your medical team straight away if you just don’t feel quite right.

- fever (temperature higher than 37.5°C)
- low temperature (less than 36°C)
- shivering and sweating
- feeling confused
- sore throat or cough
- rashes or swelling
- frequent watery poos (diarrhoea)
- a burning or stinging sensation when weeing
- unusual stiffness of the neck
- achy, flu-like symptoms

Find out more at **bloodcancer.org.uk/infection** or call us to ask for printed information.

Reducing the risk of bleeding

If you have low platelets, you may need to avoid some medicines and activities to reduce the risk of bleeding. Ask your hospital team what they recommend.

You should usually avoid taking blood thinning medicines and non-steroidal anti-inflammatory drugs (NSAIDs), unless your doctor recommends them. NSAIDs include the painkillers ibuprofen and aspirin.

It’s also best to avoid activities where you have a high risk of injury. These include things like contact sports, climbing high ladders and cycling without a helmet.

Keeping active

Being physically active can improve your fitness and strength, reduce fatigue and improve your mood. That's not just what the research says – many people with blood cancer have found it to be true.

- **Walking is good exercise** – If you haven't done much recently, start with 5–10 minutes a day and slowly build up.

- **Goals are motivating** – Set yourself goals and tick them off when they're done. Order a free activity planner from us, or use an app like Habit Tracker or Done.

- **Do something you enjoy** – If you choose an activity you like, you're more likely to keep it up.

- **Make it social** – This usually helps people stick to their plans. Find an exercise buddy (your partner, a friend, a neighbour) and follow a plan together.

- **Get tips from other people with blood cancer** – Join our online community forum and find out how other people with blood cancer are staying active.

- **Don't push yourself too hard** – If you've been through treatment your body might need time to recover. But doing a little more each time will help to build up your stamina.

You can watch exercise videos for people with blood cancer at **bloodcancer.org.uk/keeping-active**

Eating well

Eating well is important, as it will give you the nutrients and energy you need to stay healthy. Here are some general tips to bear in mind:

- **No diet, supplement or “super food”** can cure cancer – in fact, cutting out too many foods could mean you’re not getting everything you need.

- **It’s best to follow a healthy, balanced diet** – Ask your hospital team if there’s anything specific you need to eat more or less of.

- **You need carbohydrates** – Wholewheat pasta, wholegrain bread or potatoes with skin on will release energy through the day. Carbs should make up around a third of a meal.

- **Eat lots of fruit and veg** – They’re packed with vitamins, minerals, and are a good source of fibre. Boost your intake by adding extra vegetables into sauces.

- **Protein helps your body grow and repair** – Try beans, peas, lentils, fish, meat, dairy, eggs and vegetarian and vegan alternatives such as Quorn or tofu.

- **Iron is vital for energy** – You can get iron from red meat, beans, nuts, dried fruit and fortified breakfast cereals. If you’re having blood transfusions you might already have lots of iron, so check with your medical team.

We have more tips at **bloodcancer.org.uk/eating-well**

Managing fatigue (tiredness)

Fatigue is when you feel totally drained in body and mind. It can hit you even when you've rested and slept well.

Tell your hospital team if you have fatigue, especially if it's getting worse. It can be a symptom of low red blood cells, so your doctor might recommend treatment to improve your red blood cell count.

It's important to know:

- **You're not alone –** Lots of people with blood cancer get fatigue. It can be a symptom of blood cancer and side effect of treatment.

- **There are lots of things that can help –** It might seem strange, but being physically active reduces fatigue.

People with blood cancer suggest:

- **Balance activity and rest –** You need both to fight fatigue. Light exercise can actually help.

- **Learn what's doable for you –** Plan time to rest in between activities or days out.

- **Go easy on yourself –** If you need a rest day, have one. You're not being lazy.

Visit **bloodcancer.org.uk/fatigue** for more tips.

Emma

How do you cope with mental fatigue?

“Thinking little and often helps. Because I know that my concentration span isn’t good, I give myself breaks. I try to do tasks in short bursts and avoid activities where I would need to concentrate for a whole hour.”

Read Emma’s story about how she copes with mental fatigue at **bloodcancer.org.uk/emma-fatigue** or call us and we’ll post it to you.

How to help your family and friends

If you've told people about your diagnosis, you might find you're getting asked lots of questions.

If you haven't told people about your diagnosis, you might be worried about how you're going to tell them, and how it might make them feel.

It might be hard to deal with different people's reactions. We have some ideas about how to deal with difficult or unexpected reactions on page 10.

On the next page are some suggestions about ways you can help your family and friends come to terms with your MDS diagnosis.

We also have advice and support for family and friends at **bloodcancer.org.uk/friends-family**

> **My family became a big support to me and to each other. My sister would research everything and explain it all to the rest of the family. My dad was juicing everything in sight to get my strength up.**
> Kal, diagnosed with MDS in 2019

- **Help your family and friends get information** – If they want to know more about MDS, tell them not to google but to use information from trustworthy sources. Googling can cause unnecessary worry as not everything on the internet is true, balanced or up to date. You might want to give them copies of this booklet which you can order for free from **bloodcancer.org.uk/our-booklets**

- **Tell them where to find a listening ear** – If they are finding it hard to cope with your diagnosis, they are very welcome to call our Support Service to ask questions or just talk things through.

- **Be honest** – Talking openly about MDS to other people can make you and them feel better. It's not something you have to hide. People often worry more when they don't feel they know what's going on.

- **Let family and friends help you** – It's common to feel that asking for help is a sign of weakness, but this isn't true. Asking for support is a positive way to help yourself, and it also makes family and friends feel better if they have a role to play.

- **Talk to us about it** – We often talk to people about the impact their diagnosis is having on their family or friends. We can also help you prepare to tell people, whether they are family, friends, children or your employer.

Working when you have MDS

If you are working or studying when you are diagnosed with blood cancer, you should know:

- **You're protected** – Even if you're on watch and wait, you are entitled to support.

- **You have rights** – Cancer is classed as a disability in UK law, so you are protected against discrimination.

If you're worried about going to work because of the risk of infection, or you are finding it hard to do your job, your employer has to consider "reasonable adjustments" to help you stay in work. Examples include:

- having time off for medical appointments
- taking more breaks
- changing your duties or hours to help you manage fatigue
- changing your hours so you can travel when it's quieter
- supporting you to work from home.

Contact our Support Service for help talking to your employer about managing at work. We also have a fact sheet about blood cancer you can share with your employer. You can order or download it for free from **bloodcancer.org.uk/our-booklets** or give us a call.

Peter

How has MDS changed the way you work?

“I’m much kinder to myself now and I’ve learnt to set boundaries with myself and with my colleagues. It’s stopped me from forcing productivity when I’m just simply not well enough, and it allows me to feel ready to work when it’s time.”

Read Peter’s story at **bloodcancer.org.uk/peter** or call us and we’ll post you a copy.

Help with money

If you're worried about money, make sure you get the financial support you're entitled to.

- **Benefits** – If you're on a low income, you may be able to claim benefits like Universal Credit, Employment and Support Allowance (ESA) or Personal Independence Payment (PIP), or Attendance Allowance if you're state pension age or older.

- **Sick pay** – If you can't work because of the MDS or another illness, your GP or hospital doctor can give you a fit note (previously called a sick note) which gives you access to your company's sick leave policy and pay, or Statutory Sick Pay (SSP).

Ways to save money on health costs

- **Parking** – At all hospitals in Wales and most hospitals in Scotland parking is free. In England and Northern Ireland, some hospitals offer free parking to people with cancer in certain circumstances – check with the hospital.

- **Prescriptions** – These are free in Scotland, Wales and Northern Ireland. In England, you can can get a medical exemption certificate that allows you to get all your prescriptions for free. Ask your GP surgery for the form.

- **Travel to hospital** – If you have a low income, or get certain benefits, you may be able to get refunds for your travel to hospital. Ask your doctor or nurse about this.

Help paying bills

Talk to your suppliers about energy bills, council tax and mortgage payments. There is usually support available for people with cancer. Get help from Citizens Advice at **citizensadvice.org.uk**

Do you have insurance?

If you have income protection insurance or critical illness cover, contact your provider to see if you can make a claim.

Financial help from charities

Many charities offer grants that you don’t have to pay back, including Leukaemia UK and Macmillan Cancer Support.

Who else can help?

Ask your GP, doctor or nurse about financial help or ask a family member or friend to research it online. The government website MoneyHelper offers free webchat, WhatsApp and phone advice on all money matters at **moneyhelper.org.uk**

You could also call Macmillan on **0808 808 00 00.**

Places to get support

Blood Cancer UK Support Service

We will talk to you about anything that's on your mind, whether you want more information or just want a chat. Call our confidential support line free on **0808 2080 888** or email **support@bloodcancer.org.uk**

Blood Cancer UK website

Our website has more information about MDS and blood cancer in general, plus regular news articles and stories from people affected by blood cancer. Explore **bloodcancer.org.uk**

Blood Cancer UK publications

If you prefer your information in printed form, browse our booklets about conditions, watch and wait, treatment and side effects and living with blood cancer. Go to **bloodcancer.org.uk/our-booklets**

Blood Cancer UK online community forum

Talking to other people with blood cancer helps. They understand and will have tips from their own experience. You can ask questions, or just read other people's posts. Visit **bloodcancer.org.uk/our-forum**

Social media

Find Blood Cancer UK on Facebook – many people get and give support to each other in comments on our posts. You can also find us on Instagram and Twitter. You could also search online or on Facebook for MDS support groups.

MDS UK Patient Support Group

MDS UK Patient Support Group is a charity dedicated to supporting people with MDS and their families. It offers a helpline, website, booklet about MDS, chat forum, online support groups and online meetings with specialist speakers. It also has a list of MDS specialists and can give advice about seeking a second opinion.

Visit **mdspatientsupport.org.uk** or call **020 7733 7558**

Leukaemia Care

Leukaemia Care offers information and support for people with MDS and other types of blood cancer. Its services include a buddy service, which links you with a trained volunteer who is also affected by blood cancer, and support groups around the country.

Visit **leukaemiacare.org.uk** or call **08088 010 444**

Anthony Nolan

Anthony Nolan provides information and support for anyone having a stem cell transplant and their families.

Visit **anthonynolan.org** or call **0303 303 0303**

African Caribbean Leukaemia Trust (ACLT)

ACLT raises awareness about stem cell, blood and organ donation, with a focus on African and Caribbean communities. It also supports people looking for a donor.

Visit **aclt.org** or call **020 3757 7700.**

Counselling services

Many people find talking to a trained counsellor helps them come to terms with difficult emotions or life changes.

To find a free NHS counsellor:

NHS counselling

- Ask your hospital team how you can access counselling. Some hospitals offer counselling themselves.
- Tell your GP you want counselling.
- Refer yourself online. In England, go to **nhs.uk/service-search/mental-health/find-an-NHS-talking-therapies-service** and in Scotland, **breathingspace.scot/living-life**. In Wales and Northern Ireland, you will need to go through your GP.

Private counselling

Find a qualified counsellor anywhere in the UK at **BACP.co.uk** or call them on **01455 883300**.

Local cancer support centres

Cancer support centres such as Maggie's offer different types of emotional and psychological support for people diagnosed with any type of cancer and their families.

Visit **maggies.org** or ask your hospital team about cancer support centres in your area.

Extra support at home

You might find that the MDS or the effects of treatment mean you need extra help at home.

Speak to your GP or cancer specialist nurse if you think you might need support to look after yourself. They can arrange for a social worker to assess your situation and the support you may need.

If you're having treatment in hospital, speak to your hospital team. They can arrange for you to see an occupational therapist who can discuss the support you might need at home.

Travel insurance

- You can call our Support Service on **0808 2080 888** to talk through your plans and where to get more information about travel insurance.

- We've partnered with Staysure to make travel insurance easier to access for people with blood cancer: **bloodcancer.org.uk/get-involved/travel-insurance-with-staysure/**

- MoneyHelper has information on travel insurance for people with cancer and other health conditions: **moneyhelper.org.uk/en/everyday-money/insurance/travel-insurance-if-you-have-a-medical-condition**

Useful publications

Printed resources

- **Your blood cancer diagnosis: what happens now?**
- **Watch and wait fact sheets**
- **Watch and wait explained: for employers**
- **Blood stem cell and bone marrow transplants: the 7 steps**

Order free copies at **bloodcancer.org.uk/our-booklets** or call us free on **0808 2080 888**.

Online resources

- further information about MDS: **bloodcancer.org.uk/mds**
- key things to know after your diagnosis: **bloodcancer.org.uk/newly-diagnosed**
- living well with blood cancer: **bloodcancer.org.uk/living-well**
- blood cancer and infection risk: **bloodcancer.org.uk/infection**
- current blood cancer research **bloodcancer.org.uk/research**
- support and advice for friends and family: **bloodcancer.org.uk/friends-family**
- ways to get involved with Blood Cancer UK **bloodcancer.org.uk/involved**

If you don't have internet access, call our Support Service free on **0808 2080 888**.

Write any questions for your medical team here:

Because we face it together

Finding out you have blood cancer can have a big impact on your life. But we hope it helps to know that there's a community of people out here ready to support you.

Everyone needs help at one time or another. And the most important thing to take away from this booklet is that you can get help from us when you need it, and in a way that suits you.

bloodcancer.org.uk

☎ **0808 2080 888** (calls are free and confidential)

support@bloodcancer.org.uk

bloodcancer.org.uk/our-forum

Blood Cancer UK

@bloodcancer_uk

@bloodcancer_uk

Blood Cancer UK

Thank you to our blood cancer community

Blood Cancer UK is the UK's specialist blood cancer charity. But we're much more than that – we're a community of people with blood cancer, friends, family, medical professionals, researchers and everyone who works for the charity.

Many thanks to everyone involved in making this booklet. To Ally, Emma, Kal, Peter, Simon and Tony for their insights into what it's like to be diagnosed with MDS, and for steering us in the right direction. To consultant haematologists Dr Daniel Wiseman and Dr Pramila Krishnamurthy and clinical nurse specialist Samantha Miles for checking the medical content.

A list of references used in this booklet is available on request. Please email **information@bloodcancer.org.uk**

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Who are Blood Cancer UK?

We're the UK's specialist blood cancer charity, working to beat blood cancer within a generation.

Since 1960, we've invested over £500 million in research, improving treatments for leukaemia, lymphoma, myeloma, MDS and MPNs. Thanks to generous donations from our supporters, we:

- fund ground-breaking research to improve survival and quality of life
- campaign for better access to treatments and services for people with blood cancer
- provide information and support for anyone affected by any blood cancer.

Find out more at **bloodcancer.org.uk**

Or call us free on **0808 2080 888**
Monday: 10am to 7pm, Tuesday to Friday: 10am to 4pm
and Saturday and Sunday: 10am to 1pm

Blood
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Patient Information Forum

The information in this booklet was correct at the time it was printed (June 2023). Date of next full review: June 2026.