Coping with your feelings and getting support

Having leukaemia, a myeloproliferative neoplasm (MPN) or myelodysplastic syndrome (MDS) might bring up difficult emotions. On this webpage we cover how to cope with your emotions and feelings, and where to get support.

Summary

- Everybody deals with their feelings differently. However you feel is OK.
- If you're feeling low, it might seem that nothing will help. But there are things you can try that might help you feel a bit better. These can include:
    - Talking to family and friends about how you feel.
    - Asking for help from people you are closest to.
    - Contacting your medical team or GP if you have questions or concerns.
    - Connecting with people who understand what you've been through.
    - Spending time with friends and family and doing things you enjoy.
    - Looking after yourself physically by exercising or eating well.
    - Taking things a day at a time and writing down your worries.
    - Considering complementary therapies like mindfulness, yoga or acupuncture.
- It's important to ask for support and acknowledge when you need help. You might need support from:
    - Your healthcare team
    - Family and friends
    - Leukaemia Care
    - Other charities and support services
    - Communities you are a part of, such as faith, religious or spiritual groups
    - People who've had a similar experience

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Factsheet: How to cope with your feelings and where to get support

Coping with your feelings

Everybody deals with their feelings differently. However you feel is OK. There is no right or wrong way to manage your feelings. Often, even when you have effective ways of dealing with your emotions, you may still have good days and bad days. Some days you may have a lot on your mind and things can become overwhelming. This can especially be the case if you are adjusting to a new diagnosis or a change in your health. It's important to be kind and patient with yourself.

If you're feeling low, it can seem that nothing will help. But there are things you can try that might help you feel a bit better.

Coping with leukaemia, myelodysplastic syndrome (MDS) or myeloproliferative neoplasms (MPNs) can be difficult. You may need support from:

- Your healthcare team
- Family and friends
- Leukaemia Care
- Other charities
- Communities you are a part of, such as faith, religious or spiritual groups
- People who've had a similar experience

Talk to people

Being open and honest with your friends and family can help you feel supported and understood. It is OK to give yourself time to adjust to your diagnosis before deciding when and how to tell others.

We have more information about telling people about your diagnosis on our newly-diagnosed webpage.

It can help to make a list and plan what you want to say beforehand. In the conversation with your friends and family you might want to:

- Explain that you have a type of blood cancer.
- Talk about symptoms and side effects and how they affect you. Maybe you feel tired or get a lot of infections.
- Talk about how you feel.

Having information about your condition on hand can make the conversation easier.

Macmillan have more information on talking about cancer.

It can be hard to speak openly and honestly about your feelings. You may feel like you have to stay strong for your loved ones, and don't want to burden them. Sometimes your loved ones might not know how to talk to you about what is happening because they don't want to upset you. But talking about how you feel and your worries can help them understand and be there for you. This can bring you closer and help you better support each other.

Some people find it can help to speak to someone independent, so you can open up about how you are feeling and coping. We can help you access up to six sessions of remote or in-person counselling, free of charge.

You may also be able to get counselling or mental health support through your GP or haematology team.

Ask for help

Talking about your needs can be hard. There may be some people you feel you can talk to more easily than others.

Be open and honest about how you feel and how you are coping. Many people want to help you as best they can. But it is hard if they do not know what you're finding difficult.

It is a good idea to tell them what you'd like help with. They may be happy to know that they can support you by spending time with you, coming to appointments, helping around the house or doing the food shop.

If you have any medical worries or concerns, use your medical team.

Use your medical team

If you are struggling with your mental health, contact your GP or clinical nurse specialist. They can help you access support and treatment, if you need it.

For urgent mental health support, call 111 and select the mental health option.

Your haematology team should give you details of a named person to contact if you need to. Usually, this is a clinical nurse specialist. They are specialists in looking after people with the same diagnosis as you and often have lots of ideas for support for you and ways to counteract your concerns. Sometimes it might be your GP. Whoever your named person is, don't be afraid to contact them. It's what they are there for.

If they do not give you any contact details, ask for them.

Your clinical nurse specialist can also offer you a holistic needs assessment. This is where you work together to record your physical, practical and emotional needs and agree on a plan to address them. If you think this would be helpful, ask your team for an assessment.

They may also refer you to their psychology team, counselling or mental health support if you need it.

It's natural to have questions, concerns or fears about your cancer and treatment. Make sure you ask any questions you have. Your medical team will be used to this. They are there to support you, address your concerns and help you get further support if you need it.

It can help to write down questions as and when you think of them, so you remember to ask them.

Connect with people who understand what you're going through

You may be feeling alone and like no one understands what you are going through. Being able to connect with someone who can relate to your experience can make you feel seen and heard. It can help to hear that you're not the only one feeling this way. Other people may have had the same diagnosis, the same treatment and even shared the same worries, concerns or hope.

Support charities offer a range of ways to connect with others. Our services include:

- Buddy service where you are matched with someone who has a similar experience to you
- Support groups where you can connect with people in a similar situation and share your experiences in a safe space
- Online support, including Facebook communities where you can connect with others

Spend time with family and friends

Doing things with friends and family can help improve how you feel. Going out and socialising can be daunting. You might have fatigue or other symptoms that can make this even more difficult. You could keep a symptom diary to keep track of how you feel, to help you make plans at times you usually feel better.

Spend time with others in ways that work for you. Plan things based on how much you think you can manage. Let them know if you are tired, need some rest or need to change plans at short notice.

If you're not feeling up to going out, you could have people come round to relax with you instead. Even just catching up over the phone or video call can help you feel less lonely.

Your diagnosis or treatment might leave you at risk of infections. Ask your medical team about your risk, and any precautions you might need to take when seeing others.

Do things you enjoy

You might find it hard, but it is important to allow yourself time to do things you enjoy and care for yourself. Try and allow yourself to switch off. It is important to try and relax, and this can help you have more energy.

Spend time doing something you enjoy.

- You might want to go for a walk, practise mindfulness or just do something that makes you happy, like cooking or gardening.
- You could find something new to try. This might be something you didn't have time for before. Or something new to replace a hobby you don't have the energy for just now.
- If you're fatigued or in hospital, you could do things like drawing, watching sports, reading or listening to a podcast.
- If you're in hospital, ask your nurse or healthcare assistant how to connect to the internet if you need to.

Look after yourself

It's important to look after yourself physically too. This can also help you feel better emotionally.

Try to eat a well-balanced diet. This should help you feel stronger, have more energy and better manage any side effects you have.

Staying active can improve your wellbeing, quality of life and physical health. Exercise can also help you deal with your emotions. You don't have to overexert yourself, even a gentle walk can help. Choose a level of exercise that works for you and how you are feeling.

Take things one day at a time

It can help to take things a day at a time, bit by bit. This can help you focus on the here and now, without worrying about the future.

Write your worries down

It can be helpful to write down your worries, rather than letting them stay in your head. This can help you physically see them and rationalise them.

It can also help you work out what support you might need, and who you could contact to access it. And you can use it as a prompt when talking to your medical team about your worries.

Find out more about your condition

Having the information you need can help you feel on top of things.

We have online information, as well as information you can download or order in print.

Ask your medical team any questions you have. They will be used to this and will be happy to explain things to you.

In your appointments you could take notes on your phone or on paper to help you remember. Or you could ask your doctor or nurse to write things down. Sometimes it might be possible to record your consultation, with your healthcare professional's consent. You can play it back later or share it with others so you don't need to repeat things.

It can help to take a family member or friend with you for support and to help you remember what you need to. They can also remind you of things you planned to discuss.

You can also ask your medical team to give you printed information if you struggle with looking online.

Consider complementary therapies

Complementary therapies can be used alongside your treatment to help you feel better physically and emotionally.

Examples of complementary therapies include:

- Mindfulness. This involves paying attention to the present moment. Noticing and acknowledging your feelings as they arise can help you feel less overwhelmed or anxious.
- Meditation. This can help you relax. Yoga and tai chi can help you use meditation and gentle movement to improve your physical and mental health.
- Creative therapies. These use art or expression to help your wellbeing. This can include art therapy, music therapy and creative writing.

- Acupuncture. This is where a therapist places very fine needles just under your skin at certain points. It may help reduce symptoms or side effects. Ask your medical team before to see if this is suitable for you.
- Massage. This can help you relax and relieve tension in your body. Ask your medical team before to see if this is suitable for you.

You might need a supportive letter from your medical team to be able to access some complementary therapies.

Macmillan and the NHS have more information on complementary therapies.

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Support we can offer you

We are here for you whatever you are feeling. Here are some of the support services we offer.



It can help to talk to someone about what you've been through and how you feel. Our helpline offers a listening ear, emotional support and practical advice.

- Call 08088 010 444 (weekdays 9am to 4.30pm)
- Send a WhatsApp message to 07500 068065 (weekdays 9am to 5pm)
- Email support@leukaemiacare.org.uk



You might find it comforting to talk to people who know what you're going through. We run regular online and in-person support groups. These are a safe place where you can connect, share experiences and find comfort from other people who understand.



Buddy support can provide you with a personalised, empathetic way to cope with the emotional side of cancer. We can connect you with someone who's had a similar experience to you and understands what you're going through. They might have some ideas of things that helped them. Sharing a concern with someone who may have felt the same can make it easier to manage.



If you prefer to connect with people online, join our closed Facebook groups. You can connect with other people who have the same blood cancer or their carers.



You may have a lot of emotions that are difficult to come to terms with. Some people tell us that speaking to someone independent about their feelings can help. We can help you access up to six sessions of remote or in-person counselling, free of charge.



Having a blood cancer can affect your work life, your living situation or your finances. Our advocacy and welfare service is here to help. We offer advice on financial support, housing, employment issues and more.



Having the information you need can help you feel on top of things. We have online information, as well as information you can download or order in print.

You might read or hear medical terms that you haven't heard before. Check out our A to Z of leukaemia to find out what they mean.

Other places to find support

Some UK charities provide support for people with leukaemia, MDS or MPNs. Other charities can help you with your mental health. Here are some you might find helpful.

Mental health charities

- Mind: Leading mental health charity that offers information and support.
- Samaritans: Offer 24/7 help and support if you are struggling with your thoughts or feelings.
- Young Minds: Provide mental health support for children, young people and their families.
- Shout: Offer a 24/7 text service if you are struggling with your mental health.
- Hub of hope: Provide a directory of community mental health services, so you can find local support.
- Qwell: Offer self-help tools, journalling, peer support forums and expert advice.

Mental health apps

There are many apps available to help support your mental health. Some of these are free or have an initial free trial. Others need a paid subscription. Search your preferred app store to find one that suits you.

Mind, the mental health charity, have a library of recommended apps that meet their quality criteria.

Cancer charities

- Blood Cancer UK: Leading charity into the research of blood cancers.
- CLL Support: Provide support, information and advocacy for people with chronic lymphocytic leukaemia (CLL), their families and carers.
- MPN voice: Provides information, community and advocacy for people with myeloproliferative neoplasms (MPNs), their families and carers.
- MDS UK: Provides support to people with myelodysplastic syndromes (MDS).
- Macmillan: Provide free, practical, medical and financial support for people facing cancer.
- Cancer Research UK: Leading charity dedicated to cancer research.
- Maggie's: Offer free practical, emotional and social support to people with cancer and their loved ones.

General health

- NHS: Information and services to help you manage your health.

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Need support?

You are not alone. We're here for you whether you have a diagnosis yourself or know someone who has. If you'd like advice, support, or a listening ear, call our freephone helpline on 08088 010 444 or send a WhatsApp message to 07500 068 065.

Helpline and WhatsApp →

Help us improve our information

We aim to provide information that's reliable, up-to-date, and covers what matters to you. Please complete our short survey to help us improve our information and make sure it meets your needs.

Complete our short survey →

About our information

This information is aimed at people in the UK. We do our best to make sure it is accurate and up to date but it should not replace advice from your health professional. Find out more about our information.

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