The Blood Cancer Charter:

Information for people living with blood cancer

This Charter has been developed by Pfizer UK, in partnership with Blood Cancer UK through a consultancy agreement.

PP-UNP-GBR-9279 August 2024

The Charter

What is the purpose of the Charter?

The Blood Cancer Charter is designed to give you information about what you might expect from your care. We hope this encourages you to further look for support and care you need.

Who was involved in creating the Charter?

The Charter has been informed by blood cancer charities and people living with blood cancer.

We understand it's not possible to capture the experience of everyone living or diagnosed with blood cancer, but we have tried to include the most useful information about what you might experience following your diagnosis. In case you have specific questions that you cannot find in this document, please speak to your medical team.

We hope you find this Charter helpful.

Contents

You and Your Diagnosis

You have just been told you have blood cancer. This is likely to be a significant moment in your life.

- **Your diagnosis should be explained to you clearly and with compassion.** This will normally be told to you in person, and you should be given the opportunity to have someone with you.
- **You should be given the time and space to ask questions**
- **You should be provided with written information** about your diagnosis
- **You should receive plans** for a timely follow-up appointment or telephone call

Questions you may have about your diagnosis

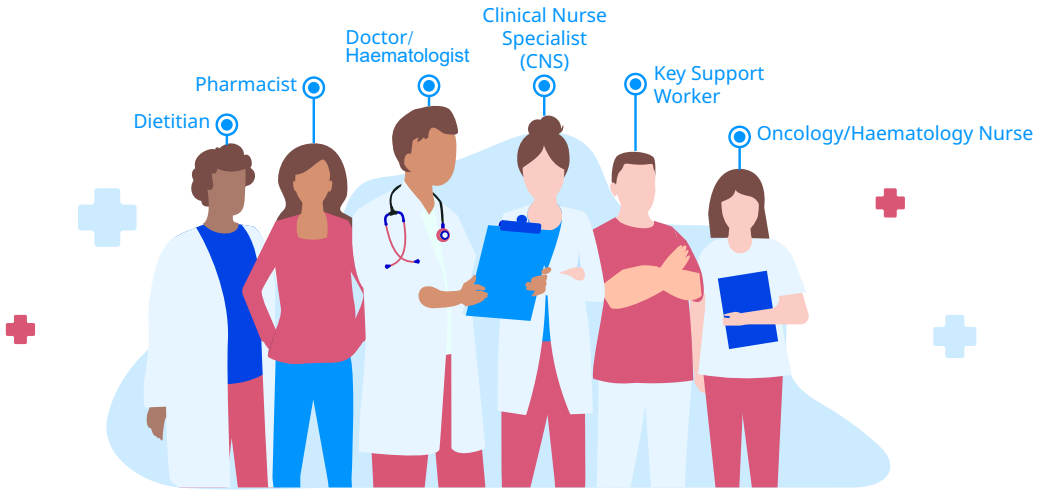
It is very normal for you to have many questions about your diagnosis and what happens next.

Blood Cancer UK have set out a list of potential questions that you might want to ask your medical team. This will help you feel safer and more confident about your care. Please click the link below to see the questions.

I've just been told I have cancer | Blood Cancer UK

First Steps

Getting familiar with your medical team - The medical team responsible for your care will consist of many healthcare professionals like:



From this team you should be assigned a named point of contact. This is a person you can go to with any questions or concerns. This person is likely to be either a Clinical Nurse Specialist (CNS) or key support worker.

You should also receive emergency contact details for out of hours.

If you are not sure who your point of contact is or haven't been provided with any emergency contact details, please ask your medical team.

Treatment and Care

Following your diagnosis, you may have further tests to make sure you receive the right treatment or care for your blood cancer. Some tests results may take longer to get back than others. But you should expect to be informed of the results on time.

Once all the test results are back, your medical team are on hand to explain what they mean and what your care options are. These options include:

- **Watch and Wait** – (also known as ‘active monitoring’ or ‘surveillance’ or ‘watchful waiting’).
  This means your cancer does not need immediate treatment right away. This could be for many reasons. You will continue to have regular check-ups and blood tests to watch your health.
- **Starting treatment** – (also known as ‘active treatment’).
  This means your medical team feel it is right for you to start treatment. They will explain and tell you of the treatments available to you.

Your Care

Your care should be personalised - Personalised Care Plan

Your medical team understand that your care should never be a one-size-fits-all model. They know that your care plan must be shaped around you, your choices, and your lifestyle.

- Your medical team may conduct something called a **holistic (complete) needs assessment** at the start and at various stages of your care.
- Holistic needs assessment gives a chance for you and your medical team to have a discussion.

Aim of this discussion is to assess:

- Your individual needs
- Concerns
- Preferences
- Diagnosis
- Personal features

This helps to come up with a “Personalised Care Plan” that is right for you. So if there is anything you feel is missing or not being included, ask your medical team for it to be included.

This plan keeps a record of:

- Conversations
- The risks and benefits of treatment(s) offered
- Decisions made
- Agreed outcomes

Throughout your care, this plan can be changed to your changing needs. This may possibly include, if appropriate, end of life care.

If you are not sure what your plan is or whether you have had an assessment, please ask your medical team.

Shared Decision Making

It is important that you are fully involved in the decisions about your care. Decisions made about your care should be made as a team. Your medical team should help you to be involved and have your say at every stage of your care.

- **Shared decision making ensures that clinical expertise is used alongside your own goals, values, and beliefs.** This helps to make decisions that are right for you from the beginning of your diagnosis and throughout your care.
- **For effective shared decision-making to take place it is important to make sure you have all the information you need, and you understand the information.** If you are not sure about the information provided or explained to you, please ask your medical team to help you understand.

Continuity of Care

During your care, you may encounter different departments or specialist centres who have specific expertise and facilities to treat your blood cancer.

- **Receiving a smooth transfer of information:** Whilst you may see different medical teams at different facilities or within the same hospital trust, there should still be the smooth communication and transfer of information between these other departments/facilities. You may have to clarify and confirm information, but your medical team are there to ensure good communication.
- **Reaching out to your point of contact:** You can always reach out to your point of contact within your hospital. You can ask any questions or raise any concerns you have about your health, regardless of your treatment plan. They are there to help you throughout your care.

The support available to you

How to ask for the support you need

Your medical team are there to provide you with the best care possible. But as your needs change throughout your care, it is important that you are as **open and honest** as you feel comfortable with them. Let your medical team know about how you are feeling and the support you need. This helps to make sure that you get the right support at the right time.

Communication

Clear, timely and open communication with your medical team, whether that be through your clinical nurse specialist or key support worker, will be very important regardless of where you are in your treatment plan.

- **Ask your medical team about the best way** to reach out to them – this could be in the form of an email, phone, or online platform.
- **When your point of contact is away**, you should be informed of another point of contact. The aim of this is to ensure there is cover while they're away. This person will cover for them until they return. This allows you to keep having open and timely communication.

Mental health support

You may find it helpful to talk to both your medical team and those around you about how you are feeling should you wish to do so. **You should ask about what access to psychological (mental health) support is available** to help you through all stages of diagnosis and treatment, including aftercare when you wish to access it.

Blood Cancer UK has a section on its website with information to help people get the emotional support that they need. You can visit their website here.

Mind and Emotions | Blood Cancer UK

Support for your family members

You may have loved ones who can be a source of support to you. If so, it's important they are supported too.

- Many blood cancer charities offer support specifically for family members and loved ones. You will find a list of charities that supported with the development of this Charter on page 10. Many of them offer this support.
- You can also speak to your medical team who will be able to guide you to the support available.

Blood Cancer Charities

You may want to access support from blood charities who can give additional support outside of your medical team. This includes things such as:

- Phone or email-based services, forums and useful information about blood cancer
- Support for conversations with your family and friends
- Financial support that may be available to you

Your medical team may be able to signpost you to useful information from Blood Cancer UK and other charities (some listed on page 10).

Blood Cancer UK is a specialist blood cancer charity in UK supporting anyone affected by blood cancer.

You can contact their nurse-led support line for anything you may need help with outside of your medical team.

Blood cancer information and support by phone or email

Information

- **Information made just for you:** Speak to your medical team so see if there is any tailored information made just for you that takes into consideration your needs and background.
- **Access to a useable format:** Some information might be available in many different forms. So, if you require an easy-to-read format or in another language, please ask.

Medical Records

If you want to see your medical records, please ask your point of contact or wider medical team about getting this information.

- **Some healthcare providers might have apps or online systems,** which allow you to look at your results and hospital correspondence. But this can vary from provider to provider.
- **You may be required to send a 'subject access request'** to receive a copy of your file.
- If you do not understand the information in your medical records, you can ask your medical team to explain it to you.

Work life – talking to your boss or manager

We understand that the result of blood cancer on your work life can be a source of great worry.

- **Information for your boss or manager:** Your medical team can provide information to give to your employers about your blood cancer. This information will help your boss or manager:
  - To have a better understanding of your blood cancer.
  - Make right arrangements for any adjustments or leave that you might need.
- **Speaking to your boss or manager:** You can ask for advice on how to inform your employer about your health problem. This helps them better understand your problem and show compassion. They may also support your needs after your diagnosis.

Financial matters

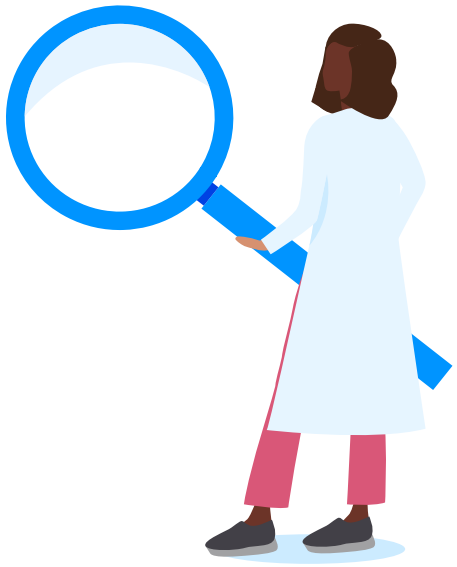
You might have concerns about your financial situation after receiving your diagnosis.

- Speak to your medical team about any concerns you have and ask them about any support you may be entitled to, like free hospital parking and free prescriptions.

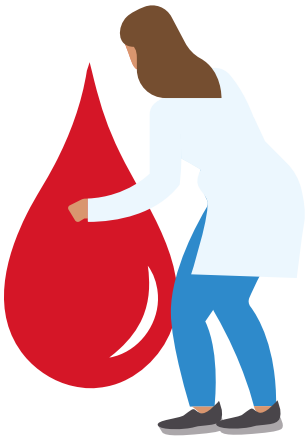
For more information about other financial support available, visit Blood Cancer UK's money and work page.

Seeking a second opinion

Should you wish to, you can ask for a second opinion on your diagnosis from another doctor. You are not legally entitled to one, but your GP or your medical team will help you to get one. Please be reassured that your treatment and care is not affected in any way by your decision to ask for a second opinion.



Clinical Trials



As our knowledge about blood cancer grows, so too does the medicines and treatments available. All new treatments go through strict testing in labs before being studied and trialled with selected people. These are called clinical trials.

- **Eligibility for clinical trials:** There might be trials running for your specific type of blood cancer that you might be eligible for. Clinical trials may be discussed at your appointments, but if this doesn't happen you can ask your medical team about this.
- **Information about clinical trials:** If you have been told about a trial that you may be eligible for, your medical team will give you support materials to help you make an informed decision about whether you would like to take part in the trial or not.

For more details on what clinical trials are, visit Blood Cancer UK's information page by clicking the link below.

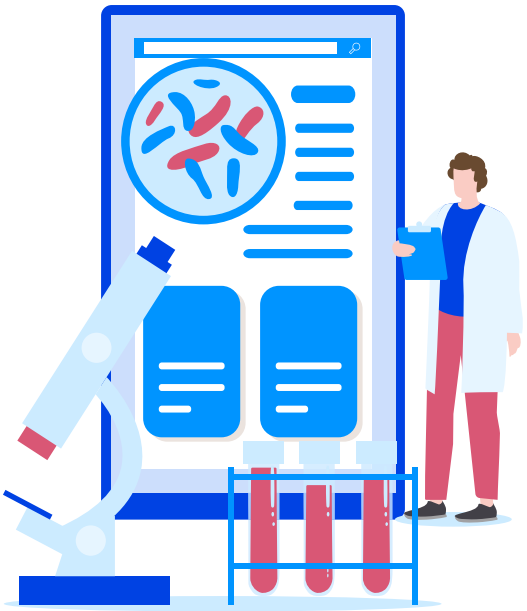
What is a clinical trial? | Blood Cancer UK

Further support available to people living with blood cancer

Pointing to key support

These blood cancer charities have joined or helped the development of this Charter. They offer resources such as information about your condition and support available to you. We have provided links to their websites below.

- **Anthony Nolan -** https://www.anthonynolan.org
- **Blood Cancer UK -** https://bloodcancer.org.uk
- **Leukaemia Care -** https://www.leukaemiacare.org.uk
- **Lymphoma Action -** https://lymphoma-action.org.uk
- **Myeloma UK -** https://www.myeloma.org.uk
- **MDS UK -** https://mdspatientsupport.org.uk/



The Briefing

To further advocate for people affected by blood cancer, we have created a separate briefing document for healthcare policymakers and regulators. This sets out six principles to improve the standards of care so that people diagnosed with blood cancer can live well after their diagnosis and feel supported throughout their care.

These principles have been developed along with blood cancer charities and people living with blood cancer. The principles are as follows:

1. Blood Cancer Awareness
2. Shared Decision Making
3. Holistic and Personalised Care
4. Equitable Access to Treatment and Support
5. Continuity in Care and Communication
6. Research and Clinical Trials

If you want to read this briefing or understand how you can be involved in advocating for improved standards of care for people living with blood cancer, please visit http://www.pfizer.co.uk/news/news-and-featured-articles/improving-standards-of-care-for-people-living-with-blood-cancer.

Acknowledgements

This Charter has been commissioned by Pfizer UK and developed in partnership with Blood Cancer UK through a consultancy agreement.

We would like to express our deepest gratitude to Blood Cancer UK for collaborating with us in developing this Charter. Sharing of their expert knowledge, guidance and insights has been invaluable and vital in the creation of this document. Their ceaseless dedication and commitment to people living with blood cancer has truly been motivating and inspiring.

We would like to enormously thank the blood cancer charities, people living with blood cancer and others for their contributions to the development of this Patient Charter by sharing their insights and/or priorities. Creation of this Charter would not have been possible without their invaluable inputs which has informed the very foundation of the principles set out within this document.

References

1. Blood Cancer UK. (2024). I've just been told I have blood cancer. Available at: https://bloodcancer.org.uk/understanding-blood-cancer/just-diagnosed/ (Accessed August 24).
2. Blood Cancer UK. (2024). Just diagnosed with blood cancer: now what?. Available at: https://bloodcancer.org.uk/understanding-blood-cancer/just-diagnosed/what-happens-next/ (Accessed August 24).
3. Blood Cancer UK. (2024). Active monitoring (watch and wait). Available at: https://bloodcancer.org.uk/understanding-blood-cancer/active-monitoring/ (Accessed August 24).
4. Macmillan. (2020). What is a Holistic Needs Assessment (HNA). Available at: https://www.macmillan.org.uk/cancer-information-and-support/treatment/coping-with-treatment/holistic-needs-assessment-hna (Accessed August 24).
5. NSHE. (n.d.). NHS England » Shared decision-making. Available at: https://www.england.nhs.uk/personalisedcare/shared-decision-making/ (Accessed August 24).
6. NHSE. (n.d.). NHS England » About shared decision making. Available at: https://www.england.nhs.uk/personalisedcare/shared-decision-making/about/ (Accessed August 24).
7. NICE. (2024). Shared decision making. Available at: https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making (Accessed August 24).
8. Blood Cancer UK. (2024). Blood cancer treatment planning. Available at: https://bloodcancer.org.uk/understanding-blood-cancer/treatment/blood-cancer-treatment-planning/ (Accessed August 24).
9. Blood Cancer UK. (2024) How to talk to your medical team. Available at: https://bloodcancer.org.uk/support-for-you/living-well/stories/blood-cancer-how-talk-medical-team/ (Accessed August 24).
10. Macmillan. (2018). Questions to ask your healthcare team. Available at: https://www.macmillan.org.uk/cancer-information-and-support/diagnosis/talking-to-your-healthcare-team (Accessed August 24).
11. Blood Cancer UK. (2024). Blood cancer: mind and emotions | Blood Cancer UK. Available at: https://bloodcancer.org.uk/support-for-you/living-well/mind-emotions/ (Accessed August 24).
12. Macmillan. (2019). Cancer and mental health support. Available at: https://www.macmillan.org.uk/cancer-information-and-support/treatment/coping-with-treatment/getting-help-with-your-emotions (Accessed August 24).
13. Blood Cancer UK. (2024). Looking after yourself when someone you love has blood cancer | Blood Cancer UK. Available at: https://bloodcancer.org.uk/support-for-you/someone-i-know-has-blood-cancer/feelings/ (Accessed August 24).
14. NHS England. (2023). Access to patient records through the NHS App - NHS Transformation Directorate. Available at: https://transform.england.nhs.uk/information-governance/guidance/access-to-patient-records-through-the-nhs-app/ (Accessed August 24).
15. Blood Cancer UK. (2021). Blood cancer and your employment rights. Available at: https://bloodcancer.org.uk/news/blood-cancer-and-your-employment-rights/ (Accessed August 24).
16. Macmillan. (2019). Talking to your employer. Available at: https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/work-and-cancer/talking-to-your-employer?gclid=eaiaiqobchmii9du2okphamvgg8gab1dqwwpeaayasaaegjfwfd_bwe&gclsrc=aw.ds (Accessed August 24).
17. Blood Cancer UK. (2024). What is a clinical trial?. Available at: https://bloodcancer.org.uk/understanding-blood-cancer/clinical-trials/ (Accessed August 24).