

Addressing concerns about your care



KNOW YOUR RIGHTS
TOOLKIT



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Introduction

Being treated or monitored in hospital for your leukaemia, myeloproliferative neoplasm (MPN; e.g. ET, PV, MF) or MDS can be daunting. Even if you have been living with a blood cancer for a long time, there is often lots of information to take on board. Usually, the service delivered by the NHS is very good and most patients do not experience any problems with their diagnosis, treatment or care. But occasionally things can go wrong. This toolkit is designed to help you think about any concerns and give you tips on how to address those concerns.

There are many reasons why patients may feel there is a lack of communication from their healthcare team, which may be impacting the quality of care they are receiving. This can cause patients and their family members or carers to express anger and frustration.

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What are your concerns?

The first thing you need to do is to document which part of your appointment or care has caused you concern. This will help you to communicate your concerns effectively and identify potential solutions.

Most complaints reported to us by blood cancer patients come down to miscommunication, which is often unintentional. Here are some common issues that may be at the root of your concerns. Many of these are linked and multiple may apply to you.

Communication issues during a consultation

As a blood cancer patient, you are likely to have medical appointments where a lot of detailed information is discussed, but appointments may only be a certain length of time. This often means there is not enough time to discuss all concerns a person may have, leading you to feel rushed or unclear on next steps.

This could be a particular

challenge for blood cancer patients when discussing treatment options, particularly those that have recently become available, when discussing blood results or when discussing active monitoring (also known as "watch and wait").

Communication on discharge

If you have been recently discharged from being an inpatient, we know this can be a scary time. You may have recently had a transplant, intensive chemotherapy or had a spell in hospital due to a serious infection. Whatever the reason for being in hospital, you should feel that you know what to do if you have any concerns and where you can go for extra support (known as signposting). Without this information, you can feel lost and unsure where to reach out.

Not being listened to

This is something you might be experiencing, but also sometimes the family and

friends of patients also feel their concerns are not being addressed. You may feel not listened to if you have previously raised another type of concern, or you may feel your feelings, opinions or concerns were not taken into account when a decision was made (e.g. when a treatment options was selected).

Misunderstanding information given in a appointment

Getting a diagnosis of a blood cancer is a shock, and we know it can be difficult for patients to retain information. Our survey at Leukaemia Care shows that blood cancer patients feel less worried if they are given written and understandable information about their diagnosis, in addition to talking it through in an appointment.

Not being informed when something changes

Many people feel comforted by routine and this can be the case for blood cancer patients, who build trust in their care team. Therefore, it can be shocking

to find that your consultant or nurse has changed. You should be told of changes and all blood cancer patients should have a point of contact, such as clinical nurse specialist or telephone helpline.

Administrative errors

There are many haematology departments across the UK and each will have their own processes for appointments, blood tests and delivery of treatments. As with a lot of big organisations, mistakes can occur. These can become frustrating, particularly if you are at a stage in your blood cancer treatment where you need many things to fall into place together (e.g. a blood test ready for your appointment).

Behaviour of healthcare professionals perceived as impolite or uncaring

This may also be linked to another concern outlined above. Healthcare professionals are human too, and as such have different styles of care and

What are your concerns? (cont.)

different personalities. As a blood cancer patient, you should feel listened to and that your relationship with your team is based on trust and mutual respect.

Lack of communication about patients prognosis and end of life care

This is a particularly challenging time for both patients and their families, as well as their healthcare team. You should be aware of your prognosis, who will be caring for you as you blood cancer progresses and how to plan for the future in a way that is right for you. You should also be signposted to extra support.

Incorrect diagnosis, symptoms missed or delays in getting a diagnosis

Blood cancer is difficult to diagnose, due to lack of awareness of the symptoms among both the public and GPs. Mistakes are very rarely intentional but feedback can be helpful. If you have experienced

delays in getting a diagnosis, it is important you continue to have any procedures or treatment you need, as further delays may be harmful.

Incorrect treatments or other medical mistakes

This is extremely rare but is serious and should be discussed with those who have an expertise in this area (e.g. specialist lawyers).

Raising your concerns with your healthcare team

The first step to resolve any issues quickly would be to directly speak to your hospital care team (or GP if relevant (e.g. diagnosis issues)). Complaints should usually be made within twelve months of the issue arising. Doing this verbally and informally in the first instance may help prevent further tensions. All blood cancer patients should have a telephone number for their department, their clinical nurse specialist or their consultant/their secretary. Additionally, a small concern may be best addressed in your next appointment.

You may also wish to speak to the Patient Advice and Liaison Service at your hospital. This is a department whose role is to resolve any concerns between a patient and their care team and can help you resolve issues informally as well as via a formal complaint. You can usually find their details on the hospital website.

If a concern is serious or continues after you have raised concerns informally, you could consider raising your concerns more formally. You could do this by writing directly to your consultant, to the department or follow the hospital's formal complaints procedure. Each hospital will have a specific policy, although you have certain rights (see "what are my rights" below).

When putting a complaint in writing, you may wish to follow the tips below:

- Make a list of the concerns you want to discuss and resolve, plus any ideas of how you could like them resolved. Remember to keep in mind hospital procedures and policies when suggesting these and be prepared to compromise if necessary.
- Set out clearly each individual concern, including the date and place of the appointment or where the issue occurred and the name of the

Raising your concerns with your healthcare team (cont.)

healthcare professional involved, if appropriate.

- Keep any relevant documents and letters as evidence to support any issues you have raised.

What are my rights when it comes to making a complaint about an NHS service?

As an NHS patient, you do have the right to make a formal complaint about any aspect of NHS care, treatment or services that you feel does not meet the expected standard of care. This is laid out in the NHS Constitution. You can find out more about the [NHS Constitution](#) and what it means for your blood cancer care in our [advocacy toolkit](#). Here are your rights specifically relating to complaints:

- You have the right to have any complaint you make about NHS services acknowledged within three working days

and to have it properly investigated.

- You have the right to discuss the manner in which the complaint is to be handled, and to know how long the investigation is likely to take and when you will receive a response.
- You have the right to be kept informed of progress and to know the outcome of any investigation into your complaint, including an explanation of the conclusions and confirmation that any action needed in consequence of the complaint has been taken or is proposed to be taken.
- You have the right to take your complaint to the independent Parliamentary and Health Service Ombudsman or Local Government Ombudsman, if you are not satisfied with the way your complaint has been dealt with by the NHS.
- You have the right to make a claim for judicial review if you

think you have been directly affected by an unlawful act or decision of an NHS body or local authority.

- You have the right to compensation where you have been harmed by negligent treatment.

Note: Our advocacy team is unable to help with any legal matters.

Other options for raising concerns

If you feel a complaint has not resolved your issues or if the issue is particularly serious, you may wish to look at alternative options for raising your concerns. This could include:

- **Taking legal action** – this is usually reserved for the most serious complaints, such as negligence. Leukaemia Care are unable to assist with this and we would recommend you seek expert legal advice.
- **Reporting your concern to the General Medical**

Council – this may be most appropriate if you have concerns with the conduct of a specific person.

- **Contacting your local Clinical Commissioning Group (CCG)** – you can complain directly to the CCG as the body that is responsible for allocating funds to and organising delivery of services (known as commissioning) in their local area. However, this is also a route to escalate a complaint if your hospital cannot resolve the issue or you are not satisfied with a response. This is also your point of contact for issues that are beyond a hospital's control, such as funding issues.

The result of your complaint and implementing changes

As stated in the previous section, you are entitled to an answer to your complaint and to have an explanation of the conclusions and any actions. If they have been unable to put in place any solutions you have requested, there should be an explanation as to reasons why and suggested compromises. If you remain unsatisfied, you should get in touch with the contact named on the response.

Changing your consultant/getting a second opinion

You may wish to change your consultant during or following making a complaint. It is not a legal right for an NHS patient to access a second opinion; however, it is rare for this to be denied. If you want to change your consultant team, you need to request this from your consultant or go back to your GP and request a referral. It is important to keep in mind certain things when deciding to change your consultant:

- Consider if a second opinion will resolve your issue, or whether a different or quicker course of action will be more appropriate. Our team can talk you through all your options.
- Changing your consultant can cause a delay in your care, including delays in your treatment. You may like to discuss this with your current consultant or another member of your care team before or at the time of making your request.
- If you have to travel further for your hospital care due to changing your consultant, this may cause additional travel costs, which you may need to consider.
- A second opinion does not always result in the person becoming your new, usual consultant. Whether this is possible or appropriate will be decided after the second doctor has seen you.

Further information

Call our Patient Advocacy team on **08088 010 444** or email advocacy@leukaemiacare.org.uk for more information on topics covered in this toolkit.

Other sources of information:

NHS Complaints Advocacy

The NHS Complaints Advocacy service is an independent service that can help you with the NHS complaint process. An advocate from the service should be able to attend meetings with you and help you to review any information you are given during the process.

Healthwatch

This is an independent body who work to feedback to NHS bodies about the work that they do. Your local Healthwatch can also help provide guidance and information about making a complaint.

www.healthwatch.co.uk/

Citizens advice also provide some information about making a complaint, including useful details for how to make complaint on someone else's behalf and templates for letters or emails: www.citizensadvice.org.uk/health/nhs-and-social-care-complaints/complaining-about-the-nhs/tips-and-tools-to-help-you-make-a-complaint-about-health-services/Letter-of-complaint-about-NHS/

Details for the **Health Service Ombudsman**: www.ombudsman.org.uk/making-complaint/complain-us-getting-started

More information about **second opinions**: www.macmillan.org.uk/cancer-information-and-support/treatment/your-treatment-options/getting-a-second-opinion

The **NHS** webpage about complaints: www.nhs.uk/using-the-nhs/about-the-nhs/how-to-complain-to-the-nhs/

About Leukaemia Care

Leukaemia Care is a national charity dedicated to ensuring that people affected by blood cancer have access to the right information, advice and support.

Our services

Helpline

Our helpline is available 9:00am – 5:00pm Monday - Friday and 7:00pm – 10:00pm on Thursdays and Fridays. If you need someone to talk to, call **08088 010 444**.

Alternatively, you can send a message via WhatsApp on **07500068065** on weekdays 9:00am – 5:00pm.

Nurse service

We have two trained nurses on hand to answer your questions and offer advice and support, whether it be through emailing support@leukaemiacare.org.uk or over the phone on **08088 010 444**.

Patient Information Booklets

We have a number of patient information booklets like this available to anyone who

has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be found on our website at www.leukaemiacare.org.uk/support-and-information/help-and-resources/information-booklets/

Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience. For more information about a support group local to your area, go to www.leukaemiacare.org.uk/support-and-information/support-for-you/find-a-support-group/

Buddy Support

We offer one-to-one phone support with volunteers who have had blood cancer themselves or been affected by

it in some way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email support@leukaemicare.org.uk

Online Forum

Our online forum, www.healthunlocked.com/leukaemia-care, is a place for people to ask questions anonymously or to join in the discussion with other people in a similar situation.

Webinars

Our webinars provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support. For information on upcoming webinars, go to www.leukaemicare.org.uk/support-and-information/support-for-you/onlinewebinars/

Website

You can access up-to-date information on our website, www.leukaemicare.org.uk.

Campaigning and Advocacy

Leukaemia Care is involved in campaigning for patient well-being, NHS funding and drug and treatment availability. If you would like an update on any of the work we are currently doing or want to know how to get involved, email advocacy@leukaemicare.org.uk

Patient magazine

Our magazine includes inspirational patient and carer stories as well as informative articles by medical professionals: www.leukaemicare.org.uk/communication-preferences/

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 34,000 new cases of blood cancer are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

Helpline: **08088 010 444**

(free from landlines and all major mobile networks)

Office Line: **01905 755977**

www.leukaemiacare.org.uk

advocacy@leukaemiacare.org.uk

Leukaemia Care,
One Birch Court,
Blackpole East,
Worcester,
WR3 8SG

Leukaemia Care is registered as a charity in England and Wales (no.1183890) and Scotland (no. SC049802).

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Registered office address: One Birch Court, Blackpole East, Worcester, WR3 8SG

Leukaemia Care
YOUR Blood Cancer Charity