Knowing your rights, accessing help, and making the most of your healthcare appointment



As a patient living with cancer and / or a blood disorder, especially if you are from an underserved community, you are not only dealing with your medical condition, but you may also face non-medical issues, such as worrying about everyday essentials like healthy food, household bills or housing. All these things can have a negative impact on your health.

This fact sheet will help you to:



Know what your rights are as a patient



Make the most of your appointments and manage your care



Learn more about benefits and resources that may be available to you

Knowing your rights:

It is important to know your rights as a patient. Some of these rights include:

- **Treatment:** You have the right to receive care and treatment that is appropriate to you, meets your needs and reflects your preferences.
- **Respect:** You have the right to be treated with dignity and respect, and to be protected from abuse and neglect.
- **Equal treatment:** You have the right to equal treatment regardless of gender, race, disability, age, sexual orientation, gender reassignment, religion, or any other protected characteristic.

You can learn more about your rights in the NHS Constitution for England: <a href="https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nh

Making the most of your appointments and managing your care

Here are some things to consider when preparing for and meeting with your health professional:

- Going through the healthcare system can be hard. You may want to bring someone with you to the appointment for support, if possible.
- Before your appointment, write down any questions you want to ask and any concerns you may have regarding your treatment plan.
- Remember, you are an expert on your own health, so don't be afraid to share your views on what treatment options may work best for you. For more information on shared decision making, visit www.patients-association.org.uk/shared-decision-making
- Tell your health professional about how your health condition impacts your daily life. This will help them to get a better picture of things you may need to help with daily functioning.
- Discuss how your care should be tailored to meet your needs, preferences, and cultural background.
- Let your healthcare professional know if you need the information presented differently, such as in paper copy.
- If there is a word or medical terminology that you cannot understand, ask them to write it down and explain.
- Let your healthcare professional know what support and help you may need, such as transportation assistance, social services, patient support groups, holistic services, translators, and advocacy services.
- Ask who to contact in emergency and non-emergency situations or if you have problems or questions.
- Keeping all your medical details in one place, such as test results and appointments, can help you and your healthcare team better manage your care. You can use the NHS App to do this: www.nhs.uk/nhs-app

Your health and wellbeing are not only affected by the type of care and treatment you receive, but it can also be affected by concerns you have outside of the healthcare system, such as worrying about everyday essentials like healthy food, household bills or housing, or paying for transportation to appointments.



Also to help with this, see these resources on financial support:

- Through the Healthcare Travel Cost Scheme, you can claim a refund if you're referred to hospital or other NHS premises for specialist NHS treatment or tests. To learn more, visit: www.nhs.uk/nhs-services/help-with-health-costs/healthcare-travel-costs-scheme-htcs
- The NHS Low Income Scheme can help you to pay for prescription charges, dental treatment charges, sight tests and glasses, etc. To learn more visit: www.nhsbsa.nhs.uk/nhs-low-income-scheme
- The Household Support Fund helps people struggling with everyday bills and expenses like energy and water bills, and food. To learn more, contact your Local Council and visit: www.gov.uk/cost-living-help-local-council
- The Personal Independence Payment (or PIP) can help with extra living costs if you have:
 - a long-term physical or mental health condition or disability, and
 - difficulty doing certain everyday tasks or getting around because of your condition

To learn more, visit: www.gov.uk/pip

A few more things to consider:

Voluntary Sector

Consider seeing what support and services are available from the voluntary sector (such as charities and local community groups) as these organisations can provide help and assistance that may be more tailored to your specific needs.

Mental Health Support

The Hub of Hope, the nation's go-to mental health signposting tool, can help direct anyone looking for support to the nearest and most relevant services to them.

https://hubofhope.co.uk

Advocacy and Complaints

You can contact the Patients Association Helpline for a range of issues, including finding out how to make a complaint:

www.patients-association.org.uk/helpline and 0800 345 7115.

If you need to complain about any service you have received through the NHS and to receive advocacy support, you can also contact the Independent Health Complaints Advocate (IHCA). The IHCA is a free, confidential, and independent service that helps guide people through the NHS complaints process. It's a statutory service that gives you rights to advocacy support. It can assist with:

- Sending you an information pack to help you make your complaint yourself.
- Providing you with an advocate who can help with writing letters and filling out forms. The advocate can also attend complaints meetings with you.

Contact your Local Council to find an IHCA in your area.

Equality Advisory and Support Service (EASS) helpline

The EASS helpline advises and assists individuals on issues relating to equality and human rights, across England, Scotland, and Wales. For example, it provides advice and resources on your rights and what to do and who to contact if you experience discrimination and racism. You can phone EASS on 0808 800 0082.

Below are national condition-specific organisations to get more information and advice:

- Blood Cancer UK
- Cancer Research Wales
- Cheshire and Merseyside Cancer Alliance
- Myeloma UK
- **OUTpatients**
- Pancreatic Cancer Action
- Pancreatic Cancer UK
- Prostate Cancer UK
- Sickle Cell Society
- Tenovus Cancer Care
- Young Lives vs Cancer



We know that living with cancer and / or a blood disorder affects everyone differently and accessing the right care and support isn't always easy. Knowing your rights and what resources are available to you can help ensure that you have the support you need during your health journey.

This fact sheet was developed by the Patients Association based on insights and ideas from patients living with cancer and / or a blood disorder and their carers. However, it can be used by all patients. We thank them for their guidance and partnership.

This work was funded by a grant from Bristol Myers Squibb.