Leukaemia Care
YOUR Blood Cancer Charity

‘The future we will create together’

Our plan to create a future where everyone affected by leukaemia, MDS or MPN gets the best possible diagnosis, information, advice, treatment and support. We need your help.

Our vision, mission, values and strategy (2022 – 2030)

Who We Are and What We Do

About Us

Leukaemia Care is the UK's leading leukaemia charity. For over 50 years, we have been dedicated to ensuring that everyone affected receives the best possible diagnosis, information, advice, treatment and support.

We are here for everyone affected by leukaemia and related blood cancer types – such as myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPN).

We believe in improving lives and being a force for change. To do this, we have to challenge the status quo and do things differently.

Our Vision

Our long term ideal

A future where everyone affected by leukaemia, MDS and MPN gets the best possible diagnosis, information, advice, treatment and support.

Our Mission

What we are doing to make that vision a reality

We exist to improve the lives of everyone affected by leukaemia, MDS and MPN.

We provide information, advice and support for anyone affected, this includes patients and their friends and families too. We raise awareness of the issues impacting people affected by leukaemia, MDS and MPN, and campaign to fix them. We are driving early diagnosis, raising public awareness, improving services, and ensuring access to effective treatments.

But most importantly, we bring people together and unite them behind our common goal. Together, we will create the future we all believe in.

Our Values – What do we stand for?

Leukaemia Care's values are at the heart of everything we do. They describe our approach to our work. They drive our thinking, our behaviours and our actions.

Mission based

We have a clear mission. We exist to improve the lives of people affected by leukaemia, MDS and MPN. We believe in doing the right thing. If it is not in the best interests of people affected by our mission, we will not do it. It is that simple. No ifs, no buts, no exceptions.

Collaborative

We are passionate about all forms of collaboration, especially with other charities. Our mission is bigger than Leukaemia Care. We know that working on our own will delay the day when everyone affected by leukaemia, MDS and MPN gets the best possible diagnosis, information, advice, treatment and support. That is why it is so important that we work in partnership with individual charities, charity coalitions, healthcare professionals and a wide range of other stakeholders to improve the lives of people affected.

Caring

It is in our name, and it is in our nature. We care deeply about every single person affected by leukaemia, MDS and MPN. We are on your side and always will be. This helps us deliver high quality support, but also underpins all other parts of the charity. We care about the people who dedicate their time to our mission – whether that is our colleagues, volunteers, supporters or fundraisers. We are a community united by a common mission and we care about each other.

Evidence based

We listen to and understand the experiences of people affected by leukaemia, MDS and MPN. We use the evidence we gather to adapt, improve our services and to focus our campaigns for change. We also work with healthcare professionals – including haematologists, nurses and GPs – to make sure we are rooted in the latest science.

Aspirational

We have ambitious goals and we set ourselves high standards to achieve them. We believe that everyone affected by leukaemia, MDS and MPN should get the best possible diagnosis, information, advice, treatment and support. Every day 44 people are diagnosed with leukaemia, MDS or MPN, we can't afford to wait. To achieve this change we must be innovators, problem solvers, challengers to the status quo and each and every one of us must go above and beyond, every single day.

Our values are key to everything we do. But we all make mistakes. If you see us acting in a way that you feel is not consistent with our values – please let us know!

Why our work is important

To paint a picture of the scale of the issue across the UK:

- Leukaemia is the **12th** most common form of cancer and 12th biggest cancer killer.
- Every year, **10,000** people are diagnosed with leukaemia in the UK.
- Every year, **5,000** people die from leukaemia in the UK.
- Every year **6,000** people in the UK will be diagnosed with conditions that may develop into leukaemia, including myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPN).
- Over **50,000** people are living with leukaemia in the UK.
- There are **34,000** people living with MDS or MPN in the UK.

Our Strategic Plan

We exist to improve the lives of everyone affected by leukaemia, MDS and MPN. Over the last 50 years, we have come a long way, but there is more to be done.

We are committed to creating a future where everyone affected by leukaemia, MDS and MPN gets the best possible diagnosis, information, advice, treatment and support.

That will not happen overnight. But we are closer than ever before, and we are working to create that future every single day.

Our Strategic Goals

Our organisational strategy focuses on the future we believe we can create, and sets clear goals for the work we will be doing until 2030 to make this a reality sooner:

Improving diagnosis – through awareness and early detection.

Ensuring everyone receives high quality information, advice and support.

Tackling issues that impact people's lives.

Advancing treatment and care.

Creating a narrative to better reflect the reality people experience.

But we need your help. If you believe in the future we are trying to create and want to help us get there faster, please get involved.

Goal 1: Improving the diagnosis and detection of leukaemia, MDS and MPN

Early diagnosis saves lives. Raising awareness is crucial to combat the many issues that prevent people from seeking help. And so is breaking down the barriers that delay diagnosis once they do.

Why it matters

Every year, 10,000 people are diagnosed with leukaemia in the UK. A third (37%) of people will be diagnosed in an emergency, over 75% more than other types of cancer. This is unacceptable.

An emergency diagnosis reduces your chance of survival, with only half (55%) of people diagnosed with leukaemia in an emergency surviving for more than a year after their diagnosis. We need to do everything we possibly can to improve the diagnosis of leukaemia and related blood cancers. And we need your help. Thousands of lives depend on it.

Tom, acute lymphoblastic leukaemia patient

The change we will create

Between now and 2030, this is what we will be doing:

- Working to make sure the proportion of people diagnosed with leukaemia in an emergency is lower than other types of cancer – and eventually zero!
- Raising awareness of the signs and symptoms, so that everyone knows how to Spot Leukaemia.
- Highlighting the urgency of common symptoms – if someone experiences them, they know to seek help as early as possible.
- Providing education, support, and tools in primary care (GP, pharmacist, dentist and opticians) and beyond to aid earlier diagnosis.
- Ensuring anyone who seeks medical attention when experiencing the signs and symptoms of leukaemia receives a blood test and if appropriate a prompt referral to haematology.
- Ensuring everyone is diagnosed in-person and with a loved one present to support them.
- Working to stop the 12% of leukaemia cases that are preventable, through ionising radiation, smoking and workplace exposures.
- Investing in research to better understand the causes of later diagnosis. It is a highly complex problem, and we need to create tailored solutions at every stage.
- Partnering with others who share our belief – we cannot get there alone!

Goal 2: Ensuring everyone receives high quality information, advice and support

We believe in a future where everyone affected by leukaemia, MDS and MPN receives the right information, advice and support. At diagnosis and beyond, tailored to their needs, tailored to their needs at diagnosis and beyond.

Why it matters

Leukaemia and blood cancer is highly complex. We know that at diagnosis people are significantly less likely to understand what is wrong with them than for other forms of cancer. Many are left worried and confused.

We know that high quality information, advice and support is key. Whilst most people receive information about their blood cancer, few receive information about emotional, practical, and financial support. Information is also more likely to be provided at diagnosis, with a drop off after treatment finishes. We are working to stop this.

Laura, chronic myeloid leukaemia patient

Between now and 2030, this is what we will be doing:

- Identifying every person diagnosed with leukaemia, MDS and MPN and making sure they receive a swift referral to Leukaemia Care.
- Offering personalised support to every person diagnosed with leukaemia, MDS and MPN, tailored to the diverse experiences of people affected by different types and helping navigate the healthcare system.
- Creating more tailored support for the family and friends of people diagnosed, focusing on them as individuals and how their needs may differ.
- Providing information, advice and support at different timepoints – e.g. diagnosis, treatment, after treatment. Identifying gaps and filling them!
- Ensuring our support is easy to access, open to a diverse range of people and meets their own individual needs. Covering topics such as emotional, financial and practical.
- Making sure all the information, advice and support we offer is the best available.
- Signposting people to all the available support, not just our own. Sometime this will be as well as our own services (e.g. Young Lives Vs Cancer, Teenage Cancer Trust) and sometimes this will be instead of our services (e.g. Lymphoma Action, Myeloma UK).
- Collaborating with other organisations to create the best possible information, advice and support. This includes joint initiatives, but it also means avoiding duplication where great support already exists.

Goal 3: Tackling issues that impact people's lives

We exist to improve the lives of people affected by leukaemia, MDS and MPN. We raise awareness of issues, and campaign to fix them. This includes tackling the tough issues, speaking out about the things that are wrong and helping implement solutions.

Why it matters

We hear every single day from people who need our help. People contact us about employment, finances, housing, insurance, treatment, clinical trials and much more. But these issues are widespread and not everyone finds us. And we don't have the resources to help everyone if they did.

We know that some problems are bigger than we can address through support, information and advice. So we look for the cause of the issue and fight to fix it. We can be a catalyst for change. But we can't do this alone.

Garry, chronic lymphocytic leukaemia patient

Between now and 2030, this is what we will be doing:

- Listening to the experiences of people affected by leukaemia, MDS and MPN and using the evidence we gather to improve our services and to focus our campaigns for change.
- Being a powerful voice for people affected by leukaemia, MDS and MPN. Representing your views and interests when decisions that affect you are being made.
- Being vocal about the things that are wrong and campaigning with solutions that improve the lives of people in our community.
- Tackling specific issues. These may include watch and wait, access to clinical nurse specialists, financial issues, inequalities.
- Creating a platform for people to share their experience. And sharing our platform with people, so they can be a powerful force for change.
- Growing our influence to support the increasing needs of leukaemia, MDS and MPN.
- Increasing our communications about our policy, advocacy and influencing work.
- Ensuring leukaemia, MDS and MPN are not disadvantaged compared to other cancers.
- Bringing people together and uniting behind a common goal. We need a solution, but we don't always need to be the solution. Collaborating with other charities to address issues – where they are broader in scope or where the combination of efforts will have a greater impact.

Goal 4: Advancing the treatment and care of leukaemia, MDS and MPN

We are passionate about improving survival, the quality of life and experience of people living with leukaemia, MDS and MPN. We can't do this without improvements in treatment and care. We work with healthcare professionals. We campaign for access to the latest treatments. We want to ensure the voice of patients is heard.

Why it matters

Every year, 5,000 people die from leukaemia in the UK. Only 41% of people survive for 10 or more years following a leukaemia diagnosis. Survival varies significantly between different types of leukaemia.

Whilst survival has more than quadrupled in the last 40 years, survival is below the average for Europe. We cannot improve survival without advancing treatment and care. New treatments for blood cancers are less likely to be routinely approved and funded for use within the NHS than for other types of cancer. We want to change this.

Dharmesh, chronic myeloid leukaemia patient

Between now and 2030, this is what we will be doing:

- Campaigning for access to the latest new treatments and ensuring the voice of people impacted by decisions is heard.
- Advocating for the involvement of patients, patient advocates and patient organisations in the design of new treatments and trials.
- Challenging stakeholders to put patients at the core of decision making.
- Identifying potential solutions within the system and working with other charities, the pharmaceutical industry, government bodies and the NHS to resolve them.
- Providing training and development opportunities for healthcare professionals to improve patient care and accelerate the dissemination and uptake of scientific advances.
- Communicating with the wide range of healthcare professionals – including haematologists, nurses and GPs – involved in the treatment and care of people affected by leukaemia, MDS and MPN.
- Working with healthcare professionals to make sure all our work is based on the latest science. Ensuring healthcare professionals are aware of the ways in which Leukaemia Care can help and are actively referring people to access this support.
- Addressing inequalities in the treatment and care of people affected by leukaemia, MDS or MPN. Working towards a consistency of outcomes and experience across the UK.

Goal 5: Creating a narrative to better reflect the reality people experience

Perceptions of leukaemia often vary wildly from the reality many face. People often tell us that before their diagnosis they knew very little about leukaemia and thought it was something that only affected children. We are determined to change this.

Why it matters

After years of campaigning, public awareness of leukaemia is now quite high (over 90%). But few know much about it before diagnosis. Some don't even know that leukaemia is a form of cancer. Only 7% of the general public know leukaemia is most common in over 65s. Most incorrectly believe it is most common in children.

After diagnosis, the experience of leukaemia (particularly chronic) can vary wildly from what people might expect. Some will live for a long time, 'look well', not lose their hair, be able to work, may not spend significant time in hospital, and not be treated with chemotherapy. All of these things can disguise the challenges that these people do face.

We hear from people living with leukaemia how difficult these misconceptions are for them. We are determined to change the narrative to better reflect this reality.

Sarah, hairy cell leukaemia patient

Between now and 2030, this is what we will be doing:

- Developing a new narrative on leukaemia, MDS and MPN to increase awareness and understanding.
- Changing the public narrative and perceptions of who leukaemia affects – to better reflect the reality of who is most at risk and how to spot it.
- Changing public perceptions based the evidence we gather of the experiences of people affected by leukaemia, MDS and MPN.
- Challenging myths, such as the misconception that 'leukaemia only affects children' and perceptions around how someone with cancer 'should' look or behave.
- Improving public understanding of incurable cancers, chronic cancers, rare cancers, and blood cancers.
- Sharing stories of people's experience of leukaemia, MDS and MPN. Being representative and the voice of the diverse range of people affected.
- Ensuring all our materials and communications are audience-led and represent the diverse experiences of people affected by different types of leukaemia, MDS and MPN.

Our Organisational Objectives

We believe in a future where everyone affected by leukaemia, MDS or MPN gets the best possible diagnosis, information, advice, treatment and support. We are driven by this vision. We work to create this future every single day. But we are limited in what we can do by the resources we have.

Why it matters

In this future we hope that excellent diagnosis, information, advice, treatment and support will be the norm. But this future is not the reality people currently face.

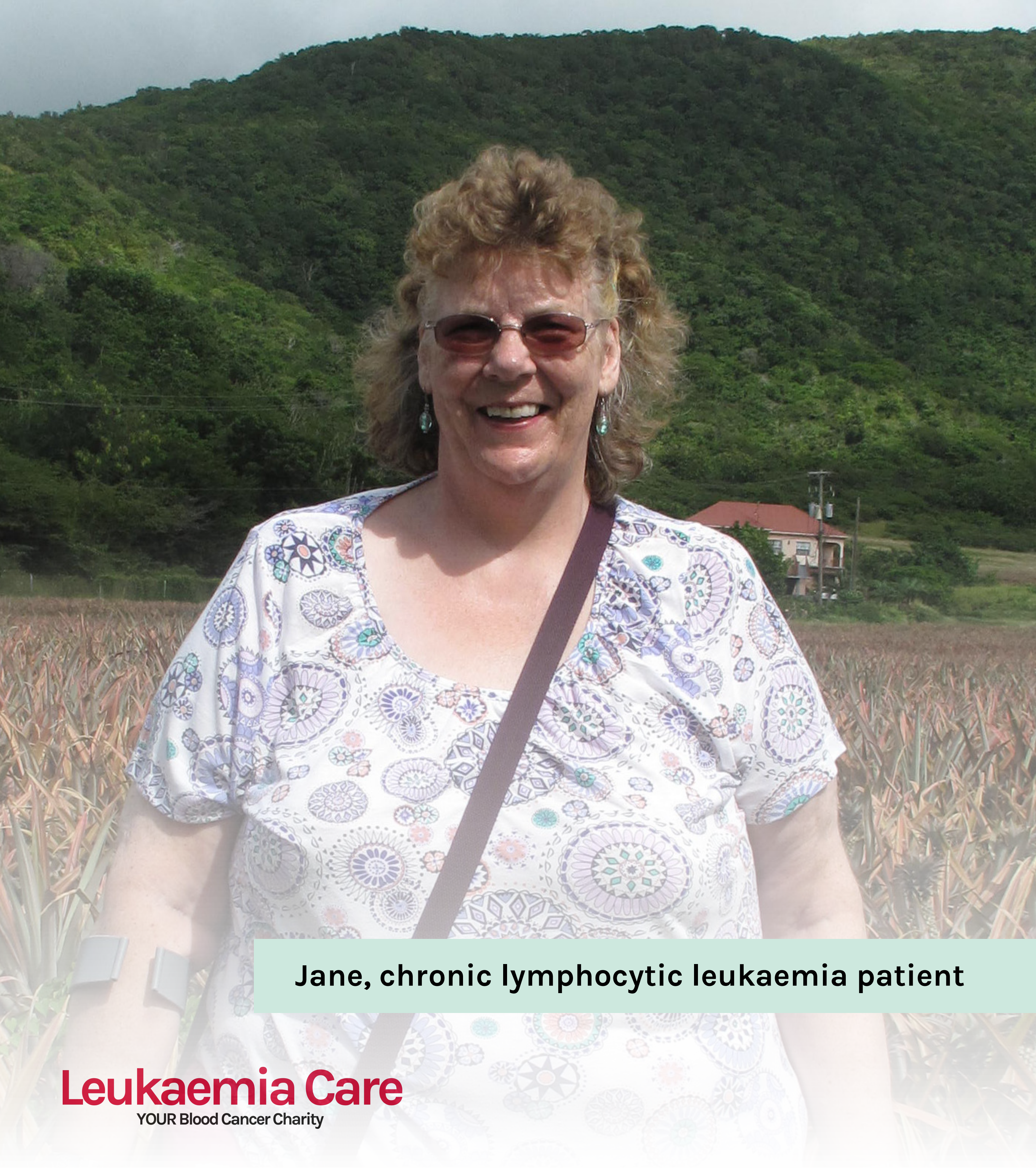
We believe that making our vision of the future come true is far more important than being the ones who create that future, and we are committed to partnering with a wide range of stakeholders to achieve this. But we also know that to create the future we believe in and to bring forward the day where our vision is realised, Leukaemia Care needs to be able to do more than we currently do.

Zack Pemberton-Whiteley, Chief Executive Officer

The change we will create

Between now and 2030, this is what we will be doing:

- Making sure everyone affected by leukaemia, MDS or MPN is aware of the wide range of ways Leukaemia Care can help.
- Improving opportunities for people to get involved with the charity – ambassadors, campaigning, volunteering, donating, and fundraising.
- Increasing our brand awareness, influence, and income by understanding, prioritising, and better engaging with our audiences.
- Improving the evidence we have available, to help make better and quicker decisions, and challenge false assumptions.
- Better demonstrating our impact – providing tangible evidence of the difference we make and sharing the stories of people we have helped.
- Removing internal barriers and improving internal communications – so we act as one community, aligned to our mission.
- Being a good and caring employer. Looking after our staff wellbeing and development. Building a diverse workforce as part of an inclusive organisational culture.
- Identifying areas of collaboration, we can do more together to achieve joint goals.
- Securing sustainable growth for the future. Raising more money to achieve our goals.
- Monitoring our impact and progress against our strategic goals and development priorities.



Jane, chronic lymphocytic leukaemia patient

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