

# **The Blood Cancer UK referral service: guiding patients through diagnosis and beyond**

**November 2025**



## **Acknowledgements**

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# The need

**Blood Cancer Action Plan recommendation:** Empower patients with self-monitoring knowledge, awareness of their blood cancer team and resources to encourage patient advocacy, including sign posting and referral into charity support services

Our survey of over 2500 people affected by blood cancer found that **58% were unaware of any support available to them at diagnosis**

# The need

Not enough people are accessing the support they need and people wish they knew about our support sooner

People from marginalised communities are less likely to find and access support

Healthcare professionals' workforce constraints mean they aren't able to provide the level of emotional support they want to.

Healthcare professionals have told us it's difficult to keep up with what support is available for patients.

This affects patient experience and patients' ability to **self-manage and cope with blood cancer**.  
The burden is on the patient to find trustworthy, relevant support when they are at their most vulnerable.

# What we did

We worked with healthcare professionals and people affected by blood cancer to co-create a service and a quick and easy referral mechanism to connect blood cancer patients, at the point of diagnosis, to our support, information and peer networks to complement the care they are provided by clinical teams.

So that...

**All** people newly diagnosed with blood cancer can be aware of available services and access what they need to feel informed, resourced and connected and through this, improve outcomes for patients.



### Getting diagnosed

Patients are generally given a confirmed blood cancer diagnosis in a hospital setting



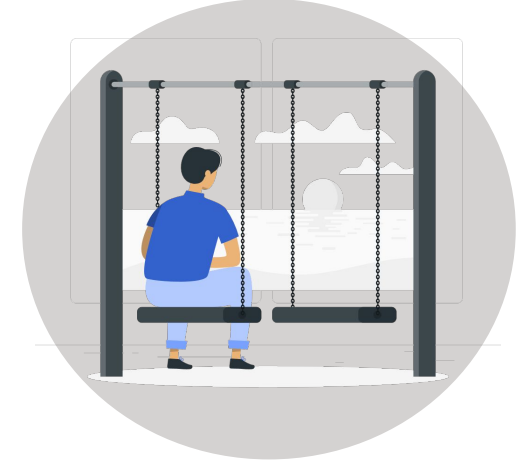
### Understanding your diagnosis and the support available

A healthcare professional spends time with newly diagnosed patients to help them understand what their diagnosis means, answer questions, provide support and signpost them to additional services that could support them



### Processing your diagnosis

Over the next few days people begin to have questions, often start wondering how to tell their family, friends and sometimes work. For many people they don't know where to go to get reliable information and often turn to google. It can be an anxious and overwhelming time for many.



### Knowing what to do next

Some patients are able to cope with their diagnosis and find and access support that works for them.

#### But many do not

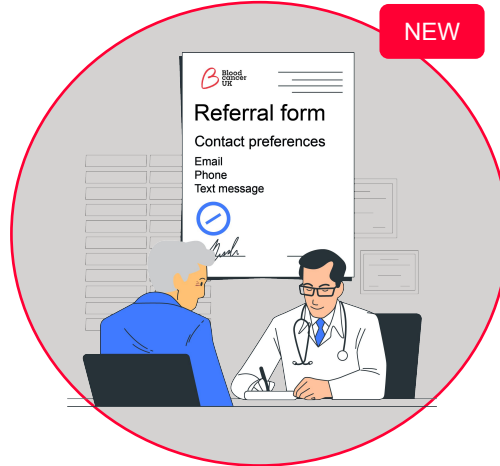
We know there are many barriers to asking for help or accessing support services and some people are falling through the cracks, **leading to increased health inequalities**

# What can happen now



## Getting diagnosed

Patients are generally given a confirmed blood cancer diagnosis in a hospital setting



## Understanding your diagnosis and the support available

### Being referred to Blood Cancer UK

In addition to supporting the patient after diagnosis, healthcare professionals are also able to offer a referral to the charity. They get consent from patients, provide a short overview of the support on offer and then fill out a quick online form with the patient's contact details



## Processing your diagnosis


Over the next few days people begin to have questions, often start wondering how to tell their family, friends and sometimes work. For many people they don't know where to go to get reliable information and often turn to google. It can be an anxious and overwhelming time for many.



## Receiving proactive communication from Blood Cancer UK

Blood Cancer UK reaches out to the patient through their preferred contact method. We welcome them to our community and listen to where they are and what they need so we can provide a blood cancer specific support journey as they navigate your diagnosis

# Email journey



## Lucy, finding out you have blood cancer is a tough thing to hear.

This is your first support email from Blood Cancer UK. You're receiving this because you were referred by a healthcare professional.

Blood cancer is the 5th most common cancer in the UK, with over 41,000 people diagnosed every year - so you're not alone.

It's normal to feel shocked, scared or numb after your diagnosis. However you're feeling, we're here to support you.


### Understanding your diagnosis

It's important to access trustworthy information about your diagnosis and avoid anything misleading.

There are many different types of blood cancer. Our website can help you understand your specific type of blood cancer, including symptoms and treatments.

[Read more about your type of blood cancer](#)

### Find your community




You can connect with others living with blood cancer in our [online community forum](#).

Just remember people with the same condition and treatments can have very different experiences.

[Go to the Online Community Forum](#)


### Speak to our Support Service Nurses

Our Support Service is free and confidential. You can call or email us to talk about your diagnosis, family, work, mental health, or even just for a chat. Your family and friends are also welcome to contact us.



Call [0800 2080 888](tel:08002080888) or [send us an email](#).

[About our Support Service](#)



## Understanding your treatment and care options

Your healthcare team will recommend a treatment plan based on the type of blood cancer you have, your health and your wishes.

You may have started treatment already, be starting treatment soon, or be on active monitoring (also called 'watch and wait'). You might also be interested in finding out about clinical trials.

Whatever your treatment plan, we can help you navigate your care and ask the right questions to your medical team.


### Understanding active monitoring (watch and wait)

If you have a type of blood cancer that develops slowly, your doctor might recommend active monitoring. This means you have regular check-ups, but save treatment for when it will have the best impact.

[Read more about active monitoring](#)

### Questions to ask about treatment


If you're having treatment now or in future, it can be hard to know what to ask. We've put together a list of questions to ask your healthcare team.

[What to ask your healthcare team](#)

### Clinical trials: facts from fiction

For many people, having treatment as part of a clinical trial is an option. Clinical trials are the main way we develop new blood cancer treatments and improve existing ones.

There are pros and cons to taking part in a clinical trial, but there are also myths that put people off. We can help you understand how clinical trials work and separate the fact from fiction.



"The kindness of the clinical trials team made all the difference, especially when I had to make tough decisions. Today, I'm living a normal, symptom-free life, and to date, I remain in remission".  
Nicky, who took part in a clinical trial in 2015.

[Find out more about clinical trials](#)

Our [Clinical Trials Support Nurses](#) can also help you understand more about your options.

## Access to

- Support and information to help navigate their diagnosis
- Reliable health information
- Patient stories
- Peer support

# Impact so far

- The service went live in March 2024, and since then we have had...



19 Trusts/Health Boards enrolled



670 total referrals  
568 patient referrals  
102 caregiver referrals



529 email support referrals



141 phone support referrals



# Timing of Referral

Figure 1

When were you offered a referral to Blood Cancer UK?

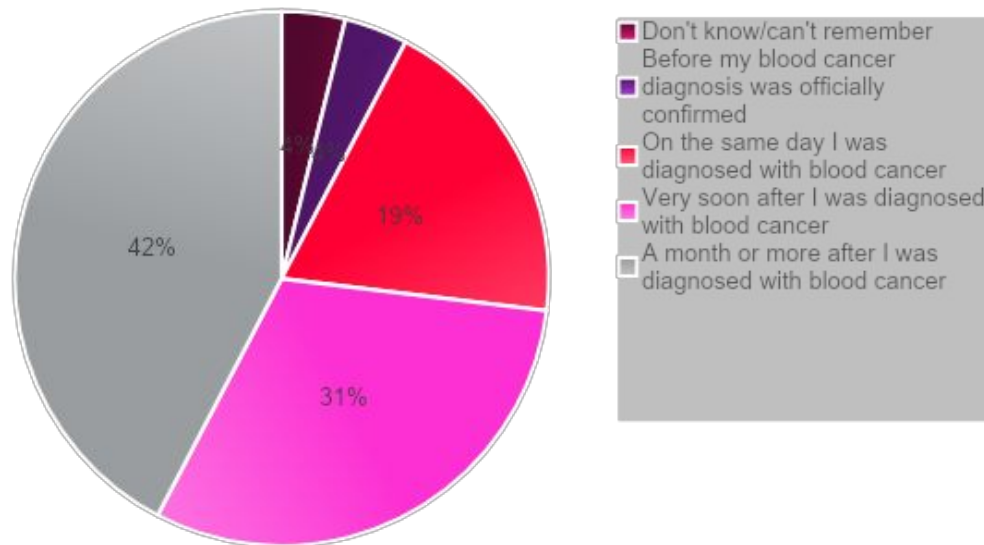
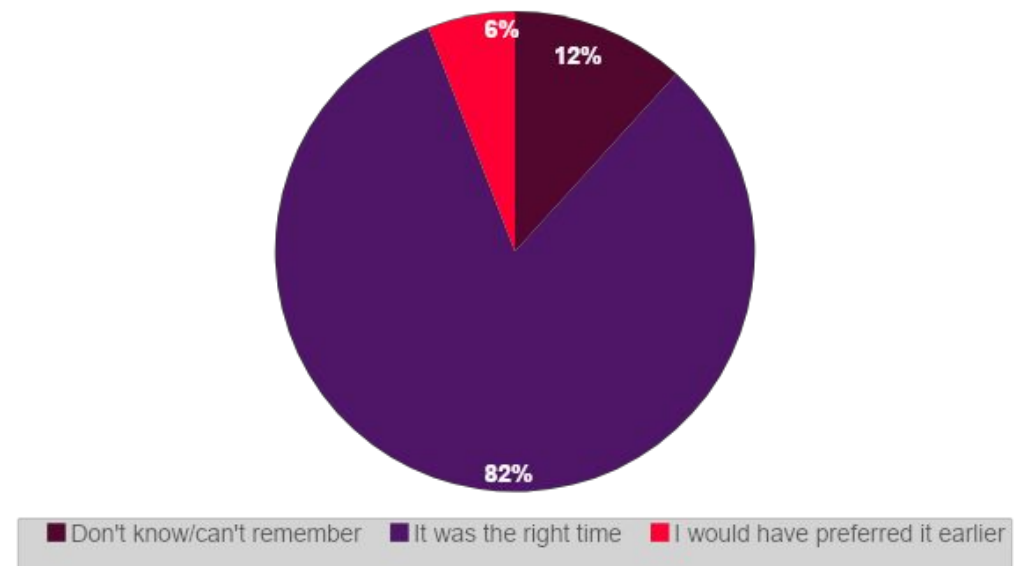


Figure 2

What did you think of the timing of being offered a referral?



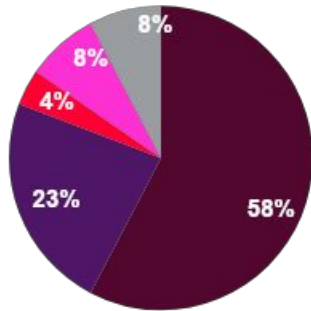
Half of the respondents were offered a referral on the same day they were diagnosed, or very soon after. 42% were offered a referral one month or more after diagnosis (figure 1).

Regardless of the timing of referral, the clear majority of respondents felt it was the right time (figure 2). This is indicative of the patient wish for early access to this kind of support and information.

# Understanding of Diagnosis

Figure 1

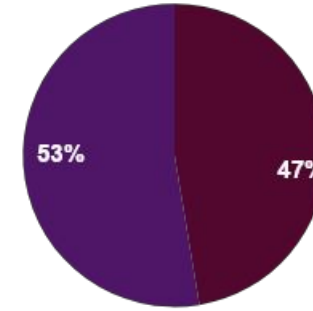
I understand my blood cancer diagnosis and what it means for me



Agree Strongly agree Disagree Strongly disagree N/A

Figure 2

I understand my blood cancer diagnosis and what it means for me

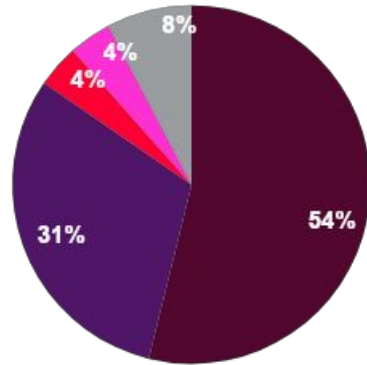


Agree Strongly agree

# Confidence in Finding Support

Figure 1

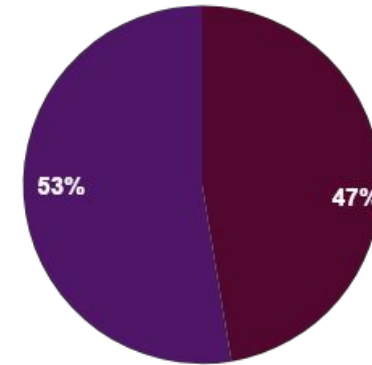
I know where I can find the right support if and when I need it



■ Agree ■ Strongly agree ■ Disagree ■ Strongly disagree ■ N/A

Figure 2

I know where I can find the right support if and when I need it



■ Agree ■ Strongly agree

# Patient Quotes


"You have helped me understand the blood cancer diagnosis for my dad, answering questions that I might not have thought of at the time."

"[It's] given me a resource to refer to when I need information, encouragement or support."

"This regular update is factually interesting and also gives me hope."

"The information provided helped [me] work through the diagnosis."

"It is good to talk this through with someone who understands."



“Excellent service.  
These emails have  
really helped me at just  
the right time.”

“Thank you. Your  
guidance notes on  
specific cancers are  
excellent.”

“Thank you for your  
emails and information  
booklets; they are so  
valuable to me.”

“What a wonderful job  
you do keeping people  
informed about what's  
happening.”

“I was very pleased how  
quickly I was contacted  
and sent the relevant  
information and contact  
numbers.”

# Next steps

- Continue to scale up service
- Continual improvement – remain responsive to need
- Remain close to other developments e.g. DHSC - Diagnosis Connect