



Hear our voice:

stories from people
affected by blood cancer

Bloodwise

The blood cancer research charity



Beating
blood
cancer

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Foreword

One in 19. That's how many of us will have blood cancer at some point in our lives.

Every one of the 40,000 people diagnosed with blood cancer in the UK every year has an experience unique to them. At Bloodwise, we are fortunate that many people feel comfortable enough to speak to us about their experience and that of their loved ones.

This publication builds on our major survey in 2015 of people living with blood cancer. We invited 10 of our amazing Patient Ambassadors, eight of whom are living with the disease and two who tragically lost their children, to share their experience. Although each experience is unique to them, together they tell the wider story of how people affected by blood cancer are being treated and cared for by the NHS across the UK.

Many of our Ambassadors have had positive experiences. But too many of them feel their care and treatment could have been better. Their psychological and emotional needs often go unaddressed. Chemotherapy, though effective, can be brutal, with consequences that only manifest years later. Diagnosis of blood cancer is, in some cases, still happening much later than it should because warning signs are missed.

People with blood cancer are telling us loud and clear that more needs to be done to ensure they are

diagnosed early, receive the support they need to cope with their disease and get access to the drugs and treatments that can save and extend their lives.

We need all of the UK governments, the health service and health professionals to join with people affected by blood cancer – to hear their voice, and to take action.

We will never stop listening to people living with blood cancer to understand exactly what they need and working hard to ensure the NHS is able to provide this. I urge decision-makers in all four nations of the UK to join us in ensuring this becomes a reality.

Gemma Peters
Chief Executive, Bloodwise



What needs to change?

People with blood cancer have told us they feel like 'fake' cancer patients.

It is clear that the experiences of people living with blood cancer are often very different to the experiences of people with other types of cancer, particularly those who have a solid tumour. They are often treated in haematology departments rather than oncology and have little interaction with other people with cancer. Only 11% of blood cancer patients have radiotherapy compared to 55% of breast cancer patients and 12% of blood cancer patients have surgery compared to 77% of breast cancer patients.

Not only do some people live with blood cancer for years, some can live with it for decades. Some people with blood cancer will spend their whole lives taking daily medication. Others will never receive treatment at all, while knowing they have cancer. Tragically, for others the diagnosis comes too late for treatment to help.

Earlier diagnosis

The vast majority of the 240,000 people living with blood cancer could not have reduced their chances of getting it: lifestyle factors do not make it more or less likely.

This is partially why awareness of blood cancer among the general public is remarkably low – 84% of people cannot name a symptom. The National Cancer Patient Experience Survey shows year after year that people with blood cancer are still having to attend multiple GP appointments before being diagnosed, more than with any other type of cancer. Derek told us that he had no idea his slight shortness of breath was something serious. It took two years of repeated visits to a GP and several hospital visits before Wendy was finally told she had non-Hodgkin lymphoma. Kate was so concerned her diagnosis was taking too long that she paid for a private scan.

Some symptoms of blood cancer, such as back pain or shortness of breath, are easy to misdiagnose. However, we also know that for some blood cancers, the difference between early and late diagnosis can significantly improve the chances of survival. The NHS needs to ensure GPs know the signs and symptoms of blood cancer and can refer patients promptly to the right specialists.

The Westminster Government has said it wants 75% of cancer cases diagnosed at stages 1 or 2. We look forward to working with ministers and the NHS to making this a reality for blood cancers.

Emotional & psychological support

Being diagnosed with blood cancer is a traumatic moment. The emotional and psychological effect can be devastating, both for the person being diagnosed and their family. Our research shows that 81% of people diagnosed with blood cancer have subsequent mental health needs.

Paul and Newton were not offered any support, but both felt they badly needed it since diagnosis. It was, however, fantastic to hear Kate tell us she visits a psychologist, funded by her local NHS, every six weeks. This is the gold standard everybody with blood cancer deserves.

There are also 27,000 people in the UK with blood cancer who do not need treatment straight away. They have to wait months or even years on 'watch and wait'. While their physical health might not require immediate treatment, their mental health often does.

The NHS in England has an opportunity to improve the situation through its new plan for the next ten years, in which mental health and cancer are two of the major priorities together with a renewed focus on personalised care for people diagnosed with cancer.

People with blood cancer need timely access to emotional and psychological support from someone who understands their needs.

Accessing treatment

The treatment for blood cancer can be gruelling, with chemotherapy often being particularly harsh. The short-term effects are tough and the long-term side effects can be significant too. Federica, Joe and Louise

told us how the treatment to save their lives when they were younger has affected them later on. Donna told us movingly about how she believes it was the treatment given to her daughter Emily that killed her, rather than her cancer.

As a result of decades of research, much of which has been funded by Bloodwise, blood cancer clinicians now have access to a wide range of drugs and treatments, including alternatives to chemotherapy.

Fundamentally, people with blood cancer need innovative treatments available on the NHS as soon as possible, because surgery and radiotherapy are rarely an option for them.

We're delighted that the revolutionary CAR-T therapy was approved in 2018 for some people living with blood cancer.

However, decision-makers must ensure that they are prepared for high numbers of very expensive treatments for small groups of patients, often with only very early stage evidence available. In making these decisions there must be a more meaningful role for people living with blood cancer when decisions are being made about what the NHS should fund, particularly in England.

Linked to this is the importance of clinical trials. Disappointingly only a third of people with blood cancer were asked whether they would like to participate in cancer research. Newton told us how he has participated in several trials but only after he requested to do so. We need more clinicians to be initiating these conversations.

Improving end of life care

Blood cancer is the third biggest cancer killer in the UK, with 15,000 people dying from it every year. Cases of leukaemia make up a third of all childhood cancers. Although many children make a full recovery, there's still further to go, with around 100 children dying of blood cancer every year.

Two of the voices we hear in this report, Donna and Allison, tell us about their children. Allison tells us how her son Jak was able to die in the place and manner of his choosing – at home surrounded by his family. Unfortunately, this is not the norm.

People with blood cancer who die within a month of diagnosis are twice as likely as other people with cancer to miss out on discussing their preferred

place of death and twice as likely to die in hospital. We also know that the low levels of awareness of blood cancer amongst GPs and the provision of care through haematology units rather than oncology mean that often nobody initiates a difficult end of life conversation with people with blood cancer.

Two thirds of people say they would prefer to die at home and the Government in England has a plan to improve end of life care, known as their National Commitment.

We are looking to the Westminster Government to reaffirm this commitment and ensure the NHS has the resources to deliver the care that people want. Importantly, this should also consider the needs of people with blood cancer.



Our recommendations:

- 1** In order to fulfil the ambition set out in the Long-Term plan for the NHS to ensure 75% of cancers are diagnosed at stages 1 and 2, NHS England should work with Bloodwise, professional bodies and people living with blood cancer to improve early diagnosis rates.
- 2** NHS services should ensure people with blood cancer have access to emotional and psychological support as part of the 'personalised care' agenda.
- 3** The National Institute for Health and Care Excellence, (NICE) and the Department of Health and Social Care in England should redesign the process for assessing medicines to ensure the patient voice is given due weight and that new innovative treatments reach patients quickly and efficiently.
- 4** The Department for Health and Social Care in England should honour the National Commitment to end variations in end of life care and ensure the experience of people with blood cancer is specifically considered.

Wendy Leigh

"I was starting to think I was a hypochondriac"

Although I knew something was wrong it took two years until I eventually received a diagnosis. My symptoms of back ache, abdominal pain and night sweats were dismissed as the menopause.

I first experienced these symptoms in 2009. The CT scan, which I insisted upon, revealed an enlarged lymph node and a note which read 'query lymphoma?'. But the GP dismissed this result, because my blood tests were clear.

My night sweats continued and following a further blood test I was referred to a gynaecologist. Luckily, he took the decision to send me to a haematologist, who discovered my lymph nodes had doubled in size over the previous year.

I was told time and time again that I was fine. One GP asked when was I going to realise that there was nothing wrong with me. Another said I had amazing blood and I should go away. This obviously caused me to doubt myself occasionally, though I knew deep down that something wasn't right.

Finally, on 23 December 2011, I was diagnosed with Stage 4b follicular non-Hodgkin lymphoma and was told it was cancer, but that it was more like a blood disease. As it had taken two years to diagnose, the last thing I thought I had was cancer. Logic told me that if I had cancer, someone would have found out by now.



"If someone who hasn't normally been to their GP a lot, suddenly is a frequent visitor, even after scans and tests come up clear, then they shouldn't be dismissed".

I've been lucky really. I had fewer physical side effects from my chemo than others experience. My side effects were much more psychological. I bottled up my feelings for quite a long time. It was a very lonely experience.

I'm currently in remission and having checks every three months. I get anxious when I get ill. I worry it's the beginning of a relapse.

Derek Loutitt

"I didn't know I'd been living with a life-threatening illness"

It wasn't until after my third visit to the GP that my condition was diagnosed. I'd been before because the GP thought I had urinary infection and I was sent away with antibiotics. By the third visit I was coughing up blood and experiencing shortness of breath. Eventually, my GP realised the seriousness of the situation and called an ambulance.

I'm an NHS paramedic and it was one of my own ambulances that took me on a blue light from the GP surgery to the hospital, where after blood tests and other checks I was told I had acute myeloid leukaemia.

The doctor told me I had a 60% chance of making it to two years. If I hadn't been diagnosed when I was, I might not have made it beyond six weeks.

I was glad I was told immediately that my disease was life threatening, may be life limiting, and was life changing - it made me more determined to fight. I had four cycles of intensive gruelling chemo. The treatment was tough, and I struggled massively afterwards.

Now I am in remission, I am back at work and things are 'normal', but my blood cancer will be with me for the rest of my life. I am eternally grateful for the care I received.

The speed of my diagnosis is why I am here today. I was lucky to get this far, and it was down to a fluke that led to my earlier diagnosis. Surviving should not be down to luck.



"I was lucky. It was a fluke that I was diagnosed. It shouldn't be down to luck."

Joe Smale

"Nothing will ever be as bad as being told I have cancer again"

I have been diagnosed with acute lymphoblastic leukaemia three times - when I was two years old, nine years old and then at 13.

I only really remember my diagnosis and treatment when I was 13. I was told a stem cell transplant was my only option. I was extremely lucky a donor was found quickly. I had very strong chemotherapy, followed by whole body radiation. I spent a long time in hospital afterwards. I wanted to see an immediate effect, but progress was slow at first. For a teenager, being in hospital is particularly difficult. Every day a different doctor or nurse visited me, so I rarely saw the same person twice.

I was isolated in a room for six months in hospital and then a further six months at home. Only family and close friends were able to visit me. For a 13-year-old boy that was tough.

My treatment has had a few side effects both short and long term. At the time, I lost my hair and the steroids made me put on weight. Some of the drugs made me feel awful.

It's now become clear the drugs have affected my growth. The doctors tried hard to remedy this with the use of hormones, which I had to inject myself every day. This became a lot of effort when I was juggling school and hanging out with friends. I was only 18 and it wasn't that important to me, so I stopped. The doctors

didn't tell us about the potential long-term effects. They were probably right not to, as they didn't want me or my parents to be discouraged from doing what was needed.

I am not concerned right now with the potential effect on my fertility. I'll probably feel differently in 10 years' time, but medical science progresses all the time, so things may well have moved on by then.

Looking back, it makes me realise that alongside curing blood cancer we need to continue to invest in treatments which work and have fewer awful side effects.



"It would have been good to be encouraged to understand the side effects more. It would have prepared me better."



"I know I needed to do something about my fertility but I had no time and now I don't know if my fertility has been affected."

Federica Nardella

"It was a very intense moment of grief"

I was diagnosed in 2006 but, looking back, it is clear now that my symptoms actually started the previous year. I started to experience intense, itchy spots as well as excess sweating. I was misdiagnosed at first. Even though my blood tests showed some abnormalities, it was put down to an infection. I continued to feel ill, with my symptoms not improving. At Christmas I felt a lump at the base of my neck and my uncle, who is a doctor, examined me and said I should get further tests.

Soon afterwards I was diagnosed with stage 3 Hodgkin lymphoma. At this stage I had to undergo six months of intensive treatment including six cycles of chemotherapy. I was left feeling seriously ill and tired, with constant pain in my veins. The hair loss that followed was extremely upsetting and I decided to shave my head in an attempt to take control.

After the chemo, the scans showed that my cancer had disappeared but ironically, this was the most difficult time for me. Patients go through a very intensive time during chemotherapy with lots of individual medical attention and then it just ends. I collapsed emotionally and the years between 2007 and 2012 were the toughest, even though my cancer had gone. I was trying to be psychologically strong for the people around me, but my family were very affected by my diagnosis and still are. I don't think about relapse as much as I used to. I can't continue to be paralysed by fear.

Looking back on my experience, I was only 19 years old when I was diagnosed, so when the doctors told me I might not be able to have children as a result of my treatment it was all a bit unreal. They offered to freeze my eggs but there was never time for me to seriously consider it as I had to start treatment straight away. I hadn't thought about starting a family, I was so young, and everything was happening so fast. I was far too shocked by the news about the lymphoma itself.

I am now nearly 32 and I suppose this potential impact is only beginning to dawn on me. All I can be is optimistic. Anxiety certainly won't help.

Newton McGrath

"With a new trial, I always feel I've got a chance"

As a British Gas engineer, I was entitled to a free health check for staff aged over 40. It was this check-up that showed my blood pressure was unusually high. I ended up having a blood test, by accident really, which showed abnormalities that were linked to pains in my back.

I had never heard of myeloma. It was a whole new world to me. I remember sitting at home, thinking 'I have myeloma' but I didn't know what it was.

I had very strong chemotherapy and a stem cell transplant, but my myeloma still came back. I asked to be put on a clinical trial immediately. I read about the relative lack of progress in research to successfully treat myeloma, compared to other types of blood cancer. I thought it was surprising that there weren't more treatments for myeloma out there, so I really wanted to be part of any trials coming up. It's so important more people can be helped by progress in research.

I needed emotional and psychological support following my diagnosis but there was nothing available or, if there was, I certainly wasn't offered it.

When I was first diagnosed, I was very worried about the fact that my myeloma was likely to come back. I feel a lot more positive about the future now because of all the new treatments. My consultant is excited about all the research and trials going on in myeloma.



"I don't think I'd have been put on a clinical trial had I not asked."

I have since been on two clinical trials and am currently on another. Trials offer me hope. I always feel I've got a chance and there's always a pipeline of drugs. In fact, I am already being lined up for the next trial, which is fantastic.

The treatment I'm on now is helping save my life, and I hope the trials I've been part of since I was diagnosed will be able to help save other peoples' lives too.

Donna Dunn

"I don't blame the medical staff – they just use what they have available"

Like many people diagnosed with blood cancer, my daughter Emily's diagnosis was not straightforward. Emily had been feeling unwell for a while. At the last of many visits to the GP we were told 'we don't know what we're looking at but it's very serious and complicated.'

Calls were made and eventually Emily was admitted, first to a gynaecological ward, then a teenage ward. Next came the awful confirmation that Emily had 'the nasty stuff'. We were told to go home and 'be a family in the few weeks we have left'. The doctor almost pleaded with us not to let Emily have treatment.

I wasn't prepared to give up so easily, so I asked for a second opinion. This led to a biopsy, we were then told Emily had Burkitt lymphoma. The word 'cancer' was never used. She was put on the treatment treadmill very, very quickly and we were told not to Google anything, it was difficult not to as the doctors used words we had never heard before.

Emily's first treatment was chemotherapy with non-stop blood tests. We were warned about the gruelling side effects that come with childhood cancer treatment but my God, none of the leaflets prepare you for the sickness.

After the chemo, Emily went into remission and returned to school. But she relapsed and was told she would need a stem cell transplant. Although we were delighted that a match was found, the preparation was gruelling. It included seven days of whole-body radiation plus chemo and six weeks of isolation.

Emily made it past the crucial 100th day and was allowed to go home. Sadly, further complications caused more and more problems. In total, she spent 300 nights in isolation post-transplant. Emily's condition continued to get worse.

Emily heard the doctors discussing her prognosis despite being unresponsive. She took control of matters and removed the ventilator from her own mouth. She was in total control until the end.



***"I want everyone to know
Emily's death wasn't
caused by cancer, but by
the treatment."***

Louise Smith

"The side effects of my treatment affect me every day"

In 2007 I was admitted to hospital after being unable to breathe properly at home. Something was spotted on my echocardiogram but they didn't know what it was immediately. After further tests I was operated on a few days later.

I was told that I had an unusual presentation of Hodgkin lymphoma - a huge mass which filled my chest and was pressing on my heart. It was also attached to my lungs and blood vessels. I had part of my lung removed and repairs to my heart in order to ensure that the mass was gone. Nothing showed in my lymph glands. I was a 51-year-old woman, so I wasn't your typical Hodgkin lymphoma patient.

In January 2008, I started a six-month course of a chemotherapy. Within months of finishing treatment, I was distraught and terrified to find lumps in my neck. My cancer was back.

I would phone the hospital if I had any questions. I limited these conversations to clinical questions as I didn't feel nurses had the time to talk about the emotional impact I was experiencing, I convinced everyone I was coping well. I had more treatment, during which the cancer seemed to be retreating, but would then come back again each time the chemo stopped.

The answer seemed to be a bone marrow transplant, which I had in March 2009. However, when I finished treatment the enormity of what I had been through

suddenly hit me, and I had started suffering panic attacks and anxiety.

Perhaps most upsetting, is that my hearing has been badly affected. I was completely deaf for a while. Music had been a big part of my life, as I used to play piano.

My resulting heart problems leave me tired and breathless. I was told it would only get worse and eventually I'd need help with my personal care.



"The long-term side effects of my treatment continue to live with me and affect my daily life. Combined, they have meant that I will never work again."



“Very often the focus is on the physical effects of blood cancer, but the diagnosis and treatment have as much of an impact on your mental state.”

Paul Carless

“I was told this is the cancer to get”

I was diagnosed with chronic myeloid leukaemia in Christmas in 2013. I ended up in A&E and then kept in hospital overnight. My diagnosis was a massive, massive shock.

I was left alone with the news that I had blood cancer for an hour before my wife arrived. My children were of an age where they didn't really understand the diagnosis and my youngest has never really known any different.

I only knew of leukaemia as a childhood cancer, so I was surprised that I had it. The one-page sheet of information I was given was of little help. One of the doctors did say that I shouldn't worry too much because if I was to get a blood cancer, this was the one to get. It was about a month after my diagnosis where I read a Bloodwise booklet, which was very useful.

I was shocked to find out my treatment would be a daily tablet I have to take for the rest of my life. I have a range of side effects that I deal with every single day which affect me emotionally and physically.

I was originally told there wouldn't be any side effects so when I experienced some it was a real worry and made me depressed.

Often the focus is on the physical effects of blood cancer, but the diagnosis and treatment have as much of an impact on your mental state. That's why it was so disappointing that I wasn't offered any emotional or psychological support at all.

Thankfully I have found coping mechanisms. Some of this via self-help groups on social media and sporting challenges have been a massive help meaning I have less time to worry about the cancer.

Kate Giles

"I look far too well to have cancer"

2010 was full of visits to the doctor and being reassured that my symptoms, including a lump in my groin and weight loss, were nothing to worry about, especially as my blood tests kept coming up clear. That August I rolled over in bed and felt a much larger lump in my groin. Google pointed me to lymphoma, so I quickly returned to my GP who referred me to a general consultant.

I decided to find a private specialist, who carried out a lymph node biopsy. Three weeks later I was diagnosed with stage 3 lymphoma. I was in complete disbelief.

Following my diagnosis, I was placed on something called watch and wait - a concept that turns everything you know about cancer upside down. To be diagnosed with stage 3 cancer and that your treatment is to watch the cancer and wait to treat it, is no easy concept. A 'fake cancer patient' is how I often felt. There is a lack of understanding for blood cancer patients like me and it has a massive effect psychologically.

The information I received, as someone on watch and wait, wasn't great. I was given a two-page print out and told to live my life. It was a few weeks after that the panic set in - the constant checking for lumps and fear that the cancer was progressing completely took over. At the time I didn't know I needed psychological support. After having a panic attack in front of my doctor I was offered the option - and thank goodness.



"Psychological care absolutely should not be a postcode lottery."

I visit my haematologist every six months. My worry level increases as the appointment gets nearer and I continue to suffer from fatigue.

I see a psychologist every six weeks through my hospital's cancer centre and have done so for eight years. I cannot tell you how much this has helped me. I have a safe environment where I can unload stresses without burdening my family and friends or have them worrying. I am also blessed in that they have the clinical knowledge of my cancer; allowing them to structure the conversation to meet my needs.

The pressure I am under reduces when I talk to my psychologist. This service, provided by the NHS, has been critical to the fact that I have only had one day off work in the past year. I have been lucky, but so many other people with blood cancer are not so fortunate.

Allison Barr

"His cancer was back with a vengeance"

My son Jak was an active 14-year-old boy. He represented his school in the county football team, was a keen musician and had just completed his Duke of Edinburgh award.

In June 2014, he began to have chest pains and suffer from severe tiredness. Soon after, he also had an upset stomach. We visited the GP a couple of times but he was sent away and told to come back if things didn't improve. He then went into a pretty serious decline and was admitted to hospital where he was later transferred to an emergency intensive care unit. And things continued to get worse. It was when the doctors

mentioned bone marrow that I suspected that cancer was a possibility. After an initial diagnosis of leukaemia, and a series of further tests, I received the news that no mother ever wants to hear - news that literally took every ounce of energy and breath from my body. Jak had a rare form of lymphoma and was not going to be cured. We were told to prepare for the worst.

We were planning for a transplant and the medical team were trying to get him ready. But our deepest fears were turned into a reality when his condition suddenly worsened. Only five months on from initial symptoms, we were told we only had days left.

Unlike many people, Jak had a choice in his end of life care. He had the option of hospital, hospice or home. He chose to be at home. Regular visits from doctors and community nurses during his last week and a half helped us all. He was also blessed in that he was in very little pain until the very last couple of days. We were all with him and it was very peaceful. He even managed to get out of the house on a couple of occasions including to the school prom for a short time.

After he passed, we were able to follow his wishes for his funeral. He had decided he wanted to be buried and who should speak at the funeral.

I will be forever grateful that Jak got the level of support he did. Not everyone has this support available to them at the end.



"Jak had a choice in his end of life care... and for that I will be forever grateful."

We won't stop until we've
beaten blood cancer





About Bloodwise

Blood cancer is the UK's third biggest cancer killer. We're here to change that.

We're thousands of supporters, researchers, nurses, volunteers and campaigners, working together to beat blood cancer.

Everything we do is focused on improving the lives of everyone affected by blood cancer, the fifth most common cancer in the UK. We want to bring forward the day when every single person affected by blood cancer is able to live a full life.

To find out more about what we do and how you can get involved, please get in touch:

E: hello@bloodwise.org.uk

T: 0808 169 5155

www.bloodwise.org.uk

If you've been affected by blood cancer and would like to talk, please call our support line:

T: 0808 2080 888

E: support@bloodwise.org.uk

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