Leukaemia Matters

AUTUMN EDITION 2018

I’m still here

When Kate started experiencing symptoms, she put them down to stress, but soon became so unwell that she was rushed to hospital. Now in remission following a diagnosis of acute promyelocytic leukaemia (APL), Kate shares the ups and downs of her story.

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Coping with everyday issues

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Leukaemia Care
YOUR Blood Cancer Charity

In This Issue

Hello,

Welcome to the Autumn issue of our magazine!

This bumper issue coincides with Blood Cancer Awareness Month and our Spot Leukaemia campaign. Throughout September, we'll be encouraging the general public and health professionals to raise awareness of the signs and symptoms of leukaemia. On pages four and five, you can find out more about the campaign and how you can get involved.

I'm also looking forward to welcoming many of you at our Spot Leukaemia reception at the Royal College of General Practitioners (RCGP). The reception will bring together a wide range of stakeholders who are working to support patients with blood cancers, as well as patients and families who have been supporting Leukaemia Care's campaign. As part of this event, we will also be sharing the key findings from our 2017 patient survey and the updated 'Living with Leukaemia' report. Learn more about the report on pages nine and ten.

Inside, you'll also find articles on protective isolation, as well as information on where you can find support for everyday issues. We also hear from Jennifer Gavin and Kate Stallard on how they have both overcome the obstacles their diagnoses have thrown at them.

See you next time,

Christopher Matthews-Maxwell
Chairman

Keep up with the latest news and patient stories online. You can find us at: www.leukaemiacare.org.uk

/LeukaemiaCare /leukaemiacareuk /LeukaemiaCareUK

Patient Services News

Catch up on the latest news from our Patient Services team.

First fatigue information day a great success

Here at Leukaemia Care, we speak to patients and their families on a daily basis, and there is one subject that always starts a discussion: fatigue.

So, on 16th June, we held our first Fatigue Patient Information Day. The day was aimed at anyone with a blood cancer who is affected by fatigue, with 50 patients, carers and family members in attendance. Dr Anne Johnson, Macmillan Consultant Occupational Therapist at the Bath Centre for Fatigue Services and Senior Lecturer/Research Fellow, University of the West of England, Bristol, facilitated the day, which ran from 11.00am – 3.00pm.

The topics we covered on the day were:

- What it is, how common it is and the impact on daily life.
- Dealing with fatigue, including everyday coping strategies and exploring expectations of yourself and others, practical strategies and ways to communicate.

We have three more fatigue information days coming up in 2018 and 2019:

- 15th September 2018 in Cardiff
- 13th October 2018 in Sheffield
- 16th March 2019 in Edinburgh

If you would like to attend one of these days, you can book online at: **http://bit.ly/PatientInformationDays**.

Or, call the Patient Services team on **08088 010 444**.

New support groups

We recently had a flurry of support group launches since the last issue. These included:

- Barnet Blood Cancer Support Group
- Bristol Bone Marrow Transplant Support Group, for anyone that is six months post-allograph
- Chronic Myeloid Leukaemia (CML) Manchester Support Group
- Cwmbran Chronic Haematology Support Group
- Durham and Darlington Haematology Support Group
- Leeds Acute Haematology Support Group
- CML Stevenage Support Group

All these groups were set up after a demand was identified for further support. Going forward we will be encouraging various speakers to attend and talk to the groups, including consultants, dieticians and benefits advisors.

If you feel there is a need for a support group where you are, please contact our helpline on **08088 010 444** or email **support@leukaemiacare.org.uk** and we can arrange for the Regional Coordinator in your area to get in touch and have a chat.

Leukaemia Care
YOUR Blood Cancer Charity

Spot Leukaemia

Go spotty for Spot Leukaemia

September is Blood Cancer Awareness Month, and this year at Leukaemia Care the Spot Leukaemia campaign has returned.

Spot Leukaemia aims to improve public understanding of leukaemia and raise awareness of the signs and symptoms. Early diagnosis saves lives. We want to ensure people are better equipped to recognise the signs and visit their GP sooner.

The Spot Leukaemia campaign first launched in 2017 following a Leukaemia Care survey of 2,019 leukaemia patients that revealed poor public understanding of leukaemia and awareness of the signs and symptoms. For example, 83% of patients had heard of leukaemia prior to diagnosis, but 68% of these people didn't know anything about it. Additionally, 83% of people did not suspect cancer before their leukaemia diagnosis, suggesting that many people fail to recognise that their symptoms are associated with blood cancer.

The latest UK statistics reveal that 37% of all leukaemia patients are diagnosed by an emergency route, which is significantly higher than the average across all cancers: 22%. Therefore, despite the Spot Leukaemia message reaching over 3 million people on social media alone last year, we have more work to do to improve early diagnosis.

So, this year, we are heading out to eight different locations across the UK on our Spot Leukaemia roadshow. These regions have been identified to have low awareness in Leukaemia Care's 2017 patient survey (more about this on page 9). Throughout September, the Leukaemia Care team will be visiting high streets in London, Liverpool, York, Nottingham, Oxford, Birmingham, Bristol and Exeter with our spotty photobooth. People will be able to take their photos to support Spot Leukaemia and be given a symptoms card to take away with them too.

The symptoms cards, which launched last year, help people to learn about leukaemia and recognise the common symptoms in each age group. This year, we have redesigned the symptoms cards and updated the most common reported symptoms in each age group based on the 2017 patient survey. You can help

Spot Leukaemia this September by ordering and sharing the symptoms cards.

The most frequently reported symptoms are:

So what else is happening this September for Spot Leukaemia?

#SpotLeukaemia

Social media is turning spotty to spread the Spot Leukaemia message. Don't forget to share and retweet our posts!

Symptom awareness

The most important part of Spot Leukaemia is ensuring people can spot the signs and symptoms. We have videos, graphics, symptoms cards, flyers and posters that will all be shared throughout September to ensure this happens, and many healthcare professionals are hosting Spot Leukaemia awareness boards.

Sharing your stories

Patients and families are helping to raise awareness by sharing their stories online, through videos and blogs, and in their local newspapers. These real-life stories are helping people to understand more about who is affected by leukaemia and how it presents.

Spot Leukaemia event at the Royal College of General Practitioners (RCGP)

To mark Blood Cancer Awareness Month, we are holding an event at the RCGP in London. As part of this event, we will be sharing key findings from our 2017 patient survey and the updated 'Living with Leukaemia' report.

Support groups go spotty

September support groups will be going spotty, with patients invited to dress up in spots and wear their badges to support Spot Leukaemia.

Spotty fundraising events

Many of you are holding your own spotty fundraising events this September to raise awareness of leukaemia and raise funds so that we can continue to support patients and improve early diagnosis.

Here's what some of our supporters are doing: a carnival day, spotty office bake sales, head shaves, walks and a Spot Leukaemia colour run!

Could you do something too? Contact our Fundraising team on 01905 755 977 or email fundraising@leukaemiacare.org.uk

Football clubs helping fans to Spot Leukaemia

Last year, we had 11 football clubs from across the UK supporting the Spot Leukaemia campaign. We have a number getting involved again this year by sharing articles online and in their programmes to raise awareness of the signs and symptoms. The Kidderminster Harriers are also supporting Leukaemia Care as their chosen charity throughout August and September.

How can you get involved in Spot Leukaemia?

1. Shout about the campaign on social media

Help us spread the word and raise awareness by using the campaign hashtag #SpotLeukaemia on Twitter and Instagram and encourage others to join in. You can download our social media infographics from our webpage.

2. Order the Spot Leukaemia awareness badges or wristbands

Show your support for blood cancer patients by wearing our Spot Leukaemia pin badge.

We'd love to see your selfies wearing your badge with pride. So, don't forget to mention us on social media and add the hashtag #SpotLeukaemia to your posts on Facebook, Twitter and Instagram.

For more information about Spot Leukaemia and to download or order the material, visit: **www.spotleukaemia.org.uk**

Campaigns Corner

Advocacy Caseworker: New member of Campaigns and Advocacy

Last issue, we introduced the newest member of our team, Charlotte. As the new Advocacy Caseworker, she's here to give you advice or find you support with issues such as housing, insurance queries and clinical trial access. The aim is to support you to access everything you need so you can concentrate on your treatment and feeling better.

Charlotte said: "There are so many issues that leukaemia patients shouldn't have to deal with; financial, emotional, and practical issues like housing. I've already had some inspirational people come to me for help, trying to get back to work or sort out their finances. Do reach out if you're facing any issues, we will do our best to help."

You can email Charlotte at **advocacy@leukaemiacare.org.uk**, or call her on **01905 755 977**.

Know Your Rights Toolkits (previously advocacy toolkits)

Know Your Rights Toolkits are a collection of leaflets that cover your rights as a cancer patient or breakdown technical information, so you can understand your treatment better.

From July to September, we released a series of four booklets on employment rights. This series covers every possible scenario in employment, from remaining employed, to what to do if you want to stop working, and what to do if you are self-employed.

Download the Know Your Rights toolkits here: **https://www.leukaemiacare.org.uk/support-and-information/campaigning-and-advocacy/know-your-rights-toolkit/**.

If you would like to suggest a topic for the Know Your Rights toolkits, email us at **advocacy@leukaemiacare.org.uk**.

Drugs Updates

Inotuzumab ozogamicin

Inotuzumab ozogamicin has been recommended for the treatment of adults with relapsed or refractory CD22-positive B-cell precursor acute lymphoblastic leukaemia (ALL) in England and Wales by NICE and in Scotland by the SMC.

Inotuzumab ozogamicin (Besponsa® and manufactured by Pfizer) is a monotherapy treatment used in the UK as a bridge to stem cell transplant (SCT). A clinical trial named INO-VATE showed that far more patients were able to have a SCT following treatment with inotuzumab ozogamicin, compared to those treated with current therapies, namely FLAG-based chemotherapy.

The SMC, in Scotland, restricted the treatment for use "in patients for whom the intent is to proceed to stem cell transplantation."

Find out more here: **http://bit.ly/SMCInotuzumabOzogamicin**

> *Before CAR-T will be available on the NHS, it must be assessed by NICE and the SMC.*

The European Medicines Agency (EMA) licenses CAR-T therapy in Europe

CAR-T is a specific type of immunotherapy that involves collecting and using the patient's own immune cells to target the cancer. There are two different CAR-T therapies that have been licensed by EMA, Kymriah® (Tisagenlecleucel-T) and Yescarta® (axicabtgene ciloleucel), manufactured by Novartis and Kite respectively.

Kymriah® (Tisagenlecleucel-T) has been indicated for the treatment of patients up to 25 years of age with B-cell acute lymphoblastic leukaemia (ALL) that is refractory, in relapse post-transplant, or in second or later relapse. It is also indicated for adult patients with diffuse large B-cell lymphoma (DLBCL) that is relapsed or refractory (r/r) after two or more lines of systemic therapy.

Yescarta® (axicabtgene ciloleucel) is used for treating adult patients with relapsed or refractory diffuse large B-cell lymphoma (DLBCL) and primary mediastinal large B-cell lymphoma (PMBCL), after two or more lines of systemic therapy.

Before CAR-T will be available on the NHS, it must be assessed by NICE and the SMC to determine if it is a cost-effective use of NHS resources. NICE appraisals of Kymriah® (Tisagenlecleucel-T) and Yescarta® (axicabtgene ciloleucel) are already ongoing, with decisions not expected until the end of 2018.

Find out more here: **http://bit.ly/CAR-T-Article**

Events

CLL and MPN Horizons – Prague

At the end of August, Campaigns and Advocacy Officers, Nick York and Bethany Torr, attended CLL and MPN Horizons. This meeting brings together patient advocates from across the globe to hear the latest scientific updates and share best practice.

Both Nick and Beth led a session for advocates on evidence-based practice and improving awareness, using the Spot Leukaemia campaign and Leukaemia Care patient survey as an example.

Other topics on the agenda included Watch and Wait, how patients can get involved in research, CAR-T therapy in CLL and presenting evidence to prove the case.

Got questions for the Campaigns and Advocacy team? Get in touch with them on **01905 755 977** or email **campaigns@leukaemiacare.org.uk**

Helping GPs to Spot Leukaemia

This September, we want to help GPs to spot the signs and symptoms of blood cancers sooner. Find out how we're aiming to achieve that.

An important part of Spot Leukaemia is ensuring that GPs are better equipped to recognise and diagnose blood cancers.

Patients often report visiting their GP several times before they receive a blood cancer diagnosis. In our 2017 patient survey, 1 in 4 people visited their GP more than twice before being referred to the hospital about cancer, and 19% of patients stated they were treated for something else by their GP before diagnosis.

Leukaemia can very easily be diagnosed through a simple blood test. However, leukaemia is relatively rare, and a GP will on average see just one case of leukaemia every three to four years. Therefore, to distinguish a potential blood cancer case from a common, unrelated illness, GPs need to be better supported to recognise the signs and symptoms.

Since Spot Leukaemia launched last year, we have been working hard throughout the year to ensure that this happens. In January 2018, we piloted our first in-person training event with the Midlands faculty of the Royal College of General Practitioners (RCGP) and we are continually signposting GPs to our accredited online eLearning modules on blood cancers.

This September, during Blood Cancer Awareness Month, we have several initiatives to ensure GPs can spot leukaemia and improve early diagnosis in primary healthcare.

In-person training event in London

Leukaemia Care are working with the London and South of England Royal College of General Practitioners (RCGP) regions to host an educational event in London on September 24th.

The Spot Leukaemia training event aims to empower primary care professionals to recognise the vagaries involved in a rare blood cancer diagnosis and be up to date of appropriate referral pathways. The events also focus on communication during diagnosis, establishing an action plan and appropriate after care.

Sharing posters and flyers with your GP surgeries

This year, we have been asking you to take flyers and posters to your local GP surgeries. These direct GPs towards our eLearning modules on blood cancer and raise awareness of the common signs and symptoms.

If you would like to support this and take material to your local surgeries, email your name and address to **campaigns@leukaemiacare.org.uk**.

Spotty awareness boards

In addition to GPs, pharmacists play a crucial role in spotting leukaemia. They may see patients presenting with symptoms and asking for over-the-counter medicines to resolve them. Therefore, this year the Spot Leukaemia outreach is extending to pharmacies who will be displaying posters, flyers and symptoms cards in a bid to raise awareness of the signs and symptoms and improve early diagnosis.

Living with Leukaemia report 2018

Find out more about the results of our latest survey and see what recommendations we've made to improve patient care.

19% of patients were initially treated for something else by their GP before being diagnosed with leukaemia

In 2016, Leukaemia Care launched our first patient survey with Quality Health to gather more information and data on the journeys of blood cancer patients through diagnosis, treatment and care. The aim was to highlight, and reveal the extent of, the issues faced by patients.

The evidence gathered from the 2016 survey has proven to be hugely valuable. With over 2,000 leukaemia patient respondents, we were able to produce ten recommendations for improving patient care in our "Living with Leukaemia" report. These recommendations have already been informing campaigns and are the foundation of our work over the next few years.

Following the success of the survey in 2016, the survey was re-run between September and December 2017. There were two main aims of the second patient survey. The first was to allow annual comparison between the results, to see if any issues are improving or worsening. The second aim was to gather greater understanding on certain issues revealed in the first survey by asking new questions.

Over 2,300 leukaemia patients responded to the 2017 patient survey and we would like to thank you if you were one of these people! With such

huge numbers of responses, we have again collected much data and evidence to represent the differing experiences of leukaemia patients throughout their journey. This has led to the production of our second "Living with Leukaemia" report and further recommendations for improving patient care.

The first three recommendations cover more generally the improvements required for all leukaemia patients in the areas of:

1. Early diagnosis

Recommendation 1: Work and campaigning needs to continue in order to improve awareness for the signs and symptoms of leukaemia, amongst both the public and the healthcare professionals who can aid in earlier diagnosis (such as general practitioners).

The Spot Leukaemia campaign was launched following the 2016 survey and seeks to raise awareness of the signs and symptoms of leukaemia in the public and support GPs to better recognise and diagnose blood cancers.

The campaign is running again this September for Blood Cancer Awareness Month, as the 2017 survey revealed that patients are still failing to suspect they may have a cancer, despite the overwhelming majority (85%) experiencing symptoms. 45% of acute leukaemia patients and 73% of chronic leukaemia patients waited over a month before visiting their GP. After visiting their GP for the first time, 20% of patients took more than three months to be diagnosed and 19% were initially treated for something else.

2. Financial implications of living with leukaemia

Recommendation 2: The support and advice given by hospitals about the financial impact of leukaemia needs to continue to improve, incorporating signposting to organisations who offer specialised financial support.

A leukaemia diagnosis can have a significant financial burden for patients and their families, who face increased costs, such as those incurred travelling to and from appointments, and often decreased income, as an impact of a patient and/or their carer reducing hours, or completely stopping work.

In the 2017 survey, 43% of patients reported a negative impact on their finances with 64% saying they had increased monthly costs and 70% stating they had a reduction in income. Unfortunately, many patients are not offered advice about the financial support available to them nor signposted to organisations that offer specialist support.

3. Emotional and psychological impact of a leukaemia diagnosis

Recommendation 3: More importance needs to be placed on the psychological and emotional needs of leukaemia patients. Signposting to appropriate services should be offered to all patients and should consider those who may be more 'at risk' from deterioration to their mental health, e.g. due to personal circumstances or treatment path.

The emotional impact of a leukaemia diagnosis is perhaps one of the most significant challenges a patient faces following diagnosis. Acute patients must deal with an aggressive illness and urgent invasive treatment, and chronic patients must come to terms with living with an incurable cancer, often not knowing when treatment will be needed, and side-effects of treatment that make forgetting about their leukaemia hard to do.

While the emotional impact is unlikely to change, there are groups identified who report greater negative emotional impacts, such as those with dependent children or who have relapsed, and there is also a significant lack of support currently offered to patients. 96% of leukaemia patients wanted information, but of these only 46% were given information on emotional support.

There are in total 11 recommendations and the additional recommendations are specific to the four main types of leukaemia. For acute leukaemia types, acute lymphoblastic and acute myeloid leukaemia, the recommendations are based around improving awareness to ensure patients are diagnosed early and improving the support and information offered to patients around their employment rights and finance.

The recommendations for chronic lymphocytic leukaemia (CLL) focus on improving support and information provision for patients on 'Watch and Wait', due to the significant emotional implications of being placed on the scheme, as well as improving clinical nurse specialist (CNS, often known as Macmillan nurse) provision. This is also one of the recommended improvements identified for chronic myeloid leukaemia (CML) patients, in addition to ensuring that CML patients are more involved in their treatment decisions and are offered more information about the different treatment options.

All the findings from the 2017 patient survey and more detail on the recommendations can be found in the "Living with Leukaemia" report, available to download from: **https://www.leukaemiacare.org.uk/get-involved/our-campaigns/living-with-leukaemia/**

Jennifer Gavin: We are family

Chronic myeloid leukaemia (CML) usually affects people over the age of 60. So, when Jennifer was diagnosed with CML at the age of 18, she was shocked. Now 30, Jennifer recounts her experiences.

My mum was the first to raise her concerns as I had lost a lot of weight over a short period of time leading up to Christmas 2006. Being an 18-year-old, I hadn't really noticed the weight loss, and felt that I was constantly eating. She thought I may have an eating disorder and booked a doctor's appointment for me.

The doctor weighed me but wasn't overly concerned. They said to monitor me over the coming months to see if I lost any more weight. I then started to get headaches and double vision but put them down to working full-time and being at evening school to study for my degree. I also had pain in my lower back, which I thought was from overdoing things, and swelling on the left-hand side of my abdomen (I couldn't see it myself, but it was very noticeable to others). This was my enlarged spleen where the additional white blood cells were being stored.

It was on the 18th January 2007 that I started to vomit and made an appointment at the doctors to see if I had a stomach bug. Whilst I was at the doctors, I mentioned that I had been having headaches and double vision and the doctor looked in my eyes. It was at that point that she said, "Can I phone a family member to come and meet you as I want you to go straight to the hospital." She phoned my mum and asked her to come and meet me at the surgery and gave me a letter sealed in an envelope to give in at the hospital. At this point I didn't have a clue as to what was wrong with me.

My GP could see the white blood cells and swelling behind my eyes and had written an estimated diagnosis in the letter that I had to take with me. When I arrived at the hospital, I waited in A&E for four hours and eventually had bloods taken. I was then admitted to a ward and put on a fluid drip.

> *I feel like the luckiest person in the world to have the most supportive family.*

It was the following morning when the doctor and his team came to my bedside. I was all alone at this point as my mum and dad had gone home to try and get some sleep. The doctor asked if I wanted to wait for my parents to come back before he explained what was wrong with me. I said yes. When my parents arrived, the nurse took us down to a private room and brought us tea and toast. The doctor then came into the room and explained that I had a condition called chronic myeloid leukaemia (CML). I couldn't really take it all in and didn't know anything about leukaemia apart from it was a type of blood cancer. He explained that I was quite a rare case as this type of leukaemia normally affects people aged 50+. He explained about treatment options and life expectancy, which were positive for such a shocking diagnosis. My parents had questions for the doctor which he answered where he could, and he informed me of two options: I could either stay at Whiston Hospital, which is my local hospital, or move to the Royal Liverpool Hospital where there was a Professor who was a specialist for this condition. I opted to move to Liverpool Hospital and was transferred via ambulance later that day.

After being transferred to Liverpool, I was fitted with a central line in my leg. I was then started on an apheresis machine which took my blood and started to separate the white blood cells from the red

ones. I had to have six attempts at the machine as the white cells kept coming back. This was trying to bring down my white cells to a normal level. At the same time, I also started on a drug called Hydroxyurea. This drug was trying to stop my bone marrow from producing more white cells.

> *I try to cherish every minute now, as I know others aren't that lucky.*

I was in hospital for a week taking the Hydroxyurea and having sessions on the apheresis machine. I was discharged from hospital after a week, with daily and then weekly blood tests required for the next few weeks. I was sent home with lots of leaflets about my condition from Leukaemia Care and Macmillan Cancer Support. I found that reading these leaflets helped me to understand what I was going to be living with.

Following the shock diagnosis, my family have supported me so much. My three sisters and one brother volunteered to be tested to see if they were a bone marrow match. Following the results, it was revealed that my little brother was a match should it be needed.

In March 2007 it was decided that my blood levels were improving with Hydroxyurea and I could be put onto a clinical trial for a drug called imatinib (Glivec). I started on the Spirit 2 Trial taking 400mg of Glivec daily. There are side effects of the drug such as feeling nauseous, headaches, tiredness, and bone pain. After trial and error, I found that taking the medication after my evening meal meant that the side effects started when I was going to bed and they didn't bother me as much as I was asleep.

I reached MMR (Major Molecular Response) shortly after starting Glivec. I am monitored every three months at the Royal Liverpool Hospital, where I have blood tests and a PCR test to check the amount of leukaemia cells in my body. The care and attention that I have received at that hospital has been second to none. I am so grateful for all that they have done for me.

I am now 11 years after diagnosis, and I've learned to live with my condition and try not to let it control my life. I have continued to work throughout and also completed my degree with honours in 2012.

In 2010, I met my now husband. He has taken time to research my condition and supports me endlessly. We got married in 2012, and then in 2015 decided we wanted to start a family. After undergoing some tests, it was revealed that we would have to undergo IVF to help us to achieve this goal. I stopped taking Glivec and was monitored closely throughout the IVF and pregnancy and my levels remained within a safe boundary. In July 2016, we welcomed our beautiful baby boy into the world.

I was lucky enough to be able to stay treatment free until November 2016 when my levels started to rise again. I went back onto Glivec and it quickly started to bring my levels back down and I have been at MMR ever since.

I feel like the luckiest person in the world to have the most supportive family, husband and now our beautiful little boy. The medical teams who have looked after me for the past 11 years are amazing! They acted so quickly and have saved my life. I try to cherish every minute now, as I know others aren't that lucky.

> *My GP could see the white blood cells and swelling behind my eyes and had written an estimated diagnosis in the letter that I had to take with me.*

Spot Leukaemia is important as it should hopefully help people to spot the signs and symptoms of leukaemia in the early stages so that they can be treated straight away. The initial symptoms are not always obvious that it could be a serious illness. Hopefully this campaign will help to raise awareness of things to look out for.

Find out more about chronic myeloid leukaemia (CML) in our booklet.

Download online at: **http://bit.ly/LCBooklets**

Alternatively, you can order a paper copy by calling **08088 010 444** or emailing **support@leukaemiacare.org.uk**

Protective Isolation

Have you ever wondered what isolation involves following a stem cell transplant? Or wondered what it's for? Find out more in this article from our Nurse Advisor, Fiona Heath.

Patients who undergo allogeneic stem cell transplants are often hospitalised in protective isolation to prevent infections. Until engraftment occurs, patients are very susceptible to infections because of a lack of white blood cells. Protective isolation procedures have traditionally been used to reduce infection for the neutropenic patient; however, the need for protective isolation has long been debated.

> *Medical staff and visitors may wear plastic disposable aprons.*

Why do transplant patients stay in protective isolation?

The risk of infection is very high for patients that have had an allogeneic stem cell transplant. The transplant conditioning regimen wipes out the cells in the bone marrow. This means that the immune system becomes severely depleted, and in the period immediately after the stem cell infusion patients will experience a period of neutropenia, as they are waiting for the new donated stem cells to engraft. During this neutropenic period patients are especially susceptible to infections due to the lack of white blood cells.

Infections may be viral, fungal or bacterial, and protective isolation aims to protect patients against some of these.

Examples of infections

Opportunistic Infections e.g. Cytomegalovirus (CMV): These are infections that would not cause disease in a healthy immune system. A compromised immune system allows the 'opportunity' for the pathogen to infect. It is now recognised that the majority of common bacterial infections in allogeneic transplant patients arise opportunistically from a patient's own normal flora during the period of profound neutropenia.

Bacterial Infections: Sources of infection may also include skin and tissue surrounding central venous catheter sites and the mouth and gut.

Fungal Infections: For example, aspergillus, which is a common airborne infection. The most common sources for aspergillus include water storage tanks, food such as non-pasteurised mould-containing cheeses, soil, gardens and plants, insulation, construction activity and ventilation units.

> *Being in protective isolation and restricting visitors may make people feel isolated and cut off from the outside world.*

Legionella and Pseudomonas: These bacterial infections are associated with contaminated water.

Clostridia difficile: This is a gastric infection associated with diarrhoea and is substantial in a population heavily exposed to antibiotics.

Respiratory: Viral respiratory outbreaks including seasonal pathogens such as respiratory syncytial virus (RSV) and influenzas.

What is Protective Isolation?

Protective isolation practices range from the use of purpose-built units with air-filtration systems and plastic isolators, to single rooms on a general ward or shared rooms within a controlled environment. Protective measures taken within these environments also vary.

How long does protective isolation last?

Generally, people stay in isolation for three to four weeks after their allogeneic stem cell transplant as engraftment normally takes between two and four weeks. This is very individual though – some people stay for a shorter time and some people stay for a longer time.

Protective Isolation Procedures

Procedures differ between institutions, but they may include:

Protective clothing

Some institutions wear protective clothing. Medical staff and visitors may wear plastic disposable aprons, as these provide an impermeable barrier to micro-organisms and are put on before entering the isolation room.

Flowers and Plants

Flowers and plants are generally not allowed because the soils of potted plants and the surfaces of dried and fresh flowers are known to harbour aspergillus and other potential pathogens.

Soft Toys

Many institutions allow new stuffed teddys or toys. Toys that have non-porous surfaces that can easily be cleaned and disinfected before and after use are often permitted as well.

Visitors

While you are in isolation the number of visitors at a time may be restricted. Anyone who is unwell or has a cold will not be allowed to visit. Many institutions also advise against young children visiting as they often pick up viruses and infections from their nurseries or schools.

> *The risk of infection is very high for patients that have had an allogeneic stem cell transplant.*

Visitors should not be allowed in if he/she:

- Has recently been exposed to communicable infectious diseases, i.e. an upper respiratory infection or flu-like illness.
- Has an active shingles rash.
- Has received an oral polio vaccine within the previous three to six weeks.

Food and Drink

Keeping up nutritional status is important during this period and hospitals will provide a neutropenic diet for transplant patients. Limitations on food and drink vary between institutions. Many institutions advise to avoid uncooked meats and eggs, seafood, unwashed fruits and vegetables and soft cheeses to prevent possible exposure to bacteria such as salmonella. Food restrictions vary between units.

Handwashing

The single most significant vehicle for bacterial transmission to vulnerable transplant patients remains the hands of healthcare workers and visitors. All people entering the isolation room must wash their hands thoroughly. Strict hand hygiene is crucial for prevention of infections. Hands should always be washed before and after patient contact. Some institutions require rings and

wrist watches to be removed and sleeves to be rolled up. Plain liquid soap is suitable for handwashing as it removes transient organisms. Bacterial alcoholic hand rub is also a quick effective means of cleansing hands.

Personal Hygiene

Whilst patients are in protective isolation, personal hygiene is very important as they are very susceptible to infections. Therefore, showering and mouth care are all very important.

Being in protective isolation and restricting visitors may make people feel isolated and cut off from the outside world. The waiting period can be a difficult, anxious and lonely time. Therefore, it is very important to plan for this time by developing coping strategies and supportive mechanisms to help manage the isolation period. Strategies that can help may include having a visitor rota so not too many visitors come at one time. Technology can also be a great asset in making people feel connected to the outside world such as skyping friends and families who are unable to visit.

Glossary

Allogeneic stem cell transplant: Stem cells are collected from a matching donor and transplanted into the patient to suppress the disease and restore the patient's immune system.

Engraftment: When the stem cells given to you during transplant begin to form new blood cells.

Neutropenia: A condition in which the number of neutrophils (a type of white blood cell) in the bloodstream is decreased.

Kate Stallard: I'm still here

When Kate started experiencing symptoms, she put them down to stress, but soon became so unwell that she was rushed to hospital. Now in remission following a diagnosis of acute promyelocytic leukaemia (APL), Kate shares the ups and downs of her story.

About two months beforehand, I started to feel very tired, and although I was exercising a lot and running at least once a week, I felt that my fitness levels were not improving; in fact, I was getting worse. I felt exhausted all the time and had trouble walking upstairs as I felt breathless, and exercising left me feeling like I would faint. I would keep having to stop when walking the dogs too as I felt like I would just collapse. I put it down to poor diet and went to see a nutritionist. I was also experiencing very painful gums and mouth ulcers, so went to see a dentist.

In addition, I had very heavy bleeding during my period. It would not stop, and I was bleeding through clothes, changing them nearly every two hours. I had a banging headache where I could hear my heartbeat in my ears so loud my head felt like it was throbbing, and it would not go away when I lay down. I had achy shoulders and neck down the left-hand side as well, and purple spots on my jaw which had been there for months. I was covered in unexplained bruises and petechia. The night sweats were awful too, and I had a temperature and felt like I had the flu a few days before diagnosis.

I had been experiencing some of the symptoms for a few months and put it down to stress as I

was going through a divorce, had lost my job as I'd worked for my husband, and was spending long hours setting up a business. It provided an excuse for the symptoms, but when they started to become worse and unbearable I went to the GP. I never thought it could be cancer.

The GP's initial reaction was that it was probably stress related and I should eat more spinach and iron rich foods if I felt anaemic. I told my GP about my sister's history of aplastic anaemia and how I was worried about that. This was dismissed. My bruises were not checked, temperature not taken, and I was told I was just having a heavy period. I had to ask for a blood test and was told I could book in for a non-urgent blood test in a week's time. I would have been dead by the time the test came around.

I staggered home and spent the next two days working and taking endless painkillers for my headache. I could hear my heartbeat in my ears so loud at times I couldn't hear people speak. I felt like I was getting the flu and I remember telling people I felt ropey.

By Saturday evening I was shaking violently with a temperature and was bleeding profusely. I live alone and was very scared at this point that something was not right. So, I called 111 at 10.30pm as I almost collapsed and I felt so ill. They booked me an out of hours GP appointment at the hospital in Worcester for 1am. I was offered an ambulance, but I drove myself there as I didn't want to cause a fuss. In hindsight I should have said yes to the ambulance!

The out of hours GP was wonderful. She looked at all my bruises, took my temperature, blood tests and urine sample, which was just blood. She said she thought I was seriously ill and would call me with the results as soon as she heard from the lab.

I drove myself home and at 3:30am she called to say my blood test was severely abnormal and she suspected I had aplastic anaemia like my sister. She offered to send an ambulance to get me, but I said I would make my own way to A&E, calling my sister to take me in. I wish I had taken the ambulance as by this point I felt very faint and feverish.

I arrived at A&E where they were waiting for me and put me straight into isolation, giving me blood transfusions, an ECG, blood tests, IV antibiotics and eventually sending me to resus. After being in A&E for about eight hours and having had my first of many bone marrow biopsies, I was told I had acute myeloid leukaemia (AML) by my consultant. I was moved to the haematology ward later that night and was told I needed urgent chemotherapy and wouldn't be leaving the hospital for weeks. I was gravely ill. The doctor drew back the curtain and the other patient's relatives who had all heard the conversation were silent. I looked at my sister and wailed. I have never felt so alone and scared in my entire life. When my sister had gone to call her husband, I was still sobbing and the nurse came over to see me. She asked if she could call my parents or husband and I had to inform her through sobs that my parents both passed away a few years ago and my husband left me nine months ago. I truly was all alone. Word got around to my friends and ten of them turned up at A&E from all over the country. I was so grateful. I cannot tell you how much that meant to me. The staff said I had a revolving door there!

After being moved from A&E to Laurel 3, the haematology ward, I rapidly went downhill. I picked up C-diff, started chemo for AML and had a Hickman line fitted after bags and bags of platelets and blood. I was told the purple spots on my jawline were Sweet's syndrome and then developed excruciating colitis and ulcers. I was moved to my own isolation room.

Two days into the chemo and after two bone marrow biopsies, I was told I actually had acute promyelocytic leukaemia (APL) which in their eyes was the 'better' one of the two as it's more treatable. So, I started on a new chemo regime.

I was devasted as the chemo went in, because I knew this would mean my chances of having my own children were being wiped out. I had begged to have egg freezing before starting but the doctors told me there was not enough time; I would be dead before the process could be completed.

I spent the next six weeks in Room 5 on the Laurel 3 ward. I never left that room. I had constant temperatures, diarrhoea, I was covered in spots that looked like chicken pox, I couldn't eat, I could barely move. I thought I was dying. I probably was. They couldn't get control of my temperature and didn't know what the cause was. I had numerous MRIs, CT scans, ultrasounds, blood cultures, but no one could stop me getting worse. My lovely long blonde hair fell out in clumps and I sobbed and sobbed as I pulled it out. I sat there in my hospital bed, body ravaged by cancer and chemo pouring into my veins, bald, bleeding, with a tube going into my right breast straight into my heart, and my divorce came through. That was my lowest ever moment. My rock bottom. I thought I would never make it.

I had a skin biopsy done on my

With thanks to Stuart Myers of
www.stuartmyersphotography.co.uk
for the photos

jawline which had now swollen up into lots of big abscesses and I was given a new antibiotic which seemed to do the trick. Finally, my temperature came down to normal and my blood counts were high enough for me to go home. I was so utterly relieved. I had spent the whole of October in hospital with no warning or preparation time, brought in urgently in the middle of the night.

I was allowed to leave, I couldn't believe it! I was left alone at home with only my cat for support! I should never have been left by myself, but I didn't have anyone to look after me and I desperately wanted to be in my own home. I felt dreadful. I took one look at my poor body in a full-length mirror and fell to my knees in waves of emotion. What had happened to me? It was utterly traumatic and life changing.

I struggled on for the next few days, trying to feed myself and sleep as much as I could. I wasn't well enough to keep my dogs overnight, but I managed to see them for a few brief visits. That kept me going. They were so happy to see me. Unfortunately, my beautiful cat had to be put to sleep a week after I came out of hospital. She was the grand old age of 20! Another blow. How much more could I take?

I started the second round of chemo and managed to stay as an outpatient, with friends driving me to and from sessions. The third round of chemo around Christmas time seemed to be going to plan, as I was told I was in remission. Then I fell quite ill again. I was experiencing high temperatures and double vision. I had the horrible headaches back again and we all thought it was side effects of the chemo. I had a few long stays in hospital again and upon being discharged my eyesight worsened. My right eye started to turn inwards, and I couldn't see well enough to even walk in a straight line. I saw the eye specialists, had more MRIs and eventually a lumbar puncture. The lumbar puncture relieved the pressure on my optic nerve and my eye righted itself. Great! All was going to plan, so I thought. Until I went in to see my consultant. I was in the room on my own expecting good news. After all, I was in remission! However, he told me the results from the lumbar puncture and latest bone marrow biopsy showed the cancer had come back with a vengeance. This time in my central nervous system, the fluid around my brain, and also low traces in my bone marrow. I was devastated. My world fell apart yet again.

I had in total 17 lumbar punctures, with chemo injected into my spinal fluid over the coming weeks. The vibe on the ward the day of my first intrathecal chemo was sombre, everyone was so disappointed and deflated that I had relapsed. I remember consultants saying I would need a stem cell transplant in order to survive. To me this was my very worst nightmare.

I was admitted to hospital and started an eight-week course of arsenic. Yes, that's right, arsenic! The last patient at this hospital on arsenic was two years prior so I quickly became known as the arsenic girl! It is administered through an IV like chemo. I imagined the world would turn black and white like an old noir film, but sadly everything stayed the same, apart from my heartbeat. Arsenic can affect your heart and so my twice weekly sessions were preceded by an ECG and more often than not a potassium infusion.

I realised during this time that I couldn't live at home alone any longer. I couldn't cope. My lovely ex in-laws asked me to stay at theirs and I will be forever grateful for their support and care.

After the first round of arsenic and intrathecal chemo I was told I was in molecular remission again, but a stem cell transplant would still be required in order to blast my bone marrow. I was very reluctant to do this and went to see the Professor at the Queen Elizabeth Hospital in Birmingham. They searched for a donor and one unrelated match was found. However, because I was in remission it was decided that I could have my own stem cells back, an autologous stem cell transplant. After hundreds of sleepless nights, calls to specialists, discussions and soul searching I decided to go ahead with the auto stem cell transplant.

I asked for a chance to have my eggs frozen, should there be any left undamaged. I was told I could go through with the procedure and now was my only chance. So, I got funding and I went to the Women's hospital in Birmingham. The whole experience was traumatic. I was a single, freshly divorced lady, whose heart and body were broken, but I so desperately want kids that I tried it. I spent a few weeks injecting myself with hormones and going in twice weekly for scans and appointments. At first there seemed to be a glimmer of hope that we might be able to harvest one or two eggs, but then disaster struck. I came down with an horrific infection in my Hickman line which meant I was hospitalised. I begged the staff to let me go to my final appointment at the Women's hospital and they let me go. Then the most crushing thing to happen to me in this process occurred. I was told there were no eggs to harvest. The treatment I had already received

had damaged my ovaries and that was it. It's not the end of the world, the doctor told me, but to me it was. I had lost everything. My glimmer of hope was gone and so was my hope for the future. I cried all the way back to Worcester hospital and there I spent the next few days in isolation recovering from this latest life-threatening infection and my line was removed. I don't normally cry in front of the nurses but this night I did. They were fantastic, holding my hand, crying with me and supporting me.

So, I geared myself up for the transplant. What else was there to do? I got shingles, which delayed the process, and I had a second Hickman line operation which went wrong and the tube ended up sticking out of my neck and I had to have it removed. I then had to go in the day before my transplant to have a third Hickman line operation. Whilst on the operating table, the QE in Birmingham called wanting me to go in that evening to start the transplant. I was so upset, scared, terrified, nervous, all of the emotions! I said no at first and called my consultants to say I didn't want to do it. But I was talked around and so I was dropped off in August on the bank holiday evening at the QE.

The transplant process began with cranial radiotherapy. A mask had been sculpted to my face a few weeks beforehand and it was like torture! It was unbelievably tight, and they screwed it to the bed to stop your head moving. I am claustrophobic, so I had to gather all my strength to get through these sessions, practising mindfulness and meditation to get me through. But I did! I have realised how strong I am.

The next stage was total body irradiation. This is the one procedure that would 100% make me infertile, no hope or chance of having kids after this. I had begged for ovarian shields but was told I couldn't have them. I even balled my hands up into fists and placed them over my ovaries in the vain hope that this would protect them and one day I could be a mother.

Then the day of transplant came! Thank goodness for me I had a friend there at the time, I wouldn't have wanted to do that on my own. My stem cells were warmed up out of their deep freeze and fed back into me through my Hickman line. At this point my bone marrow had been obliterated by the radiotherapy and chemo and this was the starting point, the reset button so to say. An exciting time! It took two days in total and the stem cells had a distinctive aroma and taste of sweetcorn. I can't touch the stuff since!

I was transported by ambulance back to Worcester for my recovery, where I was placed in isolation again and rapidly went downhill. My mouth was agony with mucositis and I was being sick. I couldn't eat and ended up on a morphine driver for the pain. I felt very low and wondered if I would ever recover again. Maybe this was all too much?

The wonderful staff got me through and after two weeks I was sent home. I went to stay with my sister and ex in-laws for a few weeks. I couldn't even walk up the stairs without help and a shower took all of my energy for the day. I would have to go back to bed after having a shower! Slowly but surely, I built up my strength.

However, and here's the hard bit for me to write, the transplant hasn't grafted properly. Unfortunately, my blood counts are struggling to reach a 'normal' level following the transplant. I am now 10 months post-transplant and I am still struggling to function normally. There have been discussions about a further allogeneic stem cell transplant, but it has been deemed unnecessary at this point. So, I have to hope that my bone marrow will start to regenerate normally in the future, or maybe this is as good as it gets. Who knows.

I do know for certain that I am in medical menopause and I am due to start HRT soon. This for me has been one of the hardest elements of the whole process.

But I am still here. Without all of this treatment I wouldn't be here at all, for certain. So, I am eternally grateful to all the nurses, doctors and hospital staff who have kept me alive. I am in remission now. I am trying to keep my mind and body active and I volunteer at Malvern Hospital looking after their raised beds garden which helps me while I try to build up my strength and hopefully brightens the patients' and staff's day.

I hope the Spot Leukaemia campaign will raise awareness of the signs and symptoms of leukaemia for both patients and healthcare professionals. I would urge anyone who has these symptoms to seek urgent medical help and demand an urgent blood test. I would also hope that on seeing this campaign GPs would request a blood test on a patient presenting with these symptoms as a matter of course.

You can learn more about acute promyelocytic leukaemia (APL) in our free booklet.

Download or order at: **http://bit.ly/LCBooklets**

Living with cancer: coping with everyday issues

Looking for help with practical issues following a diagnosis of blood cancer? Our Campaigns and Advocacy Officer, Charlotte Martin, is here to explain all you need to know about topics such as transport and pets.

A diagnosis of leukaemia can seemingly bring your world crashing down around you. Things can move so fast after diagnosis that you just don't have time to reflect on anything, especially for acute patients.

Yet leukaemia can cause changes to every aspect of your life, and patients who have spoken to us have demonstrated the many things that you need to think about after that moment. You might come to terms with the diagnosis, only to be hit by a second wave of worry; what about the kids? The dog? The house?

Macmillan released a report in 2012 entitled "Cancer's Hidden Price Tag", highlighting the financial problems faced by those diagnosed and their families. It's not just loss of earnings, there may be increased expenditure too. In this article, we have brought together a checklist of things to think about after a diagnosis. By working through it, it should

help to make home life go as smoothly as possible during your leukaemia journey.

Tell your employer

Telling your employer can seem intimidating to start with but will be a weight off your shoulders once done. Your employers are likely to be understanding, although they might not know what leukaemia is. There is a misconception that leukaemia mainly affects children. Don't feel under pressure to explain everything all in one go; you could start by saying that you have a type of blood cancer, as most people will understand the impact that a cancer diagnosis can have. You can then explain the details in future phone calls when you may be feeling better, both physically and mentally, compared to the moments after diagnosis.

A cancer diagnosis is a protected characteristic under the Equality Act 2010, meaning you are protected from discrimination at work, as well as other places like shops and restaurants. This means you are largely protected from losing your job while you are ill. However, the law does not apply unless the employer is aware of your illness. Letting work know that you are ill also means you can avoid unexpected phone calls and feel under less pressure to return to work.

Once you have told your employer, you are also then entitled to sick pay. The level depends on the company you work for and how long you have worked there. A common scenario is that you will get full pay for a certain length of time, if you have worked at the same place for more than six months. The amount of time you get full pay for is likely to increase with length of service too. Once your full pay period expires, or if you are not entitled to be paid, you can also get statutory sick pay from the government. Check your contract of employment for full details.

If you feel like you need to give up work, this is something you should consider carefully, giving yourself plenty of time to decide. You may also be entitled to some benefits if you are too ill to work; you should seek advice from Leukaemia Care, Citizens Advice or Macmillan to get information on your entitlement for your specific situation.

For more information on all aspects of employment rights with leukaemia, please see our Know Your Rights Toolkits: **http://bit.ly/KnowYourRightsToolkit**.

Childcare

If you have younger children, you will want to consider who will look after them during hospital stays, appointments and times when you are vulnerable to infection, such as after a stem cell transplant. Have a think about whether you can do this through informal care arrangements or whether you may need something more formal in place.

Informally, your partner (if applicable), family members or friends are likely to be the first place you turn to when an illness like leukaemia is diagnosed. It can feel difficult to reach out for help but don't feel guilty; close friends and family are likely to be unsure of how they can help but very willing, so asking for something specific like this helps. Your partner, whether married or not, could ask for flexible working arrangements or compassionate leave from their employer. Other family members may be able to do the same. For older family members, such as grandparents, have a chat about what they feel they can contribute versus what you need, so they don't feel overwhelmed. They will wish to help but children can be tiring. Overall, people will be more than willing to help.

If you are ill for a longer length of time, or you don't feel your informal network of people can help, you might want to consider asking for help from social services. This might seem like a scary prospect, but they are there to help everyone with the welfare of children. Social Services do not just intervene when children are in danger, they can be called upon by anyone in a time of crisis that could affect children. They can help you assess your needs and design a solution that works for everyone. This does not necessarily mean the children will be taken to stay elsewhere, although this could be an option; they could just coordinate your family and friends for you, working out who can look after the children and for how long.

Even if you feel you can look after your children yourself, or your partner can, it's important to make sure you get a break. The Carer's Trust can provide respite for anyone caring for others, whether that be a carer or someone who is ill but also has responsibility for children.

Pets

As with childcare above, caring for a pet can be difficult after your diagnosis if you are away from home a lot or if you need to avoid infections. Again, family and friends will be willing to help but they may not be familiar with looking after a pet or unable to help due to allergies or pets of their own. There are charities that offer pet fostering services, usually short term. One example is the Cinnamon Trust. Your vet may be able to inform you about local charities offering a similar service.

Food

Cooking a meal when you have leukaemia can be difficult for several reasons; you may not feel physically able to cook, you may have to follow a restricted diet, or you may not have the appetite for food due to the side effects of treatments. Although not often the first thing to come to mind,

this could be an effective way for friends and family to help you. You could ask those living close to you to bulk cook a meal and freeze it in portions. They could do this while you are in hospital or at an appointment, so you can come straight home to a fully stocked kitchen. If they don't have access to your house, they could leave things on the doorstep, acknowledging your need for help but also the fact you might not feel up to socialising too.

Transport

At certain stages of your leukaemia journey, you might not feel like driving or be able to get around yourself. Taking you to and from hospital appointments is often a simple way that friends and family can help. If you have not got this support and cannot use public transport, there may be a volunteer transport service in your local area; speak to your local council for more details.

The cost of attending appointments can also stack up. Often hospitals give free or discounted parking to cancer patients, although the policy varies depending on your location in the UK. This scheme is also not well advertised, so do ask at your next appointment. The hospital can also refund the cost of reasonable travel, such as buses, taxis or petrol, to patients in receipt of certain benefits or those who can show they have a low income.

Energy bills

Symptoms of leukaemia vary from person to person, but you are likely to be spending more time at home and need to keep warm to avoid infections. This may mean you need to spend more on fuel for heating or lighting, and this is likely to come at a time where you income drops. Help is available; for example, Macmillan have a fund with Npower that means cancer patients bills are capped at 10% of their income during treatment. Macmillan can also give out grants directly for this kind of expense if you have low income or savings.

Other healthcare

As a cancer patient, you become eligible for other healthcare costs that you may be used to paying for. For example, you can get free prescriptions if you are in England (they are free for everyone in Wales, Scotland and Northern Ireland). You might also qualify for free eye tests and dental treatments, especially if your leukaemia means you cannot work and are on a low income or certain benefits.

Grants for special circumstances/treats

Even with all the above sorted, leukaemia patients are all too often left without the income for expenses often taken for granted, like new clothes, short breaks or babysitting to go out. Grants may be available to help if you feel you are struggling to pay for an essential, like food or bills, or would like a treat to help you recover. Macmillan grants can provide for a range of things, depending on your income and savings, giving around £300 on average.

Turn2Us is a site that keeps a directory of all grant giving organisations and you can search locally for organisations, such as churches, that provide funds in your area. Importantly, those who are caring for you, or your children if applicable, while you are ill may also be entitled to this kind of help, so they can get a well-deserved break too.

Useful organisations and links

The Community Transport Association: https://ctauk.org/

Cinnamon Trust: http://www.cinnamon.org.uk/cinnamon-trust/

Turn2US: https://grants-search.turn2us.org.uk/

Macmillan advice

Energy bill advice: https://www.macmillan.org.uk/about-us/working-with-us/corporate-partners/keep-warm-without-the-worry.html

Other healthcare: https://www.macmillan.org.uk/information-and-support/bowel-cancer/colon/organising/benefits-and-financial-support/help-with-health-costs

Childcare: https://www.macmillan.org.uk/information-and-support/organising/practical-preparation-for-treatment/childcare/help-getting-childcare.html

Grants: https://www.macmillan.org.uk/information-and-support/organising/benefits-and-financial-support/benefits-and-your-rights/macmillan-grants.html

Please get in touch with our Advocacy Caseworker for more information on any practical or financial issues arising from your leukaemia diagnosis by emailing advocacy@leukaemiacare.org.uk or phoning 01905 755977. We would also welcome recommendations of organisations that can help with these practical issues so we may share this information with others.

An overview of AML Low Intensity 1 trial

Our Nurse Advisor, Angela, has years of experience in clinical trials. In this latest article, she's looking at a study for older patients with acute myeloid leukaemia (AML) and high-risk myelodysplastic syndromes (MDS).

Patients who are diagnosed with acute myeloid leukaemia (AML) or high-risk myelodysplastic syndromes (MDS) may be asked to consider having their treatment by taking part in a randomised clinical study. The study that would be offered to eligible patients is called the Low Intensity 1 (LI1) Trial.

The LI1 trial is a national study being undertaken with an aim to continue to improve treatment by comparing a number of new drug therapies which have shown some benefit in early stage trials with the existing standard treatment. LI1 trial is an option that is available for patients where it is decided that the intensive chemotherapy is not thought to be suitable or beneficial.

This study has been recruiting for some time both in the UK and across other countries, such as Denmark and New Zealand. It aims to recruit around 180 patients and is currently on its 9th update. The study has been designed in such a way that not all treatment options might always be available. The reason for this is, as each new drug therapy becomes available, the trial treatment will be reviewed and taken out of the study if it is not effective as the standard treatment. Previously, studies compared one or two drug treatments against the other, which took many years to find out if this was more beneficial for patients.

With the newer study design for the LI1 trial, it's possible for several treatments to be compared and allows for new drug therapies to be added in as the study is updated. This method of research gives patients access to newer treatment options more quickly. It is hoped that these new treatments may be as good as the current standard treatment or more effective.

As well as finding out whether the new drugs are better at controlling leukaemia, patients will also be monitored to make sure that the side effects are acceptable, and not more than would normally be expected. Some patients may be asked to give blood samples to measure the blood levels of the new drug, but this would be explained in a separate information sheet.

Part of the study will also include monitoring patients' general wellbeing during and after treatment. This will be done by asking each patient to complete a questionnaire, which asks about quality of life and other activities. This will be given to each person at the beginning of treatment and at three, six and 12 months.

Following a discussion with a haematology consultant, a decision will be made to consider treatment with less intensive chemotherapy and possible entry into the LI1 trial. After informed consent, patients who enter into the study will receive one of the following treatments. The study treatment is allocated through randomisation, and this will be clarified with each patient by their doctor and research nurse. This means that a computer

programme will be used to give an equal chance of getting any one of the treatment options.

The treatments

Treatment 1 - Is the "standard treatment" which is a chemotherapy and is called Low Dose Cytarabine. This is given as a subcutaneous (under the skin) injection twice a day for ten days. Following course one of the Low Dose Cytarabine, patients will be reviewed prior to receiving the second course of treatment. This will be repeated four times. The idea of the trial is to compare this treatment with the other, newer options.

Treatment 2 - Is a combination of Low Dose Cytarabine with the addition of AC220 (Quizartinib). This is a tablet form of chemotherapy called a tyrosine kinase inhibitor, which will also start on day one and be taken daily by mouth for 21 days, repeated with each cycle every four to six weeks.

Treatment 3 – Is a combination of Low Dose Cytarabine and Lenalidomide. Lenalidomide is an approved drug which is used in myeloma - a different type of bone marrow cancer. This study is being done because of encouraging results in a small study of AML patients undertaken by colleagues in Italy.

Low Dose Ara-C (as in treatment 1) will be combined with a drug called Lenalidomide which will be given as a capsule, to be taken by mouth once a day for 21 days. This is followed by a 14 day rest period. The intention is to give a minimum of four courses but may continue following review by your doctor. The options for continuing treatment would consist of:

- Low Dose Ara-C and lenalidomide every six weeks or;
- Lenalidomide only every four weeks.

Your consultant and specialist team would discuss which of these options may be beneficial for each individual patient. There are also other treatment options that are part of the LI1 trial that may be available; this study is constantly reviewed and updated by the trial centre.

In addition to the treatment part of this trial, patients taking part will be asked to consent to donating any excess blood or bone marrow that is left over from the diagnostic tests for research. This is an optional part of the study; a separate information sheet and consent form will be given to patients to explain the reason and importance of this.

Further information about this study can be obtained from the clinical haematology team, a summary of all clinical trials can be viewed via the link.

A summary of this clinical study will be available on: **http://www.ClinicalTrials.gov**

Talk to your medical team to find out more about this study and to see if you're eligible to take part.

Early diagnosis saves lives

Spot Leukaemia

- Leukaemia is a cancer of the blood
- People of all ages can be affected by leukaemia
- Leukaemia is often diagnosed late because symptoms are not well recognised

Ensure you can #SpotLeukaemia by visiting:
www.spotleukaemia.org.uk

Can you #SpotLeukaemia?