Philadelphia chromosome karyotype male or female. 3D illustration showing defective chromosomes 9 and 22 with translocational defect which causes chronic myeloid leukaemia.
In this issue

Hello 2018!
Blood cancer is firmly on the national agenda with the launch of a new Parliamentary report. We bring you more on the report which is making the headlines.

As well as this, we’re covering Treatment Free Remission, Relapse in AML and much more.

We’re delighted with the response to Nursing Matters and thank you for the ongoing support. From Summer 2018, we’ll be producing two hard copies per year (Autumn, Spring) and two online only editions. Make sure you are signed up to email and hard copy versions by emailing the team on communications@leukaemiacare.org.uk

Speak soon,

Shirley Aston

Shirley Aston,
Leukaemia Care Nurse Advisor

Front cover image copyright: https://www.123rf.com/profile_drmicrobe
LC hold landmark GP training event

Just a week after the APPG report on blood cancers (find out more on pages 6 - 7), Leukaemia Care held its first ever in person GP training event which saw 40 GPs receive further training on the signs and symptoms of blood cancers.

We were delighted to be joined by three haematologists on the day: Dr Manos Nikoulousis (Heart of England NHS Trust), Dr Ben Kennedy (University Hospitals of Leicester NHS Trust) and Dr Salim Shafeek (Worcesthire Acute Hospitals NHS Trust).

The day was a huge success and we hope to host more of these events across the UK to complement our free online training for GPs.

Offering high quality training for medical professionals is a key priority for Leukaemia Care and we will be shortly announcing the dates for our next Nurse Masterclasses on exciting topics. Watch this space.

Latest patient event – Fatigue and blood cancer

The results of our 2016 patient survey showed us that cancer related fatigue is a huge issue for blood cancer patients and we are launching our first dedicated patient event based on the subject of fatigue this June. You’ll find the details of this event on the back cover and we’d ask you to share this with your patients. We will also be looking to rerun this event in Sheffield in October and Edinburgh in March 2018.

Keep up with the latest news and patient stories at www.leukaemiacare.org.uk

Many thanks to these following people and for their contributions:

Helen Knight, Julie Quigley, Michael and Andy (CLL patients), Sandra (AML patient), Shirley Aston, Nicole Scully, Fiona Heath, Lauren Walton, Caitlin Evans and Nick York.
Positive appeal decision gives second chance for inotuzumab ozogamicin in the treatment of ALL

In August 2017, NICE rejected the use of inotuzumab ozogamicin for the treatment of relapsed, or refractory, b-cell acute lymphoblastic leukaemia (ALL). The committee found the treatment was not a cost-effective use of NHS resources, based upon a maximum of six cycles of treatment as per the marketing authorisation. In the case of six-cycles, the treatment is used for palliative care.

UK practice, however, would largely consist of using inotuzumab ozogamicin as a step to enable patients to have a stem cell transplant (SCT). When used as a step towards SCT normally only two cycles are necessary, plus an additional cycle in some patients and others are able to have a SCT after just one cycle.

Leukaemia Care sought to appeal the NICE recommendation based upon the grounds that the decision to not recommend the treatment is unreasonable in light of the evidence submitted to NICE. A joint appeal from the Royal College of Pathologists, Royal College of Physicians and the Association of Cancer Physicians was submitted on the same grounds. Pfizer, the manufacturer, also appealed the decision on other grounds.

On December 28th the appeal committee published their decision to uphold the appeals.

SMC makes venetoclax available to treat CLL

Venetoclax’s novel mode of action works by selectively inhibiting the Bcl-2 protein which is over expressed in CLL tumour cells. This B-cell lymphoma-2 (Bcl-2) protein mediates and promotes tumour cell survival by preventing apoptosis.

Following a full submission assessed under the end of life and orphan medicine process, in August 2017, venetoclax (Venclyxto®) was accepted for use within NHS Scotland as monotherapy for the treatment of chronic lymphocytic leukaemia (CLL):
• in the presence of 17p deletion or TP53 mutation in adult patients who are unsuitable for or have failed a B-cell receptor pathway inhibitor.

• in the absence of 17p deletion or TP53 mutation in adult patients who have failed both chemoimmunotherapy and a B-cell receptor pathway inhibitor.

NICE recommends venetoclax for use within the Cancer Drugs Fund to treat CLL

In October 2017 NICE granted access to venetoclax via the Cancer Drugs Fund managed access program.

NICE recommends venetoclax for treating chronic lymphocytic leukaemia in patients:

• with a 17p deletion or TP53 mutation and when a B-cell receptor pathway inhibitor is unsuitable, or whose disease has progressed after a B-cell receptor pathway inhibitor

• without a 17p deletion or TP53 mutation, and whose disease has progressed after both chemo-immunotherapy and a B-cell receptor pathway inhibitor

Venetoclax is anticipated to remain available through the CDF during the data collection period until December 2020 and during a subsequent appraisal, while the final guidance is reviewed. A final decision is expected in early 2021.

NICE issues restricted approval for the use of brentuximab vedotin in ALCL treatment

Brentuximab vedotin is indicated for the treatment of adults with relapsed or refractory ALCL and has been available for use through the Cancer Drugs Fund since 2013.

NICE issued final guidance in October 2017, recommending brentuximab vedotin to treat relapsed or refractory systemic anaplastic large cell lymphoma in adults - only if they have an Eastern Cooperative Oncology Group (ECOG) performance status of 0 or 1.

Their decision to limit the use to patients with an ECOG performance status of 0 or 1 was based upon a similar restriction in the criteria for entry to the clinical trials. Hence, NICE claim the evidence and conclusions on quality of life improvements and cost effectiveness were limited to this patient group.
The All-Party Parliamentary Group (APPG) on Blood Cancer launched their inaugural report, ‘The ‘Hidden’ Cancer: The need to improve blood cancer care’ in Parliament on January 17th 2018, and this was followed by a debate on the issues in the report.

What is an APPG?

All-Party Parliamentary Groups (APPGs) are informal cross-party groups that have no official status within Parliament. They are run by and for Members of the Commons and Lords, though many choose to involve individuals and organisations from outside Parliament in their administration and activities.

The All Party Parliamentary Group on Blood Cancer (APPGBC) raises awareness and promotes the needs of blood cancer patients with parliamentarians, government, NHS, and charity stakeholders - and much more

The All Party Parliamentary Group on Blood Cancer (APPGBC) was first established in June 2016. It re-formed in July 2017. The elected officers are:

- All Party Parliamentary Group Chair: Henry Smith MP
- All Party Parliamentary Group Vice-Chairs: Colleen Fletcher MP, Maggie Throup MP
- All Party Parliamentary Group Officers: Jim Shannon MP, Nick Thomas-Symonds MP, Jess Phillips MP
How was the report created?

Back in March 2017, the APPG launched an inquiry into blood cancer care in the NHS. The inquiry was the first undertaken by the APPG and looked at all aspects of blood cancer, including awareness, diagnosis, patient experience, commissioning of services and clinical research.

The inquiry looked at the areas of care identified as priorities in the Independent Cancer Taskforce’s Cancer Strategy for England 2015 -2020, and sought to identify which services patients require, where their needs are currently being met, and where services need to be extended or amended to account for the specific needs of blood cancer patients.

What were their findings?

Early diagnosis

In similar fashion to Leukaemia Care’s ‘Spot Leukaemia’ campaign, the report identifies the need for improving understanding of what blood cancers are and awareness of the signs and symptoms to the public, both of which could be leading to delays in diagnosis.

They also identified the need for supporting GPs to recognise potential blood cancer cases and refer for appropriate testing, based around the frustration of many patients who visit their GP numerous times before being diagnosed.

The final audience who the APPGBC suggest can improve early diagnosis is policy makers, so that Cancer Strategy recommendations can be more aligned to improve early diagnosis of blood cancers, not just solid tumours. In this vain, they recommend that patients presenting with one or more symptoms of a blood cancer should be sent for a diagnostic blood test.

Patient experience

Seven key areas were identified where blood cancer patients believe improvements are required. These are:

1. Post-transplant support, particularly for patients with severe long-term side effects.

2. Access to a Clinical Nurse Specialist (CNS) – Based upon the National Cancer Patient Experience Survey (CPES) the report suggests 1 in 10 patients do not have access to a named CNS. Our My CNS Matters report, however, indicates access could be much lower.

3. Ensuring all patients feel involved in decisions about their treatment.

4. Improving access to emotional
and psychological support for patients and carers – Focusing on patients with chronic, slowly progressing and typically incurable, blood cancers who are offered little support to come to terms with their diagnosis and ‘Watch and Wait’.

5. Improving financial advice offered to patients regarding employment, time-off and travel.

6. Need to both develop, and improve access, to ‘kinder’ treatments to enable more patients to tolerate the treatment and fewer patients to have long-term side effects.

7. Increase use of cancer care plans for blood cancer patients.

Living with and beyond Blood Cancer

The Cancer Recovery Package has been developed as part of the Cancer strategy to help patients return to their everyday lives after cancer treatment. However, it appears that access to the recovery package varies significantly and it fails to account for the large proportion of chronic blood cancer patients who will never live “beyond” their cancer, but live with it.

The APPGBC recommend that NHS England consider how blood cancer patients are receiving support following care, particularly in the areas of chronic blood cancers and post stem cell transplant.

Developing a modern health service

Blood cancer is currently the 3rd largest cause of cancer mortality in the UK, despite it being only the 5th most common cancer. This reflects a need to develop better treatments for blood cancer, which is not treatable by surgery or radiotherapy commonly used for solid tumours.

The Cancer Drugs Fund (CDF) was set up to provide temporary access to new drugs while greater evidence and data on the effectiveness is gathered. The report expresses concern that the time frame between CDF availability and NICE appraisal for routine availability on the NHS is not enough to gather evidence for some blood cancer treatments, as the patient group sizes are relatively small.

The APPGBC also state that an urgent review is required into the NICE drug appraisal system, to reflect new methods of treating blood cancer patients and enable affordable long-term treatment on the NHS.

If you would like to read the full report, you can find it at the following link: https://bloodwise.org.uk/actions/campaign/partnerships/appg
#myCNSmatters: an update

On the 5th December 2017, at Britain Against Cancer (BAC) we launched our latest report, ‘My CNS Matters – The invaluable role of a Clinical Nurse Specialist (CNS)’. Our Campaigns and Advocacy officers Nick York and Beth Torr broadcast live from the event on Twitter.

The report covers four different areas around Clinical Nurse Specialists:

1. **The invaluable role of a CNS**

   Looking into who Clinical Nurse Specialists are and describing the responsibilities they have in caring for cancer patients, which includes: co-ordination of patient care; being an advocate for each individual patient and a point of communication between their care providers; and being responsible for educating healthcare professionals in their area of expertise.

2. **The value added to the NHS**

   Studies have shown that the value of the work carried out by just one CNS is worth far more than a CNS is paid, making them a hugely cost-effective and cost-saving asset to the NHS.

3. **The value added to patient experience**

   It has been shown that access to a CNS is the biggest factor leading to a positive cancer patient experience. We used our 2016 patient survey to demonstrate how leukaemia patients with access to a CNS have a better
experience. This includes: being better able to understand their diagnosis and treatment decisions; feeling more involved in their treatment; receiving more information and support; and ultimately feeling more positive after using their CNS for support.

4. CNS access

In 2015, NHS England committed to achieving 100% access to a CNS, or other key-worker, for cancer patients by 2020. While we welcome this target, our survey revealed only 38% of leukaemia patients in 2016 had access to a CNS. In this section we look at the regional variations in CNS access across the UK and investigate the changes hospitals have been making to the CNS workforce since 2015 to achieve the target.

Throughout December and January patients have been sharing their experiences on social media using #myCNSmatters. These have been a great way to demonstrate how Clinical Nurse Specialists are helping to support patients, highlight issues with CNSs having excessive workloads, and reveal that many patients do not know who or what a CNS is.

For many who have access to a CNS, the stories are of overwhelming gratitude and thanks. People saying, ‘the CNS was invaluable’ and, ‘my CNS helped to make me smile again’. This is why we were saying thank you to Clinical Nurse Specialists and haematology nurses across the country, letting you know that you matter during the festive season.

We sent out personalised #myCNSmatters advent calendars, Christmas cards and a copy of the report to every haematology department in the UK. As well, our staff, patients and regional coordinators hand-delivered a holiday hamper to ten Clinical Nurse Specialists who work closely with Leukaemia Care to support blood cancer patients all year-round.

We are grateful for the valuable support you nurses offer to patients, but we want to see all leukaemia patients across the UK receiving CNS care. This is why we are saying #myCNSmatters and encouraging discussions surrounding CNS access with policy makers and senior healthcare leaders.

Find out more about #myCNSmatters and read our report at: www.leukaemiacare.org.uk/my-CNS-matters
CML and Treatment Free Remission (TFR)

Treatment free remission, or TFR, is a hot topic on the agenda for Chronic Myeloid Leukaemia (CML). The following article looks into the treatments for Philadelphia-positive CML.

Philadelphia Positive (Ph+)
Chronic Myeloid Leukaemia

Every human cell should contain within the nucleus 22 pairs of chromosomes, plus 2 sex determining chromosomes that are either XX (Female) or XY (male). The chromosomes contain all the genes required for human life.

In the 1960’s researchers identified that the cells from CML patients contained an unusually short chromosome and this was named after the location of its discovery, the Philadelphia chromosome.

It wasn’t until later that researchers were able to identify that the Philadelphia chromosome had been formed
by regions on chromosome 9 and chromosome 22 swapping (translocation). The swap occurs at a very specific point, causing the ABL gene on chromosome 9 to be joined to the BCR gene on chromosome 22 and hence a new gene is formed, BCR-ABL.

From BCR-ABL a type of tyrosine kinase is produced. This is an enzyme involved in cell signalling, which turns genes on and off. The effect of the BCR-ABL tyrosine kinase signalling is uncontrolled cell division of white blood cells; hence it is a driver of CML.\textsuperscript{i}

The Philadelphia chromosome is present in approximately 95% of CML cases.\textsuperscript{ii}

**Tyrosine Kinase Inhibitors (TKI)**

In the 1990’s, an American oncologist, Dr Brian Druker was researching into the use of tyrosine kinase inhibitors (TKIs) for the treatment of CML. These inhibitors prevent the cell signalling activity of tyrosine kinases.

Dr Druker began working with the pharmaceutical company Ciba-Geigy (now Novartis) who had been developing a range of TKIs and eventually came across a compound that reduced CML cells by over 90% in samples of human bone marrow within the lab. This compound was named imatinib, and human trials for the treatment began in 1998.

In 2001, imatinib (brand name Gleevec) was approved for use within the USA for treatment of CML. It was the first treatment to be developed that targeted a specific cancer-causing gene alteration.\textsuperscript{iii} Since this time, a number of other TKIs have been developed for the treatment of CML four of which are routinely used in the UK: nilotinib, dasatinib, bosutinib, ponatinib.

**Effectiveness of TKI drugs**

Prior to the introduction of TKI drugs in 2001, only 30% of patients survived 5 years following diagnosis. In one of the first trials of imatinib, 53 out of 54 patients achieved complete haematological response, meaning their white blood cell counts returned to normal. In the following 5-year follow up trial, 89% achieved 5-year survival.\textsuperscript{iv}

Today the five year survival is likely to be higher than 89%. This is because, with the advent of further TKI drugs, there are now more potent options for those who fail to respond to, or become resistant to, imatinib.

Most patients today will live a normal lifespan by taking TKI drugs on a daily basis and, more often than not, face greater side-effects from TKI side-effects than CML itself.
Treatment Free Remission

The majority of CML patients using TKI drugs will have very little detectable disease using the most sensitive method of detection, PCR (polymerase chain reaction).

At this level, the amount of disease is defined by:

Major Molecular Response (MMR) or MR³ – this refers to a log reduction of 3, or 1000 times fewer BCR-ABL than would be expected to be found in an untreated CML patient.v vi

Deep Molecular Response (DMR) or MR⁴.⁵ – this is smallest amount of BCR-ABL that can be detected by PCR, with between 10,000 to 100,000 times fewer BCR-ABL than would be found in untreated CML.

In recent years, the question has arisen whether patients who have achieved DMR with TKI drugs could stop their treatment and sustain DMR – this is known as treatment free remission (TFR).

Who can consider TFR?

There are many clinical trials ongoing for TFR that patients can join. The main condition for trials is that patients need to have achieved and sustained DMR for a number of years prior to attempting TFR.

One unusual exception to this is the DESTINY trial, that recruited a cohort of patients who had achieved MMR but not DMR.vii In this trial, the TKI drugs were reduced to half dose for 12 months before full removal of the drugs – in most trials this de-escalation does not occur.

In recent years, however, more clinicians are attempting TFR with their patients outside of clinical trials. Mainly due to the lack of availability within trials, and secondly because there is better guidance on safely attempting TFR outside of trials.

Nilotinib, however, is currently the only TKI to contain TFR within the marketing authorisation – this defines how a drug is presented for use within Europe by the manufacturer. It states:

“Treatment should continue for as long as the patient continues to benefit. The dose should be reduced or treatment interrupted if the patient has certain side effects affecting the blood. Stopping treatment may be considered in patients in chronic phase after treatment with Tasigna for at least 3 years, whose disease has been well controlled for at least 1 year.”viii

The European Society of Medical Oncology (ESMO) have published guidelines for considering patients to attempt TFR within the clinical setting.ix:
1. Need to ensure "proper, high-quality and certified monitoring".

Patients attempting TFR need to be closely monitored, with PCR tests guaranteed every month for at least 6 months, every 6 weeks for 6 months and every 3 months thereafter. The results also need to be reported on in a timely manner, to ensure that patients who’s BCR-ABL levels start to increase are recognised as early as possible.

Generally, this criterion is less of an issue within the UK compared to some other countries where, for example, PCR is not routinely available.

2. Typical BCR–ABL1 transcripts identified at diagnosis.

PCR for recognition of the typical BCR-ABL gene segment is very strictly regulated and standardized across the globe. However, around 2-3% of patients have slightly different BCR-ABL gene mutations (atypical), which makes identification of CML cell levels less accurate and hence, the advice is to avoid attempting TFR.

3. Must have received TKI therapy for a minimum of 5 years.

4. Achievement of MR4.5 and sustained DMR for at least 2 years.

5. Informed consent of the patients.

Patients must be given full information surrounding risk of relapse, requirements for regular testing and potential side-effects (see below).

Are there any risks associated with attempting TFR?

Side effects: TKI withdrawal syndrome

Patients involved in clinical trials have reported musculoskeletal problems following TKI withdrawal, normally localised within the hips, shoulders and/or extremities. In some cases, it appears TKI treatments improve the symptoms of arthritis which are similar to those reported during TKI withdrawal symptom. Hence, stopping treatment can reveal arthritis.\textsuperscript{x}

In most cases, TKI withdrawal syndrome is mild enough to be managed by over-the-counter medicines and cease over time\textsuperscript{xi}. It was suggested in the DESTINY trial that gradual removal of TKIs could possibly help to reduce the effects of TKI withdrawal syndrome.\textsuperscript{xii}

Emotional impact

Moving away from taking a drug every day and having a stable response can be a big step. Some patients express feelings of
anxiety and fears about relapsing with attempting TFR.

**What are the advantages?**

**A sense of ‘normality’**

Patients who achieve TFR express the feeling of ‘normality’ that comes with not taking a drug every day and living free from both the side-effects of TKIs and CML symptoms.

**Reduced side-effects from TKI therapies**

As mentioned previously, many patients respond very well to TKIs but are left with side-effects due to the toxicities of treatment and risk of adverse events increases with long-term use of TKIs.\(^{xiii}\) This can significantly impact the quality-of-life of patients.\(^{xiv}\)

Successful TFR, therefore, may mean overcoming the quality-of-life limiting side-effects. Although, the musculoskeletal issues associated with TKI withdrawal syndrome experienced in around 15-30% of patients\(^{xv}\) must be considered.

**Cost benefits**

The cost of using TKI treatments over the lifetime of a CML patient can be significant. For example, the annual cost for one patient using dasatinib treatment is £30,477.00 per year\(^{xvi}\). This cost is variable dependent on the dosage required by the patient and the introduction of generic drugs has significantly reduced costs. You can read about generic drugs in our advocacy toolkit.

Fortunately, within the UK patients are not directly responsible for covering the cost of their healthcare. However, there will be a significant cost saving for the NHS not having to pay for treatment for those who can achieve sustained TFR. These funds could then be redirected for other healthcare benefits.

**How many patients achieve TFR?**

There is a chance that patients see an increase in their CML levels upon removal of TKIs and lose Major Molecular Response (MMR). Studies have clearly shown, however, that patients can safely restart TKI treatment and achieve DMR again without any apparent impact on long-term outcomes.\(^{xvii}\)

Evidence from trials demonstrates that around 40%\(^{xviii}\) to 50%\(^{xix}\) of patients achieve long-term TFR. The majority of patients who lose MMR will do so within the first 6 months and after this time, the risk is around 10% up to 24 months TFR\(^{xx}\).

There are several factors that appear to correlate with patients attaining TFR:
1. Early molecular response (EMR) to TKIs

Early molecular response to TKIs is one of the key prognostic indicators for patients and it is correlated to patients later achieving MMR or DMR\textsuperscript{xxi}. Therefore, it could be the case that patients with EMR are more likely to achieve TFR later down the line.

2. Longer TKI treatment and sustained DMR

A clear factor that appears to influence TFR is how long the patient has sustained DMR with TKI treatment prior to attempting TFR.

For example, the EURO-SKI early data analysis found a loss of MMR within 6 months in 47% of patients treated with TKI for less than 8 years, compared to 26% of those who had been treated for more than 8 years\textsuperscript{xxii}.

3. The type of TKI patients are treated with

All TKIs inhibit the activity of the BCR-ABL gene, as suggested by the name, however, there are differences between the TKIs in both how they function and how well targeted they are. Imatinib is less toxic than other TKIs, but those developed after are generally more effective for achieving DMR.

Due to this, studies have shown that more patients treated with nilotinib, for example, will be able to attempt TFR than those on imatinib. Hence, the numbers of patients achieving TFR will be greater for those previously treated with nilotinib\textsuperscript{xxiii}.

Is TFR a cure?

Some patients feel as though stopping their treatment and living in TFR as a cure, however, the clinical community is cautious to say this.

This is because, the slowly progressing nature of CML and the older age patients may mean that MMR is not lost in patients within their life-span. However, there is still risk that given enough time the leukaemia cells will begin to increase above MMR and the EURO-SKI trial has demonstrated late-relapses after years of TFR. In this vain, patients will require regular, life-long PCR monitoring to assess disease burden.

Cure, or not, the opportunity for patients to attempt TFR and live treatment-free for an extended period of time may go far in contributing to increased quality-of-life.
For more information on CML, go to: http://www.leukaemiacare.org.uk/resources/step-by-step-on-chronic-myeloid-leukaemia
In this article, we explain what Easy Read information is, and why we produced our new Easy Read booklet.

Recently, we released our new Easy Read booklet, titled ‘All About Leukaemia’. The booklet explains leukaemia in simple, easy to follow terms, and is aimed at those with low level literacy skills or learning disabilities.

What is Easy Read?
Also known as ‘easier information’ or ‘simple words and pictures’, Easy Read takes complex information and breaks it down into simpler words, making topics more accessible to those with learning disabilities.

Why create an Easy Read document on leukaemia?
Overall, we wanted to make our information accessible to all. However, there were also some more specific reasonings behind this.

One was that people with Down’s Syndrome have an increased risk of developing leukaemia. As a result, we wanted to make leukaemia information easy to understand and available to those with Down’s Syndrome, along with other patients who have learning disabilities.

Another reason was that studies have shown that the vast majority of patient information is simply too difficult for many to understand. As See a Voice explains, "The average reading age of the UK population is 9 years – that is, they have achieved the reading ability normally expected of a 9-year-old" (See a Voice, 2010).

However, many studies have shown that patient information has a higher readability age than nine-years-old, including a study on Parkinson’s disease (PD) information, which found "Only 1% of the top 100 PD information webpages are fully comprehensible to the average adult" (Fitzsimmons PR, Michael 18
The result of this is that "Those with poor health literacy are at higher risk for seeking emergency care, have more frequent hospital admissions with longer stays in the hospital, are prone to missing medical appointments, have poor compliance with treatment recommendations, and greater disease progression" (Sameer Badarudeen and Sanjeev Sabharwal, 2010).

How do you make patient information easy to read?

There are a number of guidelines to follow when making Easy Read documents. This includes using pictures to illustrate each idea mentioned, placing pictures on the left and text on the right, using a font size of at least 14 and having no more than 15 words in a sentence.

In addition, any medical terms must be explained simply. Words like ‘haemopoeisis’ and ‘granulocytes’ will not be familiar to most. If patients are given no explanation of what these words mean, their ‘poor health literacy’ could end up detrimentally affecting their treatment and prognosis, as highlighted in Badarudeen and Sabharwal’s study. As a result, confusing medical terms must be explained using simpler words.

In our Easy Read All About Leukaemia booklet, medical terms are emphasised in bold and patients can refer to a glossary of terms at the back of the booklet.

Overall, Easy Read documents are an invaluable tool, allowing those with learning disabilities or low literacy skills to fully understand their diagnosis and treatment without being overloaded with confusing terms.

Order our Easy Read All About Leukaemia booklet

You can order or download our free booklet on our website or over the phone.

You can place an online order for hard copies here: http://bit.ly/RequestLCInformation

You can place an order for hard copies over the phone when you call: 08088 010 444

You can download a copy online here: http://bit.ly/LeukaemiaEasyRead

Stop press! Now available in: Welsh, Polish, Gujarati, Punjabi, Urdu and Bengali. Call 08088 010 444 to find out more.
In 2018, we’re launching a new, 12-month pilot scheme based in the East Midlands providing buddy support to newly-diagnosed chronic lymphocytic leukaemia (CLL) patients and carers.

We’re aiming to connect 15 buddies to provide support either over the telephone or face to face. This scheme will be essential in providing a much-needed source of support and a listening ear to patients and carers affected by CLL.

Volunteers will receive all the training they need to make sure that they can provide the best support and advice. The scheme will be run by a dedicated buddy co-ordinator who will be in charge of any training, assessments and referrals into this new scheme.

Expenses for the volunteer buddies will be paid for, and all equipment, such as a mobile phone, call sheets and catch ups with the buddy coordinator, will be provided as well as full support and training from the team.

Would your region benefit from this service?

Although this initial pilot is being held in the East Midlands area, we are keen to extend it into areas where there is a need for this level of support. We welcome further enquiries about establishing a scheme in your area.

Do you know a patient who would benefit or make a great buddy?

We’re always looking for new patients who either need support or who could support others. Please let your patients know if you think they are suitable.

To find out further information about our buddy support, please email Kay.Drew@leukaemia.org.uk or ring the patient services team on 01905 755977.
Relapse in AML

Acute Myeloid Leukaemia occurs when the production of blood cells becomes uninhibited in the bone marrow, producing too many immature and abnormal myeloid cells that flow into the bloodstream. Myeloid leukaemia becomes acute when the cells progress quickly.

If the levels of leukaemia cells have risen beyond those considered as remission, this is called a relapse or recurrence. This affects about 50% of all patients who have achieved remission after initial treatment.

Signs and symptoms of a relapse

A patient may experience some of the same symptoms they did at their initial AML diagnosis, including:

- Anaemia
- Bruising
- Infections
- Aching bones
- Swollen glands
- Feeling tired and run down
- Fever and sweats
- Headaches
- Blurred vision

Diagnosis

The patient will be asked questions about their general health, their symptoms and any illnesses they are suffering from. It will also be arranged for them to have a number of tests to confirm a relapse, including:

- A full blood count
- Lumbar puncture – a small sample of fluid from around the brain and spinal cord to taken to check for leukaemia cells.
- Chest x-ray – to see if there are any swollen lymph nodes.
- Immunophenotyping – this test is conducted under a microscope using a bone marrow sample and is used to count leukaemia cells and determine whether they are myeloid or lymphoid leukaemia cells.
- Cytogenetics – chromosomes are checked from a sample of bone marrow for any
genetic abnormalities that may be partly responsible for the development of the leukaemia.

How is AML treated?

- **Intensive therapy** – this involves two stages of chemotherapy, remission induction therapy and consolidation therapy, with the aim of achieving remission.

- **Non-intensive therapy** – this is for patients who are not suitable for intensive treatment and involves gentler chemotherapy. The aim here is to give a patient the best quality of life for as long as possible.

- **Clinical trials** – these can involve new chemotherapy drugs, drug combinations or different delivery schedules.

**Survivorship**

Survivorship aims to provide personalised care based on the patient’s need to improve their health, wellbeing and their confidence to motivate them to manage their own health and wellbeing. This can include:

- Taking care of any comorbidities.
- Offering cancer rehabilitation.
- Providing a treatment summary.

- Full preparation for the impact of relapse and side effects of treatment, both physical and psychological.
- Support and advice for social and financial difficulties.
- Receiving health and nutrition advice.

**Palliative care**

Also known as supportive care, this involves a holistic or whole person approach, which includes the management of a patient’s pain and symptoms as well as psychological, social and spiritual support for them and their loved ones. The aim is to reduce their symptoms, control their AML, extend survival and give them and their loved ones the best quality of life.

**End of life care**

When the patient is receiving palliative care but are reaching the last stages of their life, a plan will be put in place to ensure they enjoy a good quality of life until they pass away, and to do so with dignity. It is important the care provided factors in the wishes of the patient and their preferences on how and where they want to be cared for.

This information is taken from our patient information booklet entitled Relapse in AML.

We have a number of patient
information booklets available to anyone who has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be found on our website at www.leukaemiacare.org.uk/resources/filter-by-resource-type/information-booklets

Our Nurse Advisor, Fiona Heath, has shared some top tips about discussing a relapse with a patient:

Experiencing relapse after treatment can be very disappointing and distressing. Breaking bad news, such as a cancer relapse, in a reassuring manner will be of immense help to the patient at a difficult time. However, despite the importance of delivering this bad news in an effective manner, this is not always achieved. Breaking bad news is a complex skill and although it is generally the physician’s duty to give bad news, nurses have a pivotal role in shaping patients’ experiences of receiving and coping with news of a cancer relapse.

Breaking bad news is a complex process that involves many factors such as preparation, effective communication, accurate information, empathy and understanding. Many different guidelines exist in the nursing literature and it can be helpful to follow a pathway such as the one below.

Guidance for breaking bad news:

1. **Preparation is key.** Identify who needs to be present, find a setting that is private, ensure there is time available for explanation.
2. **Provide the information accurately and clearly.** Do not use jargon or medical terms without a thorough explanation. Break the information down into chunks, giving one piece of information and then moving on once you are sure the recipient has understood and continually assess preferences for additional information.
3. **Responding to reactions and answering questions.** Allow time and opportunity for emotions to be expressed and acknowledge the emotions that are expressed.
4. **Plan the next step.** Agree a plan of what will happen next so patients and relatives have a sense of control and know what to expect.
5. **Debrief.** Breaking bad news is time consuming and demanding and can have an impact on workload and the emotional wellbeing of staff. Formal and informal opportunities to reflect and provide support should be made available.

Being involved in the process of talking to a patient about disease relapse is a complex activity that requires knowledge, expertise and skill. It is important that is done well, as the consequences for patients and relatives are long-lasting and can influence their experience and satisfaction with treatment as well as relationships with the healthcare team. If done well, the process can also have a beneficial effect on the ability of patients and relatives to cope with the consequences of the illness.
You Matter - Your Blood Cancer and Coping with Fatigue.

**DATE**
16th June 2018

**VENUE**
De Vere Oxford Thames, Henley Road, Oxford OX4 4GX

10:30am - 11:00am  Registration

11.00am - 11.35am  What it is, how common it is and the impact it can have on your daily life

11:35am - 11:45am  Patient speaker: Emma Richards (CML)

11:45am - 11:55am  Break

11:55am - 12:30pm  Dealing with fatigue, including everyday coping strategies

12:30pm - 1.30pm  Lunch

1:30pm - 3:00pm  Exploring expectations of yourself and others, practical strategies and ways to communicate with others

3:00pm - 3:05pm  Closing remarks

Timings are subject to change.

Patients and their loved ones can reserve a place at this free event by ringing the patient services team on **08088 010 444** or emailing nickey.bate@leukaemiacare.org.uk

Please let your patients know!