



CLL SUPPORT

Helping people affected by CLL and SLL

Newsletter

July 2022 Issue No 07

Bringing you the latest news and developments in CLL and SLL

Our free helpline: 0800 977 4369

Welcome to our latest newsletter, and I hope you find it informative and useful.



Summer has certainly arrived, and we can look forward to some nice weather, although hopefully not too hot.

Experts had predicted that Covid-19 would virtually disappear during the summer months, but this has not happened. Instead, as this newsletter is published, Covid infections are increasing, as are hospital admissions. This is disappointing and worrying news for our members, especially after the restrictions that we have all had to endure over the last two years.

The advice must be, therefore, to make sure you are fully vaccinated, remain careful, assess the level of risk you are willing to take, and act accordingly. We continue to give more detailed advice below, and on our website.

It's been over two years since we have been able to hold our popular face-to-face conferences, but I am pleased to announce that we will have a conference in Glasgow later this year. Please see

below for some early details. The conference will also be live-streamed, which is a first for us, and something we are very excited about. We believe it could be the format for at least some of our conferences in future. I look forward to welcoming you to Glasgow.

We have been pleased with the initial interest in members joining the team and I am delighted to announce that Jackie McCreery and Debbie Yates have joined as Associate Trustees to help keep our services and support maintained.

However, we do need a few more to help maintain the accounts, webinars, and website, so please do contact me if you can spare a day or so a month to join our team of volunteers who deliver these services. I am particularly interested in someone qualified to manage the accounts, work with the website company to develop the site and members with experience of webinars and conference support.

If you are interested, please contact me at:

marc.auckland@cllsupport.org.uk

In the meantime, please stay safe and well.

Marc Auckland
Chair, CLL Support



Covid update - where are we now?

Covid infections have continued to climb across the UK, latest figures from the [Office for National Statistics \(ONS\) show](#).

Key points from week ending 22 July are:

- **Nearly 3.5 million people, or one in 17**, has the virus - that's up from 2.7m, or one in 25, the week before. **Infections across the UK were:**
- one in 17 in England - up from one in 18
- One in 17 in Wales - up from one in 20
- One in 17 in Northern Ireland - up from one in 19
- One in 16 in Scotland - up from one in 17
- The rise is being driven by fast-spreading sub-variants of Omicron, called BA.4 and BA.5.
- People are still able to catch the infection even if they have had Covid before.

The number of people in hospital with Covid across the UK is 10,081 - up by around 2,500 in a week. More than half of those will be there for other reasons, such as a broken bone or a stroke, but they still need to be managed.

The implication for people with CLL/SLL is still to take great care. This means:

- Make sure you are fully vaccinated. This currently means five jabs. A sixth will be coming in the Autumn.
- Avoid crowded places where possible. If you need to be in a crowded area, wear a mask. FFP2, FFP3 and N95 are recommended, although any mask is better than none..
- When meeting friends and relations, think about asking them to test beforehand.
- Regular handwashing is still probably a good idea, although it's not thought that hands are a primary source of infection.

Remember - Omicron symptoms can differ from the Delta variant.

- **The five main symptoms of Omicron are more like those associated with a cold, including: sore throat, runny nose, headache, fatigue and sneezing.** Smell and taste may be normal. Some people also reported loss of appetite and 'brain fog'.*
- * Data taken from the Zoe study.

If you catch Covid

If you have Covid symptoms, you should immediately take a **lateral flow or PCR test**. You will need a positive result to be assessed for treatment, which is usually needed within about five days. You can find the procedure to follow on the NHS website [HERE](#)

Guidance from the NHS, effective from 13 June 2022, for treatment of Covid patients at home is as follows:

- First-line: nirmatrelvir plus ritonavir (antiviral) OR sotrovimab (nMAB), as clinically indicated
- Second-line: remdesivir (antiviral)

- Third-line: molnupiravir (antiviral)

Note that you should be monitored after your first treatment as you may need follow up treatment if your Covid symptoms return, or you continue to test positive.

Announcing our first conference for nearly 3 years!

Save the date for our Glasgow conference!

Date; Tuesday 18th October 2022

Location: Grand Central Hotel, Glasgow city centre

Keynote speakers: Dr Alison McCaig & Martin Hannah

The conference will feature other clinical speakers and some patient stories and will be a hybrid event - both in person and streamed online. More details to follow as the programme builds but in the meantime please save the date!

World CLL Day



In September 2021 we will be joining other blood cancer charities to promote Blood Cancer Awareness Month.

September 1st is designated World CLL Day and every 1st September, the global CLL community unites to raise awareness about chronic lymphocytic leukaemia

(CLL) and give those affected by a diagnosis of CLL a much needed voice. On World CLL Day we come together to improve understanding of the vulnerability of CLL patients and the challenges involved in living with CLL.

An initiative from Abbvie, manufacturers of Venetoclax

Small things, big difference

FREE TEXT SERVICE FOR PEOPLE WITH CHRONIC LYMPHOCYTIC LEUKAEMIA (CLL). GET YOUR WEEKLY INSIGHTS, PRACTICAL TIPS AND WISDOM FROM MEMBERS OF THE CLL COMMUNITY BY SIGNING UP.

HOW DOES THIS WORK?

Text MYCLL to 88222

from anywhere in the UK (applicable with smartphones only*). You'll be sent a free, automated text message with information on how to subscribe to the service. Once you've subscribed, you will begin to receive free weekly text messages.

This is an AbbVie service. Content developed in collaboration with CLL Support with input from Lymphoma Action and Leukaemia Care.

abbvie | CLL SUPPORT | Lymphoma Action | Leukaemia Care

*Some network providers may have filters in place that may be incompatible with this SMS service or will prevent devices from receiving picture messages from organisations. Unfortunately, in the event that this occurs, you will not be able to view the messages. February 2022 | UK-ONCC-22007

We know that being diagnosed with chronic lymphocytic leukaemia (CLL) can be a life-changing experience and knowing where to look to find credible, useful information can be overwhelming.

Small Things, Big Difference is a new, free* weekly text service, launched by AbbVie with CLL Support, and our sister blood cancer charities.

It aims to provide bite-sized practical tips and wisdom from members of the CLL community on how to navigate this 'new normal'.

This totally free* service is part of the 'My CLLife' suite of resources, which help people affected by CLL to better cope with the complex and unpredictable nature of the condition. This includes the Small Things, Big

Difference booklet and the AbbVie UK YouTube Oncology playlist.

*** Please note: We have been made aware that some network providers may charge for access to this service, so please check before using.**

Life after Covid. A personal reflection by Matt Gibson



Matt is one of our Associate Trustees, an active member of our Under 60 group, marathon runner and a full time teacher. These are his reflections about Covid and how it affected him and those around him.

“Life after Covid” could mean any number of things, including:

- Reflections after a Covid infection, maybe including efforts to access antiviral drugs.
- Dealing with “long” Covid.
- The implication of changes taken during the height of the pandemic, perhaps relating to work, family, location and so on.
- Or the mental adjustment of trying to return to “normal” in whatever form that takes.

And, of course, “life after Covid” is a misnomer as, at the time of writing infection rates are on the rise again.

I have not tested positive for Covid at any time since March 2020, although I am fairly certain I had the virus at the very start of the period of heightened anxiety about what effect it would have - after a holiday in Tenerife in February 2020.

(Remember hotels being quarantined?) I was off work for a week with a horrendous headache and a hacking, persistent cough.

Ironically, I saw my consultant the week after (the last time I actually saw him) and he said, “go home and stay there.” Lockdown was announced 3 days later. So, for me, “life after Covid” is very much about the last two things from the list above.

I work in a large secondary school, working from home March - July 2020, November 2020 and January – April 2021. I got very good at online teaching! I was very grateful to my school for their support of my position. This school year has been badly affected by the pandemic, with very patchy levels of attendance and significant adjustments to public examinations in an effort to try to give some sense of fairness to the students sitting them.

Anyone who knows me would say that I am a very positive person and that I always need projects to be working on. Going back to as close to normal as possible has been that project this year, alongside training for a marathon. So, my “life after Covid” has meant returning to work full time in a school of 1600 students and 100+ staff. It has meant playing cricket, using changing rooms and bars, and sharing lifts with other players. It has meant using public transport, for example to travel to the recent CLL Support board meeting, and it has meant booking overseas and domestic trips for the summer to mark my forthcoming half century and silver wedding anniversary.

It was not ever thus. I decided at the last minute not to travel into London to take part in the 10K race that CLLSupport members and families were running in, as I had not yet got to grips with the idea of a busy train or underground. The turning point, I think, was the return to work in September.

By then it was clear that restrictions were on the way out. Students were going to be back in school and that, as a teacher, I had to crack on with it or find a more solitary occupation.

This had knock-on effects - I needed to stand in a long queue in a busy cafeteria to buy lunch, I had to take my classes to assemblies of 250+ students and staff, I had to share a staff room, use equipment that had been used by others and so on.

As we approach the end of the school year, the annual chaos of events that we

cram in like Sports Day, induction of new students, our Race for Life and a training day that is going to see 2000 adults descend on my school site are all going ahead as planned. Life, in school at least, definitely seems to be an “after Covid” environment.

I know that my experience and approach is not one that everyone will be comfortable with. I’ve had 5 jabs (4 Pfizer, 1 Moderna), had no ill effects to any of them (which I know could be both a good and bad thing) and don’t know whether I’ve developed antibodies. I’m enjoying doing the things I like doing, in the end I guess, because, if having CLL and going through FCR treatment has taught me anything, it is that life is for living!

Matt Gibson



Welcome to our new animation!

We know that being diagnosed with CLL or SLL can be very traumatic, and lead to anxiety for the patient, family and friends. We wanted to try to help patients at this 'just diagnosed' stage, so we developed this simple animation to help them understand a little about CLL. We hope you enjoy it!

We are indebted to the MDS UK Patient Support Group for allowing us to adapt the animation and to Peter Randall for generously funding it.

Fundraising!

A sincere 'thank you' to all our valued fundraisers. Without your help we couldn't do our work. Not everyone can run, cycle, skydive or climb mountains, however, so here's a couple of ways you could help without too much effort.



Do you buy from Amazon? If you do you could help CLL Support by using Amazon Smile. It doesn't cost any more than the usual site, but we receive a small donation for every purchase. Small donations add up, and to date we have received nearly £2,000.00! It's quite painless, so give it a go and help us at the same time. All you need to do is select CLL Support as your chosen charity.



This is another relatively painless way you can help. Nearly all major supermarkets and stores operate this scheme, which again works by them donating various amounts to your chosen charity for everyday purchases.

Note that our official registered Charity title is: Chronic Lymphocytic Support Association (CLLSA), and you will need to use this title to register. Happy spending!

Latest news!

Results of the Birmingham Covid vaccination study

Many of you took part in this study, which looked at the effectiveness of the Covid vaccines for CLL patients, and we've just received the results. They make interesting reading and you can find our summary of the conclusions here:

[Covid vaccination study](#)

FLAIR Trial Results

The first results of this major trial for CLL/SLL treatments have been published, and we've prepared a Plain English summary for this complex paper. You can find it here:

[FLAIR Trial summary](#)

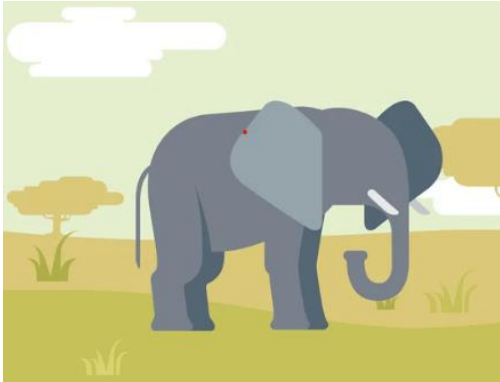
New Vaccination leaflet

Vaccination is an important part of protection for CLL patients, as we are more vulnerable to infection.

Together with the **UK CLL Forum**, we've produced guidelines for patients and medical teams alike. You can download or order a copy of the leaflet here:

[Vaccination guidelines](#)

Can elephants help?



Something a little different!

Elephants are five times less likely to die from cancer than humans. A group of British and European scientists believe they have discovered why - and this may also have implications for blood cancer.

It all comes down to the vital p53 gene which hunts cells with faulty DNA. People with CLL who also have a defective p53 gene may have less time before treatment is necessary, and may not respond as well to treatment.

These noble animals have 40 types of p53 genes, whereas humans have just two. This gives elephants a much bigger toolkit to find and tackle cancer.

The findings, published in *Molecular Biology and Evolution*, give insights that may lead to new therapies to help tackle all types of cancer, including blood cancer.

HealthUnlocked

HealthUnlocked is our very active on-line forum, where you will find support and knowledgeable, reliable advice on all things to do with CLL. The site also has a very comprehensive resource of CLL information, which is updated regularly, and is moderated by our team of Administrators and Volunteers. You can check it out here:

[HealthUnlocked](#)



Our new free Will-writing service.

We do understand that the decision to write a will can be a delicate topic and must be handled sensitively. But it is essential for most people to have a will in order to safeguard their interests after death.

It would be wonderful if you could read on before deciding if this is something you wish to do.

CLL Support is a member of **The National Free Wills Network** which gives us the opportunity to offer a limited number of valid 'simple' Wills (or mirror

Wills for a couple) **entirely free of charge and written by a solicitor local to you.**

There is no obligation whatsoever to include a gift to CLL Support in your Will, but we sincerely hope that you might consider doing so.

How does it work?

1. You tell us you are interested in using this service.
2. We refer your details to The Free Will Network. Your details are not shared with anyone else and the Network will only contact you to provide the service, never for marketing.
3. The Network send you a list of your nearest participating solicitors and a voucher to take to your appointment.
4. You meet with the solicitor at an office local to you (or online if you prefer) to discuss your wishes and prepare your Will in the usual way. Most Wills are completely covered by the free Will service. If your Will is more complex, your solicitor will advise you of this, giving you the option to continue and pay the difference if you wish.
5. Once you have made your Will, the Network tells us if your Will includes a gift to CLL Support so that we can write to thank you.

It's a very discrete and straightforward process, and if you would like more information, please ask for a copy of our explanatory leaflet here:

coordinator@cllsupport.org.uk

Or download from our website [here](#):



Any thoughts?

We would love to hear from you with any comments (good, bad or indifferent).

CLL Support is a members' charity, which means it really belongs to you, our members, and the trustees work on your behalf. So your thoughts and suggestions are important.

You may have a story to tell which could help other patients. We welcome contributions of up to 500 words, so do let us know if you have something to say. We can't promise to print everything, but we always try to.

We would like to make this newsletter more interactive, if possible, so please tell us about anything that's on your mind that could help other members.

You can contact us at membership@cllsupport.org.uk

We look forward to hearing from you!

