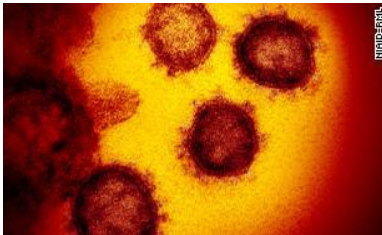


Our top stories in this newsletter



[Corona Virus Update](#)



[Latest advice UK CLL Forum](#)



[Prof Fegan Video](#)



[A message from Marc Auckland, CLL Support Chair](#)

Welcome to our latest newsletter.

I hope this message finds you safe and well during these challenging times for us all.

It is a sobering fact that CLL and SLL patients are more at risk from Covid-19 than the general population. This is because our immune systems are damaged and we are less likely to be able to fight it off. In addition, most CLL patients also fall into the vulnerable age bracket of over 60. As trustees, we all either have CLL ourselves or have a loved one with CLL, so we do understand what everyone is going through.

We all need to take extra care to avoid contracting the virus.

We have been very concerned that many CLL patients have not received a letter from the government saying that they are in the most vulnerable category, and we have been working hard to have this rectified.

The main problem is that patients on 'Watch and Wait' are not included. This is clearly an error and we have been working with the UK CLL Forum and our sister charities to have this changed. We are hopeful that this will be achieved soon.

Many of our members have used the letter from the UK CLL Forum to help them get on the list for most vulnerable status. This enables you to receive a care package including food parcels and priority booking for home deliveries.

Please see below for the latest letter and information.

We are likely to see announcements over the next few days about how the planned easing of lockdown will be managed. This will have important implications for CLL patients, and we will closely monitor the situation and keep you informed, together with our advice.

On behalf of the trustees, I would like to thank you for your support, which is more important now than ever, and I wish you and your family good health.

Marc Auckland,
CLL Chair



Latest UK CLL Forum advice letter

Along with our sister charity Leukaemia care and the UK CLL Forum we have been very concerned about those CLL patients who have not yet received the letter from the government stating that they are in the most vulnerable status.

This has happened for a number of reasons, the main one being that patients on 'Watch and Wait' were not included. We have been pushing hard to have this changed, and we are very glad that the government advice has now changed to include all CLL patients.

It may take time for this new information to filter down and for letters to be sent out. Patients who have still to receive confirmation may be able to use the following letter to help.

The UK CLL Forum, which represents CLL consultants, has strengthened its advice that all patients, whether on watch and wait, in treatment or post treatment must shield themselves.

They have produced a letter giving clear guidance on this and it can be found here:

The letter is designed for patients to show their consultant or GP so that they can confirm 'most vulnerable status', and have the benefits that this entails, such as priority for food deliveries.

Members have already contacted us to say that it has helped them. Just a few of the comments:

Chris C *"Thank you for this clarification, it's very helpful"*

Christine C *"Thank you - this has answered a few questions !"*

Jacquie *"Thank you all for supporting us during this pandemic I for one am extremely grateful for the clear advice given.
On Watch and wait at present."*

Cedric B *"Thank you for your advice. I am "watch & wait" and received the letter from NHS Scotland yesterday and have had a supportive social worker phone call as a result along with a supermarket priority delivery slot today."*

Continued...

We are in constant touch with our medical advisers and changes in the advice, as well as helpful hints on how to tackle the situation, are being updated regularly on our website.

Latest advice can be found in our 'News' section which also has a link to download the letter:

<https://www.cllsupport.org.uk/new-advice-from-the-uk-cll-forum/>

If you have not received your letter from the government, you should still register as extremely vulnerable. You can do that here:

<https://www.gov.uk/coronavirus-extremely-vulnerable>



Coronavirus webinar by Prof. Chris Fegan

Earlier this month our sister charity, Leukaemia Care, and ourselves hosted a video question and answer session with Prof Fegan, who is CLL consultant haematologist at Cardiff University School of Medicine.

In a wide-ranging talk about Covid-19 and the implications for CLL patients, Prof Fegan answered questions sent in by patients.

As always, Prof Fegan gave clear advice and the video recording is very well worth watching. It can be found here:

<https://facebook.com/LeukaemiaCare/videos/161417448414652/>

We will be holding further video calls over the coming weeks, so look out for details. We'll let you know well before the date.

STOP PRESS!!

The next video Covid-19 video Q & A will be on

Thursday 7 May at 10.00.

Dr Piers Patten, of Kings College London, and Marc Auckland, Chair of Trustees at CLL Support and CLL patient.

You can register here:

https://us02web.zoom.us/webinar/register/WN_nt0Ann8_Sx2RaL2YmKEmlQ

RADIO 4

CLL Support in the News!

One of our trustees, Michael O'Neill, has given an interview to be aired on the Radio 4 'Today' programme scheduled for **Wednesday 6th May**.

It's in the nature of these things that the interview could be postponed if there is other breaking news, but listen out for it as Michael puts CLL Support right up front!

Continued...



New Survey

A big thank you to everyone who completed the last survey, and this is already providing essential information to help CLL consultants.

Just a sample of the results:

Around 900 replies.

50% receive their information from charities like CLL Support.

20% are still waiting to receive the government letter.

93% are shielding.

47% are living alone.

There is also information about how patients are having difficulty in accessing prescriptions.

These results have helped us to lobby Government for all CLL patients to be placed on the most vulnerable list. We are pleased to say that there has been movement on this and many patients are now being included on the list.

However, there is still much to be done, and that's why we have launched a follow-up survey so that we can see how things are moving over time.

So, once again, we are asking for your help. Please take a few minutes to complete the new survey here:

<https://docs.google.com/forms/d/e/1FAIpQLSdH6povARkjk8JAJthfH-Cobb6N05naGgBNCT61elcn7pxfpA/viewform>

Many thanks for your help. It really does make a difference.



Support from The Times

Sean O'Neill is the Chief Reporter for The Times, a CLL patient and CLL Support member. He has written frequently and movingly about his views on, and experience with, CLL. Sean is a real campaigner for better understanding of the difficulties CLL patients experience and how it affects our lives.

He has kindly allowed us to use his article, which was first published in The Times, and you can find the link to the Time's website here:

<https://www.thetimes.co.uk/article/putting-millions-in-quarantine-till-2021-is-discriminatory-g2zk89s3t?shareToken=0373a4ece05ed59494700dfd6a8881f8>

We hope you enjoy it.

Continued...

An appeal



In common with many charities, our income has ground to a halt. We survive only because of the generosity of members who raise funds for us by such things as running, climbing, sky-diving, trekking, as well as from less taxing activities such as coffee mornings and baking cakes.

Unfortunately, all of these activities have stopped in the present pandemic, and so has much of our income. And this is at a time when demand for our help has increased enormously.

We are fortunate that the trustees have always been careful to make sure that we have good financial reserves to enable us to continue our work in difficult circumstances like these. However, we don't know how long the present problems are likely to last.

For this reason, we are seeking your help, if you feel able to.

We would like you to consider making a regular donation to the charity.

We do appreciate that this is not possible for everyone. However, if you feel you can help us with a regular donation, we would be enormously grateful. It would help us to maintain our efforts to help CLL patients across all our activities.

It's simple to do, just check out the page on our website here:

<https://www.cllsupport.org.uk/donate/>

Thank you.

Mindfulness



The current situation imposes new levels of stress for many people. One way to help with this is to use techniques such as mindfulness. The following link is to a free resource offering a number of different techniques, which some members may find useful.

<http://www.freemindfulness.org/download>

Under 60s' Club



We are still working to maintain the Under 60 club in these difficult times. We appreciate that many of the group are still working and that this is a very concerning time for them. The WhatsApp group welcomes new members and is a source of support and information.

Contact: norah.grant@cllsupport.org.uk

Continued...



Don't forget to smile! Even through all the problems!

Our fundraising activities have necessarily had to be cut short for the next few months at least. However, we still need to try to generate an income and one relatively painless way of helping us, and if you ever use **Amazon**, is to log on to the **Amazon Smile** site instead of the usual one. It's precisely the same, and doesn't cost you any more, but CLL Support will receive a small percentage of whatever you spend. The first time you log on you will be asked to nominate your chosen charity and CLL Support will pop up. With many of us having to self isolate, DVD boxed sets will be an essential requirement, so if you decide to buy from Amazon, just log on the Smile!

We only receive a small amount (£0.01 per £ spent), but it soon adds up so please do use it!

HealthUnlocked

HealthUnlocked HealthUnlocked is our international online Forum where you'll find advice and the latest information on CLL and the problems experienced by fellow sufferers. There are over 14,000 members, and the site is moderated by CLL Support volunteers to ensure the information is up to date and accurate. This applies particularly to information on CoV-19 , where reliable information is so important. You don't need to participate unless you want to ask a question, but if you do you will receive a warm welcome from fellow CLL sufferers. Why not have a look at:

<https://healthunlocked.com/>

Until Next Time

Be sure to follow us on Twitter, Facebook, and HealthUnlocked for all the latest information and discussion on CLL. Remember, every post you like, share and retweet helps to raise our profile, allowing other people living with CLL to discover us. CLL Support is the only UK charity dedicated to providing education, support, and advocacy to help empower people living with CLL.

Unsubscribe

Registered Charity: 1178482