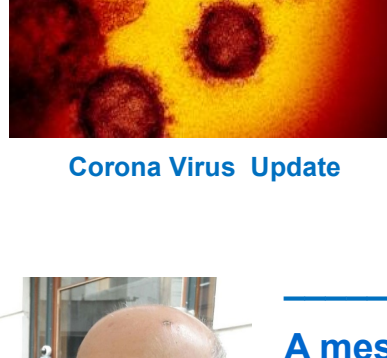
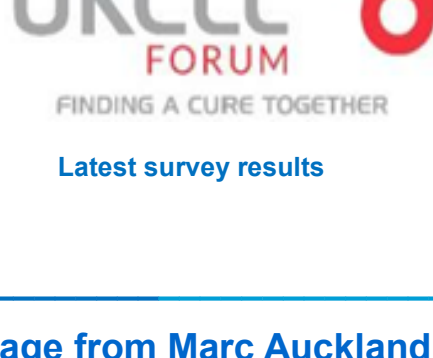


## Our top stories in this newsletter



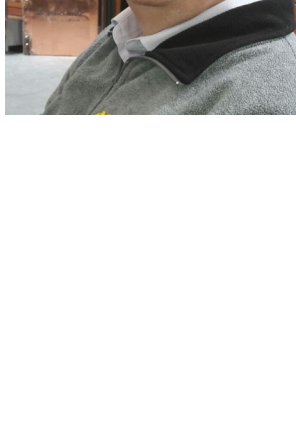
Corona Virus Update



Latest survey results



Dr Piers Patten 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.

We want to our best to keep in touch with our members during this extraordinarily difficult period for CLL patients and their families. We feel that information and support are crucial just now and I hope you will find the following articles informative and interesting.

We are very aware from your feedback that many of you have found shielding extremely difficult, and this is confirmed by our latest survey, a summary of some of the results of which are outlined below.

As the shielding restrictions are now being relaxed in some parts of the UK, it is difficult for patients to judge their level of risk. We are working closely with the UK CLL Forum who are attempting to look at all the risks involved and perhaps develop the concept of 'personal shielding' based on age, medical condition and treatment. However, a risk will remain as long as the virus is still active, or until viable vaccines and treatments are developed. Such developments may still be some way off, and patients need some hope that they can start to get back closer to normality.

We want to support those members who may be experiencing anxiety about the duration of the lockdown and the relaxation of shielding by pulling together some resources that members have found helpful. These include mindfulness and relaxation techniques as well as other psychological support methods. We will be expanding this over coming weeks. Also, please have a look at the small booklet of inspirational quotes we feature below. Many members have told us how helpful it has been for them.

We will continue to battle on behalf of patients and bring you updates as soon as we hear anything.

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

Chair, CLL Support.

Marc Auckland,  
CLL Chair

### Covid-19 update

#### Government guidance on Covid-19

The government has issued new guidance relating to the vulnerable section of the population who, until now, have been urged to shield.

A summary of the advice can be found on our website here:

<https://www.clisupport.org.uk/government-statement-on-covid-19/>

This guidance will be of concern for many patients and their families.

Please be aware that this new guidance relates to England, and other regions are following different policies. Details of this can be found on our website.

**Our advice is strictly to maintain social distancing at all times, and wash hands frequently and thoroughly. If you do go out, wear a mask and protective gloves.**

These are very basic precautions and ultimately it will be up to each individual to assess what level of risk they are willing to accept, preferably after discussion with their consultant.

We will keep you up to date with any changes in advice, so check our website regularly.

### New Coronavirus webinar by Dr Piers Patten

Earlier this month our sister charity, Leukaemia Care, and ourselves hosted a video question and answer session with **Dr Patten**, who is Clinical Senior Lecturer and Honorary Consultant Haematologist at King's College Hospital and **Marc Auckland**, our Chair of trustees.

In a wide-ranging talk about Covid-19 and the implications for CLL patients, Dr Patten answered questions sent in by patients, whilst Marc presented the patient's view.

The webinar can be found here:

[https://youtu.be/nxAkCi\\_v7ss](https://youtu.be/nxAkCi_v7ss)

We think you will find it interesting and informative. There will be regular webinars in the future in the absence of our conferences, so please keep a look out for them.

### STOP PRESS! Our next webinar will be on

**Wednesday 10th June 2020 at 13:00**

**Prof Peter Hillmen**, Consultant in Clinical Haematology at Leeds Teaching Hospitals NHS Trust and Honorary Professor of Haematology at the University of Leeds, will be speaking and answering questions on Covid-19 and the relaxing of the shielding and lockdown.

In addition, **Paul Newis** will be giving a CLL patients perspective, and our chairman of trustees, **Marc Auckland** will update us on latest news and events.

If you wish to join the Webinar, please email our Coordinator - [coordinator@clisupport.org.uk](mailto:coordinator@clisupport.org.uk)

Sign-in details will be sent out over the next few days.

Please note that numbers are limited and when the maximum is reached, further applications cannot be taken. However we will try to live stream the webinar on our facebook page to avoid anyone missing out.

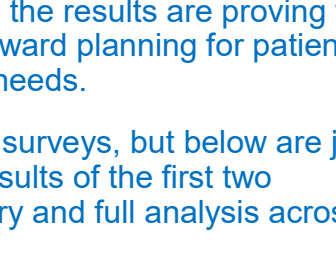
### Small things, big difference!

We have collaborated with three of our sister charities and the pharmaceutical company Abbvie to produce this small booklet.

It contains the inspiring thoughts and experiences of a variety of CLL patients and how they are dealing with the condition.

**We think you may find it an uplifting read, especially in the current difficult circumstances.**

The booklet can be downloaded from our website:  
<https://www.clisupport.org.uk/small-things-big-difference-inspirational-booklet/>



### The big survey

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

This was the third survey we have carried out in conjunction with the **UK CLL Forum** and **Leukaemia Care**, and the results are proving to be extremely helpful to clinicians in their forward planning for patients as well as ourselves to understand patient needs.

We are working on a full report covering all surveys, but below are just a few snapshot views of some of the key results of the first two surveys. We hope to publish a final summary and full analysis across all three surveys in the next few days.

#### Total number of respondents:

Survey 1 (25 March—18 April) 844

Survey 2 (20 April—27 April) 842

**Mean age of respondents:** Approx 64.7 yrs

#### % receiving a letter from the government or NHS regarding shielding:

Survey 1 44%

Survey 2 78%

#### % reporting Covid-19 symptoms:

Survey 1 7.9%

Survey 2 7.6%

(Note: only 2% of respondents had a test and only 3 in the first and 5 in the second testing positive. This is probably an indication that shielding is working.)

#### % on active treatment:

Survey 1 39.3%

Survey 2 45.0%

#### % isolating/shielding with:

Alone Survey 1 18.6% Survey 2 20.6%

With one other Survey 1 45.9% Survey 2 51.9%

With more than one Survey 1 35.5% Survey 2 27.5%

The data from all three surveys has been shared with the clinicians of the UK CLL Forum, and has informed their clinical thinking about treatment and how the step down from shielding can be best managed.

We would like to thank everyone involved in the three surveys.



### Under 60 club

**Following a suggestion from Matt Gibson, we are very keen to mark the unique circumstances we have all faced in recent weeks and months through the creation of a "Memories of Shielding" project.**

#### How would this work?

**Anyone who has a photo or thoughts about life during Covid-19 and how it has affected you, we would love to hear from you.**

**Visual or written contributions (maximum 200 words) are invited and can be sent to "matthewgibson1972@gmail.com". Images may be published online, on the website and/or in future CLL Support newsletters. Although it would be intended that as many contributions are included in the final piece, this of course cannot be guaranteed.**

**We would like to make this project a kind of 'time capsule' record of these difficult times, so get creative!**

## Warning!

It's a very sad state of affairs, but there are many people out there keen to make money fraudulently out of this crisis.

The most recent attempt we have heard of is someone telephoning to say that they are calling as part of the government **'track and trace'** scheme and that you have been identified as a contact. They then run through a genuine sounding briefing before asking for credit card details "because, unfortunately, this is not a free service, but you will receive a testing kit".

This, of course, is nonsense and you should put the phone down and refer the call to the Nation Fraud office at:

<https://www.actionfraud.police.uk/reporting-fraud-and-cyber-crime>

The consumer organisation 'Which?' have produced guidance about another scam which involves downloading a fake NHS tracking app. You can find this information here:

[https://apple.news/APzIEG\\_mAR0esAv7oEuTRYA](https://apple.news/APzIEG_mAR0esAv7oEuTRYA)

Other attempts to defraud include fake face masks and hand gel - especially online - that are expensive and less than useless.

**The advice must be to be ultra careful, suspect anything that doesn't seem right and report it if you can. The words 'stay alert' come to mind!**

### Looking after your mental health

The current situation imposes new levels of stress for many people.

As the survey results above show, there is a substantial number of patients suffering from levels of mental anxiety, and this is something we would like to help with.

**We are developing on our website a number of sources of help and advice about mental well being. The first of which is a very simple series of suggestions and tips for coping with the current situation, known as 'STAND'. This has been prepared by Julie Tanner, a counsellor in mental health. You can find it here:**

<https://www.clisupport.org.uk/information-support/support-for-you/>

We will be posting more resources over time, and if there are any aspects you would like us to cover, please do ask. Ideas and requests can be sent to: [coordinator@clisupport.org.uk](mailto:coordinator@clisupport.org.uk)

### 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.clisupport.org.uk/donate/>

Thank you.



### 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 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 15,000 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/>



### 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 nearly always do.**

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. Contact us at: [coordinator@clisupport.org.uk](mailto:coordinator@clisupport.org.uk)

We look forward to hearing from you.

### Until Next Time

**Be sure to follow us on Twitter, Facebook, and HealthUnlocked for 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.**