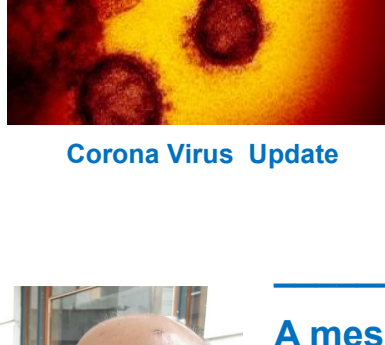
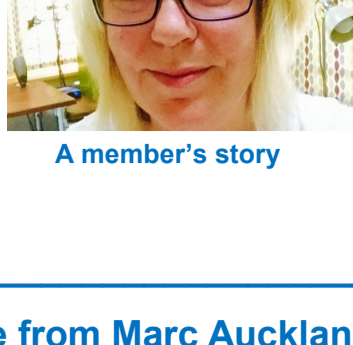




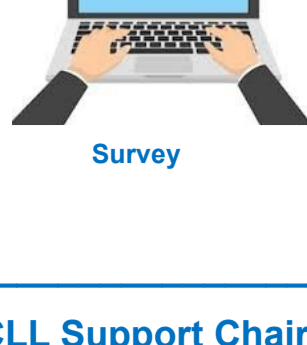
## Our top stories in this newsletter



Corona Virus Update



A member's story



Survey

### A message from Marc Auckland, CLL Support Chair.

Welcome to our latest newsletter.

During these most difficult of times, we will do our best to keep in touch with you and provide the latest information and advice on COVID-19. For this reason, we publish in full the latest advice from the UK CLL Forum, which is the organisation representing CLL doctors in the UK.

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.

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

### Coronavirus

#### Latest update

Advice is changing rapidly, and it's sometimes difficult to keep up. This is a summary of the latest advice prepared by UK CLL consultants. We are printing this in its entirety as it contains updated information.

**UKCLL FORUM** We know that a lot of the information about COVID-19 for the general public does not answer the concerns of people with CLL. The UKCLL forum has produced this information to provide extra advice for CLL patients.

Unfortunately, all CLL patients have weakened immune systems as a result of the CLL (including untreated patients). Treatment can add to this immune weakness. People with reduced immunity are at greater risk of catching & being affected by COVID-19 than the general population. The virus affects the respiratory system, so the main risks are lung infection. There are no treatments or vaccines for COVID-19 so we cannot offer treatments to prevent people from getting it. What we can do is reduce the risk of spreading it. Like the common cold, COVID-19 infection usually occurs through close contact with a person with the virus, via cough, sneezes or hand contact. Washing your hands frequently reduces the contamination risk.

#### The main action you can take is to reduce your exposure risk.

It is safer for people with reduced immunity to avoid hospitals & GP surgeries as far as possible. Doctors are therefore looking at clinic lists to see if people could have a telephone consultation instead. You will be notified if there are any changes to your hospital appointments. We would recommend the following measures to try to reduce your risk of exposure to COVID-19 as much as possible until the pandemic is over.

#### Shielding

As CLL puts you at a higher risk from Covid-19, you are strongly advised to stay at home at all times for a period of 12 weeks. You should not leave your house and should not have contact with any people outside of your household.

Visits from people who provide essential support to you such as healthcare, personal support with daily needs or social care should continue but carers and care workers must stay away if they have any symptoms of the virus. All people coming to your house should wash their hands on arrival at your house and frequently while they are there.

Some people with CLL are well and performing essential functions. It is possible that some patients may not receive a letter from NHS England advising them to shield. The UKCLL Forum strongly advises all patients with CLL to shield themselves, even key workers. Please share this notification with your line manager at work to support your request. If you think you might be experiencing symptoms and have been exposed to the virus, you should follow the same instructions as those for the general public & phone NHS 111; in addition inform your haematology care team. Make sure you tell the person you speak to about your CLL & treatment. If on chemotherapy you should also phone your normal chemotherapy helpline so they are aware.

#### Work

You are strongly advised to stay at home for 12 weeks and should not go to work. You can work from home if this is feasible. Foreign Travel- don't travel and you should avoid seeing any family or friends with a recent travel history abroad for at least 2 weeks after their return. Treatment; chemotherapy & immunotherapy- After discussion with you, your consultant may recommend deferring or delaying treatment if they feel it is in your best interest. Please do not stop any treatment for CLL without discussing this with your consultant or a member of their team first. We want to reassure you that doctors & nurses are doing all they can to ensure that they can continue your care & treatment safely. If you have specific questions about your treatment or hospital appointments please get in touch with your local team.

**If you look after or live with someone who has blood cancer**  
**If you look after or live with someone who has CLL/SLL, you should also consider staying at home for the next 12 weeks and follow the advice here.**

#### Foreign Travel

Don't travel, and you should avoid seeing any family or friends with a recent travel history abroad for at least 2 weeks after their return.

#### Treatment

Chemotherapy & immunotherapy- After discussion with you, your consultant may recommend deferring or delaying treatment if they feel it is in your best interest. Please do not stop any treatment for CLL without discussing this with your consultant or a member of their team first. We want to reassure you that doctors & nurses are doing all they can to ensure that they can continue your care & treatment safely. If you have specific questions about your treatment or hospital appointments please get in touch with your local team

#### False information on Cov-19

A reminder that there is a lot of miss-information and rumour surrounding Cov-19. Some of it goes like this:

"People with coronavirus may not show symptoms for several days, but if you can comfortably hold your breath for more than 10 seconds, you're probably not infected.

You should sip water every 15 minutes to wash the virus into your stomach, where stomach acid kills it, to prevent the virus from entering your windpipe and lungs.

Don't eat ice cream.

If you have a runny nose, you have a cold, not the coronavirus."

You can kill the virus by drinking a few drops of bleach in a glass of water."

None of this is true and the last one could actually be fatal.

There are also a number of 'scams' being perpetrated including emails which seem to come from the NHS, HMRC or other 'official' bodies which offer help or ask for information. It's often difficult to recognize these from genuine emails, so the advice must be for everyone to be extra vigilant at this time.

The best places to get good information are the NHS: <https://www.nhs.uk/conditions/>

And our website: <https://www.clisupport.org.uk/latest-advice-on-covid-19/>

**Angela Steatham is a new member and her situation was highlighted recently by the BBC. This is the transcript from the article and many CLL patients will be able to associate themselves with the sentiments she describes.**

"It would be a real problem if I caught the virus", says Angela. "I have no immune system"

Four years ago, she was diagnosed with chronic lymphocytic leukaemia, which affects the white blood cells that fight infection. The 56-year-old didn't let it stop her work as a psychologist and leadership coach, travelling around the world to work with major companies. But coronavirus changed all that, leaving her just a couple of rooms in her cottage in the village of Llanrhaeadr-ym-Mochnant, Powys, where she can feel safe.

"Now literally the whole world is dangerous to me. And I can't control that. That's what has been psychologically really scary. I know that apart from me staying in one or two rooms of my home everything is a risk," she says.

Her 23-year-old son, Charlie, has moved out to allow her to follow the stringent restrictions. Whenever her partner, Simon Corden, has contact with the outside world, he has chosen to then quarantine himself as a precaution within the house – but away from her – for two weeks before they can spend time in the same room.

They communicate on walkie-talkies due to the weaker mobile phone signal and patchy wi-fi service in their rural location, letting each other know when they need to use the kitchen or bathroom and checking they have cleaned it afterwards.

An extrovert with a busy online life and a shield emoji posted on her Twitter profile, Angela says she's had lots of supportive messages. And she stays connected with older relatives on the phone, but is unable to see their faces as they do not have videophone facilities.

"I think keeping positive is so important", says Angela, "especially in these most difficult of times".

### An important Survey

#### We need your help

We have been asked by CLL specialists to help them gather more information about the spread and impact of the Covid-19 virus on UK CLL patients.

They need this information to enable them to make informed decisions, and we have agreed to help, along with our sister charities Leukaemia Care, Lymphoma Action and Bloodwise, by creating a survey.

#### What we would like you to do

We are inviting all UK CLL patients to take part in a survey, which will be left open for the foreseeable future. If you feel you have the time we would particularly like your input, but the survey is open to all UK based CLL and SLL patients.

**We would be delighted if you feel able to help. Please use this link to the survey, which will give you more information. Completing the survey will take only a few minutes, but will provide valuable information for our doctors.**

<https://forms.gle/3KcPk956GbuXKoTK9>

Thank you

### 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@clisupport.org.uk](mailto:norah.grant@clisupport.org.uk)



### 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 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.**