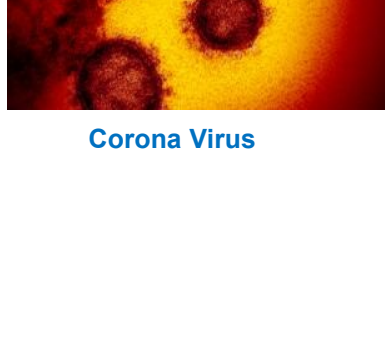
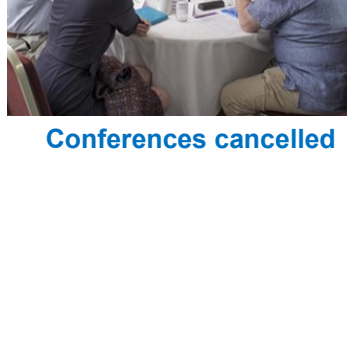


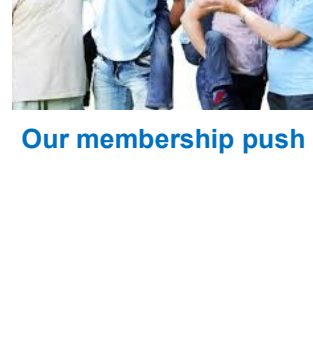
Our top stories in this newsletter



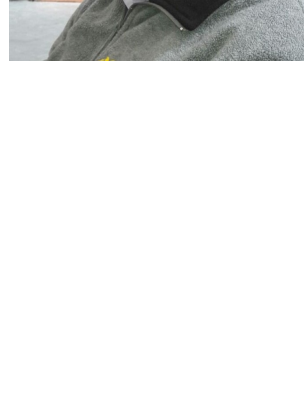
Corona Virus



Conferences cancelled



Our membership push



A message from Marc Auckland, CLL Support Chair.

These are difficult times, indeed, for everyone, but especially for CLL and SLL patients, as we are one of the most vulnerable groups for infection by the Coronavirus (Cov-19).

This newsletter is, therefore, a little more sombre than usual.

We are working flat out to keep patients, their care partners and families up to date with the latest information and advice as it is issued. 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.

As seems to happen more and more, there is a lot of incorrect or just plain false information out there, which we are doing our best to counteract. You will find some examples of the kind of things doing the rounds in this newsletter, but there are many more. The key message is to exercise caution and rely on information only from verified sources, such as the NHS and the BBC.

Thank you for your support, which is more important now than ever, and I wish you all and your family good health.

Marc Auckland, CLL Chair

Coronavirus

Latest update: 19th March 2020

Following the Prime Minister's press conference on Monday, March 16, we have updated our advice on the coronavirus for people affected by CLL and SLL.

If you have CLL you have a weakened immune system. We now advise that you stay at home for the next 12 weeks. This is because the coronavirus can have more serious effects on people with a weakened immune system.

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.

Staying at home - social distancing

Everyone in the UK is being told to limit their social interaction. People with CLL/SLL are advised to be particularly stringent. We advise that for 12 weeks, as much as possible, you:

- Avoid anyone with possible symptoms of coronavirus
- Work from home
- Avoid public transport
- Avoid large gatherings
- Avoid gatherings in public spaces such as pubs, cinemas, restaurants and theatres
- Avoid gatherings with family and friends
- Limit face-to-face interaction with family and friends - if they need to visit, be extra cautious about hygiene, touching and handwashing
- Ask family, friends and neighbours to help with food shopping, or use online services

If you don't have people nearby who can help you get what you need while at home, contact your local council.

Coping with social distancing - what you can do

These measures are severe, but they are necessary to keep everyone as safe as possible, and to help the NHS cope with the cases that do happen.

It can feel like we have no control during this time, but there are things we can do to make it easier and help ourselves to cope better.

Practical things

- Keep following the advice to regularly wash your hands thoroughly (for 20 seconds) with soap and water, or use a hand sanitiser, especially if you've just got home, are about to eat, or have just coughed or sneezed.
- Continue to avoid touching your face with your hands.
- Clean and disinfect frequently touched objects and surfaces in the home.
- Think about the things you need (food, medicines) and contact people who can help with this (family, healthcare team)
- Tell your neighbours about your situation - they may be able to help with getting food or supplies to you
- Look into local charities or local groups in your community that are offering help to people staying at home
- If you are worried about getting supplies for home and don't have anyone nearby that can help, contact your local council.
- If you do need a family member or friend to visit, get them to wash or sanitise their hands when they arrive. **People should not visit if they have a cough or any other symptoms.**

Looking after your mental health

- Spend time doing things you enjoy like reading, cooking or other indoor hobbies
- Eat healthy, well-balanced meals and drink enough water
- Keep active - exercise outside is OK if you are 2 meters away from other people. Look for ideas of exercises you can do at home on the [NHS website](#).
- Open your windows for fresh air, get some natural sunlight or use your garden if you have one. You can also go for a walk outdoors if you stay more than 2 metres from others.
- Stay in touch with family and friends by phone, online or by post. Tell them that you want to be in touch during this time.

False information on Cov-19

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

None of this is true. An easy to read summary debunking of some of the claims can be found [here](#).

<https://www.motherjones.com/politics/2020/03/theres-a-facebook-coronavirus-post-going-viral-claiming-to-be-from-stanford-dont-believe-it/>

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

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

Conferences

Regrettably, all conferences will be cancelled for the foreseeable future. As soon as restrictions because of the Cov-19 virus are lifted we will be planning for the future. We already have agreement from a number of consultants to speak and we will notify all members as soon as we can of the arrangements.

We are working on the possibility of holding a video conference where a leading CLL consultant could give a talk and answer questions. This is in the early stages of development but look out for more details.



It's a family affair!

Well, that's what we would like to make it. To explain. We currently have around 3,000 members and we would like to increase this to a lot more. The reason is simply that the more members we have, the more weight we carry when we are talking to government, the NHS and pharmaceutical companies. Our aim is to give us more clout by increasing our membership to 5,000 by this time next year. Our mission is to support CLL and SLL patients, their families and care partners, and the more members from families we have, the better we can achieve this.

How you can help

If each of our members asked just one family member to join, we would hit our target. It's very easy to join, just go onto our website and fill in the form. Of course, we appreciate that not all members can do this, but if you are able to, it would be a great help.

With many thanks

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.

smile.amazon.co.uk

Contact norah.grant@cllsupport.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

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/>

Trustee Needed!

We are looking for a new trustee. If you think you would like to help us in our work to support patients, let us know.

All our trustees are volunteers and either have CLL themselves or are related to someone with CLL. Trustees attend regular Board Meetings, usually every two months, and responsibilities can vary from helping with conferences to helping with fundraising and IT support. New trustees are given guidance and help from one of the lead trustees until they are comfortable.

If you would like to learn more about this rewarding and interesting work and you feel you may have something to offer, please contact: marc.auckland@cllsupport.org.uk

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 empowered people living with CLL.