

CLL Support Conferences - Your Questions



Have you ever attended a CLL Support Conference? Conferences have always been a core feature that we offer to our members. Here are some answers to questions about our conferences that you may have:

Why do CLL Support still focus on face-to-face Conferences now that online meetings and webinars are more prevalent?

If you attend or have attended a conference you will see why we feel so strongly about how important they are to our members. The feedback we get from them is so amazingly positive and we see the effect they have on attendees.

We have witnessed newly-diagnosed members coming into the room looking apprehensive, their world has just been turned upside down and they don't

know where to turn. After a day at our conference, listening to speakers and mixing with our Trustees and other members:

- They know where to go for help
- They know how to ask for help,
- They know a bit more about what medical help is out there for them,
- Most Importantly, they know they are not alone.

If even a little of the weight on their shoulders is lifted (as it always is) we have done our job!

How do CLL Support decide where to hold them and can I have one near to me?

This is always a difficult balance for CLL Support. There are many factors that dictate where we can hold a conference. The main one is finding guest speakers and making the location convenient to them. Many of our Consultant Speakers have to fit in their presentations as part of a clinic day so will need to get to the venue and then return to their clinics. As they give their time for free, we do our utmost to accommodate this.

We also take into account how people are going to travel to us and do our best to include accessible parking and close proximity to some form of public transport, although we can't guarantee this every time. We try to move around the country, North, South, East and West and regularly try to include devolved nations.

Why are CLL Support conferences free, can't you charge for a ticket ?

From the very beginning of CLL Support we wanted to make sure that financial issues would not prove a barrier to people attending our conferences. We want everyone regardless of their financial status to be able to attend. There are costs involved for our members for parking, travel and in some cases accommodation and we don't want to add to that. We do however welcome donations when people wish to do so and provide donation envelopes and a

card machine at our conferences.

If I come to a CLL Support conference, will I be bombarded with requests for donations of time and money?

Definitely not! As a charity it would be remiss of us not to ask for help at our conferences, but it is always approached with a light touch, and we would never want to make anyone feel obligated to donate time or money. Our primary focus is to give information to our members that helps them to have a positive approach, feel empowered to make their own decisions regarding CLL and to meet others in the same position as them.

What can I expect of a typical CLL Support conference?

We usually start by welcoming our members with refreshments and then we sit at round tables and our Chair says a few words about the charity and its aims along with a bit of current news.

Then we have our usual conference spots throughout the day with regular breaks and lunch provided:

- Patient Story – a patient speaker who talks about their experiences as a person with CLL and how it affects their life
- Consultant Presentation – a consultant who has a special interest in CLL will talk about a pre-arranged topic which will be advertised in our invitation to the conference. They will present a range of information with slides
- Round table Discussion – We will have a group discussion, usually on a topic relevant to the presentations we have seen where people can share their experiences and views. A trustee or volunteer will be on hand on each table to help facilitate the discussion and provide feedback afterwards.

We also have other health care professionals throughout the day presenting on a wide range of topics. These have included Specialist nurses, Mental health advisors and Advisors on health and fitness.

Each event has a unique focus but we always try to pack in as much help and advice on the day as we can.

Is it safe to attend a CLL Support conference with other people?

That is a question that we can't answer for everyone. We have listened to the consultants and their advice is that only individuals can assess their own risk. You are welcome to wear face masks, hand gel is provided, and we have spare masks for anyone who needs one. The rooms are usually quite large and airy, and we have a coloured badge system in place for anyone who requests extra space and less contact. We also ask attendees to take a lateral flow test the day before attending and if you are unwell, we ask you to cancel and watch online. We make it as safe as we possibly can. Remember most of our Trustees have CLL and they regularly attend the conferences and feel safe doing so.

Are anymore CLL Support conferences planned for 2024?

We are planning to hold three more conferences this year:

York – June 18th 2024

London – September xx 2024

Edinburgh – November 2024 (date TBC)

Will you still be running webinars now that face to face conferences are back?

The quick answer is yes. Over lock down we started to familiarize ourselves with this format and it has worked very well for our members. For those that are unable to travel it is good to have a mixture of face to face and online. We live-stream our conferences and have now started to have 'virtual' discussion groups for those who want to chat to others while the group discussions are taking place at the face-to-face conferences. We will continue to mix the two formats but would like to stress that if you can attend face to face give it a go as the connections you can make there can be invaluable.

Now it's our turn to ask you for a little help if you attend one of our conferences:

1. Please only book if you are sure you can attend. You don't need to 'place mark' just in case as we usually have enough spaces to accommodate everyone who wants to come (we fully understand that there may be unexpected appointments, or you may be unwell on the day though).
2. Please let us know at the earliest opportunity if you are unable to attend after booking. Most venues need to know at least 2 weeks in advance of cancellation, and we still pay for un-used places.
3. Please be respectful of other people's choices regarding their own personal safety, there may be people who wish to wear face masks and are very cautious. We are all there to feel confident and comfortable and we all have different approaches.

And finally, some quotes from members who have attended our face-to-face conferences

"Useful topics and excellent speakers, thank you!"

"I learned a lot about treatment and the main speakers were excellent"

"Something for everyone, patient, supporters and family"

"Group discussions were great, meeting others with CLL"

"Meeting and learning from like-minded people"

"So interested to hear peoples journeys with CLL"

"Friendly and great to meet others"

"Venue and presentations were excellent, what's not to like!"

"This is the first time I have met anyone else with CLL!"

"Made a confusing subject make sense"

"Good balance between getting and giving information"
