



Report on the London Conference, 21st November 2019

"I enjoyed Dr Patten's talk, so much info, so nicely put. CNS were a joy to listen to"

"Emotional well-being, clinical personnel presentations and patient presentations were best!"

Report Introduction

Above is a sample of the highlights from the 109 members who attended the sixth and final conference for this year. It was held at the ETC Conference Venue! Drummond Street, Pimlico, London. Key speakers were:

1. Members' Stories – Paul Newis and Sean O'Neill.
2. Colin Russell, Specialist in well-being and life skills
3. Dr Piers Patten, Consultant Haematologist Kings College London and Clinical Senior lecturer.
4. Karen Stanley, Haematology Advanced Practitioner Clinical Nurse Specialist
5. Ellie Wellving, Lymphoma Clinical Nurse Specialist, Kings College Hospital
6. Marc Auckland, CLLSA Chair. Association Update.

The conference included a pilot session on mental wellbeing developed from the presentation by Dr Katherine Hicks and her team from Addenbrooks. This was designed to help attendees understand the three-emotion system, its impact on us physiologically and psychologically and how to better manage the emotional impact when stressed.

The report is based on attendee feedback, it is prepared for the speakers, CLLSA trustees conference facilitators and volunteers, attendees, LeukaemiaCare and Lymphoma Action representatives and all interested in CLLSA Conferences.

Videos and slides of presentations have been mounted on the CLLSA website.

The report contains:

- What worked well, based on feedback
- What could have been better, based on feedback
- Summary of sessions
- Appendix 1. Composition of attendees
- Appendix 2. Analysis of feedback form returns

- Appendix 4. Conference Programme

What worked well

- Guest speaker content and opportunity for Q & A
- Member stories and mental well-being session
- Meeting fellow members and morning interaction

What could have been better

- More time
- Use mic for Q & A and inductive loop please
- Some felt uncomfortable with mental well-being session

Feedback summary

38% of members (39 out of 103) completed the feedback forms with only 5 first time conference attendees completing a form. The Venue and facilities were rated highly, as were the presentations. All bar two attendees rated event materials good or excellent. Lowest average score was attributed to group discussion with 4 people outside the good or excellent ratings. Attendees feedback rated the presentations as excellent or good. All written feedback is listed in appendix 2 with illustrative quotes included in the commentary below.

Patient Stories

We opened the conference with the traditional members' CLL stories. Paul Newis spoke about his unexpected diagnosis through a sudden call at home from the hospital to come in straight away. He shared the shock discovering he had gone to the Cancer unit through to accepting his diagnosis and living to date with no treatment but managing the 'watch and wait' He explained about his changes to lifestyle with attention to hygiene from home to dining out and his insistence that food is piping hot.

Sean spoke candidly about his journey from the shock of diagnosis at an early age, its emotional impact and his concerns that he may not see his young children grow up. He talked through monitoring and initial FCR treatment leading to a remission. He then spoke about secondary treatment required and the fight to get Ibrutinib as advised by NICE policy rather than the repeat FCR regime as initially offered. Sean shared the mental stress of the disease and need for support.

Both acknowledge the value of having a dedicated charity to support CLL patients and families and to campaign for better treatments. Please watch the video clips on the website to see the Paul and Sean share their stories.

Feedback included: *'Best was members patient stories', 'Paul and Sean were excellent'.*

Mental Well-Being

Colin Russell and Marc Auckland presented a new session on mental wellbeing. This was driven by member feedback and based on the core 3 emotions model presented at the Cambridge Conference by Dr Katherine Hicks and her Psychology team from Addenbrooks. The aim is to develop the session and content in order that it can be used on future conferences and potentially as a session local groups could run. The vision is for mental wellbeing materials and resources would be built up and available on the website. The session aims were:

- To explain the 3 emotional systems model (Threat, Drive and Soothing) that drives the human physiological and psychological reactions to stress and threat.
- Understand how to assess your emotional state at any given time using the self-assessment 'Living Scale'
- Explore how you can help manage and balance the three emotional systems
- Practice some simple techniques and tools to help with emotional wellbeing

Marc explained the three emotional systems model using his personal experience and reactions to his own CLL diagnosis. Colin Russell invited Marc's wife Breda to the front to demonstrate the 'Living Scale' as a partner of a loved one with CLL. Colin then led the audience through some tools, techniques and questions to explore their own experience of the model as a CLL patient or supporter of a loved one with CLL. There were short exercises and whole audience Q and A after each exercise. The slides used and video of the session are loaded onto the website.

Feedback included: *'The well being session was very good and missing from previous conferences. 'Best session was the Emotional well being session'. 'The mental well being session was a bit intense, a lot to take in over a short time.'*

CLLSA Update

Marc Auckland closed the morning programme with a CLLSA update.

Marc started with an update CLL in the UK, number of cases, where CLL is ranked in terms of common cancers and morbidity. He stressed what an exciting year it has been for the members charity, with new trustees Norah Grant, Lewis Troke, Michael O'Neill joining the board while saying a fond farewell to David Innes (departing Chair) and Olga Janssen who had been key to the current structure and style of the much valued conferences.

Marc then listed some of the key achievements including the new website, new logo, the refreshed member booklets and leaflets through to the launch and growth of the under 60's group, managed by Norah Grant. He also announced we have over 3,000 registered members now. We would like many more CLL patients and their partners to join to increase our lobbying and influencing presence further.

Marc went on to share examples of Advocacy led by trustees and champions all on a voluntary basis and aimed to ensure members had access to the best treatments and source available. Marc then focused on the future of the charity. The need to raise awareness in all GP surgeries and Hospitals, at the moment only 8% of relevant consultants and 4% of Nurses are aware of the charity. Those specialists that do know the charity value its resources and

share with patients. We need to raise exposure so all have the opportunity to join and benefit. The new website and development work so far has received much praise from current members on Twitter, Facebook and the HU CLL forum.

The five year strategy and next year's business plan are under review and will be launched shortly. Marc closed by thanking all for fundraising activities as funding is critical to keep membership free and maintain the current level of activity. He pointed out that we will be launching a wills service shortly and that a member, through a codicil in their will, paid for the review and relaunch of the new modern website. He asked for all to let us know of any fundraising activities planned so we can promote through the website and e bulletins. Once again, the briefing and slides with the details are on the website.

Dr Piers Patten

Piers is a Consultant Haematologist and Clinical Senior Lecturer based at Kings College and Guys and St Thomas hospitals in London. Piers presentation was split into three sections with a short Q and A between each one.

1. Treatment of CLL in 2019

Piers emphasised modern diagnosis is now based on trends in results based on a range of key markers. At the recent Edinburgh CLL specialist forum, seven key indicators were agreed to be the core universal indicators for CLL diagnosis and staging. He then moved on to share the key drugs used today to treat CLL and how they are selected, administered and work.

Key factors to consider in treatment options are speed of disease progression and profiling such as 17p deletion and TP53 mutation which impacts on the effectiveness of various treatment options. NICE and the NHS set guidelines that select the treatment pathways generally. Piers did say if you are working and have private or personal health care insurance it is worth seeing if Cancer treatment is covered which could mean you have a wider choice of treatments to select from. He also mentioned seeking a CLL specialist opinion when treatment is required and exploring what clinical trials are open and available which may give you access to more treatment pathways.

Piers then moved on to explain the treatment options for relapsed patients especially the use of the newer drug regimes. He emphasised at all treatment points the patients views and preferences should be heard and impact on the pathway chosen, He pointed out the pros and cons of Ibrutinib versus Venetoclax with Rituximab. No right or wrong but need to understand their profiles, the nature and history of your CLL when deciding on the best treatment for you. We then had a short Q&A.

2. CLL Supportive Care in 2019

Piers started by advising what should be discussed and agreed at your first watch and wait session and then what should happen at subsequent visits during the active monitoring period. He explained the aims of the initial consultation and what advice he and the care team give at the start. Piers also stated the information he sent to the Patients GP. This would include recommendations on the vaccinations required and to warn that the patient may need antibiotics to fight infections. The first visit should include who the Clinical Nurse Specialist is and how to contact them for advice and

support. Piers also recommended patients should connect with the CLLSA, an excellent source of resources, support and information. He finished this section emphasising the dangers of infections and need for vaccinations and antibiotics when needed. The second short Q & A was held.

3. Best way to follow up CLL in 2019

In this section Piers explained the challenges and variety of supportive care around the country. The overall aim was to find the most cost effective support. There was an increasing pressure to move the support in watch and wait back to primary care and the GP. Piers explained the process at Kings currently and summarised how the current four pathways across the UK operate:

- Discharge to primary care
- Remote monitoring only
- Remote monitoring with remote consultation
- Remote monitoring to support traditional clinics

Piers asked for a show of hands to indicate preference. The greatest show of hands by far was for the fourth, remote monitoring with traditional clinics. This followed the final short Q & A. A key concern was impact of Brexit in access to and development of new drugs. The vast majority of attendees wanted the UK to continue to be part of the current European Medicines agency. That way we are still seen as part high value large demand market, like the US. Thus, we would still be part of big priority markets for pharmaceuticals to target develop and supply latest drugs to.

Feedback included: *'Dr Pattens presentation was interesting, helpful and informative'*.
'Fantastic presentation by Piers.' Piers was very good, picked up some new tips.

Karen Stanley

Karen is an Advanced Haematology Nurse with over 20 years' experience, 12 as a CLL/Lymphoma Clinical Nurse Specialist (CNS) and works at Guys hospital. Karen started by explaining what is a Clinical Nurse Specialist (CNS). They focus on a particular genre of disease and their aim is to support patients and their family to ensure the best quality of care and health outcomes possible. Where possible they try to equip patients and their families to help themselves and self-support. This starts with education on diagnosis, treatment aims, potential side effects through to encouraging life style changes. They make sure the patient is involved throughout the treatment pathway, try and counsel and support where possible. Karen went on to emphasise the CNS should aim to ensure all the information is tailored and understood by the patient and family. The challenge for the CNS is to move away from one size fits all to tailored support and education that fits the patients' needs and capabilities.

Ellie Wellving

Ellie is also a CNS with 12 years' experience including CLL treatment working in Kings College. Ellie took over from Karen going on to explain about lifestyle, diet and immunisation. Ellie started by recommending a balanced diet, what to avoid or reduce intake of and what foods are beneficial. She cautioned on alternative remedies especially

if ion treatment as they may have an adverse effect on the drug regime. Ellie advised that you should always consult the CNS in these matters. Ellie also recommended exercise to maintain fitness but cautioned about strenuous exercise if you are neutropenic or have low platelets. If you become unwell, always consult the GP if on Active Monitoring (Watch and Wait). If on treatment follow the instructions on contact guidelines provided to you by the consultant and/or CNS. Emotional wellbeing is equally important, if stressed, share with the CNS. Talk with your trusted friends and family. Both Karen and Ellie also promoted the services and resourced of charities such as CLL Support and Leukaemia Care. If you are working and treatment or disease is impacting on your ability to work and financial circumstances, talk to your CNS they can often point you at agencies that may be able to help. Ellie then spoke about Intimacy, if your Libido is affected, talk to the CNS. She advised against getting pregnant while under a treatment and spoke of help if you are incurring heavy periods. Ellie concluded with Immunisation recommendations, travel advice and considerations for minor surgical procedures such as a tooth extraction.

Karen and Ellie as well as Piers then stayed to answer questions from the floor.

Feedback included: *'CNS's were informative and evidence based'. 'CNS was a joy to listen to'. 'Insight into CNS was one of the best parts.'*

Donna Munro from CLLSA's sister charity LeukaemiaCare and Rona Eade from the Lymphoma Association were present providing information and literature to members.

Video Clips to welcome attendees at the start of the conference

A series of video clips of CLL patients as well as a short talk from Professor Fegan of Cardiff University were shown while people arrived and awaited the start of the conference. This was well received as it helped provoke conversation and interest for early arrivals.

Meeting fellow members

Attendee were allocated table groups based on their post code to try and encourage local contacts where possible. They sat with partners or friend to help encourage pairs discussions during the emotional well being session.

Feedback included: *"Good one to one conversation', Best was opportunity to meet other people', Glad I managed to meet a trustee I first spoke to via the helpline', 'would have been good to have more time to engage with facilitator'.*

Organisation and timing

The conference agenda was busy and involved the introduction of a new conference element – The emotional wellbeing session. Positive feedback was received for the information in the packs such as the jargon buster.

Table seating and venue

Venue and facilities received very positive feedback (93%), though some concern about too few comfort breaks and need to make better use of roving mikes. Table seating and space was an improvement on last year with more space available due to reduced staging. There were no concerns this year about cramped dining seating.

Feedback included: *'Air con was sometimes too hot or cold', 'refreshments good', 'Well run venue'.*

103 out of 122 attendees booked turned up. The 5 no shows who did not call to let us know they could not come have been emailed to ascertain they are well and did not show because of an issue with the conference organisation, illness or accident.

Marc Auckland
4th December 2019

Appendix 1

We received high satisfaction scores for all five aspects measured: advertising and registration; location and facilities; event materials; group discussions; presentations. (Appendix 2)

Composition of Participants at the London Conference Nov 2019

Attendees:

Total places booked	122
Total in attendance	103
Cancellations before the day	23
Cancellations on the day and no show on 21/11/19	14 5
Waiting list, not accommodated	9

Late cancellation/no show 19/122 = 16% Cancellation and no-show rates averaged 11% in 2016 and 2017, and rose to 14% in 2018. The 5 no shows have been contacted and responded with apologies. With adequate notice we are able to reallocate relinquished places. We do our best not to turn anyone away.

First time member attendees	10 (17%)
Returning member attendees	43 (74%)
(Unknown status members	(5) (9%)

Total members 58*

**Information from feedback forms. Some members did not complete a feedback form.*

For comparison, first timers were 51% overall in our 5 conferences in 2017 and 49.5% in 2018 (4 conferences).

Trustees: MA;BG;NG;RB;LT;FM;GW;MO	8
Healthcare Professionals:	
Clinicians: SM	3
Charity Reps:	
Leukaemia CARE:	
Lymphoma UK	2

Analysis of returned feedback forms from participants

Satisfaction levels for each aspect measured at London, 21 Nov 2019

	Not so good	Fair	All respondents			Total responds	%*	% 1 st time attend	% 2 nd plus attend	% 2018 all 4 conferences
			Average	Good	Excellent					
Advert, register	1	0	4	22	29	56	88%	50%	50%	50%
Location, facilities	0	0	0	18	38	56	94%	70%	96%	67%
Event materials	0	0	3	28	25	56	88%	50%	96%	40%
Group discussions	2	3	5	25	20	55	81%	40%	94%	34%
Presentations	0	0	3	17	35	55	92%	80%	95%	59%

Notes

1. %* Percentages are calculated by multiplying “not so good” by 2, “fair” by 4, “average” by 6, “good” by 8 and “excellent” by 10. The sum is divided by the number of respondents, to give an average out of a maximum possible score of 10. This figure is multiplied by 10 to give a percentage score. Figures are rounded to a full % figure.
A score of 80% would indicate overall: “good”.
A score of 100% would indicate all respondents rated it “excellent”.
2. There were 57 completed feedback forms, from a total of 103 attendees i.e. 57% return. We aim for a minimum return of 60% to be confident of findings. Trustees, (8) CLL coordinator (1) and visiting speakers (4) do not complete a feedback questionnaire. Charity reps (2) sometimes do.
3. Of the 57 completed feedback forms, 4 did not indicate whether they were first time attendees. Of the remaining 53 returns, 10 were from first-time conference attendees, i.e. 10%. This compares with; Newcastle (July 2019) 66% Bournemouth (May 2019) 71%; London ((November 2018) 36%; Bristol (July 2018) 69% Birmingham (May 2018) 51% Leeds (March 2018) 51%; London (November 2017) 43%; Oxford (September 2017) 69%; Leicester (July 2017) 28%; Liverpool (May 2017) 53%, and Cambridge (March 2017) 60%.

Most liked - Feedback Comments

57 of respondents commented, often giving more than one factor as best. There was hardly any difference between first timer attendees’ and returners’ positive comments. As at other CLLSA conferences, clinical presentations, meeting other CLLers and sharing experiences were the aspects most liked.

Presentations Feedback (what was best)

13 respondents gave positive feedback on the two members stories.

Members stories were best

CLL stories

Member stories

Members CLL stories

The patient stories were very interesting

Patient presentations

Members CLL stories
Hearing personal stories
Paul Newis and Sean O'Neill excellent
Members CLL stories
Member CLL stories
Members stories brilliant
Good Stories

13 respondent gave positive feedback on the wellbeing session

Talk was informative and interesting
The well being session, very useful and missing from previous conferences
Emotional wellbeing
Mental well- being session
Mental wellbeing
The session on mental health and well-being
Living with CLL – mental well-being session
Mental well-being very useful for all
Mental well-being session helped me to reflect
Mental well-being session particularly interesting
Session on mental well-being very good pitched at the right level to understand
Time given to mental well-being
Managing Stress

24 respondents identified the expert speaker as the best aspect of the conference.

Key note speaker was very interesting
Dr Patten was very good.
Presentation by Scott Marshall.
Dr Patten's presentation was best.
Enjoyed the whole day and in particular the presentation by Dr Patten.
Consultant was best.
Piers was very good, picked up some new tips.
The very open and honest presentation by Dr Patten including how new treatments are accessed and introduced.
Dr Patten's contribution was best.
Update from specialist in field on current CLL diagnosis and management.
Piers statements on the role of finance and the politics of care was best.
Afternoon session with Dr Patten was best.
I enjoyed Dr Patten's talk, so much info, so nicely put.
Specialist speaker was best.
Talk by Dr Patten was very informative and encouraging.
The presentations in the afternoon were really interesting and informative however they were very long, prefer a quick summary and handouts with discussion.
Dr Patten was excellent.
Piers informative talk.
Piers Patten – solid info although sometimes hard to hear, hard to read some slides and maybe hard to understand for those not familiar with the whole CLL scene.
Dr Patten's presentation interesting, helpful and informative.
Excellent presentation by Dr Patten.
Dr Piers Patten talk.
Fantastic presentation by Piers Patten.
Dr Patten's engaging and professional.
Dr Patten's Presentation.
Dr Patten was very down to earth and helpful.
CLL treatments
Opportunity for update on CLL treatments

Specialist speaker Q & A

9 respondents gave specific positive feedback on the CNS session

The CNS's were informative and evidence based

Medical presentations

CNS presentation

Clinical personnel presentations

Nurses great

Nurses

CNS were a joy to listen to

Insight into CNS

Professionals Presentations

Conference facilities, organisation and general comments

38 respondents gave non session specific or general positive comments

Meeting other people and hearing their journeys

Learning what should happened and what we should do

Communication, awareness and the ability to meet other CLL sufferers.

Information was very helpful

All very informative

Networking and speaking with other delegates, sharing experiences

I really enjoyed the environment and people were so friendly and communicative making you feel at home

Meeting other people with CLL was great to finally talk to others

Lectures and meeting other people

Being more informed and meeting others with this condition, Norah was very helpful and welcoming

Meeting other patients and supporters and all the talks were really informative and interesting

Opportunity to hear about and meet other people's CLL journeys

Good one to one conversations

I am glad I got to meet a trustee who I spoke to 6 months ago when I first called the helpline

Being with people who understand what we are going through

Interactions, networking, content

Opportunity to meet with other people, share experiences, key note speakers in the afternoon

Talking to fellow CLLers on W and W, not ready for support group but will go for it when I am

Variety of speakers, all very good

All morning best

Overall a very good day

Information, treatment options, talking to others with CLL

Meeting others with CLL Jargon buster sheets

Meeting others with CLL

Informative and reassuring

All in balance and all aspects relevant and interesting, group discussion and keynote expertise

Experiences, talk by professionals and table interaction (more time would be good)

Awareness and more detail information

Catering great

Meeting other people, shared stories

Extremely informative

Well run event especially Marc Auckland

All good

Nothing worst, a very informative day, thank you

Refreshments

Nothing worst thank you Marc and the team

Extremely well organised thank you All very much

Well run event especially Marc Auckland

Least liked

25 of the 57 respondents left this question blank or simply wrote “nothing”, “N/A” or “all good!” type comments

Presentations

14 respondent gave negative comments predominantly concerning the well-being session.

I would have preferred the afternoon sessions in the morning as they had a lot to take in and I had become very tired

I didn't get much from the well-being session

Colin Russell rather too energetic

Did not find the wellbeing session particularly useful although I appreciate its value to others, Although SLL was mentioned in some talks, its implications for monitoring options was not acknowledged or identified

CNS- direct reading from information slides. Difficult to find the right mix for W&W patients v post treatment

It really wasn't where I was, the mindfulness element in the morning was too dominant.

Afternoon nurses

Morning in mood management

Group exercise in the morning was perhaps too exposing re diaries. Soothing etc, needs a rethink perhaps

The mental well-being session I felt were a bit intense, a lot to take in over a short time

Sorry but I found the red measuring tape a bit patronising, Piers over filled slides, if not time to read them why show them?

Living with CLL, physical well-being, CNS role very passive and felt like just being talked down to us, better if audience is involved in the talk

Mental well-being – Colin Russell presentation not at all helpful! But rather banal, I could not engage at all, although that is probably me

The well being session, not my thing, sorry!

Conference facilities, organisation and general comments

15 respondent gave negative comments, key themes were more breaks, heat in room and not hearing questions

Less chance to meet people around the table

It was all good but more time for the facilitators to engage with table members would be good

Need a toilet break in the afternoon

Air con being too hot or too cold, had trouble hearing speakers

No coffee break

Absence of induction loop, do not let this happen again

I wish it could last longer

Nothing I did not like, would be good to have a speaker from a specialist travel insurer to explain process

Too warm in room, difficult to fight tiredness

Questions from audience not always hearable, please use mic

Lack of comfort breaks

Odd having speakers at far right of room, room very hot

Quite a long time sitting between break

The lunchtime food, fish course

Not being able to hear some of the questions asked by the audience due to no wandering microphone

Appendix 3

CLL Support Association Conference – London

Thursday 21st November 2019

Victoria, 1 Drummond Gate Pimlico, London SW1V 2QQ

See website for details: <https://www.etcvenues.co.uk/venues/victoria>

10.00 a.m.	Arrival, refreshments, meet table companions	
10.30 a.m.	Welcome and introduction to the day	Marc Auckland
	Trustee conference host introduces self and agenda	
10.40 a.m.	Members' CLL Stories	
	Senior Manager BBC (Retired)	Paul Newis
	Chief Reporter Times Newspaper	Sean O'Neil
11.00 a.m.	Living with CLL – Mental Wellbeing	
	How to manage stress so you enjoy life despite CLL. Coping strategies, tips and exercises.	Colin Russell and Marc Auckland
12.30 p.m.	Association Update	Marc Auckland
	Briefing on your association highlights, challenges priorities for the future and how you can help.	
12.45 p.m.	Lunch	
1.30 p.m.	CLL - What should I know now that I have it, what treatments are on offer and what might the future hold?	Dr Piers Patten MB ChB MRCP FRCPATH PhD
	Dr Patten is a UK-trained clinical haematologist and has been in his current position since 2014, where he provides clinical services for the King's Health Partners lymphoma service. He is particularly interested in chronic lymphocytic leukaemia (CLL), a common lymphoma subtype, which was the subject matter of his PhD undertaken at King's College London. He is very actively involved in clinical trials for CLL and other lymphomas through full participation in the National Cancer Research Institute portfolio and commercial studies.	
3.00 p.m.	Living with CLL – Physical Well being	
	Role of the Clinical Nurse Specialists (CNS). Advice from CNS on the frequently asked questions and their answers.	Karen Stanley and Ellie Wellving (CNS)
3.55 p.m.	Conference Wrap up and Close	Marc Auckland

CLL Support Association

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