

2026 CLL Support Patient Survey – a summary of the results

This is the third biennial survey we have completed. We again asked our 3000+ members to complete a survey to enable us to:

- understand the current experiences and concerns of those with CLL and SLL
- share the findings and represent the views of the UK CLL and SLL community with the UK CLL Forum of specialists, researchers and scientists
- provide the services and support members of CLL Support most value
- compare the results with the 2024 and 2022 surveys

This year we asked partners and family members to complete a separate dedicated survey to enable us to understand their needs better. The links to the surveys were shared through an email invitation to all our members and via our newsletter, website, Health Unlocked, social media and our Under 60s WhatsApp group. At the end of this document we provide a recap of interesting findings and our proposed action points.

Who replied?

- We received 894 responses from people with CLL or SLL (2024, 1,009; 2022, 656)
- 96% of respondents had CLL and 4% SLL (2024, 3%)
- 57% of responses were from women reflecting CLL Support's membership, although more men than women are diagnosed with CLL or SLL.
- When diagnosed, 47% were over 70 (2024, 43%), 36% between 61-70 (2024, 36%) and 17% were under 60 (2024 21%).
- Responses came from members across the UK.
- 28% of women and 17% of men were living on their own (this was a new question in 2026)



Current situation

- Over half the respondents (65%) had been diagnosed over 5 years ago (2024, 64%).
- 54% (2024, 55%) were on active monitoring (watch and wait), 24% (2024, 26%) on treatment and 22% (2024, 19%) in remission (on active monitoring after treatment).
- 74% reported some comorbidities: 30% mentioned hypertension, 24% arthritis and 16% other cancers.

Diagnosis

- The vast majority of respondents (63% - 2024, 67%) had been diagnosed incidentally through a routine medical appointment for another illness or condition. Only 18% of respondents (2024, 18%) had been diagnosed with CLL/SLL because of specific signs or symptoms.
- The majority were diagnosed in the last ten years but some had had CLL/SLL for over 30 years.
- 26% (2024, 45%) of those replying indicated they had no other health conditions. (This year we gave respondents the opportunity to tick the most common conditions that had previously only been covered by 'other'.)
- The scores given for various aspects of the initial diagnosis were between 6.1 and 7.6/10. How the diagnosis was delivered was felt to be the least satisfactory aspect.

- Men were more satisfied with most aspects of their diagnosis than women.
"CLL is a very individual experience and I remember at diagnosis I did not understand this, that CLL is genetically diverse. Everything I read about CLL I thought applied to me and it took a long time to understand the wide variation."
- The wider aspects of CLL and SLL, such as nutrition and exercise, had been discussed more with those diagnosed in the last 5 years.

Current signs and symptoms

- Fatigue was mentioned as an issue by 60% (2024, 58%; 2022 56%) of the respondents. Pain (joints, bone) – a new category in 2026 - was mentioned by 32%. 27% (2024, 26%) mentioned bleeding or bruising easily with slightly lower numbers mentioning getting infections often (21% - 2024, 25%), swollen glands (19% - 2024, 21%) and night sweats (16% - 2024, 17%).
- Fatigue was mentioned by 53% of respondents on active monitoring (2024 58%), 63% of those on treatment (2024 62%) and 62% of those in remission (2024 52%).
"Fatigue is most debilitating aspect for me and I don't feel it is taken seriously. Never suffered with fatigue in my life before!!!"
- Women were more likely to experience fatigues, bleeding/bruising, swollen glands headache and pain: men were more likely to report no signs or symptoms.
- More than 50% experienced the most common symptoms on a daily basis. Getting infections was most described as occurring on a monthly basis.
- In general women rated their symptoms as having more of an effect on their daily lives, particularly night sweats, swollen glands and swelling/discomfort in tummy.



Impact on quality of life

- From both a physical and emotional perspective, CLL/SLL impacted the quality of life more for those under 70 than those over 70.
- Respondents were asked how much their diagnosis of CLL/SLL had affected their quality of life, from a physical perspective (men 4.54/10, women 5.55/10) and then from an emotional perspective (men 5.07/10, women 6.07/10)
"The mental side of CLL is the hardest to deal with, the not knowing what the future has to hold."
- Respondents on active monitoring rated the lowest impact on their quality of life.



Issues around treatment

- Virtually all care for those on treatment or in remission is provided in hospitals and 70% of those on active monitoring are seen in hospitals (2024, 67%).
- There are a similar proportion of face to face consultations as in 2024.
- Respondent satisfaction with the support received in 2026 was similar to that in 2024 apart from GP nurses. Scores ranged from Consultants (8.1/10), Clinical Nurse Specialists (7.9/10), support from GP nurses (6.4/10, 2024 8.0/10) and GPs (6.4/10).
"Very little support from GP. Just a Full Blood Count every 12 months, with no feedback other than online test results."

- Respondents on Active Monitoring feel less well informed about treatment than those on treatment or in remission (from 6.3 to 8.4 and 8.3/10) but that is not unexpected.
- Of those on treatment, by far the most common was acalabrutinib (35%). This year we also asked what therapies were being received. The most common by far was 'acyclovir (or other antivirals)' which 53% of those on treatment were receiving.
- Of those who had received treatment, 61% had had a single line of treatment.
- There were no real geographical differences: only that acalabrutinib was prescribed more in London and the South East than in the Midlands and Zanubrutinib was prescribed more in the Midlands than in London and the South East.
- A small proportion of respondents on active monitoring (3%) and in remission (9%) reported they were currently receiving a preventative therapy.

Vaccinations and Covid

- Respondents scored an average of 7.7/10 for how well informed they felt about which vaccinations are important.
- 91% had had a Flu vaccination in the last year (2024 90%), 69% Shingrix (2024 54%) and 30% the new RSV vaccine despite the latter only being available on the NHS to those aged 75-79.
- 78% had been vaccinated against pneumonia with an even split between pneumovax23 and prevnar where respondents knew which they had had.
- 82% of the sample had been vaccinated against Covid in the past 15 months with the numbers increasing from 59% in spring 2025 to 67% in autumn 2025 and 77% in spring 2026.
- The mean score for how well informed respondents felt about which vaccinations are important increased to 7.7/10 in 2026 (7.1/10 in 2024; 7.0/10 in 2022).



Apps and wearable devices

- This year we asked respondents about their experience of and interest in apps and wearable devices
- While only a minority of respondents currently record how they are feeling, either through a written record or using an app, 45% would be interested in using an app to do this.
- 18% already use technology to manage their life with CLL or SLL and a further 47% think it could be helpful.
- 30% use a wearable device regularly to capture data on exercise or health measures and 5% use one occasionally: a further 36% would be interested in using one.



CLL Support

- 91% of members felt that CLL Support understands their needs very/quite well, 69% feel very/quite well supported by CLL Support and 90% are very/quite confident that CLL Support represents the interest of people affected by CLL and SLL.
"I don't always use the services of CLL Support but I know it's there when I need it and that is so important."
- 85% of respondents knew they were members of CLL Support (2024, 83%).

- Respondents were asked about their awareness of the various services CLL Support provides and whether they had accessed them. The greatest awareness was of the website, webinars, conferences. Health Unlocked CLL Forum and newsletters.

“CLL is such a weird disease, to be able to walk into a conference room full of people who “get it” was a huge relief.”

- Men were more likely to access the newsletter and women forums and Support ACT.
- Extremely high levels of satisfaction were reported across all the services offered and this was the case for those at all stages of treatment.

“Very grateful to have access to CLL Support and all the resources that it provides - the clue is in the name!”

Next steps

The Trustees are extremely grateful to the 894 individuals who completed the survey. Thank you so much. Without you we would not have all this really valuable information. We will be sharing the full results with all those who took part in the survey and requested a copy and will be presenting the results to the UK CLL Forum. We will also be considering what further actions to take in response to this immensely helpful feedback. The Trustees plan to repeat the survey in another two years.

Some interesting findings

- More men are diagnosed with CLL/SLL but more women completed the survey and are members of CLL Support
- 96% of respondents had CLL and 4% SLL: an increase from 3% in 2024
- 28% of women and 17% of men are living on their own
- The vast majority of respondents had been diagnosed with CLL/SLL incidentally: less than 1 in 5 had been diagnosed through visiting a GP with CLL/SLL signs/symptoms
- How the diagnosis was delivered was the least satisfactory aspect of diagnosis
- The majority of those with CLL/SLL on active monitoring and virtually all those on treatment or in remission are seen at hospital rather than by their GPs
- CLL treatment guidelines were updated in 2025 so that wider aspects of CLL are discussed at diagnosis; this is beginning to happen with more recent diagnoses
- Fatigue remains by far the biggest side effect, with pain (joints, bone) now being mentioned by a significant number.
- CLL/SLL has a greater impact on the quality of life from both a physical and emotional perspective for those under 70
- Men are more likely to report no signs or symptoms, were more satisfied with most aspects of their diagnosis and felt CLL/SLL had less impact on their quality of life
- Respondents were more satisfied with those who supported them in hospitals than those in GP practices
- Over half of those on treatments are also receiving a preventative therapy
- The proportion receiving vaccinations has increased since 2024
- Overall respondents are in favour and open to apps and wearable devices to help them manage their CLL/SLL
- While there are some differences in the CLL Support offerings men and women access, satisfaction with what CLL Support offers is very high

In response to the survey findings the Trustees are planning to:

INFORM

- encourage those with CLL and SLL to join CLL Support and access our information
- continue to provide high quality up-to-date information on our website and through our newsletters, in line with our PIF Tick accreditation
- continue to promote our CLL Support Booklet, Vaccinations Passport (produced with the UK CLL Forum) and other publications
- encourage those with CLL/SLL to have the vaccinations that will benefit them

SUPPORT

- explore whether there is more support we could offer those who have SLL
- continue to promote Support ACT and our nutrition, exercise and health content
- continue with our online Zoom calls such as those for men, those living on their own, those for partners and our Breathe In Sing Out sessions
- consider if there is more support we should provide for those living on their own
- consider if there is more we can do to support the quality of life of those under 70

REPRESENT

- work with patients, partners and health care professionals to continue to improve patients' experiences when their diagnoses are given
- work with other blood cancer bodies to seek to improve the path to diagnosis
- work with the CLL community, including the UK CLL Forum and CLL CNS network
- continue to any initiatives related to bringing care for CLL and SLL closer to the community and which help increase primary care awareness of CLL/SLL
- contribute to the Blood Cancer Parliamentary Group (APPG) on active monitoring
- contribute to any wider research such as that conducted by the global body CLLAN

HELP YOU THRIVE

- continue our current research into fatigue in order to help patients have a more informed conversation about this with their healthcare team
- find out more about patients' experiences with pain in their joints and bones with a view to seeing if we can provide further support
- explore opportunities to help develop apps or wearable devices to help people manage their CLL or SLL

Some useful links

- [To join CLL Support](#)
- [A guide for those affected by CLL or SLL](#)
- [Vaccination guide and log for people with CLL/SLL](#)
- [Support ACT – our interactive wellbeing app](#)
- [Health Unlocked – our online forum](#)
- [Some FAQs including on travel insurance](#)

Thank you so much to all 894 of you who completed the survey!!

For further information, or to share any further thoughts, please contact

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