

2026 CLL Support Partner Survey - a summary of the results

Partners, family members and friends play a vital role supporting those with CLL/SLL. Following our previous member survey in 2022 and 2024 that covered patients and partners, in 2026 we created a survey specifically for partners to enable us to:

- understand the specific experiences, needs and concerns of partners
- share the findings and represent the views of partners with the UK CLL Forum of specialists, researchers and scientists
- ensure the services and support we provide reflect what matters most

The survey was completed online, the link being shared through email invitations to all our members, social media, CLL Support website, HealthUnlocked and our Under 60s WhatsApp group.

Who replied?

- We received 116 responses (2022, 46; 2024, 101)
- 88% were spouses/partners of someone with CLL/SLL
- Respondents were predominantly female, 65%
- 21% of respondents were aged 61 to 70, 41% 71 to 80 and 22% were 81 and over
- 63% had been providing support for between 5 and 20 years, 34% for less than 5 years



Current situation

- 45% were supporting someone on Active Monitoring, the remainder were evenly divided between treatment and remission

Medical Appointments

- Over half (54%) of respondents always attend hospital appointments with the person they are supporting, with a further 34% attending sometimes
- Partners have good understanding of what is discussed at appointments. At the last appointment 69% understood everything the healthcare professional said, and a further 26% understood most.



Feelings when talking to the person with CLL/SLL

- 55% of respondents felt able to offer emotional support
- 41% felt they had enough information to offer support or helped find answers
- 31% reported worrying a lot, feeling overwhelmed, helpless or sad
- 24% didn't want to say or do the wrong thing, or just listened.

"It takes time to adjust to new normal: you will grieve for the life plans you had, but in time you will learn to live with it, adjust to the fear of the unknown and forge a new path together."

The current situation of the person with CLL/SLL impacted these feelings:

- Respondents supporting someone on Active Monitoring reported significantly more listening, not wanting to say or do the wrong thing and feeling helpless or sad.

- Those supporting someone on treatment felt they had enough information or helped find answers significantly more than those supporting on Active Monitoring or Remission.

“There is plenty of time to get informed about the condition, and when you have researched RELIABLE sources, you are likely to feel more optimistic and to be reassured.”

Time since diagnosis also impacted feelings:

- Those supporting someone diagnosed less than 5 years ago reported significantly more worry, feeling overwhelmed, helpless, sad, not wanting to say or do the wrong thing, just listening.

Practical Support differed by gender

- **Male respondents**, 80% provided support with household tasks, 65% provided transport to appointments, 25% advocated/communicated with the healthcare team and 13% assisted with medication management. None reported nothing/don't know.
- **Female respondents**, 47% provided support with household tasks, 34% provided transport to appointments, 38% advocated/communicated with the healthcare team and 18% assisted with medication management. 12% reported nothing/don't know.

Who do you talk to for support for yourself? differed by gender

- **Female respondents** were significantly more likely to talk with friends 53% (males 20%), and also family 24% (males 10%), children 17% (males 3%) and use online forums 21% (males 5%).
- **Male respondents** significantly reported not talking to anyone 48% (females 16%) and more talked to the person with CLL/SLL for support 43% (females 26%)
- No respondents talked to a counsellor for support



Impact on Quality of life

- Respondents rated the emotional impact of supporting someone with CLL/SLL at 6.79/10 compared with 5.17/10 for physical impact. These are higher scores than those with CLL/SLL gave to the same questions (emotional 5.63/10, physical 5.11) (2024 physical impact carers 6.15/10, those with CLL/SLL 5.35/10; emotional impact carers 7.26/10, those with CLL/SLL 5.56/10)
- 44% said they sometimes feel mentally exhausted or fatigued because of their supporting role.
- Among personal impact, increased stress or anxiety was scored highest 5.69/10, followed by sleep disturbance 4.44/10 and feeling overwhelmed by supporting responsibilities 4.27/10
- Respondents did not report a particularly high impact on everyday life. Balancing other responsibilities was rated as 4.36/10, less time for oneself 4.14/10, interference with daily routine 3.76/10
- Males and females reported comparable overall levels of emotional and physical impact, although females reported significantly higher stress/anxiety 6.08/10 (males 4.98/10) and sleep disturbance 5.03/10 (males 3.38/10)

What advice would you give to someone whose partner is newly diagnosed with CLL/SLL?

“Develop a good support network-in-waiting for yourself early on, so it’s there if and when you may need to draw on it.”

“Join a support group like CLL Support and learn about the disease through trusted information. Attend appointments so you understand what is going on and can support better. Don’t Google and worry yourself. Keep positive.”

“Get emotional support from someone who’s experienced on how to live and support someone with CLL/SLL.”

“Try and live life as normally as possible. Don’t let fear overtake you... be kind to yourself and don’t feel guilty for being sad. Make sure you try and invest in your own well-being, so you are fit and strong for any future caring needs.... Understand the only thing that has actually changed is a diagnosis and try to live life exactly as you would have done before, but with an awareness and a little more caution to risk factors.”

CLL Support

- 49% of respondents said they were members of CLL Support
“I didn’t know [CLL Support] is for supporters as well, I thought it was support for patients.”
- 77% of these members said CLL Support understood the needs of people affected by CLL/SLL very well. 49% felt very well supported by CLL Support. 82% were very confident that CLL Support represents the interests of people affected by CLL/SLL
- Respondents were asked if they were aware of, and if they had accessed CLL Support Services. The greatest awareness was:

Service	Aware of	Accessed
CLL Support Website	65%	52%
Online Webinars & support sessions	63%	40%
Conferences	62%	27%
Electronic newsletter	40%	33%
Members booklet	35%	31%
Telephone helpline	34%	8%

“I have found attending the conferences really helpful. It is good to speak with others in the same boat as we don’t know anyone else with the disease. The CLL Support group has been a godsend to us for information and support. Thank you for all you do.”

- The lowest transfer of awareness to access was conferences, online webinars and telephone helpline.
- There was limited awareness and access of Support ACT sessions and the Support ACT website

Service	Aware of	Accessed
Support ACT sessions	26%	8%
Support ACT website	21%	4%

- Extremely high levels of satisfaction were reported across all services offered
“My husband was on watch and wait and moved to receiving treatment during the pandemic and this was a hugely stressful time for me as the person supporting him. Your organisation was really my main source of support at that time, so I am hugely grateful.”

Next Steps

The Trustees are extremely grateful to the 116 people 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

- Partners are active participants in care: most attend medical appointments: most report understanding what is discussed
- Partners often function as an extension of the care team: attending appointments, interpreting information, providing practical help and supporting the person with CLL/SLL emotionally
- The emotional impact on partners is greater than the physical impact, and also greater than the impact on the person diagnosed.
- Emotional impact changes with time and for partners is highest in the first 5 years following diagnosis
- The time in active monitoring also has higher emotional impact with more helplessness, sadness and uncertainty than when the person with CLL/SLL is on treatment or in remission
- The practical support provided and support networks accessed differed by gender
- Satisfaction with CLL Support services is high, but only 49% of respondents were members of CLL Support.
- There are some significant gaps where partners do not know about CLL Services or that they can access them

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

INFORM

- ensure partners continue to be a core part of future strategy
- have a membership drive specifically for partners (51% of respondents were either not members or didn't know if they were)
- recognise partners as a distinct audience with some differing needs to patients. (One respondent said they assumed CLL Support was just for patients)
- improve the rates of awareness and access to services by exploring what is stopping partners accessing them

SUPPORT

- explore with partners what further information and support they would find helpful and respond to those needs
- seek to develop a specific resource for supporting someone newly diagnosed and their family members, focussing on the first 5 years (This will also be of benefit to those with CLL or SLL, but with a slightly different emphasis)

REPRESENT

- work with patients, partners and health care professionals to continue to improve patients' experiences when their diagnoses are given

HELP YOU THRIVE

- strengthen emotional wellbeing support for partners and promote that partners would seem to need support even more than those with CLL/SLL
- provide clear signposting to available emotional support, for example Support ACT, and make it more visible and acceptable for partners to access

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 116 of you who completed the survey!!

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