

We are the only patient led UK charity supporting those affected by CLL and SLL and our purpose is to:

- **hold regular meetings with CLL consultants, researchers and other specialists**
- **provide up-to-date information on CLL and treatments**
- **provide an informative website: cllsupport.org.uk**
- **spread the word about CLL and its treatment**
- **support research into the treatment of CLL**
- **offer support and information about CLL and SLL**

Helpline: 0800 977 4396

Membership is FREE

Third National CLL Survey:

8 May – 29 July
2026

Second National CLL survey: March – April 2024
First National CLL Survey: May - June 2022

Why we did the survey

CLL Support repeated the survey in its 22nd Anniversary year so we can:

- 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 and their partners, family, carers and friends most value – for which this bespoke survey was developed and fielded

Methodology

As a patient-led charity, we invited (1) UK patients with CLL or SLL and (2) their partners and family, carers and close friends to complete one of two anonymous surveys.

The link to the surveys were shared with several follow up reminders, via:

- email invitation to members inviting them to participate
- CLL Support Under 60s WhatsApp Group
- Website, social media and HeathUnlocked

We received 1010 responses across the 2 surveys

894 patients completed the patient' survey

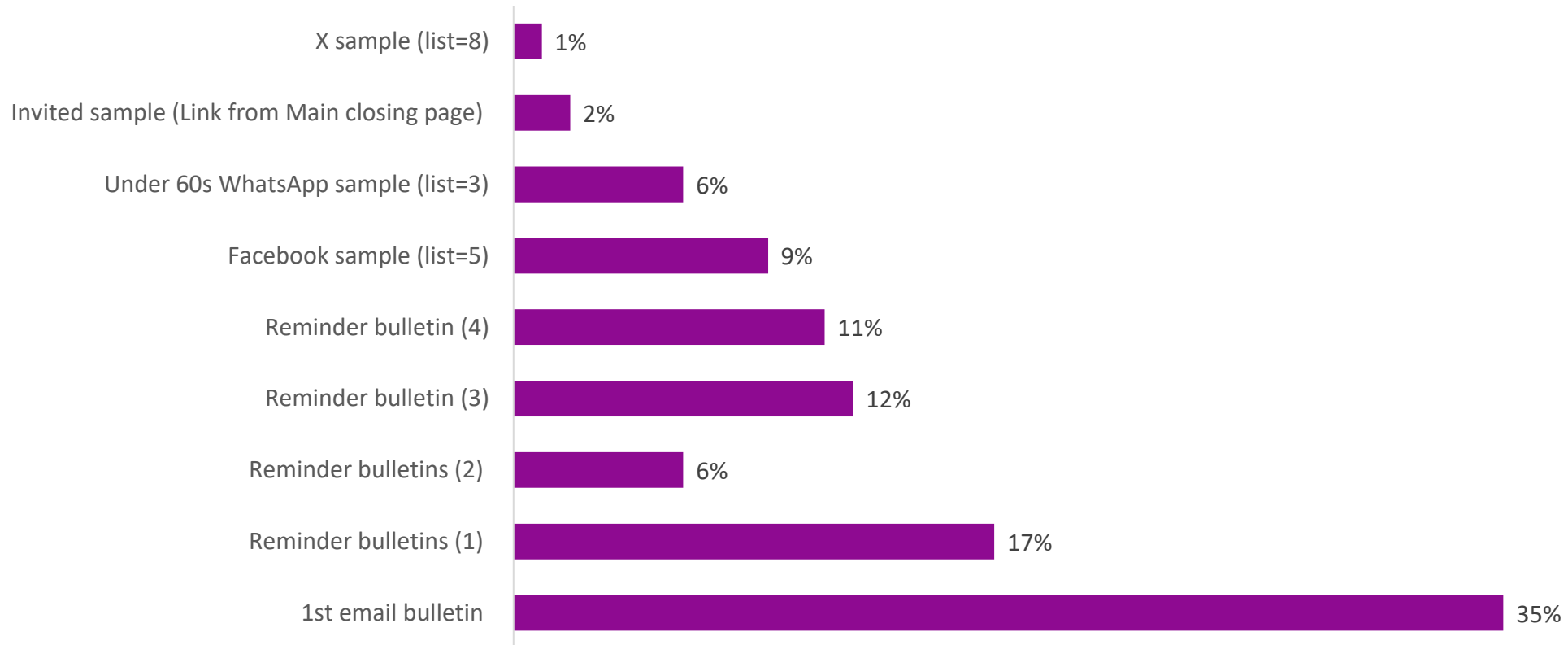
116 partners/family completed the partner survey

(Comparative partner sample sizes: n=116/1010 in 2026; n=101/1110 in 2024; n=46/702 in 2022)

Sample

Respondents: 116 partners and family members of people with CLL/SLL completed the survey

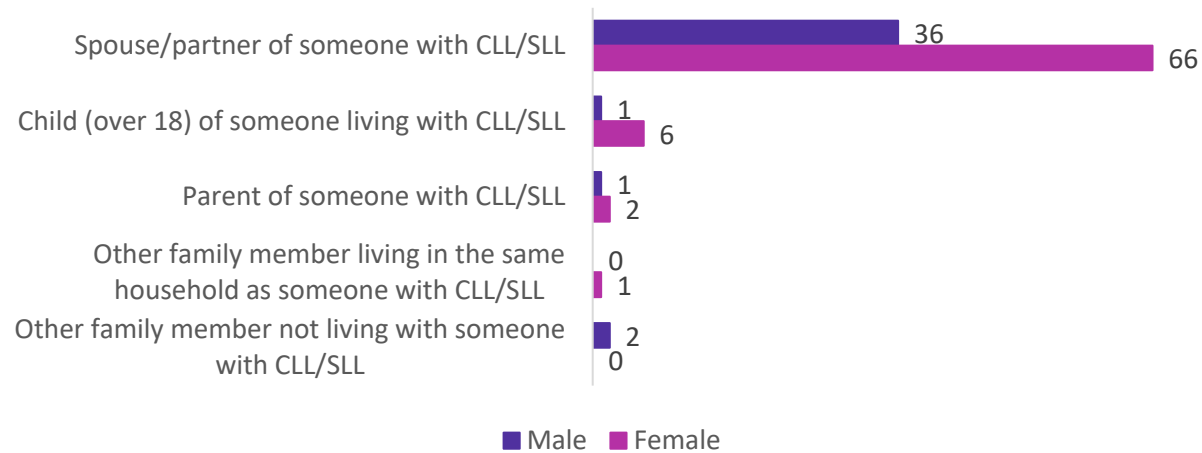
Most respondents (58%) completed the survey via direct member email, followed by the 'website, HealthUnlocked, PPIE reg' (12%), Health Unlocked (11%) and then Facebook (9%)



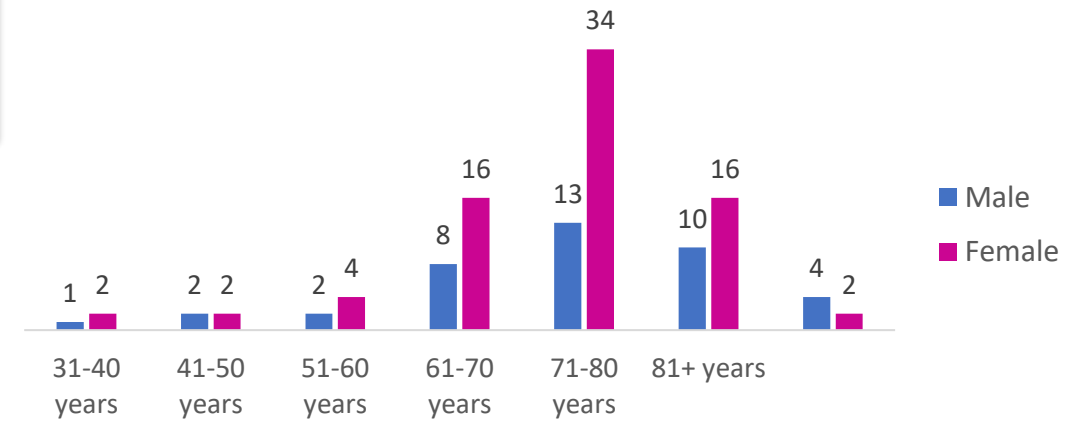
Carer respondent characteristics: 2026 Survey

Most carer respondents were the spouse/partner caring for someone with CLL/SLL (102, 88%). Respondents were predominantly female and aged over 61 years. More than two-thirds had provided care for 5 to 20 years.

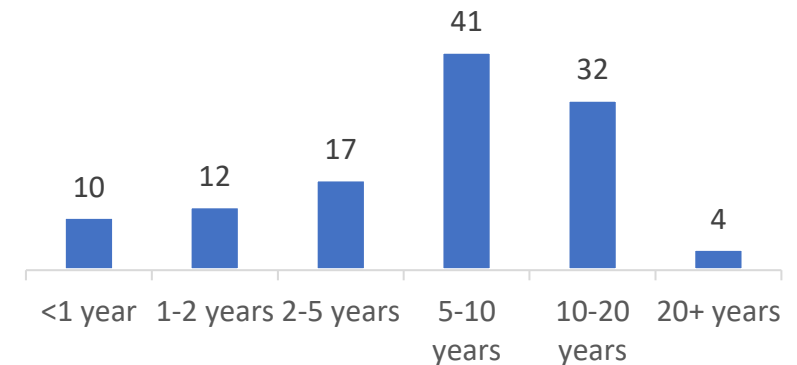
Relationship to patient



Age of respondent by gender

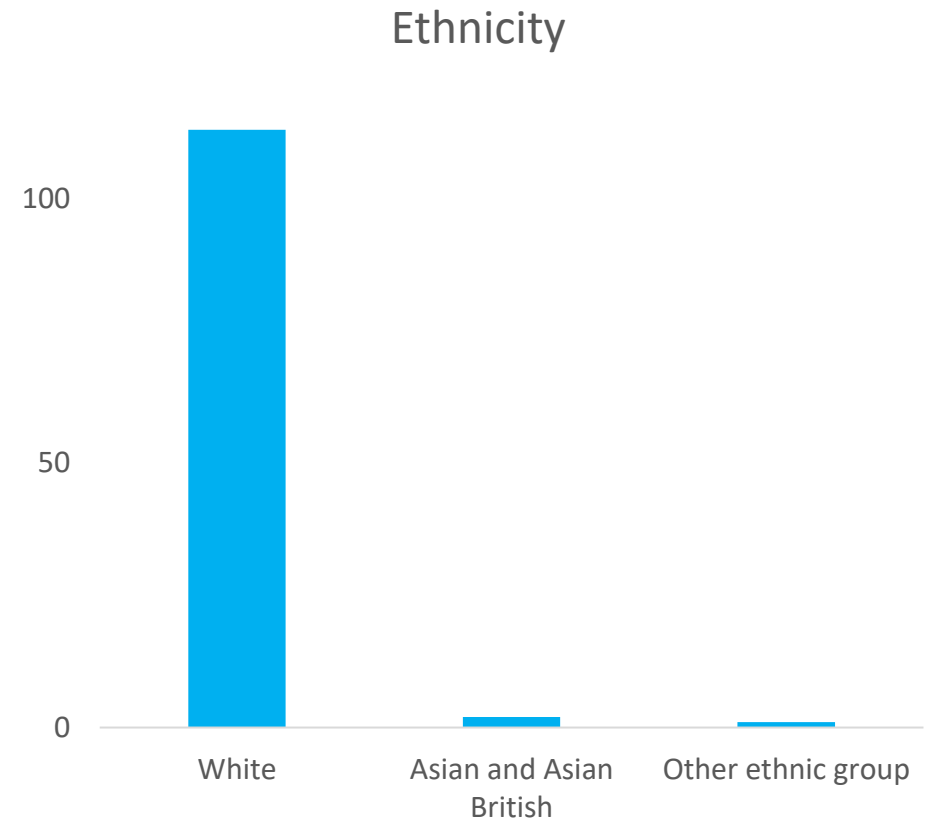
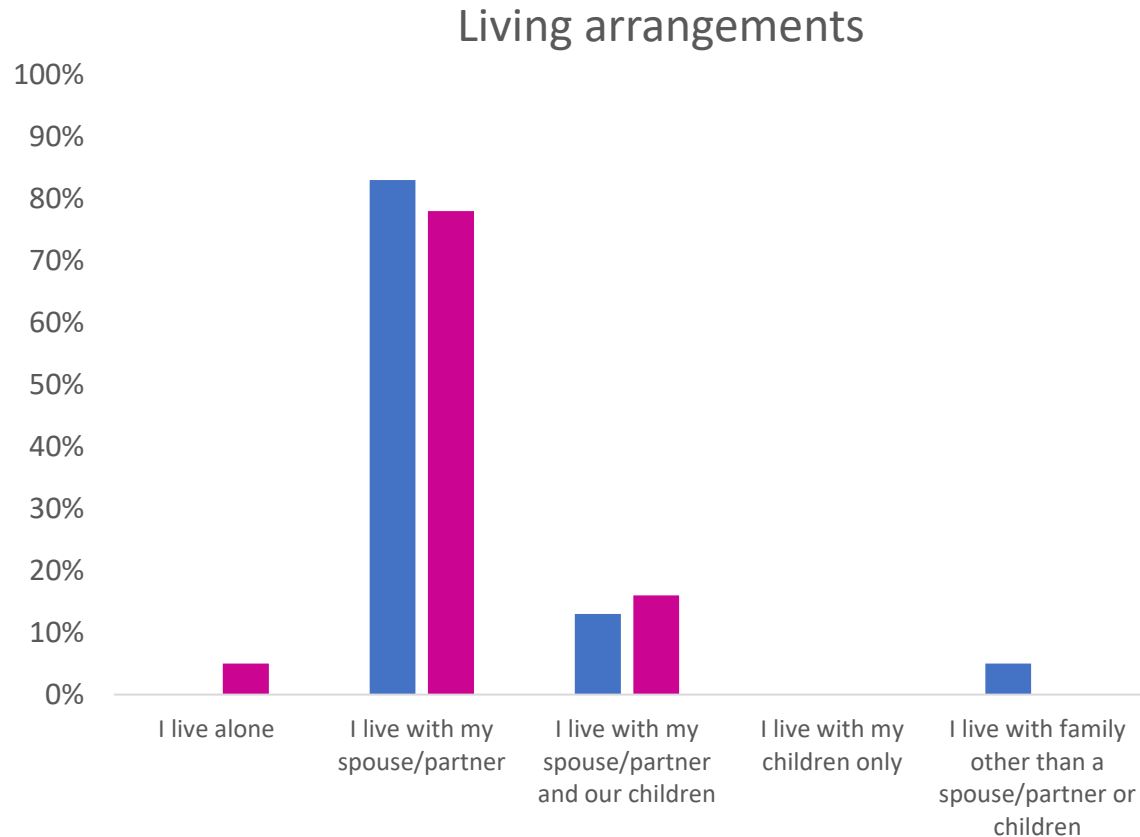


Number of years caring



Patient sample characteristics – household makeup

- Significantly more men live with family other than a spouse, but the majority of respondents live with their spouse / partner
- Most of the sample were white British



In summary

Summary of 2026 learnings

- The vast majority of respondents were partners, and nearly half of those are living with someone on Active Monitoring vs remission or treatment
- Partners typically attend appointments and understand what is discussed well
- Informational needs appear to be satisfied, but partners are impacted emotionally by their situation, with the first five years appearing to have the greatest negative emotional impact - after that there seems to be some positive uplift as they become more used to living with CLL
- Emotional impact is rated higher than physical impact
- Partners also rate higher on emotional scores than their partners who are diagnosed with CLL/SLL, and women more so than men
- Women respond by talking through their experience with other people, more than men do, to friends and family and online forums
- Partners rate CLL Support highly for support, but not all feel they need it as much as those who have been diagnosed
- Partners have good awareness of the offerings of CLL Support and a significant proportion also engage with the services available
- Overall, they are very grateful for the support and information provided via CLL Support and many would recommend to others in their situation

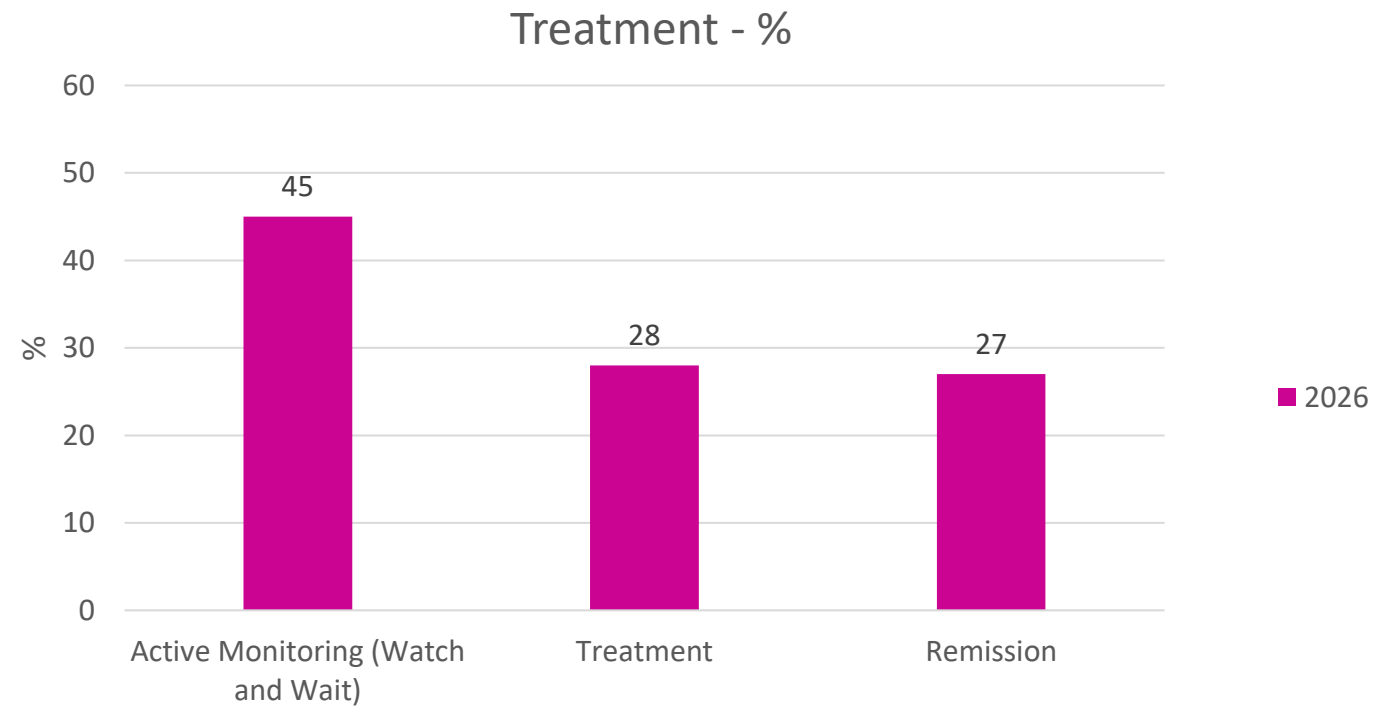
Survey results

Interpreting the results:

- Score /10 where 10/10 is the highest rating and 1/10 is lowest rating for each parameter

Current situation

45% of respondents were caring for someone on 'active monitoring'; the remaining two thirds were fairly evenly split across being on 'treatment' and in 'remission';

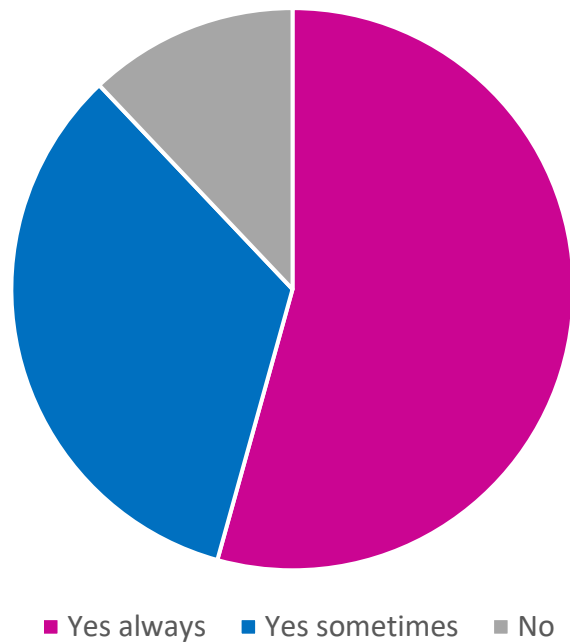


***Remission was defined as 'back to active monitoring after treatment'**

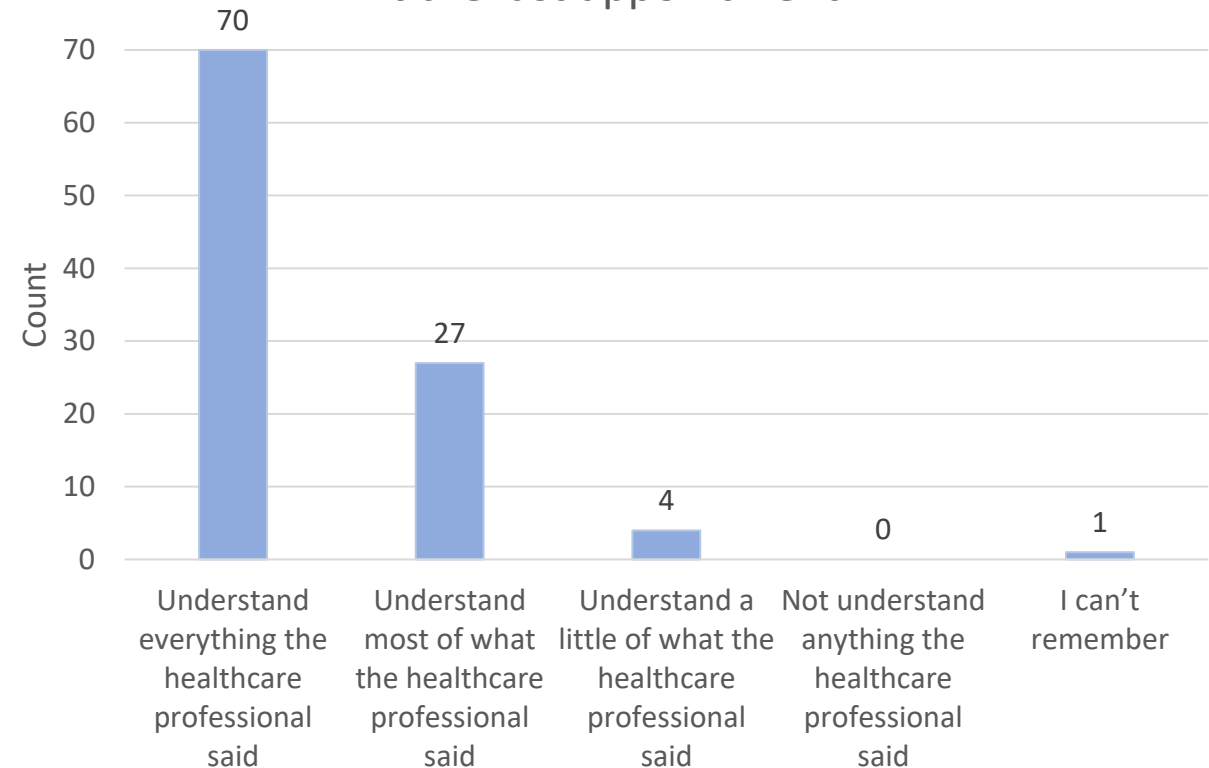
Medical appointments

Most family members go to appointments most of the time, and generally they have a (very) good understanding of what is discussed in medical appointments

Attend medical appointments



At the last appointment:

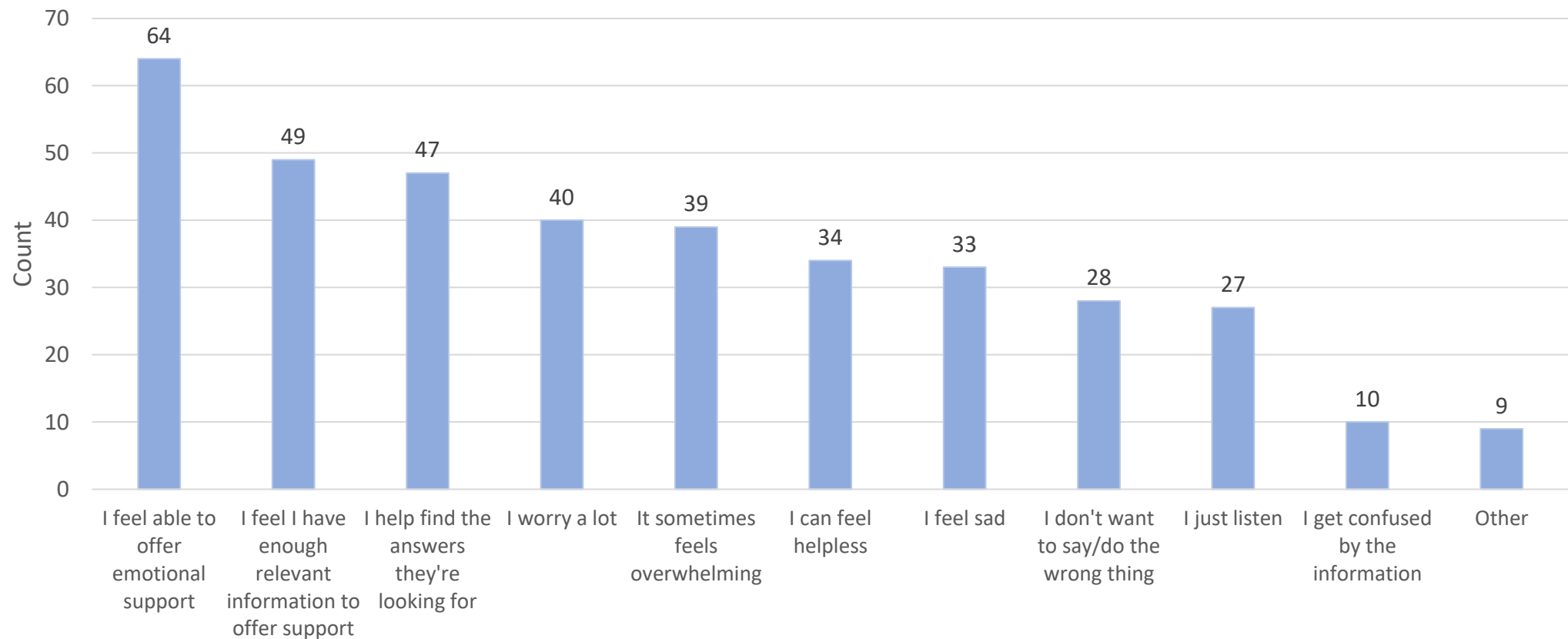


Q4. Do you attend medical appointments with the person you support? [Base n=116]

Q5. If you do attend appointments, at the last appointment you went to, did you... ? [Base n=102]

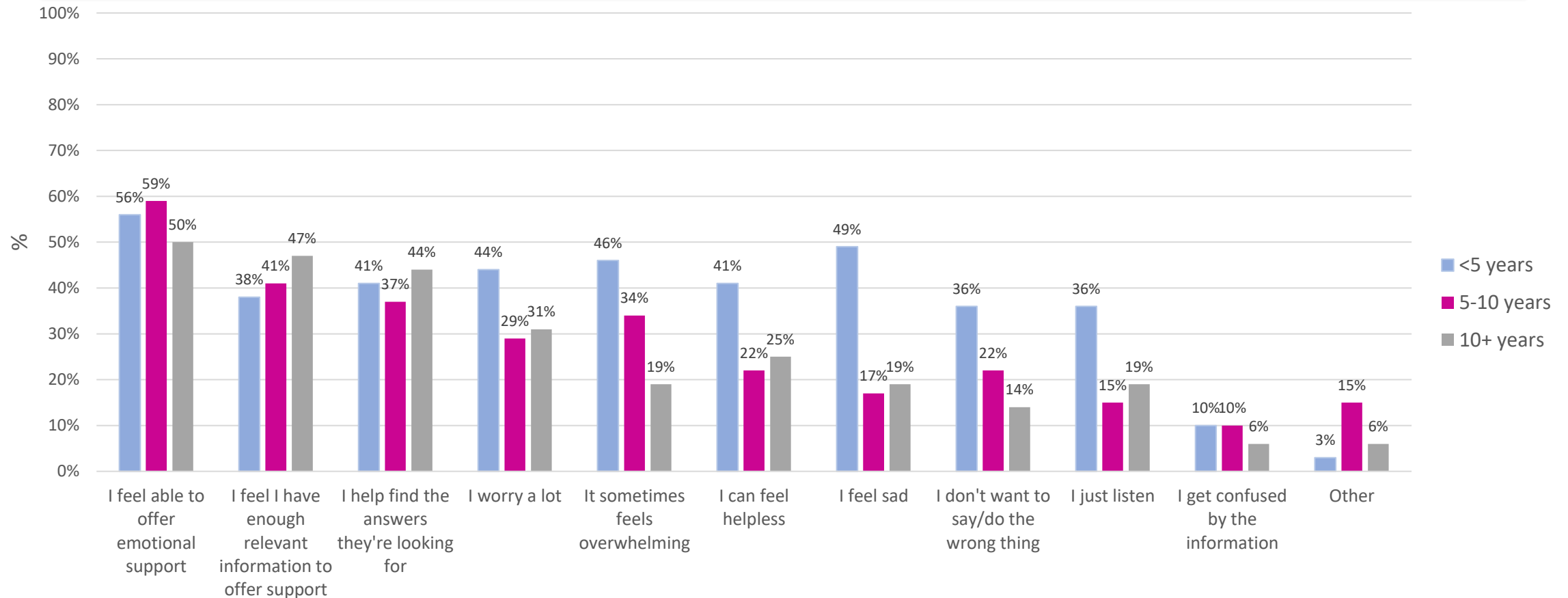
Feelings when talking to person with CLL/SLL

Half feel they are able to offer emotional support and informational needs to the person they are caring for; nevertheless, around a third also note various more emotional experiences for themselves



Feelings when talking to person with CLL/SLL

Time since diagnosis impacted the feelings of family: if their loved one was diagnosed less than 5 years ago, respondents noted significantly more (i) listening [vs 5-10 years ago] (ii) not wanting to say the wrong thing [vs 10+ years ago] (iii) feeling overwhelmed [vs 10+ years ago] (iv) sad vs [5+ years ago] – suggesting that over time, there are positive changes



– over time, there seem to be positive changes

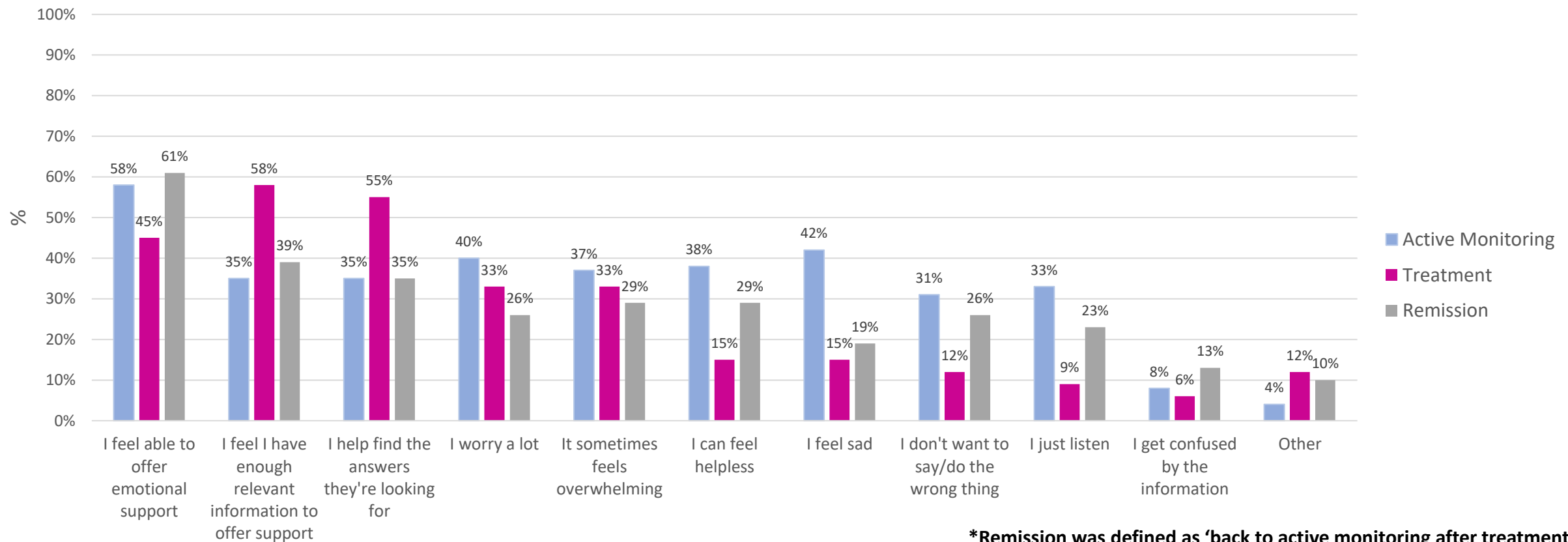
Initial **fears will subside** when success of treatment is realised

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.

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

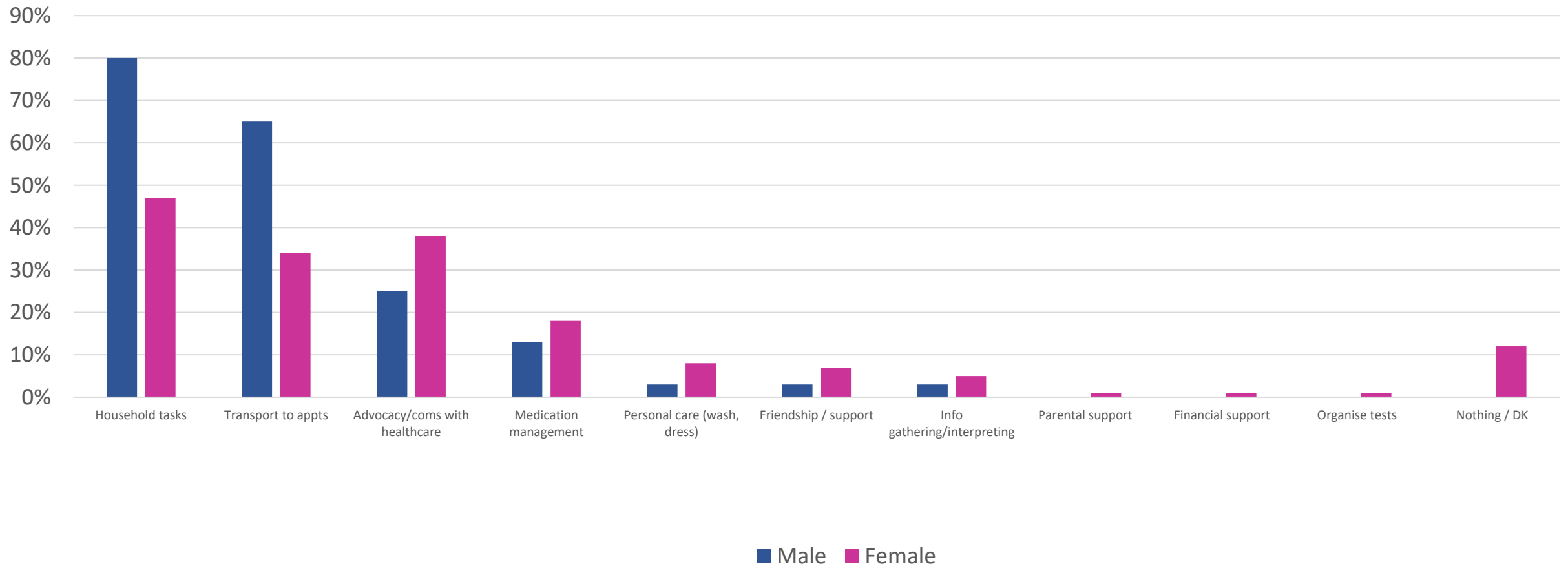
Feelings when talking to person with CLL/SLL

‘Current situation’ impacted feelings: if caring for someone on active monitoring, they noted significantly more (i) listening [vs if on treatment] (ii) feeling more helpless [vs if on treatment] (iii) not wanting to say the wrong thing [vs if on treatment] (iv) feel sadder [vs if on treatment or remission] – reflecting the emotional impact of Active Monitoring. On a more positive note (v) those on treatment significantly felt they had enough relevant information vs those in remission, reflecting feeling supported from an information point of view



Practical support

Male family members provide significantly more transport to appointments and perform significantly more household tasks
Female family members claimed not to know (did nothing) significantly more

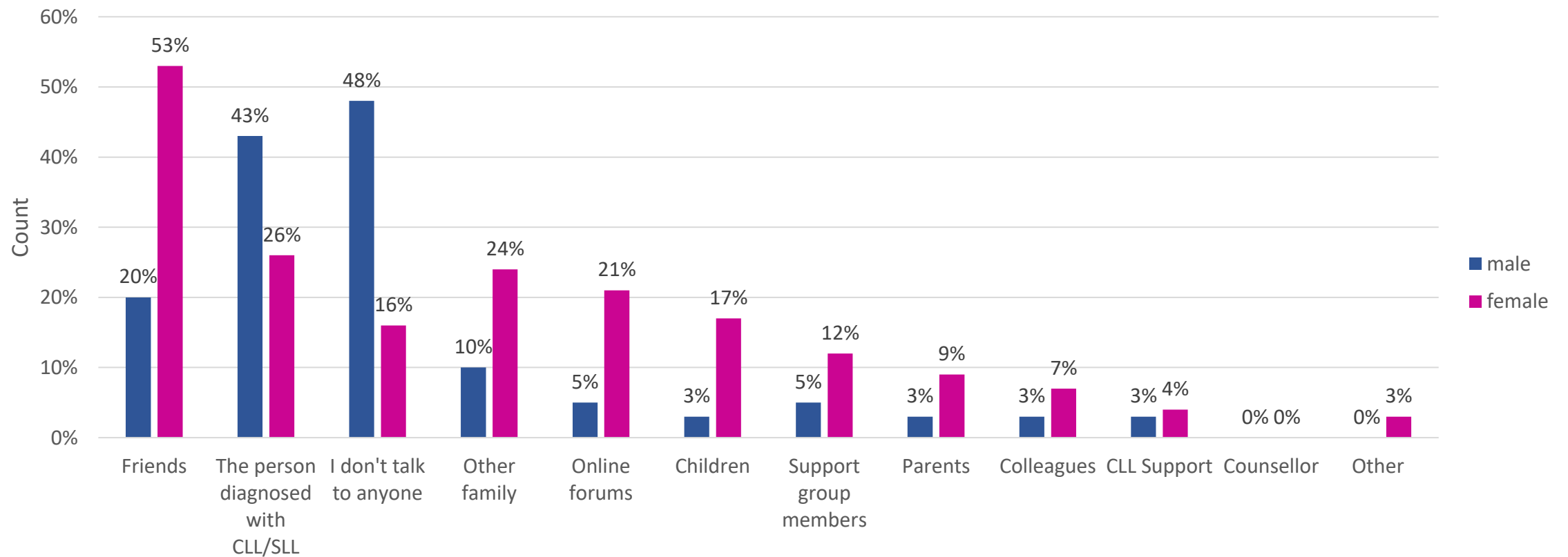


Q7. What type of practical support do you provide in connection with their CLL / SLL? [Base n=116]

Q24. What is your gender? [Base n=116]

Who do you talk to for support?

Friends are significantly the key people women talk to, but women are also more likely to talk to their children, friends and use online forums, than men; men are significantly less likely to talk to anyone. Neither claim to talk to a counsellor

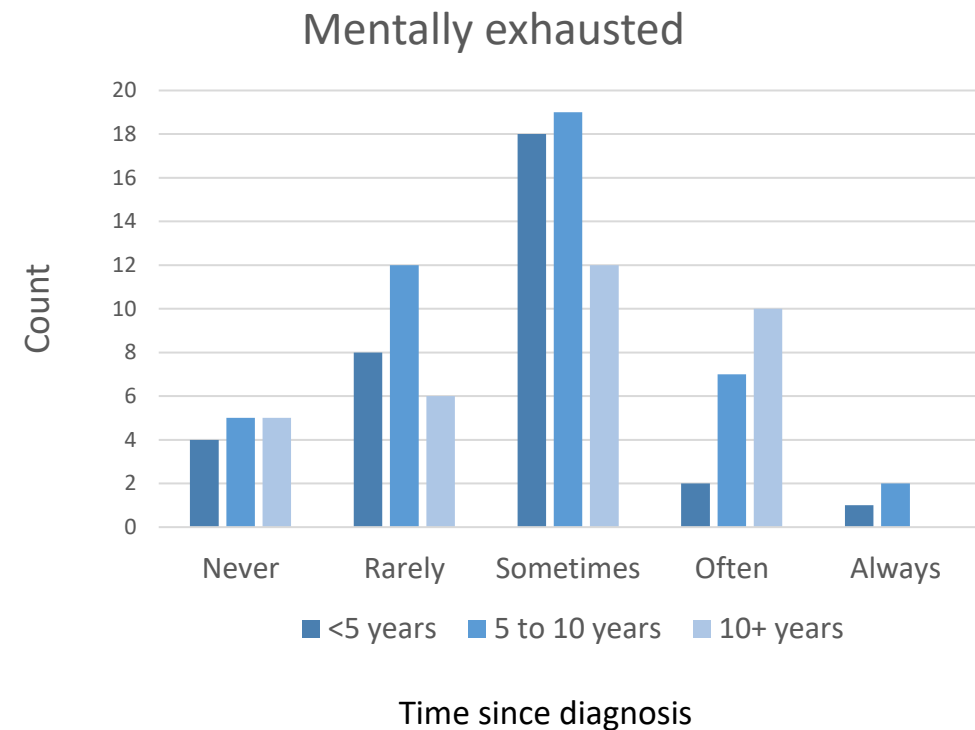
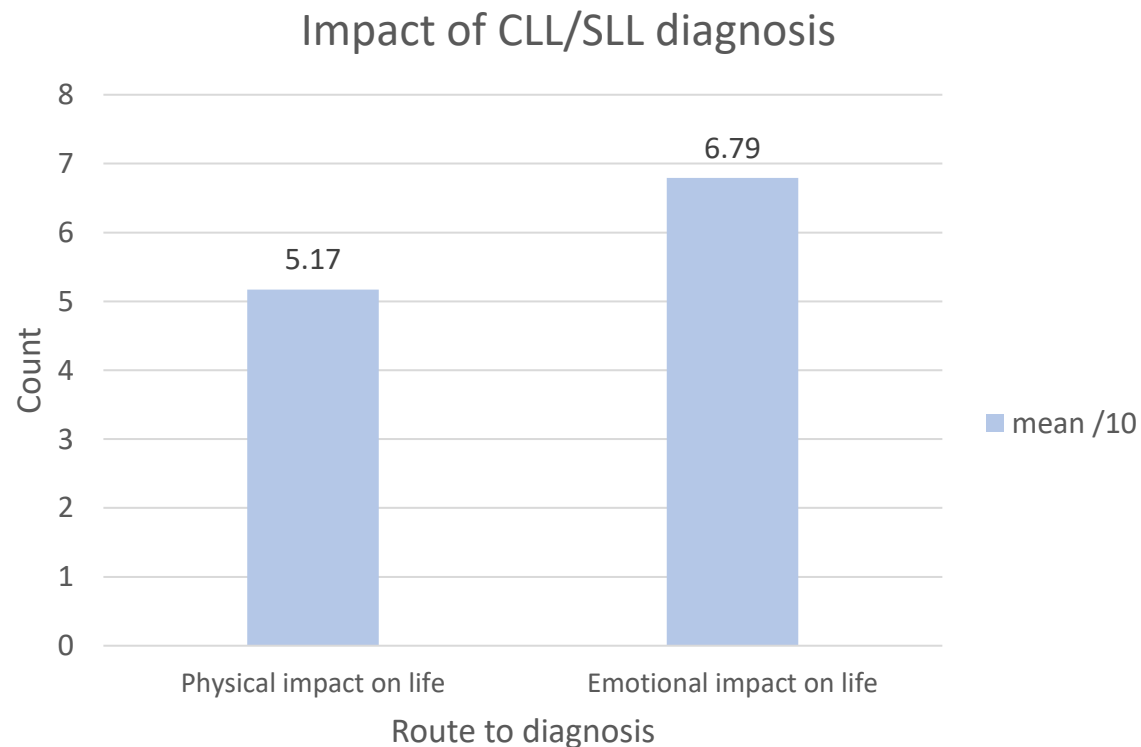


Q8. Who do you talk to, to get support for yourself? [Base n=116]

Q24. What is your gender? [Base n=116]

Physical and emotional impact

Respondents report that the diagnosis of their family member has both physically and even more so, emotionally, impacted them. In terms of 'mental exhaustion and fatigue', 44% of the sample said they felt it 'sometimes'. Looking at 'time since diagnosis' it is rated 'often' by significantly fewer of those in the first 5 years of diagnosis than by those 5 and more years after diagnosis.



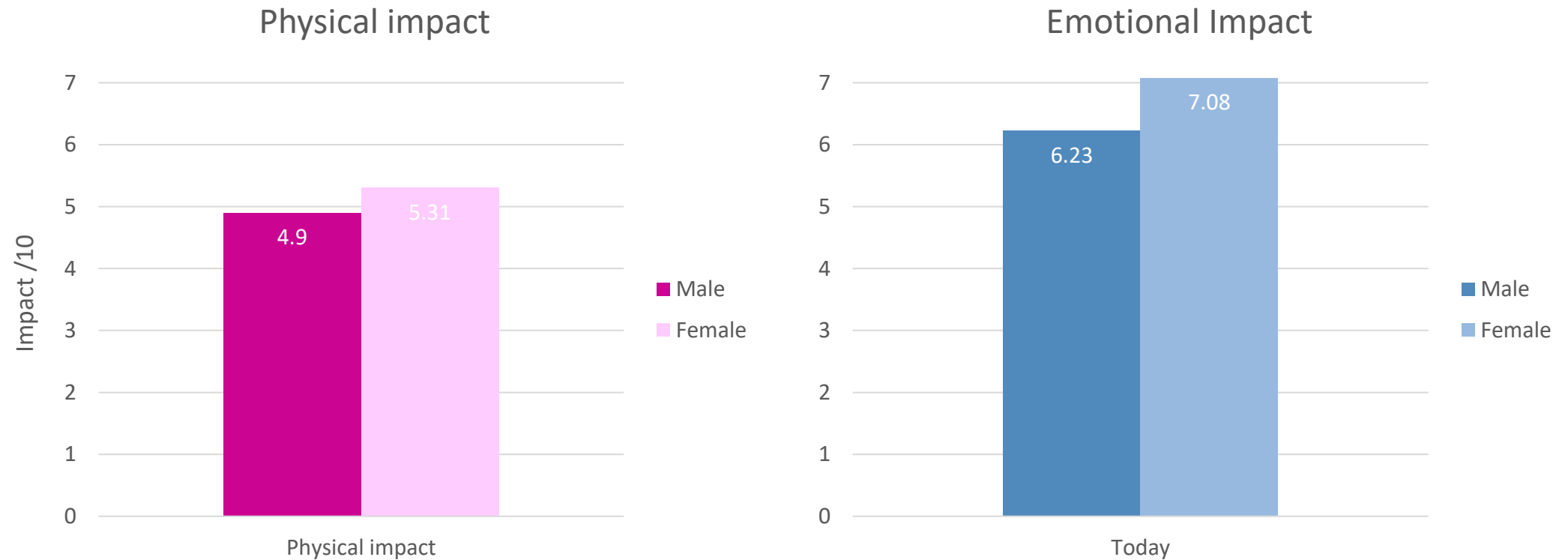
Q9. How much has their diagnosis of CLL/SLL affected YOUR quality of life from an emotional perspective? ? [Base n=116] – Score/10

Q11. How much has their diagnosis of CLL/SLL affected YOUR quality of life from a physical perspective? [Base n=116] – Score/10

Q12. Do you ever feel physically exhausted or fatigued because of your supporting role? [Base n=116]; Q3. Current situation.[Base n=116]

Impact on quality of life across gender

Women and men were comparable in the level of their emotional and physical impact to CLL / SLL

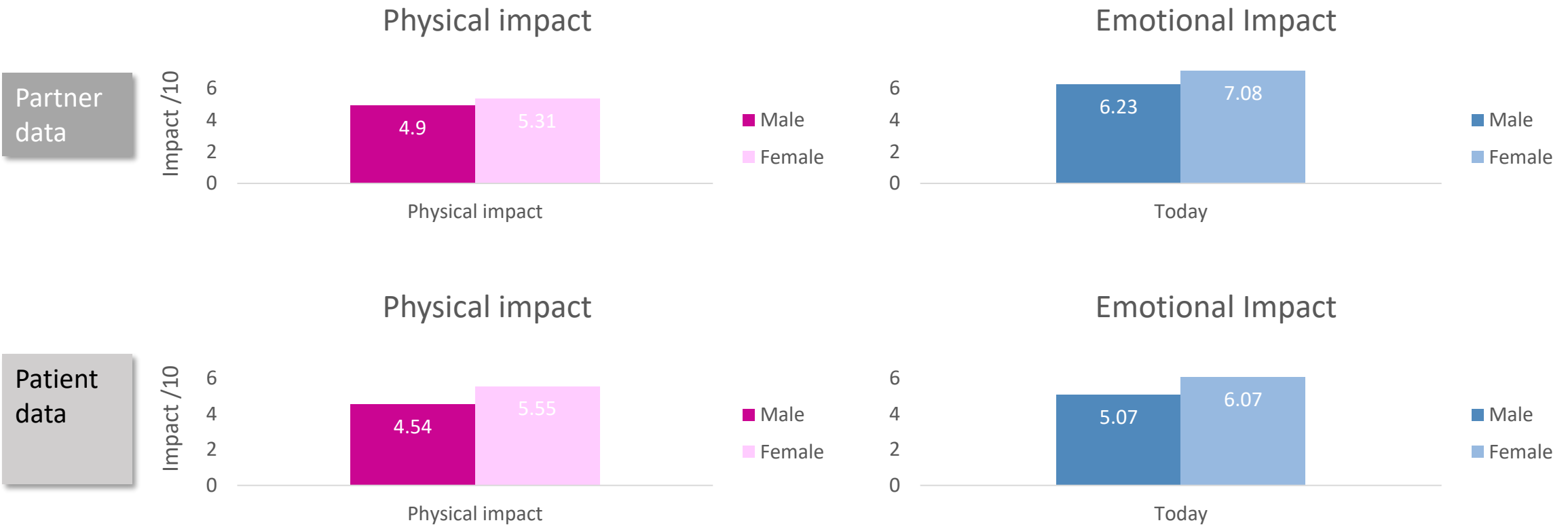


Q9. How much has your diagnosis of CLL/SLL affected your quality of life from a physical perspective? [Base n=116] – Score/10

Q11. How much has your diagnosis of CLL/SLL affected your quality of life from an emotional perspective? [Base n=116] – Score /10

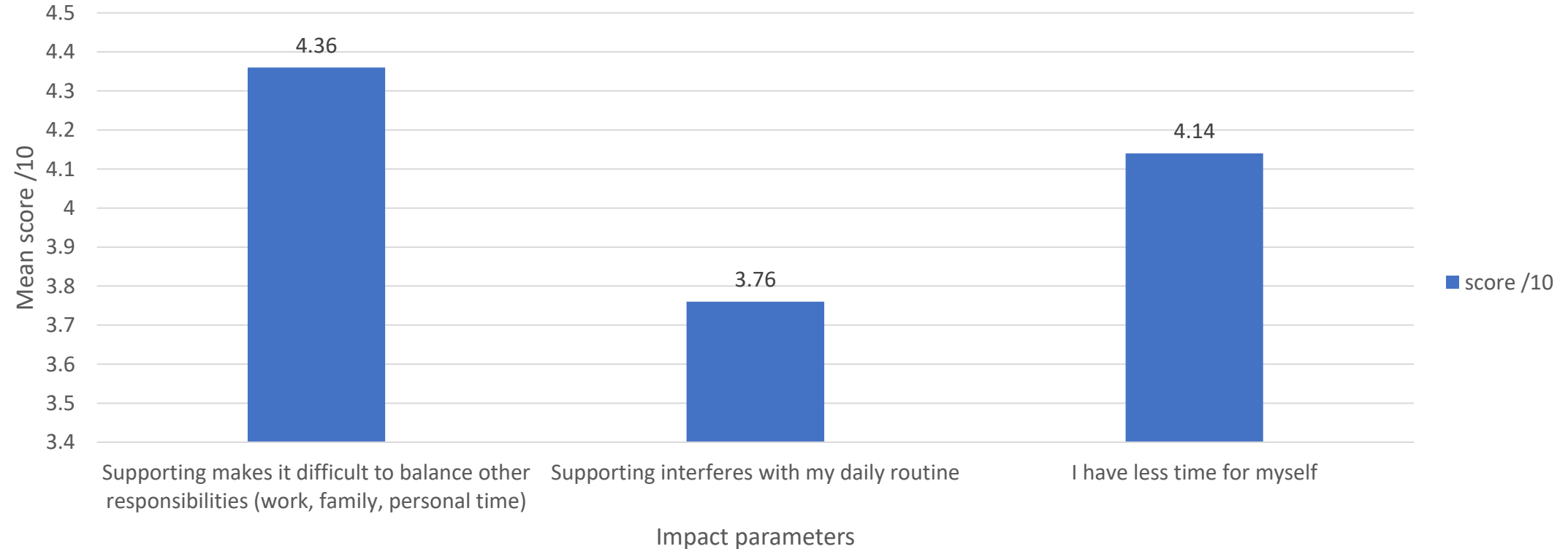
Comparison with PATIENT DATA: Impact on quality of life across gender

These data reflect that partners rate their emotional impact as higher than the people they are caring for rate impact on them



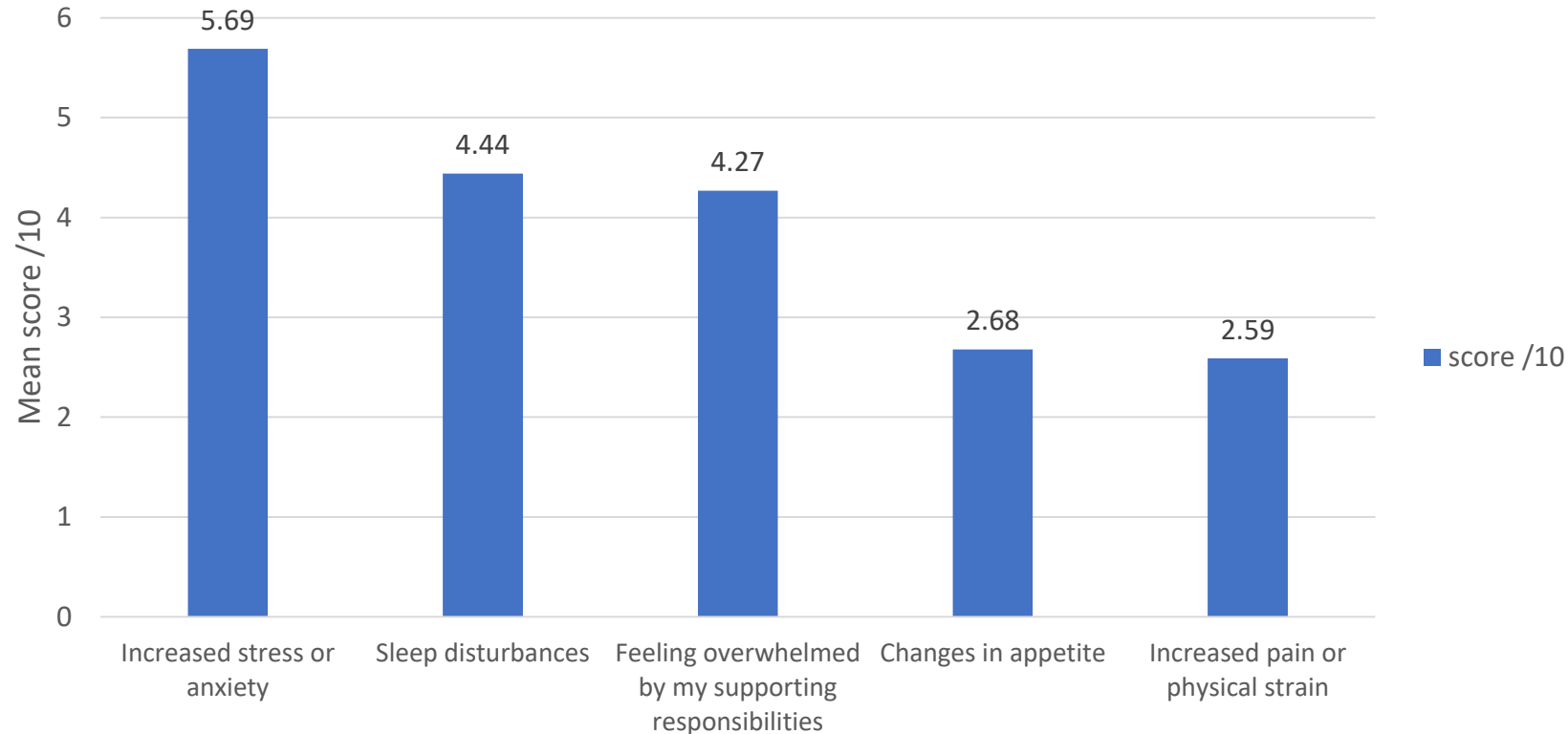
Impact on everyday life

Family looking after someone with CLL/SLL do not rate the level of interference on their lives, very highly



Impact on personal parameters

Ratings for elevated stress / anxiety were highest, but overall scores reflecting impact were modest.
Partners had a moderate score for accessing emotional support, however 2 in 5 were DK/NA suggesting a large proportion are not trying to

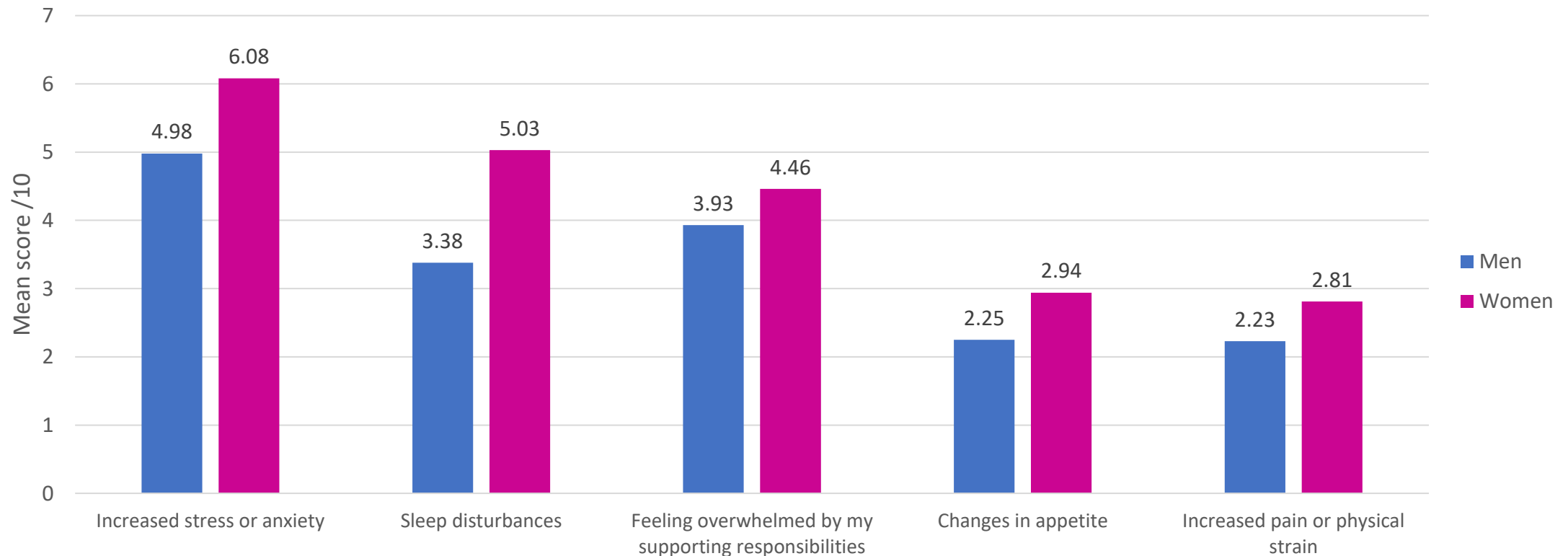


Q15. Please rate how much you have experienced the following because of your supporting responsibilities. [Base n=116]

Q10. How easy is it for you to access emotional support for yourself? [Base n=116]

Impact on personal parameters

Women rated 'sleep disturbance' and 'stress/anxiety' significantly higher than men – other scores reflect greater ratings by women but not statistically so



Q15. Please rate how much you have experienced the following because of your supporting responsibilities. [Base n=116]

Q24. What is your gender? [Base n=116]

“What one piece of advice would you give to a partner of someone 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.

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

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

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

Most respondents reported feeling that their needs were understood well...

I have found CLL Support invaluable so thank you

...impressive organisation

CLL Support has been such a wonderful support to me and my husband, and your volunteers are fantastic to give up their time. The conference in Nottingham a few years ago was excellent. Thank you so much.

It is doing an excellent job!

Advice to others re CLL Support

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.

Make use of support organisations: CLL Support, Health Unlocked, Blood Cancer UK. Fight for information from health services. Use this as a reminder to enjoy every minute together.

Take advice from trusted sources and join the under 60s CLL WhatsApp support group

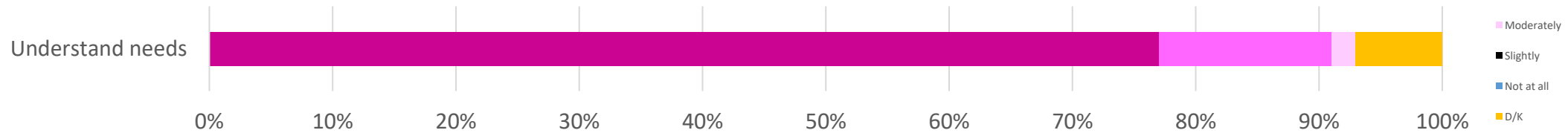
If they're looking for info help them find it - share links e.g. read the CLL Support website, info on Facebook.

Get on the CLL community of practice (Health Unlocked) --ask ask ask questions!

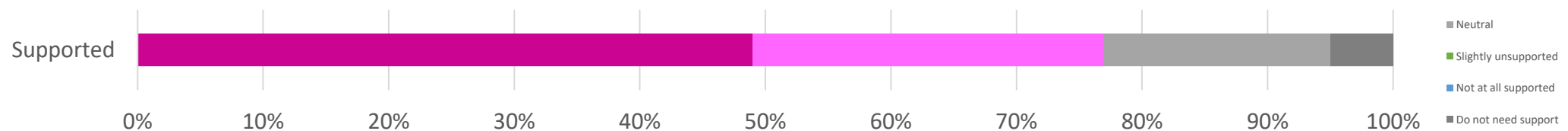
Level that members feel their needs are understood and supported, and have confidence in CLL Support

Most respondents reported feeling that their needs were understood well, and confident that CLL Support represents those affected by CLL/SLL well. Around 1 in 5, however, were more ambivalent about feeling / needing support

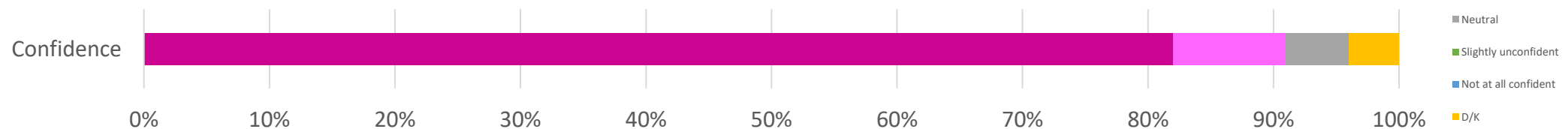
CLL Support understands the needs of people affected



Extent to which feel supported by CLL Support

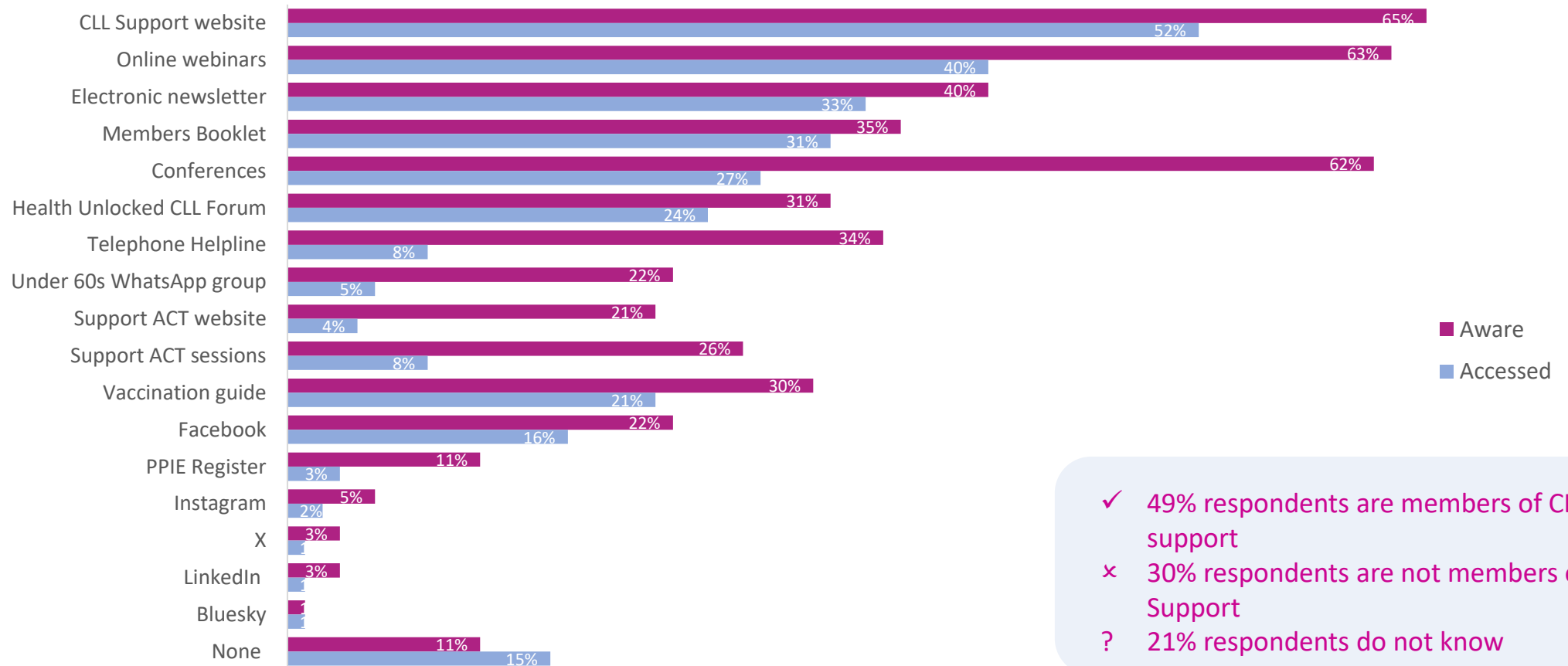


Confidence that CLL Support represents the interests of people affected by CLL



Service awareness and access in 2026

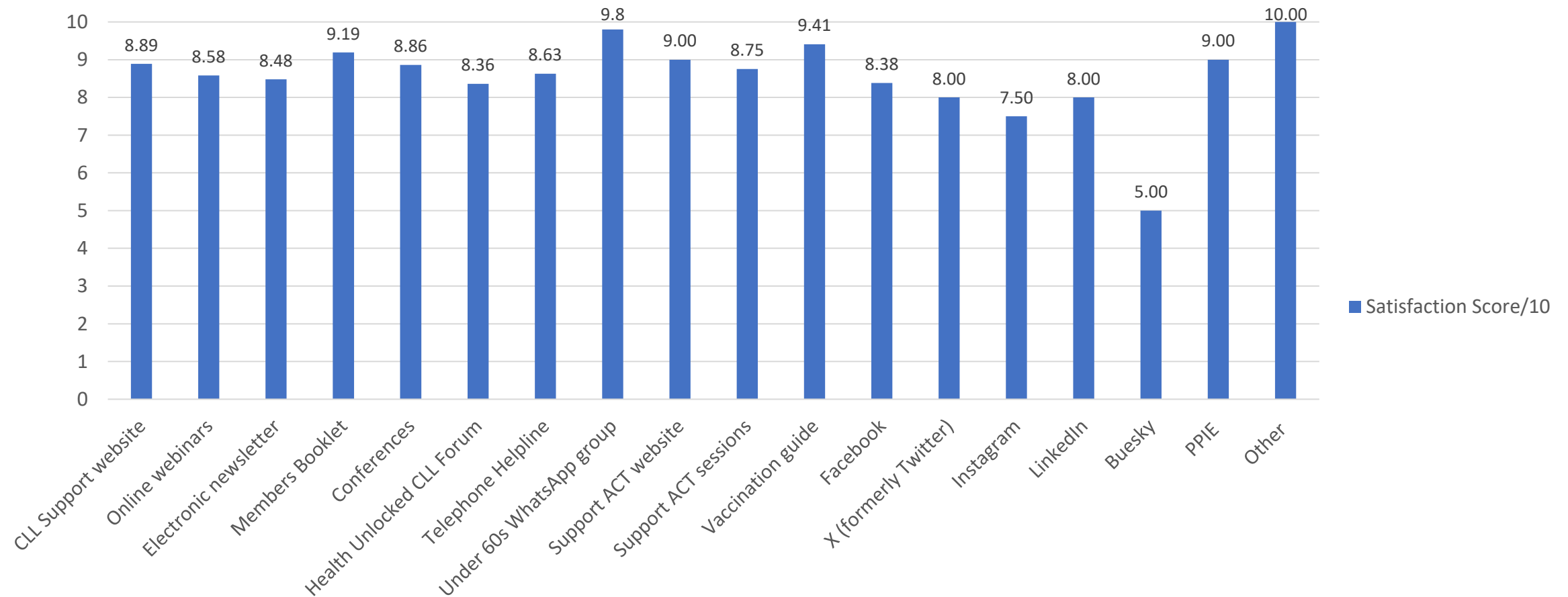
The lowest transfer of awareness to access was in online webinars, conferences and telephone helplines



- ✓ 49% respondents are members of CLL support
- ✗ 30% respondents are not members of CLL Support
- ? 21% respondents do not know

Level of satisfaction with CLL Support services

High levels of satisfaction were reported across all services offered



“Anything you would like to share about your experiences of supporting someone with CLL/SLL”

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.

It's very much a roller coaster sometimes up sometimes down - I suppose you just have to take each day at a time and enjoy the good days. Try to stay organised it helps a lot if everything else is running smoothly what you don't want is any more stress to cope with. There will be bad moods to contend with from time to time which you just have to except it, it's all part of the CLL and or the medication.

My husband was in denial for a long time and I needed to educate myself on things around CLL so that I could make sure I could watch out for any changes, symptoms etc. He was so anxious at appointments that I needed to be there to support him but also listen and often take notes during the appointments and treatment. Thankfully he is now in remission and has accepted that he has CLL, he lives with it and has a happy and active life ! We've had excellent support all round



CLL Support is very grateful to Dr Bee Laird and to Keith at Research Interactive for their help with this survey.

We are indebted to the following pharmaceutical companies for the financial support they have provided towards the costs of preparing and analysing the CLL Support 2026 surveys. They have had no input into the content of the surveys.

abbvie



AstraZeneca



BeOne



Lilly