2022 CLL survey – a summary of the results

In the absence of face-to-face conferences and the opportunity this would have provided to meet with our members, we instead asked our 3000+ members to complete an online survey. The survey was designed to help health care specialists involved in CLL/SLL treatment; to help patients, partners, family and friends to 'live well with CLL'; and to inform our lobbying to Government, medical institutions and pharmaceutical companies. The link to the survey was shared through Facebook and Twitter and by an email invitation all our members.

Who replied?

We received 702 responses, including 46 from partners, carers and close friends.

Slightly more women (372) than men (329) replied, reflecting the membership of CLL Support, although more men than women are diagnosed with CLL.

As expected, the largest age group was 61-70 (41%) followed by 71+ (36%).

Responses came from members across the UK including Scotland, Wales and Northern Ireland, with the biggest numbers unsurprisingly being from London and the south-east (31%).

The vast majority of respondents (97%) described their ethnicity as white.

Current situation

Over half the respondents (57%) had been diagnosed over 5 years ago

58% were on active monitoring (watch and wait) with 27% on treatment and 15% in remission.

There was a bigger gap between the numbers on active monitoring and the numbers on treatment or remission for those diagnosed less than five years ago. There were no significant differences across age or gender when looking at stage of treatment and very few geographical differences.

Diagnosis

The vast majority of respondents (68%) had been diagnosed incidentally through a routine medical appointment for another illness or condition. Less than a quarter of respondents (21%) had been diagnosed with CLL/SLL because of specific signs or symptoms.

The majority received their diagnosis within the last ten years but some had been living with CLL/SLL for over 30 years.

45% of those replying indicated they had no other health conditions.

At the time of initial diagnosis there was relatively high satisfaction with the time taken to diagnose CLL/SLL, the explanation of the next steps and the patient's involvement in decision making about their treatment. There was a somewhat lower satisfaction with the explanation of CLL/SLL by the Doctor or Specialist and lower satisfaction with the reading materials or further sources of support provided. However all the scores were between 6.9 and 7.5/10.

Those diagnosed more than ten years ago had been more satisfied with their involvement in decision making about their treatment but less satisfied with the reading materials and further sources of support than those diagnosed more recently.

There was no difference in satisfaction levels between partners and carers.

Men were more satisfied with most aspects of their diagnosis than women.

Satisfaction scores were in the main similar across all geographical areas.

Current signs and symptoms

Fatigue was mentioned as an issue by 56% of the respondents. 26% mentioned bleeding or bruising easily with slightly lower numbers mentioning swollen glands (24%), getting infections often (20%) and night sweats (17%).

Respondents who had said they were in remission generally noted fewer signs and symptoms than those on treatment or on active monitoring.

Women were more likely to experience swollen glands and swelling and discomfort in the tummy.

The symptoms most frequently experienced on a daily basis were anaemia, fatigue and swelling and discomfort in the tummy. Getting infections was most described as occurring on a monthly basis.

Anaemia, fatigue, getting infections and having a high temperature were described as the aspects having the most impact on day-to-day life, with scores between 7.2 and 6.6/10. Women were more likely to mention night sweats and swollen glands.

Impact on quality of life

Respondents were asked how much their diagnosis of CLL/SLL had affected their quality of life, first from a physical perspective, both pre-Covid and today, and then from an emotional perspective, pre-Covid and today.

Pre-Covid the emotional impact of CLL/SLL on the quality of life was greater than the physical impact (4.9 vs 4.4/10) but today both the emotional and physical impacts are similarly high (6.1 and 5.9/10).

The physical impact of CLL/SLL was the same for men and women pre-Covid, but greater for women today. The emotional impact of CLL/SLL is consistently greater for women than men (today this was 6.8 vs 5.5/10).

Carers and patients were equally impacted physically pre-Covid, but carers significantly more so today (7.3 vs 5.8/10). However carers were significantly more impacted emotionally compared with patients, both pre-Covid (5.7 vs 4.9/10) and today (8.1 vs 6.0/10).

Issues around treatment

74% of patients receive treatment in hospital, regardless of their current situation or where they were diagnosed. Patients who are being monitored may also be seen by their GP.

There is a mix of remote consultations and those carried out face-to-face, across all treatment settings.

Respondents were most satisfied with the support received from Consultants (7.9/10) and Clinical Nurse Specialists (7.7/10), with support from GP nurses (6.6/10) and GPs (6.0/10) ranked lower by the minority of the respondents who had accessed that support.

Women were in general less satisfied with the clinical support they received than men, although both groups were less satisfied with the support from GPs.

Respondents were asked what treatments they had been on since diagnosed with CLL/SLL. The most frequently received treatment was FCR (Fludarabine/Cyclophosphamide/Rituximab) followed by Ibrutinib. Currently the most commonly prescribed regimens are Venetoclax/Obinutuzimab and Acalabrutinib.

Respondents on Active Monitoring feel significantly less well informed about treatment than those on treatment or in remission (6.5 vs 8.2/10). This could be an unmet need for more information or because they do not yet need more information.

Women rated themselves as less well-informed than men did (7.0 vs 7.5/10). Across the age groups, those from 51-60 felt less well informed than those in other age groups.

Vaccinations and Covid

As of May 2022, virtually all respondents had received the 3 Covid Vaccines (98%, 98%, 94%) and most (89%) had had the booster. However, having done so, respondents only felt moderately safe (5.7/10) from Covid.

30% of respondents reported that they had had Covid. 27% of the 30% had ongoing symptoms.

Virtually all respondents (96%) had had a Flu vaccination in the previous year.

Apart from Prevenar 13 (47%) the take up of other relevant vaccinations was less than 25%.

CLL Support

Virtually all respondents were members of CLL Support.

Respondents were asked about their awareness of the various services CLL Support provides and whether they had accessed them. There were few gender differences but men were more likely to be aware of the Champions Group, the newsletter and our lobbying activities and women of the Health Unlocked CLL Forum. Men were more likely to access the newsletter and women health Unlocked and the Helpline. Women tended to have higher satisfaction scores with the services they engaged with.

Extremely high levels of satisfaction were reported across all the services offered.

Next steps

The Trustees are extremely grateful to the 702 individuals who completed the survey. Thank you so much. Without them we would not have all this really valuable information.

The Trustees 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. They will also be considering what further actions to take in response to this immensely helpful feedback. The Trustees plan to repeat the survey at an appropriate time in the future.

Some interesting findings

- The vast majority of respondents had been diagnosed with CLL/SLL incidentally through a medical appointment related to another matter and showed no signs or symptoms.
- Nearly half of those with CLL/SLL indicated they had no other health conditions.
- The CLL/SLL diagnosis has more impact on the quality of life of carers, both physically and emotionally, than it has on the patients themselves.
- The vast majority of patients receive treatment at hospital rather than with their GP, regardless of the stage of any treatment
- Women rated themselves as less well-informed about their CLL/SLL diagnosis and treatment than did men
- Just under a third of respondents reported that they had had Covid.

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

- promote further our CLL Support patient booklet
- distribute our new GP Guide to the healthcare community
- develop guides to help patients know what questions to ask at each stage of their diagnosis and treatment
- use our Conferences to seek the views of patients and carers, both formally and informally
- develop and promote Support ACT and all our emotional wellbeing, diet, exercise and health content
- explore what information and support the carers and partners of those with CLL/SLL would find helpful.
- consider what further information would help patients on Active Monitoring
- encourage further research into the issue of fatigue
- seek to increase access to pneumonia and other vaccines needed by those with CLL/SLL.

Some useful links

- To join CLL Support
- A guide for patients and others affected by CLL or SLL
- Myelo's Hope for CLL and SLL – a short video
- Support ACT – our interactive wellbeing app
- Health Unlocked – our online forum
- Vaccination guide and log for people with CLL/SLL
- Some FAQs including on travel insurance

Thank you so much to all 702 of you who completed the survey!!

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