

## CLLSA quality of life survey – Q&A

### What was the main aim of the quality of life survey?

- The aim of CLLSA's quality of life survey was to explore and understand the quality of life issues faced by those living with CLL in order to outline recommendations for future research and improved care management

### How many people completed the survey?

- A total of 282 CLLSA members completed the quality of life survey between January and December 2013

### What questions were included in the survey?

- The survey consisted for four free-text box questions:
  1. How long have you been diagnosed with CLL?
  2. If you are still in 'watch and wait', what have been the key issue(s) that have most affected your quality of life?
  3. If you have had treatment, please indicate the nature of the treatment
  4. Post-treatment, what have been the issues that have most affected your quality of life?

### How were the answers analysed?

- In order to quantitatively analyse the feedback from the participants, answers were categorised depending on whether respondents reported being in 'watch and wait' or whether they had received treatment
- Answers relating to quality of life issues were further categorised into five areas:
  - **Physical issues:** infections, fatigue, exercise, swelling, sweats, aching bones etc
  - **Emotional wellbeing:** anxiety, concern, stress, self-esteem, helplessness etc
  - **Issues around security:** Money, work, planning for the future, insurance etc
  - **Fun/social issues:** social life, hobbies, holidays etc
  - **Relationship issues:** friends, family, isolation, support etc

### What was the average length of time respondents had lived with CLL?

- The length of time that respondents reported living with CLL ranged from 1.5 months to 288 months (24 years)
- **'Watch and wait':** the average time living with CLL was 58.17 months (4.8 years)
- **Post-treatment:** the average time living with CLL was 90.43 months (7.5 years)

### What were the main quality of life issue for those in 'watch and wait'?

- 148 respondents answered the question relating to quality of life issues during 'watch and wait'.
  - 107 people mentioned physical problems affecting their quality of life
  - 68 people mentioned emotional issues
  - Security, relationship and fun issues were less frequently reported
- Fatigue and tiredness were the most reported physical issues among 'watch and wait' respondents
- Anxiety was the most reported emotional issue

### What were the main quality of life issues for those who had received treatment?

- 109 respondents answered the question relating to quality of life issues post-treatment
  - 76 people mentioned physical problems affecting their quality of life
  - Emotional issues were less frequently reported, as were issues to do with security, relationships and fun
- For those post-treatment, the most commonly reported physical issue was infections, which was reported by 37 respondents. This was closely followed by fatigue/tiredness, which was reported by 36 respondents

### What were the conclusions from the survey?

- Overall, physical issues were the most reported quality of life issues across both 'watch and wait' patients and post-treatment patients
- Fatigue/tiredness was the most reported physical issue in 'watch and wait' patients, however, infections was the most commonly reported physical issue post-treatment
- The incidence of emotional quality of life issues was high among the 'watch and wait' group (85% of respondents stated experiencing anxiety, concern or uncertainty about living with CLL) but this was lower in the post-treatment group (57% of respondents reported experiencing anxiety, concern or uncertainty about living with CLL)
- Issues around security, fun/social life and relationships were less frequently reported in both 'watch and wait', as well as post-treatment patients

### What were the recommendations from the survey?

- **Education on the disease progression of CLL**
  - For '**watch and wait**' patients, education on symptom progression and monitoring will be important
  - For **post-treatment** patients, education on monitoring side effects will be important
- **Advice on managing fatigue and tiredness**
  - Fatigue and tiredness were an issue for 'watch and wait' patients, as well as those post-treatment. This suggests it would be beneficial to ensure advice is available on how to manage this
- **Research into new treatments**
  - Infections and immune system issues increased post-treatment. Therefore research into treatments for those who have already incurred immune system problems is needed for CLL patients
- **Holistic treatment**
  - The incidence of quality of life issues suggest that patients would benefit from being treated in a holistic manner, in which their care is managed by a multidisciplinary team. This would ensure that physical issues, such as infections and emotional issues, such as anxiety, would be managed by the most suitable healthcare professional
- **Conducting a follow-up survey**
  - It is recommended that future surveys should further explore the physical and emotional impact of living with CLL, particularly what support and advice people living with CLL have received
  - A good understanding of what support to offer patients and at what stage of the disease may help towards addressing the anxiety and concern 'watch and wait' patients experience whilst living with CLL, as well as offering guidance and support to those who need practical advice on dealing with the side-effects of the disease or treatments currently available

- Furthermore, a follow-up survey would allow a deeper analysis of the issues related to security, relationships and social life/fun, in order to find out how CLL affects quality of life beyond the physical issues
- Finally, a future survey would also benefit from gathering further demographic data such as age and ethnicity in order to separate out issues related to older age and issues associated with disease progression, as well as initial diagnosis information such as lymphocyte count