Broader considerations in the management of CLL

Best practice CLL monitoring and follow-up guidance for HCPs

Monitoring and follow-up

All members of the MDT are involved in patient follow-up. Ultimately, the consultant is responsible for the care of the patient but follow-up varies from hospital service to hospital service. Some patients are discharged back to primary care at the early stages, with others being monitored by CNS or ANP teams.

It is important that whichever system is used **matches the needs of the population and accounts for the unexpected.** Additionally, it must be able to methodically monitor patients who are either on watch and wait for evidence of disease progression, or on treatment to detect and monitor TEAEs.

Monitoring is dependent upon:

- Symptoms
- Response to treatment
- Blood results
- Time to remission
- Side effects

How often should follow-up happen?

Life-long observation and follow-up is recommended for all people living with CLL.[1] The nature and frequency of follow-up review and investigations will be tailored by disease presentation, treatment type, treatment toxicities, disease-related effects, comorbidities and psycho-social factors.[2]

In totally asymptomatic cases, it is recommended that follow-up occurs **every 3–12 months** depending on the dynamics of the disease.[1]

People living with progressive disease will require more frequent monitoring **(1–3 months)** depending on the pace of change.[2]

Those established on oral targeted therapies will need to be seen for assessment of response, tolerability to the medications and repeat prescriptions. Intervals of **12 weeks** is common for this.[2]

Those on follow-up after completion of treatment should be seen as **clinically appropriate,** reverting to the same schedule as those exhibiting stable disease if there is no sign of recurrent disease.[2]

Remote systems for follow-up should be considered, with several options in existence and evidence of high levels of patient-reported satisfaction.[2]

What is included in monitoring and follow-up?

As well as discussing current health status and symptomology, the following procedures can be completed as clinically indicated.

Regular monitoring and follow-up

Blood testing: FBC, lymphocyte doubling time, urea and electrolytes, LFTs, B2M test.[3] Special attention should be paid to the appearance of autoimmune cytopenia [1]

Physical examination: Including palpation of the lymph nodes, spleen and liver[1]

Patient education: Supporting the patient in understanding risks that can develop because of CLL. All patients should be made aware of the risks of secondary malignancies and of the increased risk of cardiovascular disease[1,2]

Carried out upon disease progression

Genetic testing (FISH, genetic genotyping): To identify abnormal genes

Imaging (X-Ray, CT, PET): To investigate certain symptoms or evaluate disease progression. Surveillance imaging is not recommended[3]

BMB: In cases with atypical features or to rule out other causes of anaemia/thrombocytopenia[2,3]

Available services

Using the Royal Marsden Hospital, London as an example, below are some examples of services available to patients that demonstrate best practice guidance in monitoring and follow-up:

- Easy route for patients to either email or call their CNS if there are issues
- 24-hour hotline contact centre for patients with urgent queries relating to their diagnosis
- Providing patients with consultant contact cards so patients have a point of contact

More information

Important avenues of support for people living with CLL include:

- **Direct and easy access** to the CNS or ANP team via email or telephone
- **CLL Support** is a patient-led UK charity that aims to empower those affected by CLL through education and access to reliable information. It supports people living with CLL by informing them of advancements in treatments and research
- **The Leukemia & Lymphoma Society i**s the world's largest non-profit health organisation dedicated to funding blood cancer research
- **Lymphoma Action** is the UK's only charity dedicated to lymphoma, providing a support network and information endorsed by medical experts
- **Cancer Research UK** provides high-quality information to help inform those living with CLL and their families, as well as access to support organisations
- **Blood Cancer UK** is a charity that aims to ensure that everyone affected with blood cancer has access to the right support at the right time
- **Macmillan Cancer Support** is the UK's leading cancer care charity, which focuses on raising money to provide a range of support services and networks to people living with cancer

Best practice guidance

Monitoring protocols can vary from one service to another and need to be individualised for the person living with CLL:

- Those newly diagnosed with CLL should be seen again soon after the initial appointment – not from a medical viewpoint, but from an educational perspective, to provide guidance on who will be involved in their medical care so they can identify the appropriate HCPs to direct specific questions to
- CNSs usually follow up with patients a week after diagnosis to answer any further questions and during the watch and wait period, patients are followed up with a mix of face-to-face and virtual appointments
- Depending on the dynamics of the disease, follow-up may occur at 3 or 6 months, or annually. As the need for therapy approaches, the time between appointments shortens, and the discussion around treatment or clinical trial suitability begins
- When on treatment, the time between appointments is dictated to a certain degree by the type of treatment being administered and when each cycle needs to be prescribed. Efficacy of the selected drugs and potential toxicities should also be evaluated

ANP, advanced nurse practice; B2M, beta-2 microglobulin; BMB, bone marrow biopsy; CLL, chronic lymphocytic leukaemia; CNS, clinical nurse specialist; CT, computerised tomography; FBC, full blood count; FISH, fluorescence in situ hybridisation; HCP, healthcare professional; LFT, liver function test; MDT, multidisciplinary team; PET, positron emission tomography; TEAE, treatment-emergent adverse event

1. Eichhorst B, et al. Ann Oncol 2021;32:23–33; 2. RM Partners. Pan-London haemato-oncology clinical guidelines. 2020. https://rmpartners.nhs.uk/wp-content/uploads/2020/01/Pan-London-CLL-Guidelines-Jan-2020.pdf. Accessed 3 October 2022; 3. Blood Cancer UK. CLL (chronic lymphocytic leukemia) symptoms and diagnosis. 2022. https://bloodcancer.org.uk/understanding-blood-cancer/leukaemia/chronic-lymphocytic-leukaemia/cll-symptoms-diagnosis/cll-tests-after-diagnosis/

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