Information for GPs on managing and supporting patients living well with high-count Monoclonal B-cell Lymphocytosis or CLL

You are receiving this leaflet because one of your patients has been diagnosed with either high count monoclonal B-cell lymphocytosis (MBL) or chronic lymphocytic leukaemia (CLL). This leaflet gives general practitioners information about referrals to OUH Haematology Services, and other issues pertinent to supporting people with these conditions.

About CLL

CLL is a chronic lymphoproliferative disorder. It is staged as follows:

Stage A	**Less than three groups of enlarged lymph nodes*** **No anaemia/thrombocytopenia**
Stage B	More than three groups of enlarged lymph nodes* No anaemia/thrombocytopenia
Stage C	More than three groups of enlarged lymph nodes* Anaemia and/or thrombocytopenia

Figure 1 Binet Stage system for CLL patients

*as assessed clinically

The indications for treatment depend on the stage and include:

- progressive, bulky lymphadenopathy
- "B-symptoms" (see table below)
- progressive anaemia, progressive thrombocytopenia or rapidly rising lymphocytosis.

About MBL

CLL arises from a pre-malignant condition called monoclonal B-cell lymphocytosis (MBL). High-count MBL is defined as the presence of a clonal B-cell population of greater than 0.5x10^9/l but less than 5x10^9/l when tested by flow cytometry

Individuals with MBL have an annual progression risk to Stage A CLL of approximately 4%.

Referral to OUH

Individuals with high-count MBL or Stage A CLL should be considered by the GP for referral to the OxCom clinic. Please see referral contact details below.

If the patient is asymptomatic, this appointment is **not urgent**.

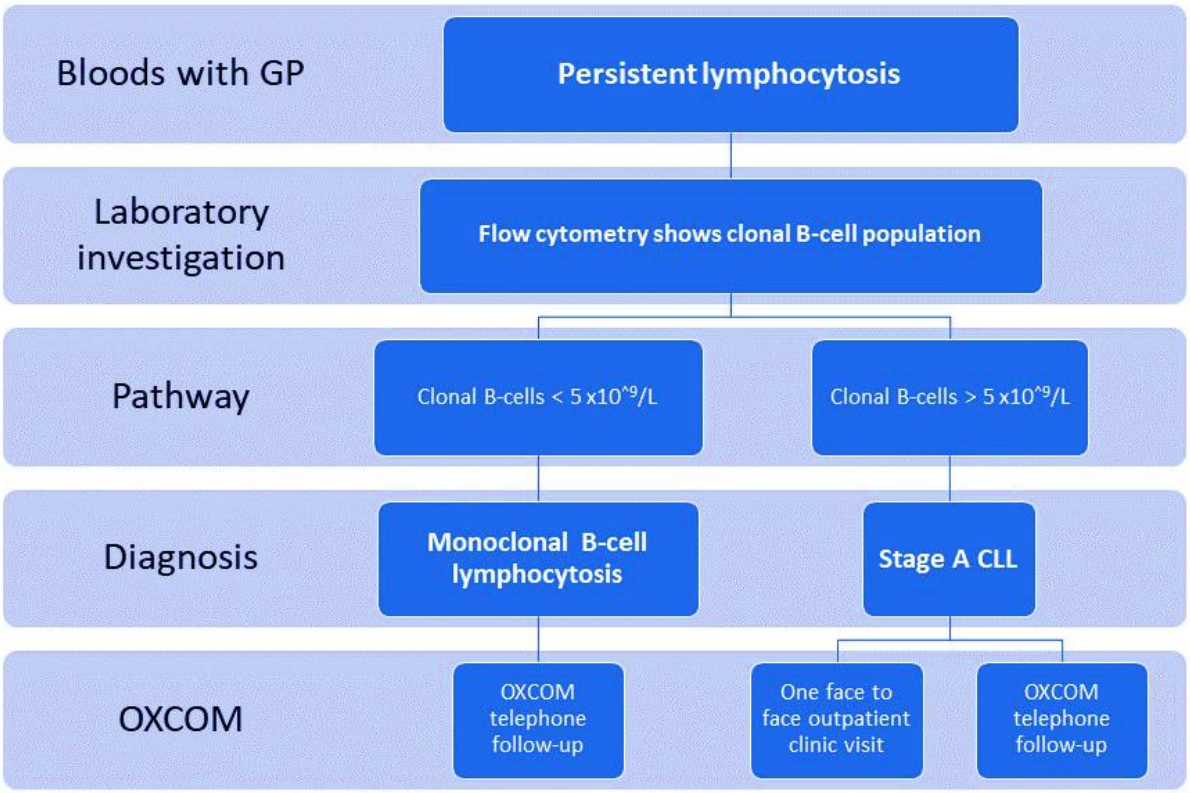

Figure 2 Referral pathway for new lymphoproliferative disorders

If a patient has known CLL and has been stable for some time in primary care, their follow up is generally moved to the OxCom service from the very start.

Stage B and C patients will be managed in the CLL outpatient clinic.

Progression of CLL

For patients with features of progressive CLL, please treat as an urgent referral and **refer the patient under the 2WW pathway** to the CLL clinic. Please refer to the ALERT symptoms below:

Progressive falling blood counts **(Alerts to be sent by OUHFT lab)**	Haemoglobin < 110 g/L Platelets < 100 x 10^9/L Lymphocyte count > 25 x 10^9/L and lymphocyte count doubling ≤ six months
New swelling/lump	
B-symptoms	Fever of unknown cause Drenching night sweats Persistent new fatigue Weight loss ≥ 10% in six months

Figure 3 ALERT symptoms of progressive CLL of any stage that require referral to specialist CLL Team

Blood tests

Blood request packs will be sent to the patient by the OxCom clinic every six months or at the appropriate interval.

All patients will either attend the GP phlebotomy service or - if not available - the OUHFT phlebotomy service.

Management of Chest infections

Patients with CLL are prone to chest infections and development of secondary bronchiectasis. Most patients with CLL will develop secondary immune defects including secondary hypogammaglobulinaemia. We manage **recurrent** chest infections with Immunology and Respiratory services.

1st line	Co-amoxiclav 625 mg tds for 14 days
2nd line	Clarithromycin 500 mg bd for 14 days
Recurrent/unresolved chest infections	Please discuss with haematology team (see contact details below)

This guidance may be modified to account for the patient's personal history e.g allergies, previous infections.

Vaccinations

CLL patients should receive the seasonal flu vaccine annually. Members of the same household as the person with CLL should ideally have the seasonal flu vaccine annually. The live attenuated vaccine for seasonal flu is typically administered to healthy children between 2 and 18 years. While there is a theoretical risk of transmission of the virus from a child receiving the vaccine to an immunocompromised person, there have been no reported cases of illness or infections from the vaccine virus. However, as a precaution, patients should avoid contact with children for one week after the live vaccine.

CLL patients are at increased risk of mortality from invasive pneumococcal infection. In line with the **updated Department of Health recommendations**, CLL patients should receive, the pneumococcal conjugate vaccine (Prevenar® (PPV13)) followed by the pneumococcal polysaccharide vaccine (PPV23, Pneumovax II®) at least two months later, irrespective of previous vaccinations. Pneumococcal polysaccharide vaccination should be repeated at five yearly intervals.

Patients who have been previously vaccinated with pneumococcal vaccine **only (PPV23 Pneumovax II®), should receive a "catch up" dose of the pneumococcal conjugate vaccine (PCV13, Prevnar®)**

CLL patients should NOT receive live or attenuated (weakened) viruses. These include yellow fever, oral polio, measles, mumps and rubella (MMR) and the live shingles vaccine (Zostavax). **Please be aware of vaccination requirement if the patient is seeking to travel abroad and avoid live vaccination.**

CLL patients should receive the non-live (Shingrix) shingles vaccine if eligible. If a patient has a history of shingles, then they should still receive lifelong Aciclovir as secondary prophylaxis in addition to the Shingrix vaccine.

If a patient has received chemoimmunotherapy or venetoclax plus anti-CD20 antibody treatment, we recommend the above vaccinations for CLL patients, to be given once the absolute lymphocyte count is > 1.0 x 10^9/L OR the patient is beyond 6 months from the end of treatment, whichever occurs sooner.

The current approved Covid-19 vaccinations (Pfizer, AstraZeneca and Moderna) are safe for CLL patients. We recommend all CLL patients to have the vaccine. CLL patients are in the 'clinically extremely vulnerable' group regardless of their stage of CLL. Household contacts over of people with CLL should be vaccinated against COVID-19 to minimise the risk of transmission.

General health advice

CLL patients who have had shingles should receive lifelong Aciclovir 200mg TDS as secondary prophylaxis once initial treatment has been successfully completed.

Patients should be encouraged to stop smoking.

CLL patients are at increased risk of UV-related skin damage and skin cancers. CLL patients should be encouraged to wear sunscreen daily with at least a SPF30 and a 5-star UVA rating.

Useful links

CLL Support Association: http://www.cllsupport.org.uk/

Bloodwise: https://bloodwise.org.uk/info-support/chronic-lymphocytic-leukaemia/what

Leukaemia Care:http://www.leukaemiacare.org.uk/chronic-lymphocytic-leukaemia

Macmillan: https://www.macmillan.org.uk/information-and-support/leukaemia/chronic-lymphocytic

Cancer Research UK: http://www.cancerresearchuk.org/about-cancer/chronic-lymphocytic-leukaemia-cll

Haematology Website: http://oxford-haematology.org.uk

Contact information

CLL Clinical Nurse Specialist:	01865 235284 (Monday, Wednesday & Thursday)
Contact for Re-referral or Any Queries:	Secretary 01865 235184
Haematology Registrar:	via Hospital Switchboard: 0300 304 7777
OxCom Service	Sharon Gray pathway coordinator and Julia Evans Specialist nurse 01865 235980 ouh-tr.oxcomcllservice@nhs.net