

Please delete before use		Letter Name	Haem_TS_CLLWatchandWait_v1_072024  Version 1.0
Ratified by Pathway Board	July 2024	Created	Circa 2020
Consulted	Haematology CNS teams across GM	Reviewed	July 2024
Contact point for amendments	iennifer.roche8@nhs.net Pathway Board Manager  Andrea.webber@nhs.net Personalised Care Manager	Next Review date	July 2026

Please delete this title and box after reading these instructions.

**GM Cancer standard template** 

Chronic Lymphocytic Leukaemia (CLL) - Watch and Wait

Remove all wording that does not apply to a particular patient in order to personalise it to the individual.

If you need to localise this treatment summary, e.g. job titles do not match those used in your Trust or adding your Trust logo, please do so, but please retain all other information.

Remember to ensure sections don't overrun onto the next page or titles separate from the body of the text before sending.

Font should be Arial size 12

#### For GP use only: please code this letter as cancer treatment completed:

Snomed code 413737006	Cancer hospital treatment completed (situation)	
8BCF.00	Read	Cancer hospital treatment completed

Please take this with you to any planned or emergency visits to hospital. It could help the doctors and nurses with your care.

Patient Name	Hospital Name
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Patient Address Hospital Address

Date of Birth: Hospital No:

NHS No:

#### Dear [INSERT PATIENT NAME]

Please find below the summary of your diagnosis and ongoing management plan for your haematological malignancy.

Your doctor and your multidisciplinary team have reviewed all your clinical findings and results. Currently you do not need treatment for your underlying blood condition as it is not causing any symptoms. Many people diagnosed with CLL remain stable for months or years and some people never need treatment. If you do eventually need some treatment, you will respond just as well to this as if treatment was started immediately.

You will see your Haematologist or GP for regular monitoring; based on these assessments we will tell you if your disease is starting to require some treatment. The assessment will be in the form of blood tests, assessment of your wellbeing and a physical examination. Your Haematologist will decide how frequently you need to be seen- this may range from every 2-3 months to once a year.

Please remember that if you do feel anxious or would like further advice or to talk through a concern or symptom at any time you are welcome to contact the haematology team. They are there to support you and know about a wide range of resources and services that have been designed to help you.

#### **Your Key Contact Numbers:**

Clinical Nurse Specialist	Name:
•	Control Namehous
	Contact Number:
Cancer Care Coordinator/ Cancer	Name:
Support Worker	Contact Number:

Please note that there is no haematology service at the weekend/bank holidays. If you require immediate support, please call NHS 111, or the district nurses (if you have a designated district nurse) for advice. If you feel you need more immediate attention, please attend your local Accident and Emergency Department.

# **Diagnosis and Treatment to Date:**

Diagnosis:	Chronic lymphocytic leukaemia (CLL)	Date of Diagnosis:	
BINET Stage:			
MDT Management Decision: Watch and Wait			

# Alert symptoms that require referral back to your specialist team.

If you develop any of the symptoms below, in-between your regular clinic appointments, you should contact the department for advice:

- Unexplained weight loss
- Severe night sweats (drenching the bed)
- Swelling of your glands

# Secondary Care Ongoing Management Plan (tests, appointments etc) [Delete AS APPROPRIATE]

Your Haematologist will discuss your out-patient follow up with you. You can usually expect to see your doctor or a member of the team at regular intervals:

- 3-4 monthly in the first year
- 4-6 monthly in the second year
- Ongoing monitoring dependent on signs of any disease progression but may extend up to 6-12 monthly from year 3.

At these appointments you will have some blood tests undertaken and a physical examination if needed.

Additional investigations may be required if there are signs of change.

Summary of the consultation about your cancer and future progress		
Please avoid medical jargon.		

# General Information relating to your lifestyle, wellbeing and support needs:

A number of lifestyle choices can affect your ongoing health and wellbeing. This is an important time for you to regain or feel more in control of your health and wellbeing.

#### Managing your wellbeing: Looking after yourself in good times and bad

We can all struggle on a day-to-day basis. Dealing with a diagnosis of cancer and undergoing treatments can be particularly challenging and it may add an additional level of complexity in looking after yourself when you are not feeling your best. You may notice that you are more worried and stressed than usual, or you may feel sluggish and low. Adjusting and adapting to everything you have been through can take time, and sometimes it needs a bit of extra support and effort to figure out how to be okay when life is proving challenging.

# **Exercise and Physical Activity:**

It has been proven that engaging in regular exercise or physical activity (ideally 3 times a week) can address feelings of anxiety, experience of fatigue and low mood. It can also improve heart health, muscle strength and maintaining a healthy weight. Even a small amount of physical activity is helpful if you are able. You may need to change the type of activity you do to your specific needs and limitations, so we advise talking to your GP before you start. Please visit <a href="https://www.prehab4cancer.co.uk">www.prehab4cancer.co.uk</a> for more information and helpful resources.

#### **Eating Well:**

Eating a healthy balanced diet is an important part of maintaining good health and can help you feel better. This means eating a wide variety of foods in the right amounts and maintaining a healthy body weight. Depending on the surgery you have had on your bowel you may need additional advice and support to achieve this.

# Stopping smoking:

If you are a smoker, giving up smoking will improve blood circulation, lower blood pressure, reduce the risk of a stroke, improve your immune system (ability to fight infection), and help to improve your breathing or stop it from getting worse.

# Reducing alcohol to within safe limits:

The current UK guidelines to keep health risks to a low level for both men and women are to avoid or not to regularly drink more than 14 units a week (6 pints of average-strength beer or 10 small (125ml) glasses of low-strength wine).

Patient Information Guide on Chronic Lymphocytic Leukaemia

If you would like more help and advice, please speak to your Haematology Team.

Treatment Summary Completed by:	
Copy sent to GP:	
Copy sent to consultant:	
Copy sent to other Health Care Professional(s):	[INSERT DETAILS]

Personalised Care and Support Plan   (attached)		
Prescription Charge exemption certificate	Free prescription reminder	
Health and Wellbeing Information and Support given	See referral advice given on services available	
Advice given to apply for benefits assessment if required	Yes/No/Not applicable	
Advise entry onto primary care palliative or supportive care register?	Yes/No/Not applicable	

# SR1 application completed?

Yes/No/Not applicable

Required GP actions (e.g. ongoing medications/ osteoporosis screening, Cancer Care Review Date(s) due)

- Annual flu vaccination.
- Annual well person review
- COVID vaccinations as per government guidelines
- Shingles (non-live) vaccination. Shingrix is recommended for immunocompromised patients

Additional resources and information for primary care staff are available through www.gatewayc.org.uk