

European Insight Paper

Time Off Treatment in CLL: The ECLLA European Holistic Framework

Introduction

This European Insight Paper was developed by the European CLL Association (ECLLA) to explore the evolving role of treatment-free care in chronic lymphocytic leukemia (CLL). It brings together published evidence, international patient experience data, and the key themes emerging from the ECLLA Multi-Stakeholder Panel Discussion, translating these into practical recommendations through the ECLLA European Holistic Framework.

Despite significant advances in CLL treatment, comparatively little attention has been given to how patients are supported during treatment-free periods. ECLLA developed this publication to help address this gap and encourage a more holistic approach to care across Europe.

The publication introduces the ECLLA European Holistic Framework for Treatment-Free Care, highlighting the importance of integrating clinical excellence with shared decision-making, psychological wellbeing, survivorship, care partner support, and equitable access to care across Europe.

It is intended to support healthcare professionals, patient organisations, researchers, policymakers, care partners, and other stakeholders working to improve treatment-free care in CLL. Patient perspectives are intentionally integrated throughout to reflect the principles of person-centred care and the lived experiences that informed the ECLLA European Holistic Framework.

This publication was developed by the European CLL Association (ECLLA) and supported by AbbVie through an educational grant. ECLLA retained full editorial responsibility for the content. To our knowledge, this is the first European multi-stakeholder insight paper exploring treatment-free care in chronic lymphocytic leukemia from a holistic perspective.

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Why Time Off Treatment Matters

Advances in targeted therapies, offering greater precision and improved efficacy, have enabled time-limited treatment approaches, including **fixed-duration therapies**, transforming the management of chronic lymphocytic leukemia (CLL).

Increasing numbers of people living with CLL are now able to experience planned treatment-free periods as a result of these advances, creating new opportunities to improve quality of life and reduce treatment burden.^{1,5}

According to the **2026 EHA Guidelines on the Management of Chronic Lymphocytic Leukemia and Richter Transformation**¹, time-limited treatment can achieve deep and durable responses for a significant proportion of patients while reducing long-term treatment burden. As treatment-free periods become an increasingly achievable outcome of modern CLL care, they also represent a new phase of the patient pathway requiring ongoing support, education, and follow-up.

Both continuous and fixed-duration targeted therapies are established approaches in CLL, with the most appropriate strategy depending on the biological characteristics of the disease and the individual patient. Fixed-duration therapies offer a time-limited treatment option that enables patients to experience planned periods without active therapy. **Treatment duration should always be individualised through shared decision-making based on disease-related prognostic factors, individual patient characteristics, the best available evidence, and patient preferences.**^{1,16}

Beyond individual patient benefits, treatment-free care may also have wider implications for healthcare systems and society. These broader benefits should be considered alongside patient experience, quality of life, and equitable access when shaping future CLL policy and care.

For many people living with CLL, treatment-free periods represent far more than a clinical milestone. They offer an opportunity to regain independence, reconnect with work and family, and live beyond the routine of treatment. At the same time, they may bring uncertainty about disease progression, future treatment options, and long-term health.

Treatment-free care should therefore be recognised as an active phase of CLL management that extends beyond disease control. It requires structured monitoring, shared decision-making, psychological support, patient education, and equitable access to multidisciplinary care to help people live well between treatments.

Why are fixed-duration therapies changing CLL care?

- Deep and durable clinical responses
- Planned treatment-free periods
- Reduced cumulative treatment exposure and potential toxicity burden
- Future treatment flexibility
- Potential quality-of-life benefits

Patient Evidence Box

58% of patients view treatment-free periods positively.⁹



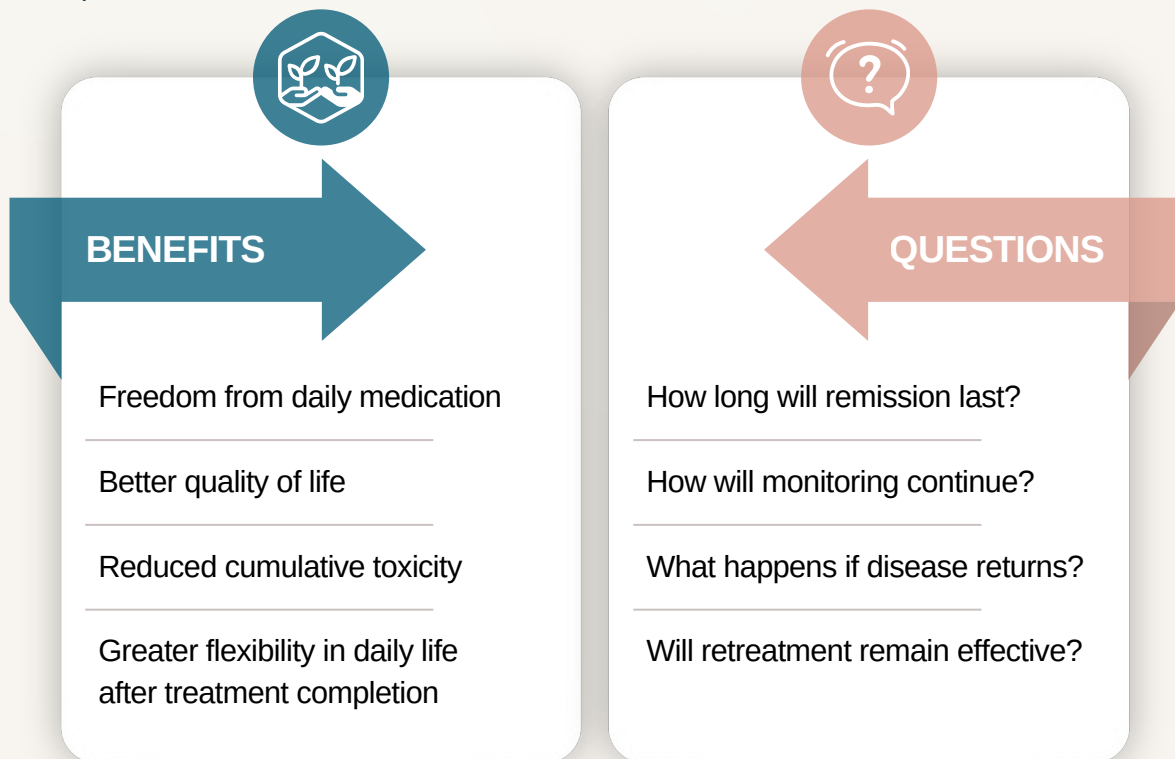
Treatment-free care is not the absence of care. It is a new phase of comprehensive CLL management.

ECLLA Panel Insight

Redefining Success

Traditional measures of success in CLL focus on progression-free survival and overall survival. While these outcomes remain essential, patients increasingly define success in broader terms: **freedom from treatment, fewer hospital visits, improved quality of life, and the ability to return to everyday activities.**⁷

Fixed-duration therapies produce successful treatment outcomes for many people living with CLL by enabling planned treatment-free periods.⁵ However, they also require careful planning, communication, and follow-up.



Questions to Support Shared Decision-Making

- ☐ Is fixed-duration treatment appropriate for the patient?
- ☐ What happens after treatment ends?
- ☐ How will the patient be monitored?
- ☐ What treatment options remain if the patient relapses?

Patient Evidence Box

- 52%** of CLL patients reported being involved as much as they wanted in treatment decisions.⁹
- 70%** were not given more than one treatment choice before their most recent therapy (supporting the need for shared decision-making as a measure of success).¹¹
- 76%** preferred to make treatment decisions themselves.¹¹

Living Beyond Treatment

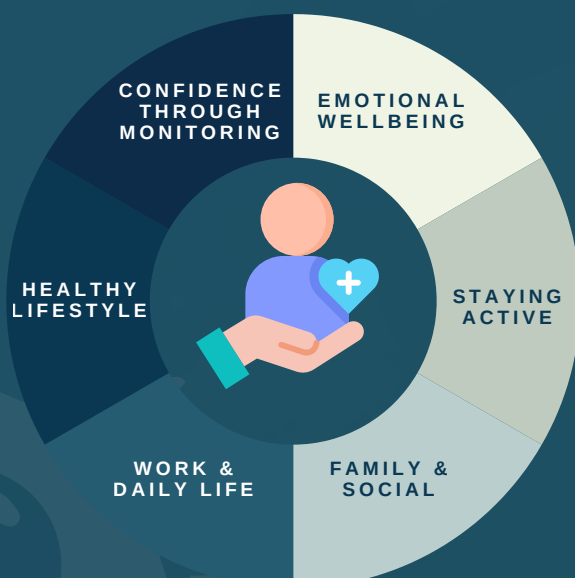
Treatment-free periods often represent both hope and uncertainty. Many patients describe relief at completing treatment while simultaneously worrying about disease progression or relapse. These emotions are a normal part of living with chronic lymphocytic leukemia and reinforce the importance of psychological support throughout the CLL pathway.^{11,15} Family members and caregivers also experience uncertainty. Their emotional wellbeing influences patient outcomes and should be recognised within holistic care models.

The Emotional Pathway of Time Off Treatment

This pathway illustrates common emotional experiences reported by people living with CLL during treatment-free periods.



Living Well Between Treatments



Patient Evidence Box

46% reported being afraid of relapse or disease progression.¹¹

66% reported feeling anxious since diagnosis.⁹



"Treatment-free does not always mean worry-free."

ECLLA Panel Insight

Time Off Treatment Is Still Active Care

Stopping treatment does not mean stopping care. Patients continue to require monitoring, education, infection prevention, fatigue management, and support for emotional wellbeing.^{1,17} **Treatment-free care should therefore be considered an active phase of survivorship.**

The Four Pillars of Treatment-Free Survivorship

1.

Monitoring: Regular clinical monitoring provides reassurance, enables early detection of disease changes, and supports timely clinical decision-making throughout treatment-free care.

2.

Immune health: Maintaining immune health through infection prevention, vaccination, and healthy lifestyle measures helps reduce complications and supports overall wellbeing.

3.

Education: Access to clear, reliable information empowers patients to understand their condition, recognise important symptoms, and actively participate in their care.

4.

Psychological support: Emotional support helps patients manage uncertainty, build resilience, and maintain confidence post CLL diagnosis and beyond.¹⁵

Patient Evidence Box

- 44%** were given written information at diagnosis.⁹
- 45%** of patients on active monitoring felt "definitely confident" recognising symptoms of progression.⁹
- 48%** did not receive information about clinical trials.¹¹
- 51%** fully understood explanations of their diagnostic results.¹¹
- 52%** self-managed symptoms without professional support.⁹

These findings collectively demonstrate the need for better education, communication, and structured follow-up during treatment-free periods.

Supporting Treatment-Free Care

- ✓ Know your monitoring schedule
- ✓ Report new symptoms
- ✓ Maintain vaccinations
- ✓ Stay physically active
- ✓ Follow regular cancer screening recommendations
- ✓ Seek emotional support

The ECLLA European Holistic Framework

The ECLLA European Holistic Framework for Treatment-Free Care in CLL is ECLLA's proposed model for delivering high-quality, person-centred treatment-free care across Europe. It recognises that living well beyond treatment depends on more than disease control, bringing together six interconnected pillars that support the clinical, emotional, and practical needs of people diagnosed with CLL across Europe.

01

Evidence-Based Personalised Care

Deliver evidence-based, personalised care that reflects the latest scientific advances and each patient's clinical profile, preferences, and goals.¹ High-quality care should be consistent, multidisciplinary, and centred on achieving the best possible long-term outcomes.

02

Shared Decision-Making

Empower patients to become active partners in decisions about their care by providing clear, balanced, and accessible information. Meaningful dialogue builds trust, supports informed choices, and ensures that treatment aligns with individual values and priorities.¹⁶

03

Psychological Wellbeing

Recognise emotional wellbeing as an essential component of high-quality CLL care. Access to psychological support and treatment, peer networks, and open communication can help patients manage uncertainty and maintain resilience throughout their treatment journey.^{11,15}

04

Monitoring & Survivorship

Treatment-free periods require structured follow-up that extends beyond routine clinical monitoring. Ongoing education, symptom awareness, infection prevention, and survivorship support help patients live well between treatments.^{1,17}

05

Care Partners & Patient Organisations

Care partners and patient organisations play a vital role in providing practical support, education, advocacy, and reassurance. Recognising and involving them as partners in care strengthens outcomes for both patients and their families.

06

Equity & European Policy

Every person living with CLL should have equitable access to innovative therapies, specialist care, multidisciplinary survivorship services, and reliable information, regardless of where they live. European collaboration should support implementation of evidence-based guidance, reduce disparities and promote high-quality, person-centred care across Europe.¹⁸

A European Call to Action

The future of CLL care is not defined solely by longer survival. It is defined by how well people live during and beyond treatment. As treatment-free periods become an increasingly achievable goal, healthcare systems must evolve to ensure that every person diagnosed with CLL receives the support, information, and confidence needed to thrive throughout this phase of active care.¹⁸

Achieving this vision requires collective action. **Healthcare professionals, policymakers, researchers, patient organisations, and industry** all have a role in advancing person-centred, equitable, and holistic treatment-free care.

We call on stakeholders to:

Healthcare professionals (HCPs)



Recognise treatment-free care as an active phase of CLL management by embedding shared decision-making, patient education, and holistic survivorship support throughout the patient pathway.

Healthcare Systems



Develop integrated multidisciplinary survivorship pathways that provide structured monitoring, psychological support, education, and coordinated care during treatment-free periods.

Researchers



Generate robust evidence on patient-reported outcomes, quality of life, survivorship, and the long-term impact of treatment-free care to inform future practice and policy.

Industry



Work in partnership with patients and healthcare professionals to advance patient-centred innovation and strengthen the evidence supporting the holistic value of treatment-free care.

Policymakers



Promote equitable access to evidence-based diagnosis, innovative therapies where clinically appropriate, and high-quality supportive care while encouraging implementation of clinical guidance across Europe.

Patient organisations



Educate, empower, and connect people living with CLL and their care partners, while advocating for person-centred care, equitable access, and meaningful patient involvement in decision-making.

Consensus Statement

Time off treatment is not time off care. It is an active phase of the CLL pathway that should be recognised as requiring structured monitoring, shared decision-making, psychological support, survivorship planning, care partner engagement, and equitable access to person-centred care for all people living with CLL across Europe.

ECLLA calls on all stakeholders to work together to recognise treatment-free care as an essential phase of CLL management and to ensure equitable access to holistic, person-centred care across Europe.

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Imagine a Europe where:



every patient **understands** their disease



every patient has access to **shared decisions**



every patient receives **structured survivorship care**



every patient **lives well** during and between treatments



Together, we can make this a reality for **every person** living with CLL.



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