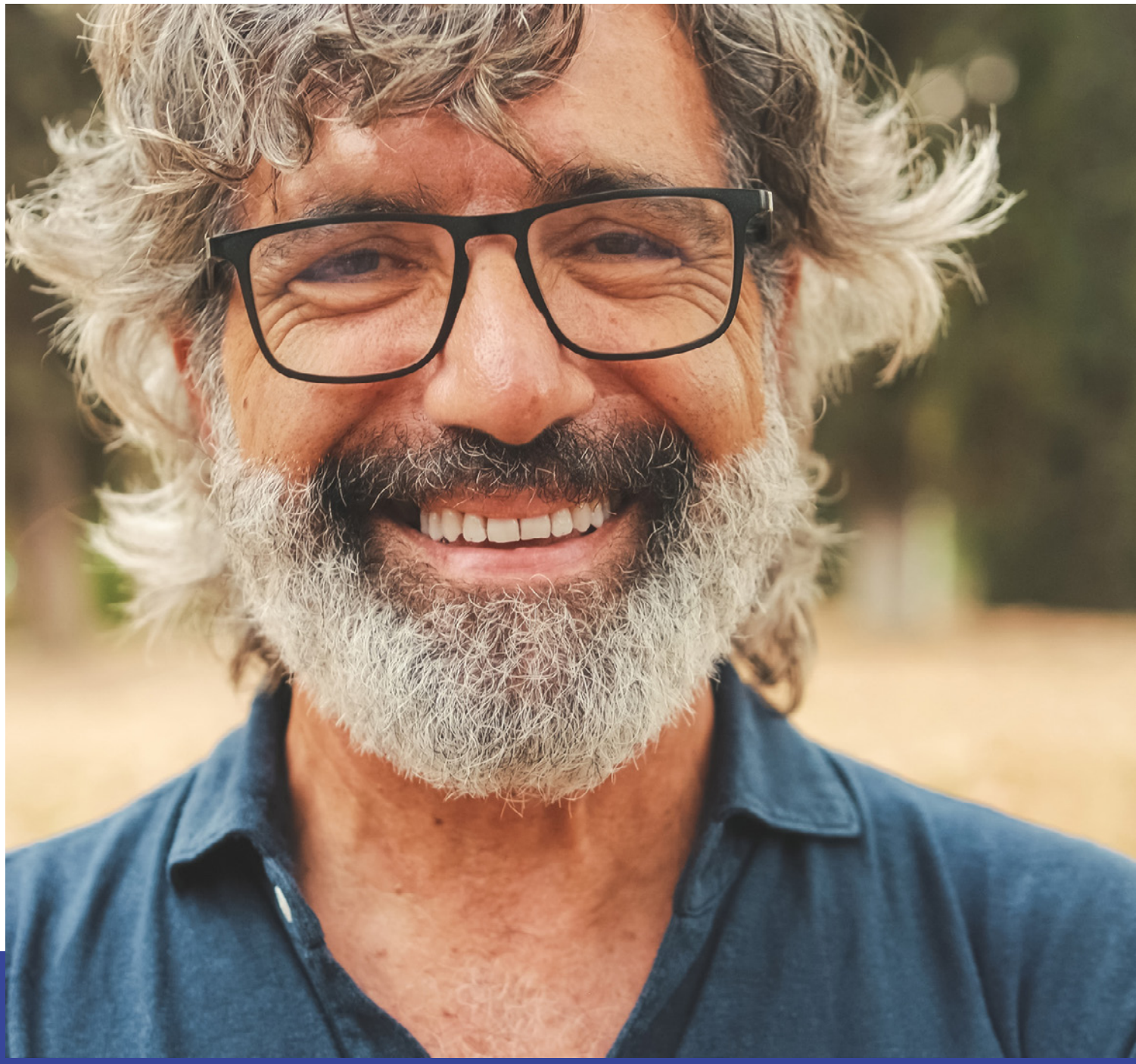
A Charter for Improving Care for People Living with Chronic Lymphocytic Leukemia

Six Principles for Excellence



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Foreword

CLL is the most common leukemia in adults in the Western world, and it predominantly affects older people.[1] It is a complex disease with a highly variable course because it can be slow-growing and people living with CLL may be asymptomatic, or it can be aggressive and life-limiting.[2] The chronic nature of CLL means that people with the condition have different needs to other types of cancer. We know that there are a range of unmet needs experienced by people living with CLL and that some of the thingsthat matter most to them are not currently supported through their journey.[3]

As global patient advocates, we believe it is essential to raise awareness and understanding among people living with CLL, caregivers, healthcare professionals, policymakers and the public about the impact of CLL and opportunities to improve care. We believe that people living with CLL deserve an accurate diagnosis and should be empowered to play an active role in their care. They should be treated holistically as a person, not simply by their CLL diagnosis.

This charter has been developed with input from patient advocacy organizations, people living with CLL and clinical specialists. It highlights the elements of care and support that matter most to people living with CLL as they navigate life with their diagnosis. We urge health services, healthcare professionals, policymakers and patient support services to review this charter and embed its principles within their work to ensure that the things that matter most to people living with CLL are hardwired into healthcare systems, support and services.

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Introduction

Chronic lymphocytic leukemia (CLL) is a form of slow-growing blood cancer. Lymphocytes are a type of white blood cell and a crucial part of the body's immune system. When a person has CLL, their body makes abnormal lymphocytes. This compromises their immune system and makes them less able to fight off infections.[4]

CLL is the most common type of leukemia in adults in the Western world[1] and incidence is increasing, with over 100,000 new diagnoses reported globally in 2019, more than a 150% increase compared to 1990.[1] CLL typically occurs in adults but is commonly diagnosed in people 70 and older.[1] As the global population ages, the incidence of CLL is predicted to continue rising.[1] CLL is also more common in men than women,[4] and white people more than people of African, Asian or Latin American origin.[5]

CLL is a chronic and variable disease. It is often discovered by chance following routine blood tests.[6] Some people may experience no symptoms (asymptomatic disease) and require no treatment, while others may have aggressive disease resistant to treatment, leading to a short overall survival.[2] CLL also often manifests as a chronic, incurable multisystem inflammatory disease.[7] Given the nature of the disease, people living with CLL, clinicians and the advocacy community have identified many unmet needs.[3]

Encouragingly, studies have shown that mortality rates from CLL are reducing due to more effective and less toxic therapies becoming available.[7] In the US, a study found that people diagnosed in 2015 had a relative five-year survival rate of more than 92%, compared with 87% a decade earlier.[7] This trend of improving five-year survival rates has been seen in several countries, including Australia,[8] the Netherlands,[9] the Nordics[10] and Germany.[11]

Although some international guidelines for CLL exist,[12,13] these are mainly focused on the clinical approach to managing and treating the disease in people living with CLL. They do not take a holistic view of all the care and support needs an individual with CLL might have.

This charter sets out the standards of care that people living with CLL worldwide deserve. The ambition to improve care and quality of life for all people living with CLL globally underpins all the principles in this charter. Therefore, it recognizes and considers the disparities between higher income and lower-and-middle-income countries, how this may determine local optimum care models and the feasibility of implementing policy recommendations.

100,000 new diagnoses reported globally in 2019, more than a 150% increase compared to 1990.[1]

About the charter

This charter was initiated and funded by AstraZeneca following a roundtable meeting at the 2024 European Hematology Association Annual Conference, which brought together leading patient advocacy groups and clinicians to discuss the key unmet needs facing people living with CLL and the opportunities to reform and improve care. The charter has been further refined by a wider group of clinicians and patient advocacy leaders across a series of meetings in 2024.

This charter outlines six principles that we, as global CLL patient advocates, believe anyone living with CLL should expect from their healthcare experience, which align with bestpractice clinical guidelines, personal preferences and local health system specifics. The charter aims to mobilize governments, healthcare providers and healthcare decision-makers worldwide to deliver meaningful improvements in CLL care.

CHARTER PRICIPLES

Principle 1:
I deserve access to an ***accurate and definitive*** diagnosis

Principle 2:
I deserve access to ***high-quality information,*** tailored to my needs and care pathway, in a language I understand

Principle 3:
I deserve access to ***shared decision-making*** throughout my care pathway

Principle 4:
I deserve access to ***affordable, effective care and a full range of specialists*** to support me through my cancer journey

Principle 5:
I deserve ***emotional and psychological support*** from clinical, allied health professionals and support networks

Principle 6:
I deserve access to a ***care model that recognizes CLL's total impact,*** including its secondary effects and complications

PRINCIPLE 1:

I deserve an *accurate and definitive* diagnosis

- A complete blood count and flow cytometry test are essential for ensuring an accurate and definitive diagnosis of CLL.[14,15] The variable nature of CLL means people living with the disease should be tested for their sub-type when treatment is required. This enables the person living with CLL to receive the correct treatment, care and support at the right time.[16] Once the sub-type has been defined, it is important that this information is shared with them and explained in a way they understand.
- However, access to diagnostics varies worldwide,[17,18] and access to even these most basic tools is lacking in lower-and-middle income countries due to factors like cost and distance from a local doctor.[1,19,20] The lack of hematologists and oncologists in these settings also means that general practitioners may have to interpret test results.[21] This can make diagnosis particularly challenging because specialist knowledge is often required to diagnose CLL accurately and definitively.[22]
- A global survey found that many people living with CLL reported difficulties in obtaining an accurate and definitive CLL diagnosis. About a third reported that they did not receive a correct first diagnosis, while 49% said they saw a doctor three or more times about their symptoms before receiving a correct diagnosis.[23] Inaccurate or confusing diagnoses can impact the mental wellbeing of a person living with CLL and their ability to engage with in discussions regarding disease management and treatment options.[24]
- In higher-income countries, clinical guidelines recommend several other biological and genetic markers to help gather more information once a diagnosis has been made and therapy is required.[12,13] Genetic and genomic tests have been used for several decades to understand the biology of CLL, riskstratify people living with the disease and determine who could benefit most from specific targeted treatments.[2]
- Yet, there are data showing that people living with CLL who would benefit from these tests do not always receive them as recommended in international guidelines.[25,26] These tests are also entirely out of reach for people in lower-and-middle-income countries who do not have access to the most basic diagnostics.[27] The WHO Science Council has recommended accelerating access to genomic technologies, particularly in lower-and middle-income countries.[28]

49% of patients who experienced symptoms saw a doctor three or more times about their symptoms before receiving a correct diagnosis.[23]

PRINCIPLE 2:

I deserve *high-quality information*, tailored to my needs and care pathway, in a language understood by me

- The provision of high-quality information is crucial for people living with CLL, carers and family members. It has been shown to improve quality of life and reduce anxiety and depression.[29] Good quality information should be accurate, understandable, and up-to-date.[30] However, not all people living with CLL, carers and family members have their information needs met.[24,29] A global survey found that many people living with CLL are unaware of their subtype,[23] which can help predict survival,[31] and that they do not always understand the terms used to describe their disease.[23] There is also variability in the nature, quality and timing of information provision.[29] People living with CLL should be able to expect information that they can understand and is shared appropriately as a key element of their care throughout their CLL journey.
- For people with chronic hematological malignancies, including CLL, who need active treatment, information can help them make informed decisions about their treatment options and to express their psychosocial needs.[29] However, a global survey found that 41% of people living with CLL expressed that they did not have enough information on CLL and their treatment options to make informed decisions about their treatment.[24] People living with CLL should be able to access comprehensive information regarding their care. This should include the treatment options available to them and the duration, efficacy and potential side effects of those treatments.

- People with chronic hematological malignancies, including CLL, may find engaging with information at diagnosis difficult.[29] They are more likely to engage with information when they have had time to process the shock of their diagnosis.[29] Appointments following initial diagnosis provide an important opportunity to understand a person's information preferences and needs for the future and tailor and "front load" education if appropriate.
- People have different physical needs and levels of health literacy and can be from culturally diverse backgrounds. Therefore, specialists and people living with CLL should be able to access information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations, and should be culturally appropriate. Inclusivity can help make the information accessible to people with different needs and backgrounds, improving communication, promoting trust and increasing engagement.[32]
- Personal relationships also help meet information needs.[29] A global survey found that people living with CLL prefer receiving information directly from a trusted healthcare professional.[24] However, having the time and opportunity to have this dialogue with a healthcare professional is not something everyone living with CLL has experienced.[29]

41% of people living with CLL said they did not have enough information to make informed treatment decisions.[24]

PRINCIPLE 3:

I deserve access to *shared decision-making* throughout my care pathway

- Shared decision-making is when clinical teams and individuals under their care work together to make joint care and treatment decisions. They consider diagnosis, personal goals, lifestyle and preferences. There are three main steps to shared decision-making. First, knowing that a decision is required; second, having access to and understanding the best available evidence; and third, considering the the individual's personal preferences and goals alongside the provider's guidance.[33] The benefits of shared decision-making include greater satisfaction with care and treatment[34] and better health-related quality of life.[35]
- People living with CLL want to participate actively in their treatment and care decisions. A global survey found that 78% wanted to be involved in treatment decisions, but only 44% reported that they had actually participated.[24] Meanwhile, a different global survey found that 27% of people living with CLL reported that they did not have a choice.[23]
- Some countries are beginning to prioritize SDM,[36,37] however further efforts are required to ensure that every person who wants to be involved in decisions about their care can participate.[38] Most research on shared decision-making has focused on higher income countries.[39] The ambition to incorporate shared decision-making in lower-and-middle-income countries is particularly constrained by limited resources, where simple access to and time with a doctor is challenging and literacy is low.[17,40] While the values of shared decision-making still hold in these settings, constraints like this must first be addressed to facilitate a pathway towards adoption.
- Barriers to shared decision-making can include a patient's health literacy and education, time constraints, healthcare professional communication style, rapidly changing treatment options and a lack of tools to enable shared decision-making.[41] The difference in opinion between the healthcare professional and individuals under their care can sometimes be a further barrier, but maintaining a strong relationship built upon meaningful communication can help mitigate this.[42]
- International clinical guidelines on CLL[12,13] do not explicitly discuss shared decisio nmaking. However, work has been done in some countries – including Norway, the UK, Taiwan and Australia – to develop guidelines and tools that could be applied in the CLL.[43] The Leukaemia and Lymphoma Society has developed shared decision-making tools specific to chronic leukemias like CLL,[44] which people living with the disease and healthcare professionals can use to facilitate shared decision-making.

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PRINCIPLE 4:

I deserve access to *affordable, effective care and a full range of specialists* to support me through my cancer journey

- CLL is a chronic disease that requires ongoing management, including regular blood tests and clinical examinations to monitor disease progression and response to treatment.[45] This is especially important for people living with CLL on active monitoring, an approach commonly employed in early-stage disease when a person does not need immediate treatment. Doctors instead monitor for changes to the cancer to decide if the person under their care can continue to be observed without treatment, and some people never need treatment.[29,46] Given the importance of ongoing management, regular follow-up visits should be the minimum standard in CLL care. Yet, limited access to care is particularly acute in lower-and-middle-income countries and must be addressed.[19,47]
- There are now a broad range of treatment options than a decade ago when chemoimmunotherapy was the standard treatment.[48] Clinical education should ensure awareness of the latest available treatments to maximize their benefit. Although most people living with CLL can expect their disease to respond to initial therapy, current treatment options are not considered curative, and most will experience one or more disease relapses during the course of their disease.[49] There are also issues surrounding the affordability of these treatments,[50] which must be addressed to ensure equitable access, particularly in lower-and middle-income countries.[51]
- Recent progress in genomic science means that it is now possible to use an array of clinical, biological and genetic factors to choose the most effective treatment for each individual and their form of CLL.[2] However, despite guidelines recommending them, these tests are not being used to their full potential.[25,26] Access to basic diagnostic tests that are prerequisites for recent therapeutic innovations is also out of reach for many people in lower-and middle-income countries.[1]
- Even higher-income countries face challenges in harnessing the potential of innovative treatments like cell and gene therapies due to their high costs.[52] Barriers preventing timely access must be overcome, such as manufacturing requirements, value assessment, system planning, data infrastructure and early information sharing,[53] to accommodate these technologies that may have potential application in CLL in future.[48]

- Access to clinical trials offers people living with CLL an important chance to access the latest treatments and contribute to the advancement of medical research. However, a recent survey shows that less than half of people living with CLL (48%) are informed about these opportunities.[23] People living with CLL should be consistently presented with opportunities to participate in clinical trials in settings where it is feasible.
- As CLL treatments improve and people live longer, other conditions and complications are likely to arise over time. Comprehensive services need to address the needs of all people living with CLL, beyond medical treatment. These services should incorporate clinical and non-clinical services and qualified primary care providers[7]. This may include, but is not limited to, geriatric services for managing frailty,[54] social work to support with financial challenges, psychological and emotional support[55] (discussed in principle 5), access to dentistry[56] and community care.[57] By accessing a range of professionals, people living with CLL can benefit from a coordinated care plan that addresses their unique needs and promotes a better quality of life.
- People living with CLL who are on active monitoring can sometimes feel abandoned in the periods where they do not have regular contact with their healthcare team.[58,29] Healthcare professionals should signpost these people to support groups that may help.

Less than half of people living with CLL (48%) said they feel informed about clinical trials that may offer access to the latest treatments.[23]

PRINCIPLE 5:

I deserve access to *emotional and psychological support* from clinical, allied health professionals and support networks

- As a chronic condition, the CLL pathway can be variable, uncertain and unpredictable for people living with the disease and their families. This can lead to stress and anxiety.[29,58] The active monitoring phase can last months, years or even the rest of the person's life.[29,46] Other people may require single or multiple treatments to remain in remission, reduce symptoms and prolong life.[29,59]
- A global survey of people living with CLL found that the most common psychosocial effects they experienced were fear of disease progression, fear of relapse and anxiety and depression.[23] However, 40% of said that their healthcare provider did not provide them with any recommendations to help them with their worries or concerns.[23] Another global survey found that 62% thought that their mental health issues were 'not correctly' addressed or were 'neglected'.[24]

- People living with CLL do not get to a permanent survivorship phase where they are considered cancer-free[60] and must deal with the uncertainty of living with cancer for the rest of their lives. This can create a significant psychological burden on people living with CLL and their families.[61] A study conducted in the US assessing the wellbeing of people living with CLL after their diagnosis found that 75% were still worried about their disease worsening 5-6 years after diagnosis. 50% were worried about dying.[62]
- Everyone living with CLL deserves access to emotional and psychological support at the point of diagnosis and across their entire care journey. CLL is mostly diagnosed in older men,[4] who are less likely to ask for mental health support.[63] Therefore, proactive support should be provided to encourage anyone to speak up and get the support that they need.
- Furthermore, screening to monitor emotional quality of life should be conducted regularly for people living with CLL,[7] who should also be informed about the range of support services available to them early in their CLL journey. This includes those provided by support groups and their team of healthcare professionals, including allied healthcare professionals.

62% of people living with CLL thought that mental health issues were 'not correctly' addressed or were 'neglected' in their country.[24]

PRINCIPLE 6:

I deserve access to *a care model that recognizes CLL's total impact*, including its secondary effects and complications

- There is an increasing number of people living with CLL.[1] This is particularly true in higher-income countries,[8,10] due to the availability of less toxic and more effective therapies.[7] CLL's characteristics and the older demographic presents specific challenges that need recognition and action to support high-quality and holistic care.
- People living with CLL are at increased risk of several physical health conditions, which include, but are not limited to: infection; autoimmune disease; cardiovascular disease; secondary cancers, including non-melanomatous skin cancers; osteoporosis and fragility fractures; dental disease and frailty.[7] People living with CLL also often experience lower psychosocial wellbeing and quality of life,[7] as well as fatigue.[64]
- As many as 30-50% of the deaths in people living with CLL are infection-related,[65] and even people with early-stage disease receiving no therapy are at increased risk.[66] Everyone living with CLL need to be informed that they are immunocompromised and understand how to reduce their infection risk. Appropriate and timely vaccination is one important way to do so.[66] Support groups have produced information about relevant vaccinations for people living with CLL[67] and a card to log vaccinations.[68] It would be helpful for healthcare professionals to encourage people living with CLL to access these resources.
- There are currently no clear global guidelines focused on reducing infection incidence in people living with CLL.[66] Global guidelines should include vaccination recommendations and support healthcare professionals in taking a uniform approach to monitoring and managing immunosuppression in all people living with CLL, regardless of treatment status.
- The complex needs of people living with CLL are not addressed by current care models, which focus too much on treating the cancer itself rather than considering their overall physical and psychosocial health. Ultimately, a shift towards a multidisciplinary, survivorship and chronic disease management approach is needed to optimize care and improve health outcomes and quality of life for the increasing number of CLL survivors.[7]

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