

# Chronic Lymphocytic Leukemia: The Patient Journey

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# **Chronic Lymphocytic Leukemia: The Patient Journey**

## **Introduction**

A group of patients, caregivers, and thought leaders from key advocacy organizations and cancer centers held a roundtable on November 13, 2018, in New York City to discuss the patient experience for individuals diagnosed with chronic lymphocytic leukemia (CLL).

The objective of this roundtable was to align strategies to optimize the patient journey (experience) for those diagnosed with CLL. Discussions from the roundtable led to the development of this whitepaper. Its goals are to (1) highlight the current experience for patients with CLL from diagnosis through treatment, (2) identify challenges faced by patients, and (3) develop an action plan to address these challenges.

## **The Diagnosis Experience for Patients**

Learning about a CLL diagnosis can be a frightening experience for patients; however, how patients are informed of the diagnosis and information given during the initial consult can help decrease patient fears. Key factors that were identified as important during the initial diagnosis include informing patients of the diagnosis in an appropriate setting, providing information on what the diagnosis means to their daily life, discussing the importance of biomarker testing (both at the time of diagnosis and when starting new treatment), providing patients with additional resources to learn more about their disease, discussing requirements for ongoing follow-up, and providing information on treatment options (including the right time to start treatment). Unfortunately, the diagnosis experience does not always meet these criteria for all patients.

For example, providers are increasingly informing patients about their CLL diagnosis over the telephone. The use of such an approach provides immediate answers to the patient, and avoids the uncertainty and anxiety associated with waiting for their next appointment. However, the setting in which the patient receives the news (eg, at work, in front of kids, etc) often cannot be controlled. When information about the diagnosis is presented in settings outside of a scheduled appointment, there is the possibility that the patient will not have family or friends present to support them at the time the news is delivered. In addition, patients can have tremendous difficulty absorbing the news of a CLL diagnosis, which is further exacerbated if the information is received over the phone. A phone conversation may not be conducive to asking questions nor allow the patient time to formulate questions and could limit the amount of information a patient receives at the time of diagnosis.

The process for patients who receive their diagnosis in person is also not always ideal. Short consultations with their physician are increasingly common. As a result, the initial conversation a patient has with their doctor regarding CLL can result in limited information (beyond that the patient has a “good” or “treatable” cancer). Such vague reassurances, without additional information on what to expect, can leave patients feeling unsure about their diagnosis and lead to a lack of trust in their care team. Limited information at the time of diagnosis also leaves a vacuum, which can lead patients to seek information online, where it can be hard to identify reputable sources. Having a support person or family member present at the initial discussion is helpful to aid the patient with note taking and formulation of questions to ensure they receive as much information as possible.

To ensure patients receive the support and information they need at diagnosis, the following points should be considered:

- Adequate time with the physician/care team. At the time of early visits with hematologists, it is important to fully educate the patient regarding what to expect with their CLL diagnosis. These discussions should include information about biomarker testing and the results of these tests, as well as what they mean to the management of CLL. Each conversation with the patient should be structured within the context of the specific case at hand. It is also important to involve the patient’s entire care team from the beginning and include education regarding the roles of

each member of the medical team. All of the patient's questions should be answered to the patient's apparent satisfaction.

- Second opinions. Obtaining a second opinion, ideally from a CLL specialist, can be helpful for patients diagnosed with CLL to confirm the initial diagnosis and treatment recommendation, or to provide the patient with additional options, including potential clinical trials. Seeking an opinion from a CLL expert can help ensure access to the latest information and research. Even if care is not continued at the center where the CLL specialist is located, the CLL expert should be consulted at initial diagnosis and before each new treatment. However, some patients are hesitant to seek a second opinion, especially if they have a strong relationship with their provider, for fear it will be viewed as a betrayal. It is, therefore, important to educate patients on the fact that a second opinion is okay and encouraged. Patient advocacy groups can provide scripts to help patients when discussing getting a second opinion with their doctor. Physicians are also becoming increasingly more accepting of second opinions as this approach becomes more common.
- Biomarker testing. Biomarker testing should be done for all patients with CLL at diagnosis and prior to initiating frontline treatment, as part of standard of care to help inform treatment decisions. Current biomarker tests that are recommended by the National Comprehensive Cancer Network (NCCN) guidelines (2020) include: immunoglobulin heavy chain variable (IGHV), del11q, del17p, TP53, del13q, and +12. It is essential to retest before each new treatment regimen and/or if there is a significant change in the clinical course of the disease. While biomarker testing is often being done in major cities and cancer centers, the same is not necessarily true at community hospitals or in rural settings where knowledge of guidelines and availability of tests may be more limited. However, the distinction between major cities/cancer centers and community or rural hospitals is not black and white (with the quality of care varying in either setting). Awareness and cost are key reasons for biomarker testing not being done.
- Role of caregivers. When and how to involve caregivers for patients diagnosed with CLL is a very personal decision and varies from patient to patient. More and more, support systems come from outside the nuclear family, and sometimes professional support is needed. As such, at initial diagnosis, it is important to ask the patient who

their caregiver is and what other support is available to them, as well as how and when to include caregivers in the patient's journey.

## The Treatment Experience

A “watch and wait” strategy or “active surveillance” (close observation) is the recommended approach for most patients diagnosed with CLL who do not have symptoms or low platelet or red blood cell count. For those patients who do not have factors that indicate a need to start treatment, the rationale for continued observation is important because this approach can be counterintuitive and contradictory to what patients are accustomed to when they think about cancer. As such, it is important to talk about the benefits of waiting to treat (eg, science is progressing quickly; better options may be available later; toxicity, side effects, expense of currently available treatments). Giving patients a care plan during this period can be beneficial. This can include providing reputable sources of information for patients and caregivers to learn about the disease and treatment options, if and when the decision to treat is made.

When the time comes to treat, it is important to provide patients with a clear explanation of available treatment options and resources, including the following points:

### *Key issues when determining treatment approach*

- Length of treatment (eg, 6 months with rituximab/bendamustine; 1 year with a venetoclax-based regimen; ongoing treatment with ibrutinib until progression of disease).
- Impact of current treatment on future treatment options. Patients should be made aware of the impact of initiating a particular treatment on future eligibility for other treatments or clinical trials.
- Information on clinical trials. Balanced information on clinical trials as a treatment option should be provided, including potential benefits (emerging new treatments) versus potential risks (exploratory, efficacy, and side effects not established).
- Clear explanations of treatment side effects. The long lists of side effects that often accompany drug profiles can be overwhelming and need to be carefully explained, including information on approaches to effectively manage side effects. When explaining side effects, it is important to keep in mind that a patient's focus may differ

from the physicians. For example, a patient may be more concerned with questions such as, “Will my hair fall out? Will I feel sick?” rather than, for example, white blood cell counts. It is also important to provide patients and caregivers with information on which side effects to report and who to call (including after hours).

- Potential long-term health effects and long-term toxicities. Informing patients of any potential long-term effects of CLL is also important. For example, CLL and/or accompanying treatments can increase the risks of secondary cancers, which should be discussed with the patient in advance of treatment.

#### *Key issues during treatment*

- Realistic information on what to expect from a given treatment. Having accurate information on possible adverse effects, including worst-case scenarios, can help patients manage their feelings. Patients can feel underprepared and overwhelmed when side effects of their treatment are worse than they expected. Nonetheless, setting realistic expectations should be carefully balanced with reassurances (eg, how side effects can be managed if they arise) to avoid alarming patients. For newer drugs, long-term data on side effects may not yet be available, and providers need to be transparent in this regard.
- Repetition of information on treatment benefits and side effects. Patients can be overwhelmed upon initial diagnosis and may not absorb all information the first time they are educated about their treatment. Furthermore, as side effects develop or continue, patients may begin to question their treatment. Reiterating the goals and benefits of treatment can help the patient remember why the treatment was initiated in the first place.
- Importance of adherence and compliance. Patients need to understand that skipping even 1 dose can have consequences and impact efficacy of treatment. In addition, doctors need to do better at asking patients if they are taking medications as prescribed. Strategies to help patients remember to take their medication as prescribed (eg, daily or twice-daily pill boxes, electronic calendar reminders for mobile phones) can be beneficial. Enlisting the expertise of a social service provider, such as a social worker or counselor, can help address any psychosocial obstacles to treatment adherence.

*Key nonmedical issues*

- Importance of communication with the care team. Patients may avoid discussing symptoms or side effects for fear the treatment will need to be stopped or because they want to stay on schedule. As such, oncology health care providers should emphasize that adjustments to treatment schedules and dosages might be possible due to adverse side effects, but only in consultation with the physician's office. In fact, holding treatment or reducing the dose due to toxicities can allow patients to stay on treatment. When possible, doctors should present alternative treatments that might provide equivalent results with different or fewer side effects, so patients are aware that their current treatment is not the only option. It is also important that patients know which symptoms are most important to discuss and when they need to call their providers to notify them of symptoms. In addition, the patient's comorbidities should be taken into account when deciding on treatment options.
- Financial assistance. Patients may be reluctant to talk with their health care team about their financial needs. They also may not be aware that financial assistance from drug companies and patient assistance programs might be available to help them with treatment costs. Multiple nonprofit organizations offer grants to help patients with living expenses. However, funding for all of these programs can change on a month-by-month or day-to-day basis, making it hard to keep track of what is available at any given time. Having family members or friends monitor the status of various financial resources and websites can be very helpful. A designated "point person" (at hospitals or treatment centers or within patient advocacy organizations) who is specifically assigned to help patients navigate financial assistance options is also useful, when available. Health care providers can initiate discussions by asking patients and/or their family members if there are any concerns with costs of treatment.
- Additional sources of information. Nurses and advanced practice providers (eg, physician assistants, nurse practitioners) can be helpful for answering questions patients may have, as they are often more accessible than physicians. Pharmacists can also be a good resource for information on potential side effects of various treatments. Social workers can provide information regarding financial assistance, housing, social support, and other similar types of nonmedical information. Some patients may have language preferences other than English. In these circumstances,

the health care team can ask for a translator to help with the discussion. Patients can also be referred to online or written resources in their preferred language.

- Referrals for emotional support services. Receiving a CLL diagnosis is stressful and can lead to anxiety and/or depression. Patients with a history of depression and/or anxiety prior to the CLL diagnosis are more likely to experience a re-emergence of these difficulties. Professional clinicians with psycho-oncology experience, such as social workers, psychologists, and psychiatrists, can help patients and caregivers manage the stress of their diagnosis and develop new coping skills. Therapists and counselors can provide patients with someone to talk to when they do not want to talk to their family or do not have a strong support system. In addition to professional support, many organizations offer peer-to-peer counseling, with patients trained in peer-to-peer support. Professional and peer support for caregivers are also available. Support groups, facilitated by professionals and peers, are excellent ways to lessen the isolation felt by many people affected by cancer.

## Resources and Patient Education

The educational resources that patients receive at diagnosis vary in quality and quantity. In some cases, the information may be more treatment focused, without as much background on CLL itself. In other cases, patients may receive general information or pamphlets on cancer and treatment, but not information specific to CLL. As such, it is important that patients have access to current, appropriate, and relevant educational materials and resources. Furthermore, it is recommended that patients receive updated materials at least every 2 years so that they are aware of new treatment options as they become available.

**Table 1** highlights a number of different resources that are available to patients with CLL. The availability of information on CLL and treatment options in different forums and formats helps to ensure that a range of patient preferences are accommodated (internet vs print, brief vs detailed, etc). Furthermore, for any given patient, different resources may be more or less useful at different time points in their disease or treatment. Many resources are also available in languages other than English.

Referrals to cancer organizations and patient advocacy groups can also open the door to an abundance of useful information and resources.



<b>Table 1. Examples of Educational Materials Available for Patients With CLL</b>		
<b>Resource</b>	<b>Benefits</b>	<b>Considerations</b>
<p><b>Printed materials (brochures/pamphlets/fact sheets)</b></p> <ul style="list-style-type: none"> <li>• Can include materials from pharmaceutical companies, patient advocacy groups, oncology (cancer) centers, physician practice groups, etc</li> </ul>	<p>Easy to have at hand and refer to as needed</p> <p>Accessible to patients without access to/not comfortable on the internet</p> <p>Can add personal notes/questions</p>	<p>Need to be updated and reprinted regularly</p> <p>Need to ensure patients have access to updated materials when available</p> <p>May not be available in certain oncology settings if developed by pharmaceutical companies</p> <p>May be a higher education level</p>
<b>Reputable websites</b>	Readily available source of up-to-date information	Patients need ways to identify reputable sources of online information
<b>Webinars/telephone workshops</b>	<p>Allow patients to learn directly from experts</p> <p>Option for live Q&amp;A</p> <p>Can be recorded for later viewing at patients' convenience</p>	Access can be limited due to technical/scheduling issues
<b>Helplines</b>	<p>Access to live person to talk to and answer questions</p> <p>If developed by a pharmaceutical company, no cost to patients/oncology groups</p>	If offered by a pharmaceutical company, focus may be related to a specific drug and global information may not be available
<b>Q&amp;A documents/checklists</b>	Can help patients identify/prioritize questions to go over with their doctor	
<b>Patient-driven list services and support groups</b>	<p>Provide patient-to-patient connection</p> <p>Allow patients to hear about/learn from other patients' experiences</p>	Information provided by other patients is generally not verified and can include misinformation if not from a monitored site

<b>Table 1. Examples of Educational Materials Available for Patients With CLL</b>		
<b>Resource</b>	<b>Benefits</b>	<b>Considerations</b>
<b>Live meetings/workshops</b>	Provide access to CLL experts and researchers  Facilitate in-person networking and support	May require travel and associated costs
<b>Mobile apps</b>	Customizable  Can include a variety of features including links to helpful resources, information checklists, medication tracking functionality, and ability to record conversations with doctors	Require smartphone or tablet
<b>Guidelines (eg, NCCN)</b>	Current and developed by experts in the management of CLL	Need to be updated frequently

The following points should also be considered regarding educational information provided for patients:

- Individual patients and caregivers differ on how much information they want, and this can vary over time. As such, educational materials should be developed as both simple, easy-to-digest pieces and more detailed and complex pieces
- Educational materials should be regularly updated to keep pace with the constantly changing treatment options. It is also important to ensure that medical providers and patients replace outdated materials. Changing the covers (eg, replacing images and dates) on printed material when substantive content is updated can make them easily identifiable as new
- Educational materials should be developed by experts in the management of CLL
- Awareness about the variation in patients' health literacy level has increased. As a result, educational materials are being developed to meet different reading levels, and software is available to scan and assess reading level. Continued efforts will help ensure that materials are written at a sixth grade reading level to ensure patients understand the material (eg, The Leukemia & Lymphoma Society's [LLS] *The CLL Guide, Information for Patients and Caregivers* and *Chronic Lymphocytic Leukemia*, and the Lymphoma Research Foundation's [LRF] *Understanding CLL/SLL Chronic Lymphocytic Leukemia and Small Lymphocytic Lymphoma*)

guides). It should be noted that the inclusion of medical terminology/treatment names can cause publications to be assessed at a slightly higher level

- Additional effort is needed to make educational materials available in multiple languages and accessible to those who are visually impaired
- Providers often neglect to give patients referral information for emotional health, psychotherapy, supportive counseling, and support groups, when available. Only 1 of 3 patients at the roundtable was provided with a referral/access to a therapist at diagnosis, although all acknowledged wanting therapy and eventually sought it on their own. Part of the problem is that demand exceeds the availability of professionals trained to provide this type of counseling (eg, counselors, social workers, psychologists, licensed therapists, or psychiatrists). This may be the case at treatment centers/hospitals and outside in the community, where variability in health insurance coverage and out-of-pocket expenses are also a major barrier. In these situations, patients can be referred to faith-based providers or online support services such as *CancerCare*

## Identifying Gaps and Challenges

The top 5 challenges identified during the roundtable for patients diagnosed with CLL are listed below, as well as proposed solutions and implementation plans. It is always beneficial to include representatives from key stakeholders, including patients, caregivers, family members, industry, and health care when discussing and implementing a plan to address these challenges. Diversity in terms of income, ethnicity, gender, and age are also critical factors to consider when identifying these stakeholders.

### *Challenge 1: Defining the medical team*

**The challenge:** Patients do not always know who all the members of their medical team are or who to address specific questions to.

**Proposed solution:** Develop a medical team fact sheet.

#### **Implementation:**

Step 1: Determine who will develop the fact sheet and how to best disseminate the information. *CancerCare* or other patient advocacy organizations are good options to take the lead on development and dissemination of the fact sheet.

Step 2: Secure funding. Look for industry partners or other potential sources of funding.

Step 3: Develop the fact sheet. The following points should be considered during the development stage.

1. Research to see what is already available in terms of describing the different members of a CLL patient's care team and the roles of each member of the team.
2. Develop standard definitions defining each medical team member. Definitions should include who each team member is and their role in patient care. In addition, medical team members can be grouped in tiers (or concentric circles) as follows:
  - *Tier 1:* The core care group, including a primary nurse contact to consult regarding severe symptoms or adverse side effects
  - *Tier 2:* Others involved in patient care (including those the patient might not see face to face, such as the pathologist)
3. The variability within each medical center/setting needs to be considered. As such, the fact sheet should describe different scenarios a patient might encounter based on where they are receiving care. Patients should also be encouraged to learn the specific processes, and who is involved, at their hospital, clinic, treatment center, or doctor's office

### *Challenge 2: Access to emotional support*

**The challenge:** Awareness of the emotional/psychological needs of CLL patients and access to psychological or emotional support are lacking.

**Proposed solution:** Educate patients and physicians on the importance of early access to emotional support and provide them with information on how to find these resources.

### **Implementation:**

Step 1: Determine the best format or formats to provide information to patients about emotional support (eg, online resources, fact sheet, etc).

Step 2: Determine who will develop the patient resources on emotional support and how to best disseminate the information. CancerCare or other patient advocacy organizations are good options to take the lead on development and dissemination of information on emotional support.

Step 3: Secure funding. Look for industry partners or other potential sources of funding.

Step 4: Develop patient resources related to emotional support. The following points should be considered during the development stage:

1. Research what resources are currently available to patients and explore how social workers or counselors are currently being used, as well as how referrals for emotional/psychological support are handled. A survey could potentially be utilized to gather this information.
2. Consult with organizations involved in patients' emotional well-being, such as the Association of Oncology Social Workers (AOSW), to see how they support the emotional needs of patients.
3. Encourage contact with social workers, counselors, or psychologists early on, if possible. When social workers or counselors are available at the hospital/clinic/cancer center, patients need to be made aware of this so that they can request to be put into contact with one.
4. Develop a fact sheet or online resources on what services social workers/counselors provide. This information would need to take into account different services available at different medical centers or institutions.
5. Develop a directory of social workers/counselors (or other clinical providers with cancer expertise) to help patients find one in their area. However, a lack of trained clinical social workers or counselors with cancer knowledge could present a barrier. Even if social workers or counselors are not available in a patient's immediate area, raising awareness of a patient's emotional needs can encourage them to seek support or a referral to another psychosocial oncology provider.
6. Compile a list of psychosocial oncology providers who specialize in the care of patients with cancer, categorized by location.
7. Develop a list of support groups available in various locations (consider statewide or those in specific towns/cities) for patients with CLL.

### *Challenge 3: Biomarker testing*

**The challenge:** Not all patients are getting biomarker testing at diagnosis or when new treatments are initiated.

**Proposed solution:** Create a fact sheet on biomarker testing (common mutations, required tests, etc) to ensure all physicians and patients know what tests are needed, and when, to ensure the best treatment option is identified for each patient.

#### **Implementation:**

Step 1: Determine who will develop the fact sheet and how to best disseminate the information. CancerCare or other patient advocacy organizations are good options to take the lead on development and dissemination of the fact sheet. Consider physician-based versus patient-based information.

Step 2: Secure funding. Look for industry partners or other potential sources of funding.

Step 3: Develop the fact sheet. The following points should be considered during the development stage:

1. Identify the target audience for the fact sheet. This would likely include a version geared toward physicians and a separate fact sheet geared toward patients.
2. Conduct research with patient advocacy groups and other organizations to see what is currently available and what can be repurposed, to identify any gaps.
3. Determine the potential for completing testing in various settings (eg, cancer center/medical center vs community hospital vs large labs).
4. Ensure patient-directed materials are developed at a reading level accessible to most patients (eg, fifth- or sixth-grade level).
5. Materials will need to be updated periodically to stay consistent with clinical guidelines for diagnosis and treatment of CLL, which change over time.

Step 4: Consider sharing the fact sheet (or presenting the information it contains) with large hematology-associated organizations.

#### *Challenge 4: Financial assistance*

**The challenge:** Patients are often unaware of financial assistance that may be available to them, and databases (eg, CancerFAC.org) that serve as resources for financial assistance are often not updated frequently enough to keep up with the constantly-evolving financial landscape.

**Proposed solution:** Set up a system for regular updates of CancerFAC.org, a financial resources database hosted by CancerCare.

#### **Implementation:**

Step 1: Investigate the CancerFAC.org website to assess what is currently included and where updates might be needed. A proposal should also be created to ensure the database is regularly updated, which is currently only being done annually.

Step 2: Identify sponsors to support the financial needs for both the initial evaluation and updates, as well as the implementation of regular updates moving forward.

Step 3: Update the database and schedule regular updates. Ensure that the database includes both financial assistance programs offered to patients by drug makers, as well as by organizations such as LLS, LRF, and CancerCare. Consider pharmaceutical companies to see if they have copayment assistance programs for medications they distribute. Financial counselors at cancer centers could be a useful resource for additional information on resources available to patients that can be included in the database.

#### *Challenge 5: Clinical trials*

**The challenge:** Patients are often not aware of clinical trial options available to them, and often view clinical trials as a last resort.

**Proposed solution:** Identify or develop resources accessible to patients that educate them on the potential benefits of clinical trials, as well as easy-to-navigate listings of ongoing trials.

#### **Implementation:**

Step 1: Determine who will develop the educational resources and how to best disseminate the information. CancerCare or other patient-advocacy organizations are

good options to take the lead on development and dissemination of educational resources on clinical trials.

Step 2: Secure funding. Look for industry partners or other potential sources of funding.

Step 3: Develop the educational resources. The following points should be considered during the development stage:

1. Identify or develop resources to help educate patients on what clinical trials are and who they benefit. Many patients think of clinical trials as a last resort; education is needed to dispel this misconception.
2. Develop strategies to help patients navigate clinical trials. Clinicaltrials.gov can be difficult for patients to navigate and understand; thus, more patient friendly options are needed. The LLS and LRF have patient-friendly clinical trials resources (LLS' Clinical Trials Support Center [CTSC] and LRF's Clinical Trials Information Service). Both LLS and LRF have trained clinical trial nurse navigators qualified to research, identify, and discuss clinical trial options for patients. The CTSC works one on one with patients throughout the clinical trial process, including education on clinical trials in general, identification of appropriate trials for the individual patient, navigating the enrollment process, and follow-up during the trial.

## **Conclusions**

A CLL diagnosis represents a challenging time for both patients and caregivers. However, appropriate information and guidance from the health care team, as well as access to up-to-date and easy-to-use resources can help alleviate anxiety and improve the patient experience. The first step to achieve these goals is to identify the challenges faced by patients with CLL and to develop an action plan to address these challenges.