



KEY FINDINGS FROM THE 2020 CANADIAN CLL REPORT CARD

Canadian CLL Patients

Results from the 2020 Lymphoma Coalition, Canadian Lymphoma Patient Survey.

To view the full report card, please visit the Lymphoma Canada website at www.lymphoma.ca.

Toll Free: 1-866-659-5556
Charitable Registration Number: 87346 1040 RR0001

| | PRE-DIAGNOSIS SYMPTOMS | DIAGNOSIS | TREATMENT & SIDE EFFECTS | RELAPSE | FOLLOW-UP CARE |
|---|--|---|---|---|---|
| INFORMATION NEEDS & DECISIONS ABOUT CARE | <p>14%</p> <p>Of CLL patients feel overwhelmed managing their health condition and care.</p> | <p>38%</p> <p>Of patients need for information was greatest during the first month following diagnosis.</p> <p>45%</p> <p>Of patients were not given enough information at diagnosis.</p> | <p>60%</p> <p>Wanted more information on CLL treatment options at diagnosis.</p> <p>Patient's healthcare decisions are most influenced by:</p> <ul style="list-style-type: none"> 74% Recommendations from Healthcare Providers 16% Personal Preferences | <p>For patients that discussed their fear of recurrence with their doctor (50%), their doctor helped by providing them with either:</p> <ul style="list-style-type: none"> 33% Verbal or written information 17% Medication | <p>17%</p> <p>Of CLL patients want more information on support for self-care.</p> <p>CLL patients receive support from family/friends (85%) and doctors (83%) in the form of:</p> <ul style="list-style-type: none"> 58% Emotional Support 25% Practical Support 20% Financial Support |
| COMMUNICATION | <p>Besides a patient's doctor, CLL patients communicated their worries and concerns with:</p> <ol style="list-style-type: none"> 1 Did not speak to anyone else 2 Friends/Family | <p>All CLL patients understood from their doctor that they received a diagnosis of cancer.</p> <p>25%</p> <p>Patients were not told they had the CLL subtype of lymphoma at diagnosis.</p> <p>78%</p> <p>Of patients were diagnosed with lymphoma less than 6 months from their first appointment with their General Practitioner compared with</p> <p>10%</p> <p>10% that were diagnosed greater than 6 months from their first appointment</p> | <p>Thirty percent of patients communicated their treatment needs with their doctor and chose a treatment recommended by their doctor. Only 2% of patients did not communicate their needs to their doctor, but would have liked to.</p> <p>19%</p> <p>Of patients asked for a second opinion and switched their doctor as a result.</p> | <p>50%</p> <p>Of CLL patients have a fear of progression and only 50% of these patients discuss this fear with their doctor.</p> <p>Patient's fear of recurrence manifests as:</p> <ul style="list-style-type: none"> 78% Thinking about the cancer returning 67% Examining self for signs of cancer 44% Having thoughts about dying | <p>96%</p> <p>Of patients receiving treatment understand how to take their medicines at home.</p> <p>22%</p> <p>There are some CLL patients that will wait until their health issues can no longer be ignored before seeking help.</p> |
| PHYSICAL IMPACTS | <p>Top three symptoms for CLL patients:</p> <ul style="list-style-type: none"> 71% Fatigue 40% Easy bruising/bleeding 38% Abnormal Swelling of Lymph Nodes | <p>Top symptoms experienced for more than eight years throughout a patient's journey with CLL:</p> <ul style="list-style-type: none"> 23% Skin rashes/ lesions 22% Easy bruising/ bleeding 14% Fatigue | <p>Top three treatment side effects experienced by CLL patients:</p> <ul style="list-style-type: none"> 71% Fatigue 38% Easy Bruising/Bleeding 34% Skin/hair/nail problems | <p>Coping mechanisms that help patients manage their fear of recurrence:</p> <ul style="list-style-type: none"> 64% Exercise Programs 14% Mind-body interventions (yoga, reiki) 14% Nutritional Counselling | <p>91%</p> <p>Of patients are confident they can manage their day-to-day health problems.</p> |
| QUALITY OF LIFE (QoL) IMPACTS | <p>Most patients agree that their symptoms have impacted their:</p> <ul style="list-style-type: none"> 46% Ability to perform everyday activities (exercise, chores) 41% Social Life | <p>63%</p> <p>Of patients do not find that managing their health condition is overwhelming.</p> <p>82%</p> <p>Of patients agree that they are able to positively impact their health.</p> | <p>Side effects have negatively impacted certain aspects of a patient's QoL:</p> <ul style="list-style-type: none"> 42% Everyday Activities (exercise/chores) 32% Ability to Work 30% Social Life 16% Relationship with Family/Friends | <p>11%</p> <p>Fear of relapse has negatively impacted patient's QoL by affecting day-to-day activities, difficulty making plans for the future, and feeling very alone.</p> | <p>With their day-to-day health, patients are able to:</p> <ul style="list-style-type: none"> 89% Implement lifestyle changes like diet and exercise. 60% Keep their symptoms/side effects from interfering with the things they want to do. |
| PATIENT QUOTES | <p><i>I have been in the watch and wait phase for over ten years but realize that the disease does affect my life through fatigue and the resulting need to adjust work and social activities</i></p> | <p><i>I was diagnosed after annual blood work. I am lucky to have no symptoms develop.</i></p> <p><i>I had to state a very strong case before getting genetic testing for my CLL as the protocol in my province is not to test until treatment is necessary. I think this should be available to patients at any point should they want it.</i></p> | <p><i>Due to now being treated, my fatigue has largely disappeared. I did not realize how fatigued I had become until I started treatment and regained my energy to almost normal.</i></p> | <p><i>I feel very fortunate to have had two 5-year remissions - with the 2nd one still ongoing.</i></p> <p><i>I have made some lifestyle modifications as far as diet, exercise and stress reduction.</i></p> | <p><i>I do all I can to keep myself informed. Generally doing quite well and am planning on being around for a long time. Must keep pushing myself physically.</i></p> |