



# KEY FINDINGS FROM THE 2020 CANADIAN LYMPHOMA REPORT CARD

## Canadian Lymphoma 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](http://www.lymphoma.ca).

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	PRE-DIAGNOSIS SYMPTOMS	DIAGNOSIS	TREATMENT & SIDE EFFECTS	RELAPSE	FOLLOW-UP CARE
<b>INFORMATION NEEDS &amp; DECISIONS ABOUT CARE</b>	<p><b>20%</b></p> <p>Of patients experiencing fatigue did not ask their doctor for help because they did not believe their doctor could help (40%) or they thought they could deal with it on their own (28%).</p>	<p><b>52%</b></p> <p>Patients need for information was greatest during the first month following diagnosis.</p> <p><b>35%</b></p> <p>Patients were not given enough information at diagnosis.</p>	<p>Patients want more information on lymphoma treatment options (55%) and treatment side effects (39%)</p> <p>Healthcare decisions were most influenced by:</p> <ul style="list-style-type: none"> <li>Recommendations from Healthcare Providers: <b>76%</b></li> <li>Personal Preferences: <b>17%</b></li> </ul>	<p>Majority of patients are confident in:</p> <ul style="list-style-type: none"> <li>Their ability to get the information they need from their doctor: <b>81%</b></li> <li>Finding reliable information about lymphoma (i.e. online resources): <b>79%</b></li> </ul>	<p><b>18%</b></p> <p>Of lymphoma patients want more information on support for self-care.</p> <p><b>15%</b></p> <p>Of lymphoma patients did not receive information on how to manage treatment side effects.</p>
<b>COMMUNICATION</b>	<p>Besides a doctor, patients have communicated their worries and concerns about fatigue and its impact with:</p> <ul style="list-style-type: none"> <li>Family/Friends: <b>59%</b></li> <li>Nurses: <b>16%</b></li> <li>Complementary Therapists: <b>8%</b></li> </ul>	<p><b>9%</b></p> <p>Of patients that received a lymphoma diagnosis from their doctor were not aware they received a <b>diagnosis of cancer</b>.</p> <p><b>19%</b></p> <p>Were <b>not told their lymphoma subtype</b> at diagnosis.</p> <p><b>68%</b></p> <p>Of patients were diagnosed with lymphoma less than 6 months from their first appointment with their General Practitioner compared with</p> <p><b>25%</b></p> <p>25% that were diagnosed greater than 6 months from their first appointment</p>	<p><b>22%</b></p> <p>Of patients communicated their treatment needs with their doctor and chose a treatment recommended by their doctor.</p> <p><b>8%</b></p> <p>Of patients asked for a second opinion and switched their doctor as a result.</p> <p><b>74%</b></p> <p>The majority of patients reported definitely discussing their treatment side effects with their doctor.</p>	<p>Forty-seven percent of patients have a fear of progression and 56% of these patients discuss this fear of recurrence with their doctor.</p> <p>Patient's fear of recurrence manifests as:</p> <ul style="list-style-type: none"> <li>Thinking about the cancer returning: <b>88%</b></li> <li>Examining self for signs of cancer: <b>65%</b></li> <li>Having thoughts about dying: <b>39%</b></li> </ul>	<p><b>96%</b></p> <p>Of patients receiving treatment understand how to take their medicines at home.</p> <p><b>21%</b></p> <p>There are some patients that will wait until their health issues can no longer be ignored before seeking help.</p>
<b>PHYSICAL IMPACTS</b>	<p>Top three symptoms experienced by lymphoma patients:</p> <ul style="list-style-type: none"> <li>Fatigue: <b>71%</b></li> <li>Abnormal Swelling of Lymph Nodes: <b>33%</b></li> <li>Shortness of Breath: <b>32%</b></li> </ul>	<p>Top symptoms experienced for more than eight years throughout a patient's journey with their lymphoma:</p> <ul style="list-style-type: none"> <li>Fatigue: <b>31%</b></li> <li>Skin rashes / lesions: <b>15%</b></li> <li>Easy bruising / bleeding: <b>10%</b></li> </ul>	<p>Top 3 treatment-related side effects experienced by lymphoma patients:</p> <ul style="list-style-type: none"> <li>Fatigue: <b>74%</b></li> <li>Numbness &amp; tingling of arms/legs/feet: <b>44%</b></li> <li>Hair loss: <b>41%</b></li> </ul>	<p>Coping mechanisms that help patients manage their fear of recurrence:</p> <ul style="list-style-type: none"> <li>Exercise Programs: <b>48%</b></li> <li>Mind-body interventions (yoga, reiki): <b>33%</b></li> <li>None: <b>27%</b></li> </ul>	<p><b>83%</b></p> <p>Of patients are confident they can manage their health problems day-to-day.</p>
<b>QUALITY OF LIFE (QoL) IMPACTS</b>	<p>Most patients agree that their symptoms have impacted their:</p> <ul style="list-style-type: none"> <li>Ability to perform everyday activities (exercise, chores): <b>54%</b></li> <li>Social Life: <b>48%</b></li> </ul>	<p><b>51%</b></p> <p>Of patients do not find that managing their health condition is overwhelming.</p> <p><b>79%</b></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"> <li>Everyday Activities (exercise/chores): <b>53%</b></li> <li>Ability to Work: <b>34%</b></li> <li>Social Life: <b>43%</b></li> <li>Relationship with Family/Friends: <b>22%</b></li> </ul>	<p>Fear of relapse has negatively impacted a patient's QoL causing:</p> <ul style="list-style-type: none"> <li>Thoughts that impact day-to-day activities: <b>13%</b></li> <li>Difficulty making plans for the future: <b>25%</b></li> <li>Patients to feel very alone: <b>17%</b></li> </ul>	<p>With their day-to-day health, patients are able to:</p> <ul style="list-style-type: none"> <li>Implement lifestyle changes like diet and exercise: <b>80%</b></li> <li>Keep their symptoms/side effects from interfering with the things they want to do: <b>56%</b></li> </ul>
<b>PATIENT QUOTES</b>	<p><i>I experienced lymphoma symptoms for many years, but did not even think of lymphoma as the cause.</i></p>	<p><i>I got my diagnosis pretty quick. But the staging took over 2 months. I found the waiting very hard, the unknown. It had a big impact on my emotional health.</i></p>	<p><i>As treatments get better and better and the survival rate is higher, these long-term effects are going to be more prevalent and the medical field needs to be aware of these and plan for them. I would like to suggest, encourage, and implore someone to look into these effects so that we can seek and access help, or at least, answers to these issues that are affecting us.</i></p>	<p><i>After speaking with my doctor and nurse, my fear of relapse has dissipated. I've been in remission for over ten years and had started to feel that maybe my luck was running out. I no longer feel that way.</i></p>	<p><i>We are all of course so grateful to be alive but we also want to thrive and not just survive cancer. I believe there is much to learn with aftercare in the years following a cancer diagnosis and survival. I also feel a strong need for alternative care to be offered throughout the process, during treatment as well as in the following years.</i></p>