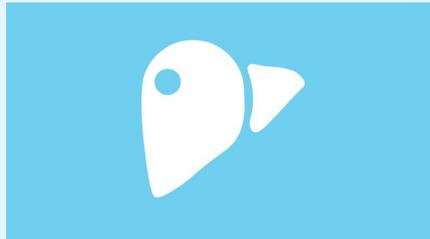


## The Canadian Cancer Survivor Network 2018 Liver Cancer Survey



From May 15th to July 31st, 2018, the **Canadian Cancer Survivor Network (CCSN)** hosted a survey for Canadian patients and caregivers affected by liver cancer. The purpose of this short survey was to help CCSN better understand the issues that patients and non-patients face with primary liver cancer diagnosis and treatment.

Through participation in this survey, individuals have helped CCSN to shape messages for its upcoming advocacy efforts aimed at improving the lives of liver cancer patients, with the goal of furthering treatments and removing stigma.

The anonymous survey included questions about treatment options, important issues to patients & caregivers, and what improvements they feel could be made to Canada's health care system for liver cancer.

### **Distribution & Response**

Throughout the campaign, the survey was distributed through CCSN's website and social media channels, and was shared by some of our patient group partners. It was also distributed to various liver cancer support groups throughout Canada and internationally. Informational postcards were also distributed to hepatologists, oncologists, interventional radiologists and primary care physicians from across Canada.

Seven patients and nineteen caregivers across Canada completed the survey. Upon analysis, CCSN believes the low participant response suggests issues associated with stigma and a lack of access for care in rural communities, among other issues.

A summary of the survey responses are contained in this report.

## Key Messages for the CCSN Liver Cancer Survey

Canadian Cancer Survivor Network (CCSN) will use the data from this survey to help raise awareness and help influence stakeholders in improving the liver cancer environment in Canada.

### Issues to be addressed include:

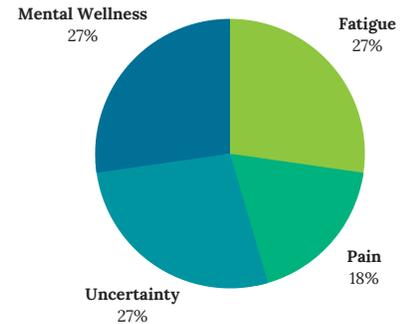
- Increasing rates of liver cancer diagnoses in Canada over the past 25 years
- Improved access and coverage to treatments for liver cancer
- Addressing stigma surrounding liver cancer and challenges reaching patients
- Better mental health services for patients and caregivers
- Lack of liver cancer specialists – declining rates of interested specialists
- Lack of screening & education for Hepatitis C and B

We welcome your input. If you have any questions, or would like to participate in our continued awareness efforts for liver cancer in Canada, please email us at [info@survivornet.ca](mailto:info@survivornet.ca)

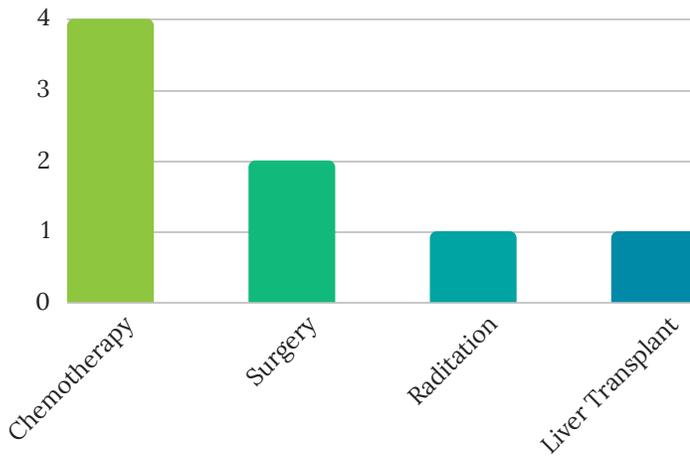
## Part One: Liver Cancer Patients

### Symptoms and problems experienced with primary liver cancer that affect day-to-day living and quality of life, and which are most important to control

Patients cited fatigue, living with uncertainty and managing anxiety, depression and panic as the issues that affect them the most, and the issues they would want to have better control over. Several patients also cited pain as a primary problem that required better control.



### Therapy & treatment(s) currently being used to treat primary liver cancer, and desired effectiveness of treatment(s)



Of the patients surveyed, four patients reported that they are currently receiving chemotherapy for their cancer. Two have had surgery for their cancer, while one has had radiation therapy and one has had a liver transplant.

One patient commented that they are taking cannabis oil to support their medical treatment.

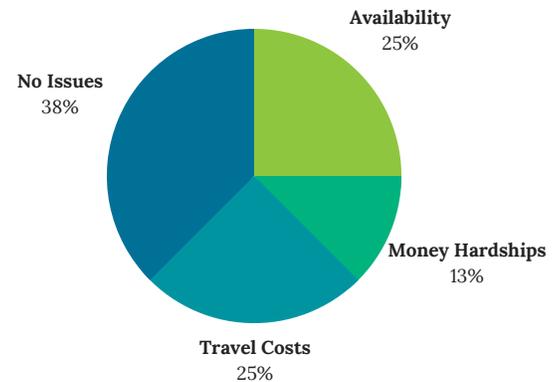
3 out of 4 patients felt their chemotherapy was effective. The remaining three patients also reported satisfaction with their treatment.

### Issues accessing current therapy

Two patients felt that treatment availability in their community was limited, as well as travel costs associated with getting to their therapy.

One patient reported financial hardship due to treatment cost.

Three patients reported experiencing no issues with treatment access.



## Part One: Liver Cancer Patients

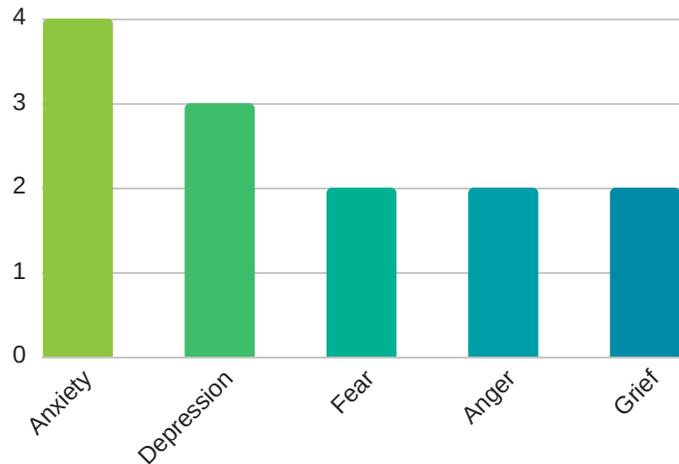
### Satisfaction in current therapy for liver cancer

Patients stated that their needs are being met with their current treatment(s) and that they feel well-informed about their treatment options. One patient stated that they felt their needs were not met, but chose not to clarify the statement further.



### Psychological and mental health issues facing patients

Patients were asked to choose all situations that they felt applied to them. Anxiety and depression were the most prevalent issues, with fear, anger and grief coming in equally afterwards.



*A series of open-ended questions followed for patients.*

### Changes in family dynamic after diagnosis of liver cancer

80% of respondents stated that their family dynamic shifted upon their diagnosis of liver cancer.

**"[There is] more concern about my health, diet, work and general well being"**

**"They worry about me much more than previously."**

### Issues particular to patients and survivors of liver cancer

When asked this open-ended question, respondents shared some insights on stress, mental health and uncertainty.

**"Mental health services. Waiting times for treatments."**

**"The uncertainty of the future and declining health with age (the cancer returning)."**

**"Need more therapy on how to deal with the day to day fatigue and the feelings that go with having cancer. Help with travel to another city for treatments, and treatment to deal with feelings and stress"**

## Liver Cancer Patients continued

### Most helpful experiences in the health care system when undergoing cancer treatment

When asked this open-ended question, patients lauded their experience with medical professionals.

**"My oncologists and cancer care nurses are the best! Always there to answer my questions and concerns."**

**"I had received great care and plenty of follow up after the [liver transplant] surgery."**

**"Awesome nurses [and] doctors and how they are on the ball to help me."**

**"The medical professionals who looked after me were exemplary."**

### What could be changed in the health care system when undergoing cancer treatment

When asked this open-ended question, the survey participants had a variety of responses.

**"Faster treatment and surgery times; delays just let [the cancer] grow and spread."**

**"I wish there were more organs available for other people on the waiting list as sadly some people die while waiting."**

**"Make chemo and medication thereafter free for patients."**

**"Make physical activity part of the treatment. A fit patient is a better patient both physically and mentally."**

## Part Two: Liver Cancer Caregivers

Caregivers were asked several open-ended questions.

### Challenges faced in caring for a loved one with liver cancer

When asked this open-ended question, caregivers expressed worry and feelings of being overwhelmed.

"Diagnosis bomb drop; go home with very little information. Life stops, work stops., Labs, MRI, doctors, nurses, total chaos. Told not to go online to research. Whole new world."

"Not sure if I could manage giving pain meds, needles [...] Did not think I was strong enough."

"[...] overwhelmed with the challenges of always trying to make the healthiest meals, finances and the inability to obtain the supplements that my husband needs to help him stay strong and combat this deadly disease."

"Wondering if I am able to look after my husband, and not feel guilty when I've had enough."

### Caregiving and the effect on daily routine and/or lifestyle

When asked this open-ended question, the respondents spoke of planning day-by-day and being unable to escape.

"Everybody's life gets turned upside down."

"Don't know what to expect day to day, living each day as if it was his last, making sure I have enough help to manage."

"We will not be going on many vacations now; we stay home a lot because he is always tired; [we] don't see friends much anymore."

"I feel worn out. I can't afford to get out much at all."

### Challenges related to patient's current therapy or treatment

When asked this open-ended question, caregivers cited issues with fatigue and stress of hospital travel.

"Fatigue. Sad. Lonely. Feel [the] need to talk [but] no one to talk to."

"Going to the hospital sometimes three times a week."