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Welcome!
Welcome to the second issue, volume 3 of the 2026 Cholangio-Hepatocellular Carcinoma Canada (CHCC) newsletter.

HTA submissions for ivosidenib (Tibosovo) and Enhertu have been submitted to the CDA. Thank you to everyone who participated. We hope to have the recommended reimbursement decisions by the CDA in a few months. Thank you to CCRAN for their role in the submission.

Clinical trials that are happening across the country

Go to clinicaltrials.gov for any worldwide trials using this link.
***Or try the Cancer Trials Canada link.* (the number of clinical trials is ever-changing)**

***Clinical trials at the PMH in Toronto** (Number of locations in Canada mentioned):*

BOLD 100 https://clinicaltrials.gov/study/NCT04421820 for CCA patients who are also on FOLFOX. Five locations in Canada.

NEOTOMA https://clinicaltrials.gov/study/NCT05440864 for resectable HCC patients prior to surgical resection and post surgical resection.

BeyondIO (HMLTO002) https://clinicaltrials.gov/study/NCT05185505 pre-transplantation of liver. Although the clinical trial states Texas is the only site, there is a researcher in Toronto who is running this trial.

ARTEMIDE- Rilvegostomig in combination with Bevacizumab with or without Tremelimumab as first line treatment of HCC HCC01 https://clinicaltrials.gov/study/NCT06921785 in 6 Canadian locations (not all recruiting yet)

STRIDE (Durvalumab + Tremelimumab) With Lenvatinib vs STRIDE Alone in Unresectable Hepatocellular Carcinoma (SLIDE-HCC) https://clinicaltrials.gov/study/NCT06880523 in 12 Canadian locations.

CABO-TX https://clinicaltrials.gov/study/NCT04204850 for liver transplant patients whose cancer has recurred. One location in Canada.

TYR430-101 Safety and Preliminary Anti-Tumor Activity of TYRA-430 in Advanced Hepatocellular Carcinoma and Other Solid Tumors With Activating

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FGF/FGFR Pathway Aberrations (SURF431)
https://clinicaltrials.gov/study/NCT06915753 One location.

BANTAM-01 for HCC patients (radioligand)
https://clinicaltrials.gov/study/NCT06764316. Four locations.

NEOLANGIO for complete resection for cholangiocarcinoma
https://clinicaltrials.gov/study/NCT06569225 One location.

DESTINY-BTC01 Phase 3 Study of T-DXd and Rilvegostomig Versus SoC in Advanced HER2-expressing Biliary Tract Cancer
https://clinicaltrials.gov/study/NCT06467357 Five locations.

HERIZON-BTC-302 Efficacy and Safety of Zanidatamab With Standard-of-care Therapy Against Standard-of-care Therapy for Advanced HER2-positive Biliary Tract Cancer https://clinicaltrials.gov/study/NCT06282575 Three locations.

ARTEMIDE-Biliary02 STRIDE (Durvalumab + Tremelimumab) With Lenvatinib vs STRIDE Alone in Unresectable Hepatocellular Carcinoma (SLIDE-HCC)
https://clinicaltrials.gov/study/NCT06880523 Twelve locations.

S095031-210 Ivosidenib Plus Durvalumab and Gemcitabine/Cisplatin as First-Line Therapy in Participants With Locally Advanced or Metastatic Cholangiocarcinoma With an IDH1 Mutation
https://clinicaltrials.gov/study/NCT06501625 One location

BiomarkerHelp helps you find personalized options to fight cancer – for free. Simply upload your biomarker test report. Their focus is on YOU – they don't partner with anyone for profit. This is a change from genomic focus. It is run by Matt Reidy. **BiomarkerHelp** has a clinical trials map that will show any clinical trials that match your tumor biomarkers.

BiomarkerHelp's website: https://biomarkerhelp.com/

Patient care kits

Thanks to AstraZeneca, Incyte, Merck, Servier and two local dentist's office in Red Deer and Edmonton, we can provide patient care kits for new patients diagnosed with either cholangiocarcinoma or hepatocellular carcinoma. Your well-being is our priority. If you know anyone who is newly diagnosed or without a patient kit, please click on this link.

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Mentorship program

CHCC has a mentorship program that provides a supportive network for those affected by cholangiocarcinoma and hepatocellular carcinoma, offering guidance, shared experiences, and emotional support. To access a mentor (as a mentee) or to volunteer as a mentor, please click on this link. We look forward to working with both mentors and mentees.

Meet-ups across the country (Please let us know of any other local meetups so we can include them so everyone has a chance to join.)

Victoria/Vancouver - Meet ups are at 11:00am on the last Sunday via Zoom. Next one is on Sunday June 28th. We warmly welcome all those associated with cholangiocarcinoma.
Contact mychcc.ca if you would like more information.

Calgary – Meet up on the last Wednesday of every month. As of January 2026, the venue will be changing monthly as the patient group wishes to try different venues across the city. The next meet-up is June 24 at **Olive Garden** on 36th Street and Memorial Drive N.E.

Everyone is welcome to attend either meet-up. If anyone requires more information go to Cholangio-Hepatocellular Carcinoma Canada.

Register for the Canadian support groups

To register, please click on the following links:

- Bereavement Support Group (Register)
- Canadian Advocates Meeting (Register)
- Patient Support Group (Register)
- French Support Group (Register)

Thanks in advance for reaching out.

Register for the 2026 CCRAN Biomarker Conference June 18-19, 2026

Click on this link to register.

Biomarker testing

As of December 31, 2025, C3 will not be covering the cost of the biomarker testing. Information for your physicians can be obtained from C3 or CHCC. The cost is approximately $2000 -$2200.

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OncoHelix-2 is transitioning to OncoHelix-3, their next-generation genomic profiling assay expanding coverage to 523 clinically relevant genes, including **integrated immuno-oncology markers such as MSI, TMB, and HRD**.

All variants previously detectable with OncoHelix-2 remain fully covered in OncoHelix-3, with additional genomic insights applicable across solid tumours. Here is the link for OncoHelix. Go to order a test and then cancer genomic profiling.

Update to Pemigatinib (Pemazyre) in Cholangiocarcinoma

Pemigatinib (Pemazyre) for the treatment of adults with unresectable locally advanced or metastatic cholangiocarcinoma (CCA) with a FGFR2 fusion or other rearrangement. Patients must have received at least 1 line of prior systemic therapy and have good performance status. Pemigatinib should be continued until disease progression or unacceptable toxicity. Patients who are intolerant to, but have not progressed on, first-line treatment may receive Pemigatinib provided they meet criteria.

The provinces that now have Pemazyre on the formulary are:
QC, NB, NS, SK, AB and BC.

Patient Story Corner

In every newsletter, we invite you to share your patient stories. Thank you for sharing, as your experiences of hope and encouragement can make a difference in the lives of other patients. You are not alone in this journey. If you'd like to share your story, please contact info@mychcc.ca.

HW's Story

My name is HW, I'm 60 years old, and I live in Toronto. I'm a professor, a wife, and the dog-mom to two English Setters. I love hiking, reading espionage novels, and going to the movies. It's been one year since I was diagnosed with cholangiocarcinoma.

My patient story began in April 2025 when I thought I had gastritis. I was experiencing lots of belching, early satiety (feeling painfully full after eating only a small amount), and a dull ache under my right ribcage. I also felt exhausted – so much so that I was taking naps at work, something I had never done before, and I had to sit and rest on a bench on my walk to the

subway in the evening. I couldn't find anything online that said gastritis caused this much fatigue.

My family doctor agreed with my self-diagnosis of gastritis, and prescribed some medicine, but was also worried that I could have gallstones, so she sent me for an abdominal ultrasound. It was immediately after the ultrasound that I began to suspect that something might be terribly wrong. The technician, who had been so talkative and cheerful before the scan, wouldn't meet my eyes afterward, and just kept looking at the floor.

And it turned out there was something terribly wrong: the ultrasound showed a 10.5 x 8 cm mass in my liver. In rapid succession I had a contrast-dye CT scan, MRI, colonoscopy, blood work, and a biopsy. I remember sitting next to the surgical oncologist as he showed me images from the MRI on his desktop. The tumour looked enormous. He gave me the hard news that it was too big, and encroaching too much on the main portal vein, for surgical resection. "So, are you telling me I am going to be dead in 6 months?" I asked. He replied that most patients made it through chemo-immunotherapy, and he was hopeful that treatment might eventually make resection possible.

I was terrified and angry. I was too filled with dread to do any research about cholangiocarcinoma. I lay awake every night having the same compulsive thoughts about everything I had to do before I died. I hadn't updated my will in 15 years. I needed to go through my closets and drawers and figure out what to donate or throw away. I refused to talk to my mother on the phone about my diagnosis because I knew I would cry, and I was already crying all the time. I looked at strangers on the street and thought that if an evil genie appeared and offered to take my cancer away by giving it to one of those strangers, I would agree in a heartbeat. I thought a lot about work colleagues I disliked and how I would give my cancer to them if I could. Everyone says you need to have hope to get through this disease, and I did not have hope.

I started seeing a therapist online who cautiously suggested that I try antidepressants. I think she was used to patients resisting the idea of taking medication for depression and anxiety, but I knew that something had to change. I had to reach some degree of emotional stability so that I could find the courage to do research about my cancer, participate in webinars, join a support group, and so on. So, I quickly agreed to give antidepressants a try, and I would say they have turned things around for me. The fear diminished, the rage receded, and hope and I are no longer strangers.

My chemo-immunotherapy infusions (gem/cis/durva) began in early July 2025, and I completed 8 cycles over 6 months, finishing in late December

2025. I've been lucky: although I often felt very achy and tired immediately after the infusions, within a day or two I would feel almost back to normal. I never experienced severe pain and never had to deal with nausea or vomiting. As time went on, the side effects did get worse: some tingling in my toes, ringing in my ears that sounded like the tinkling of broken glass, increased fatigue, terrible constipation, insomnia that only responded to sleeping pills, thinning hair, dangerously high blood pressure, and a defunct thyroid gland. I've gone from being a person who took nothing but calcium supplements to being on 6 different daily medications. By the end of cycle 8 my hemoglobin and platelet levels were too low to continue the chemo-immunotherapy, and so I followed the standard protocol of getting durvalumab infusions once/month beginning January 2026. The chemo-immunotherapy protocol succeeded in shrinking my tumour down to 8.3 x 4.5 cm., but this is still not small enough for resection.

And now chapter 2 of my treatment story begins! The comprehensive genomic profiling of my tumour showed that it has both the IDH1 mutation and the very rare NRG1 fusion mutation. My oncologist advised that I try zenocutuzumab (Bizengri), a relatively new and extremely expensive therapy that targets the NRG1 fusion mutation and was recently approved by the FDA and the NCCN (National Comprehensive Cancer Network) in the United States, which means that insurance companies in the US must reimburse it. It has shown excellent results in the eNRGy clinical trial, and my oncologist believes it will be more effective in shrinking my tumour than ivosidenib (Tibsovo), a targeted therapy for the IDH1 mutation.

However, the drug developer, Merus, has not applied for approval in Canada, and has not granted the compassionate use request my oncologist submitted. Partner Therapeutics, the drug manufacturer in the US, only has rights from Merus to sell the drug in the US, and they claim they cannot grant compassionate use or a discounted price to a patient in Canada. So far Ontario Health has refused to pay for this treatment. Therefore, after receiving special access approval from Health Canada, my husband and I have been paying out of pocket to buy the drug and have it shipped to Toronto. It is $35,000 per dose, and the protocol is one dose every two weeks. (If you are gasping right now, yes, I agree, this is shocking.) We have managed to pay for 6 doses, and I've had 4 of them so far. In early July I'll have a CT scan that I hope will show whether it is working or not. I feel great right now, better than I have in a year, and I hope this means the zeno is killing that nasty clump of cancer cells in my liver. At some point quite soon, we will run out of savings to pay for this drug, and I don't know what we will do then. Probably I will go back on durvalumab, or maybe I'll try ivosidenib, both of which would be free. Beyond my own case, I wonder about the future

of cancer care in Canada. Precision oncology – that is, therapies targeted to specific mutations in a tumour – seems to be where cancer care is headed, but they are very expensive, and Canada is egregiously slow to approve these new drugs. And who knows if the manufacturers of targeted therapies will even bother to apply for approval in Canada since so few patients will need them. As far as I know, I am the only patient in Canada currently taking zenocutuzumab.

I am still sad and angry that my life may be cut quite short. I want to stay alive to attend my niece's high school graduation and see where she goes to university and what she majors in. I want to go on hikes in the Rockies and the Alps. Sometimes I think to myself that I will really miss hugging my husband when I'm dead. (And I will definitely miss his cooking! He cooks dinner every night!) But I will also say that I've had some amazing interactions with people that wouldn't have happened if I didn't have cancer. One day early on in treatment I suddenly had to use the toilet while on a run – whether this was a side effect of the chemotherapy or my antidepressants, I don't know. I desperately explained my situation to a woman gardening in her front yard, and she immediately brought me into her house to use the washroom. Rosie is her name, and she has become a friend. Another time, I happened to be the only customer in my local bank branch, and the tellers wanted to know why I was requesting such a large bank draft for an infusion clinic (it was for the zeno). They gathered around as I explained cholangiocarcinoma and wrote it down for them so they could look it up later. They all said they would pray for me. The kindness of both friends and strangers fills me with awe and wonder and sometimes seems almost magical. I wish moments of awe and wonder for you too as you make your way on this hard, hard journey.

Editor's note: Thank you for sharing your story with us. Your attitude is amazing! We are rooting for you!

Fundraiser for CHCC.

We linked up with the Calgary Marathon this year and were able to raise over $ 9,000 in funds for the charity. **Thank you to everyone who participated and donated** to the cause.

Some photos are on the website but the stars were our two six-year-old runners!

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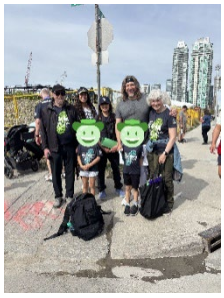

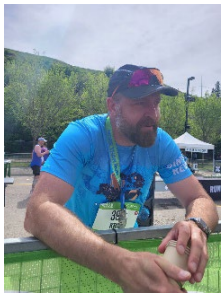


We also had virtual runners in Calgary, Red Deer, St Albert, Toronto and Sweden.

Recent Webinars

All the webinars are posted on the website and YouTube channel. Check them out!

Upcoming Webinars

Jessica Anderson RD hosted a nutrition webinar in May. The link to watch is here.

Education Corner

AMMF Charity Conference

The annual AMMF cholangiocarcinoma conference was held the second week of May at the Stansted Airport. It is the conference for the UK and Europe.
All the presentations occurred in the same room, with patients, caregivers, medical oncologists, surgeons, other specialists and researchers present. Most of the presentations contained information applicable to patients and caregivers. All the presentations can be found in this link. I am including some items not found in the conference agenda which I feel are worthwhile knowing.
Some takeaways were:

- **Helen Moreland (CEO and Founder of AMMF)** began by stating that when they started the AMMF in 2002, the three issues they felt were important were:

A. Raise awareness
B. Provide information and support
C. Encourage and fund research

Twenty-four (24) years later, these are still the top three priorities, despite the advances that have been made in CCA. They started the **Rethink Liver Cancer Campaign** in 2025.

- Jess's rule. Jess was a 27-year-old who saw doctors 20 times before becoming diagnosed with cancer and she lived for 3 weeks after her diagnosis. Her family campaigned and the NHS now has posters in doctor's offices regarding three strikes and physicians are asked to **reflect**, **review** and **rethink**.

  - **Reflect:** Think back on what the patient has said and consider what has changed or been missed. Offer ongoing **episodic** continuity of care for future direct patient care. If previous consultations have been remote, see the patient face-to-face and conduct a physical examination (NHS, 2026).
  - **Review:** Where underlying uncertainty exists, consider seeking a view from a peer and review any red flags that may suggest another diagnosis, regardless of the patient's age or demographic (NHS, 2026).
  - **Rethink**: If appropriate, refer onwards for further tests or for specialist input (NHS, 2026).
- Another takeaway from conversations is that when a patient has jaundice, even if they cannot place a stent in, the patient can still have gemcitabine and cisplatin. Link here.
- Liver transplantation for iCCA and pCCA (with PSC), but with very strict guidelines.
- There were so many topics that were interesting. Please go to the website and watch the various presentations

Helen and Brenda

Helen is the founder of AMMF Cholangiocarcinoma Charity. Her husband died from CCA and Helen started this charity 24 years ago in his memory. She has a quiet strength and is an amazing individual who leads the work that this charity has accomplished. What a privilege to meet her!

Wellspring Canada is an organization for all cancer patients. It has a physical presence in Alberta, Ontario and New Brunswick with online availability Canada-wide. The programming is evidence based. They have paid professional facilitators, and it is offered at no cost to the patient. To register, go to www.wellspring.ca. Once you become a member, you can sign up for any online courses that are offered. It is a great organization and worthwhile checking it out!

Board Updates

The annual general meeting is scheduled for August 2026, the exact date TBD.

Two new Board members will be elected/appointed at that time.

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Brenda Clayton will be seeking re-election. She is one of the founders of the charity and has served in the capacity of President since its' inception.
Donna Jone is seeking a seat on the Board. She is a Registered Nurse and has been volunteering with CHCC in a fund-raising capacity.

June 11 is Global Fatty Liver Day

The second Thursday in June is designated Global Fatty Liver Day. On this day, buildings across Canada are lit green to raise awareness about fatty liver disease.

Fatty Liver disease, also called MASLD (metabolic dysfunction-associated steatotic liver disease) is a risk factor for liver cancer. It affects approximately 25% of all Canadians and can occur when too much fat is stored in the liver; this is non-alcoholic in nature (Medline, 2026). Our Ask the Dietitian column this month addresses "Fatty Liver Disease."

Ask the Dietitian with Jessica Andersen, RD

This month there was a request to talk about fatty liver disease. Known as **MASLD (metabolic dysfunction-associated steatotic liver disease)**, fatty liver impacts 1 in 4 Canadians. If left unchecked, it can progress to MASH (metabolic dysfunction-associated steatohepatitis) which could progress to liver fibrosis, which can move to liver cirrhosis which can ultimately lead to liver cancer. Now, not everyone progresses from fatty liver to liver cancer or even irreparable liver damage such as liver cirrhosis, but if you know you have fatty liver, it is important to make some lifestyle changes to decrease the risk of further liver damage.

Who is at risk?
In short- almost anyone. Those who carry extra weight, those who have had bariatric surgery or recently lost a lot of weight in a short period of time, those with hypertension and diabetes and high levels of fat in the blood or a genetic link to fatty liver are all at increased risk. Consider asking your doctor to screen you for fatty liver.

I have fatty liver- now what?
MASLD is luckily able to be managed and even reversed with changes to diet and lifestyle. However, it is worth noting that all changes should be maintained long-term, as there is no known cure. The approach to manage

fatty liver is multi-pronged: **get active, eat a balanced diet, limit alcohol, take medications as recommended, and manage your weight.** Diet will be addressed in a coming section.

Getting active is important for your metabolic health, if you haven't exercised in a long-time, check with your doctor about what kinds of activities and how strenuous you should be with getting active. Aim for eventually hitting 150 minutes of moderate intensity exercise per week. If you can be active every day- even better!

Limiting alcohol is a no-brainer, alcohol is processed in the liver and contributes excess calories to the body without providing any additional nutritional benefits. If you drink, the best recommendations are that you decrease considerably or stop altogether for best liver health. Consider only having a drink at special occasions such as weddings and abstaining otherwise altogether.

Take medications as directed- if your doctor recommended a medication for management of a chronic disease, take it as directed. In addition, take over-the-counter medications as directed, as taking them too often could also lead to liver damage. If you are taking any unregulated supplements, check with your doctor or pharmacist if they can lead to liver damage, as well.

And the last piece is about weight management: some diet and lifestyle changes are likely to lead to some weight changes. If you are actively gaining weight, attempt to stabilize your weight. If your weight is stable, some mild weight loss (5-10% of your weight if you carry extra weight) can help improve your fatty liver.

Diet and managing fatty liver

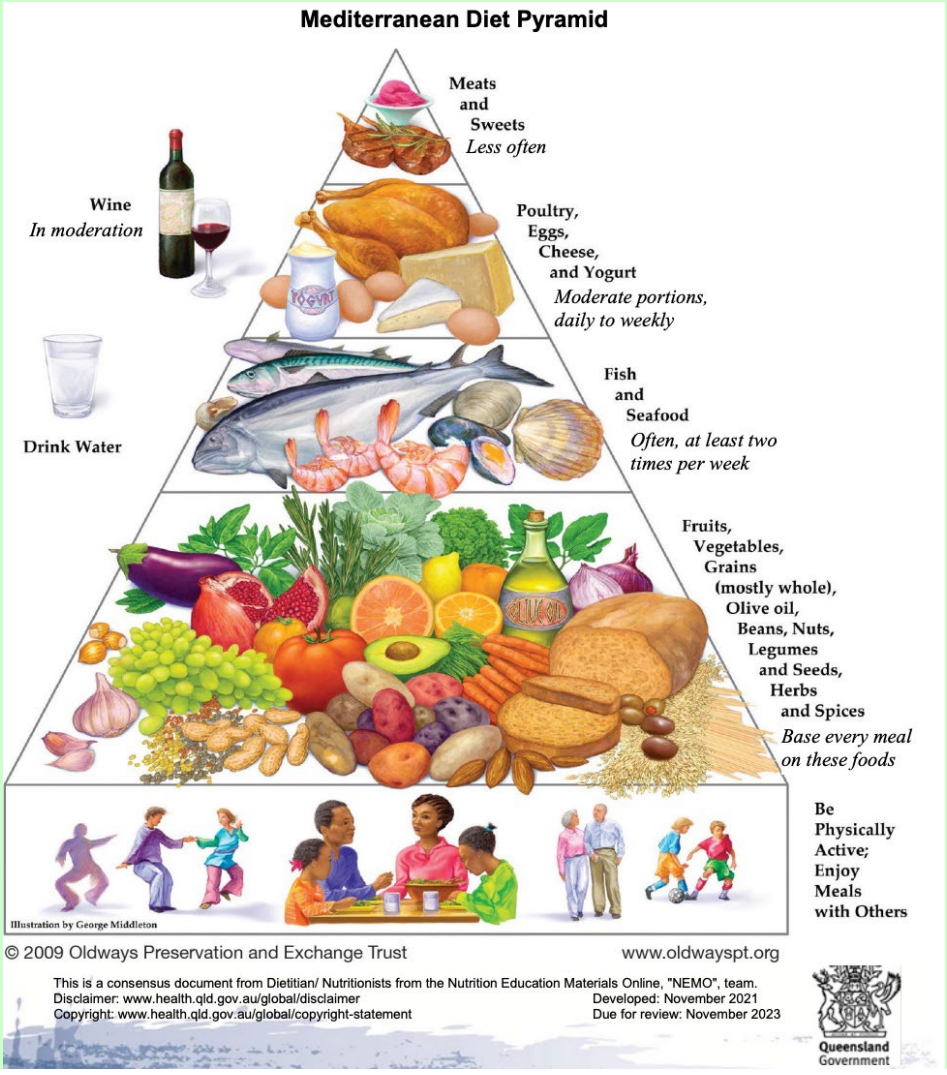
There is no one single diet pattern recommended for fatty liver. However, one of the most frequently recommended is the Mediterranean Diet. So, we will focus on this today.

A Mediterranean diet is high in fruits and vegetables, with a variety of vegetables at as many meals and snacks as possible, aiming to have vegetables as about half your plate.

Include fish in your meal, for their omega-3 fats, at least twice per week. Eat red meat once per week or less, replace with lower-fat meats like poultry, or substitute with meat alternatives like eggs, lentils, nuts and tofu. Your protein

source is recommended to be about a quarter of your plate. When having dairy products (cheese, milk or yogurt), the low-fat version is recommended.

Grain products are recommended to be the whole grain version. This increases the fibre content, and grains are recommended to be a quarter of the plate as well. When looking for a fat to add to meals during cooking, consider using olive oil (or other vegetable oil) instead of butter or animal fats. The Mediterranean diet also includes a social aspect - meals are recommended to be enjoyed with friends and family. Sweets are recommended to be enjoyed infrequently, and water (as opposed to pop or other high sugar drinks) should be the number one drink. There is also some evidence that black coffee 2-3 times per day can reduce your risk of liver cancer, but the benefits vanish with the addition of anything to your coffee.



Do I have to limit sugar?

There have been a lot of questions about whether sugar 'feeds' cancer. To be very clear- cancer is a part of you. That is why it is so hard for your body to identify and fight cancer on its own, these are your own cells. Sugar (carbohydrates) feeds you; protein feeds you, fat feeds you - these are the building blocks of your food. So technically sugar does feed cancer, but it also feeds you. And there is no link stating sugar specifically feeds cancer or makes it grow faster.

Your brain's favourite thing is carbohydrates (sugar is a simple form of carbohydrate). I do not suggest you stop feeding yourself, it is very important you feed yourself to be strong enough to get through treatment and keep your muscle mass up so you can metabolize your medications and be able to do the things you need to do. However, there are changes you can make to make sure you are getting the most out of your nutrition.

There are different types of sugar. Natural sugars come from things like fruit, vegetables, grain products and milk products. These items have fibre and vitamins and minerals your body needs, there is generally never a reason to limit these items. Added sugars however, which are often found in candy, chocolate, desserts and pop, are an area you could cut back. There are still calories for energy for your body in these items, but these are often not nutrient-dense items and they often don't fill you up or give your body other nutrition.

Decreasing added sugar in your diet and focusing on less processed foods is best for your overall health. The Canadian Cancer Society recommends 10% of your calories or less coming from added sugar. But, still live your life! At a birthday party, eat the cake. Going to the movies, get your favourite candy. There is no reason to cut out added sugars entirely. Food is social and a pleasure of life, I would never recommend removal of anything, even added sugar, from the diet entirely.

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Upcoming Dates:

- **Jun 16 –** Patient support group
- **Jun 23 –** French-speaking support group
- **Jun 24 – Meet-up in Calgary**

- **July 7 –** Bereavement support group
- **Jul 14 –** Canadian advocates meeting
- **Jul 21 –** Patient support group
- **Jul 28 –** French-speaking support group
- **Jul 28 – World Hepatitis Day**
- **Jul 29 – Meet-up in Calgary**

- **Aug 4 –** Bereavement support group
- **Aug 11 –** Canadian advocates meeting
- **Aug 18 –** Patient support group
- **Aug 25 –** French-speaking support group
- **Aug 26 – Meet-up in Calgary**

- **Sep 1 –** Bereavement support group
- **Sep 8 –** Canadian advocates meeting

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- **Sep 15 –** Patient support group
- **Sep 22 –** French-speaking support group
- **Sep 30 – Meet-up in Calgary**

Venues across Canada lit green for World Liver Day and Global Fatty Liver Day

St. John's City Hall
St. John's, NL

Calgary Tower
Calgary, AB

To support patient advocacy, donate here.

To volunteer with CHCC, please go to the "Contact Us" tab on our website (or click on the link) or message us at info@mychcc.ca.

We would love to hear from you! We are just a text, email or phone call away. We are always available if you need to reach out.