

Living with cholangiocarcinoma: managing your nutrition needs



This booklet was designed with support from two gastrointestinal oncologists and a dietitian to help support the nutritional and dietary needs of patients who have recently been diagnosed with cholangiocarcinoma.

What is cholangiocarcinoma?

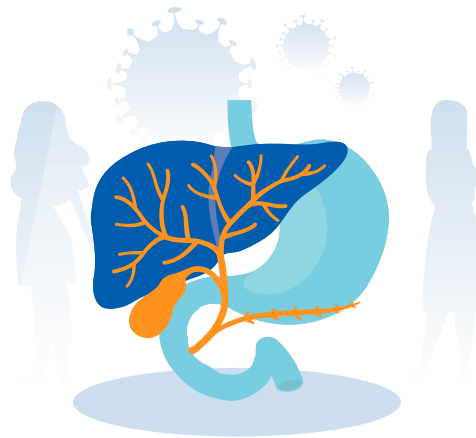


Cholangiocarcinoma (*pronounced ko-LAN'-jee-o-car-sin-O'-ma*) is cancer that forms in the bile ducts. You might also hear this referred to as bile duct cancer.^{1,2}

Bile ducts are the thin tubes that connect your liver, gallbladder, and small intestine. Their job is to carry the digestive fluid known as bile, which is made in your liver and helps break down fats.^{1,2}

Doctors divide cholangiocarcinoma in to different types based on where it occurs. These are called intrahepatic and extrahepatic cholangiocarcinoma.³

- Intrahepatic means the cancer affects the bile ducts *inside* the liver³
- Extrahepatic means the cancer affects the bile ducts *outside* your liver, nearer to the intestine³
- There are two forms of extrahepatic cholangiocarcinoma. These are called perihilar and distal cholangiocarcinoma³



Understanding the type of cholangiocarcinoma you have will help your doctor decide how to treat your cancer.

The benefits of healthy eating



We all know healthy eating is important for everyone. However, making sure you have a good, balanced diet is especially important for people living with cancer.

Malnutrition is a term used to describe when your body is not getting all the energy (calories) and nutrients (particularly protein) it needs from your food. People with malnutrition may experience a loss of weight and muscle mass, which can have a negative impact on treatment tolerance (side effects), quality of life and how well you will respond to treatment.⁴

Malnutrition is estimated to affect around 4 in 10 people living with cancer and is more common in those who are older and have advanced disease.⁴

Malnutrition is caused by both the cancer and some cancer treatments. The cancer can compete with your body for energy and nutrients, affect your body's ability to digest food properly or affect your appetite. Cancer treatments can cause side effects, for example, being or feeling sick, that make it difficult to consume or digest enough energy and nutrients.⁵

There are steps that you can take to prevent malnutrition. Research has shown that working with healthcare professionals to improve eating habits can be beneficial for those living with cancer.^{4,5}

This booklet offers advice about dietary changes you can make while undergoing treatment for your cholangiocarcinoma.



Your nutrition is personal and everyone will have different concerns and needs. If you have any questions, please speak to your doctor or dietitian who will be able to provide you with tailored, individual support.

Eating a balanced diet

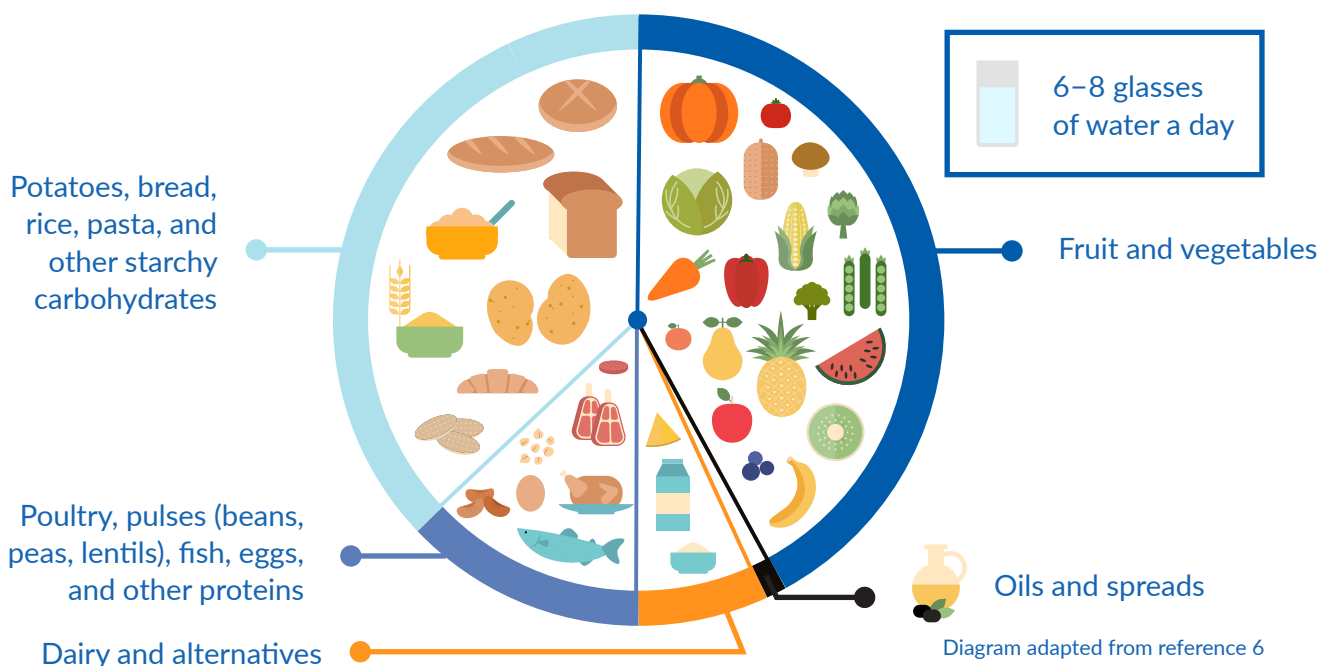


Eating a balanced diet is important to ensure you are getting all the nutrients you need from your food.

Helpful tips for balanced eating:⁴⁻⁶

- Try to eat a wide variety of different types of foods – think different colours, textures, and tastes
- Aim to eat at least 5 different portions of fruit and vegetables every day
- Make sure each meal has a good source of protein. This includes poultry (chicken, turkey), pulses (beans, peas, lentils), fish, and dairy sources (milk, yoghurt, cheese)
- If you can, try to eat less red and processed meat (although you should not remove this from your diet completely)
- Choose wholegrain or higher fibre options where possible. This includes wholegrain, seeded, or brown bread; wholegrain pasta, rice, and cereals
- Pick foods that are lower in sugar and salts
- Drink lots of water – aim for around 1.2 litres (6–8 glasses) every day and reduce the amount of carbonated (fizzy) drinks you consume
- Limit the amount of alcohol you drink

Guide for achieving a healthy, balanced diet



Nutritional support in cholangiocarcinoma



For many people, early symptoms of cholangiocarcinoma can include nausea, loss of appetite, weight loss, and general tiredness. This can mean your nutritional status may be poor before you even begin treatment.^{5,7}

For this reason, your doctor or dietitian may work with you to improve your nutrition before starting treatment or undergoing surgery. This is called nutritional therapy.

Goals of nutritional therapy include:⁵



Optimising your nutritional status to ensure you are healthy enough to begin and continue treatment



Maintaining your immune system to defend against infection



Increasing lean body (muscle) mass and preventing body tissue from breaking down



Coping with side effects of anticancer treatment

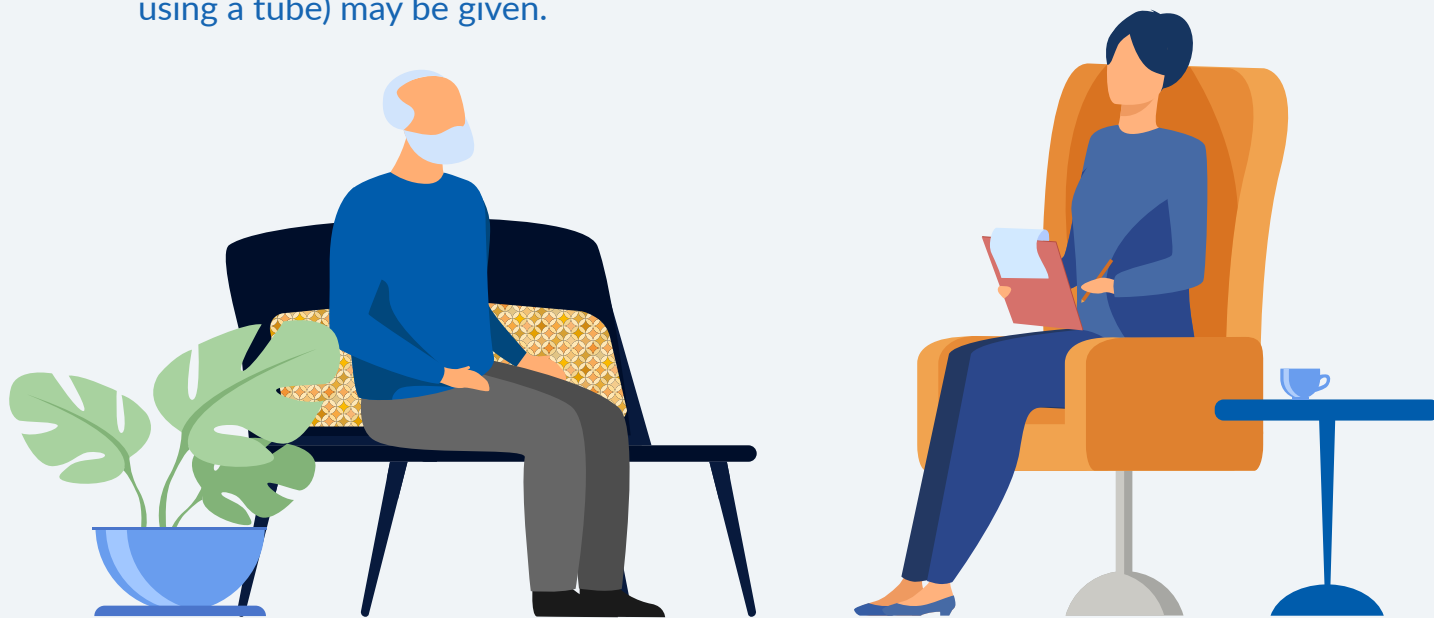


Maintaining your strength



Making sure you continue to enjoy food

Nutritional therapy may be needed, either temporarily or long term, to help cope with your symptoms. This often includes counselling, oral supplements or both. In some cases when supplements are not sufficient to cover your caloric and protein needs, artificial nutrition (nutrients and energy provided using a tube) may be given.



Maintaining your weight during treatment



Maintaining your weight and muscle mass is important for people diagnosed with cancer. Being underweight may impact your symptoms or how well you respond to treatment.^{4,8}

As many people with cholangiocarcinoma will experience weight loss, you may need to try and eat extra calories and protein to maintain your weight. Here are some practical tips to help:^{4,5}



Try to eat 3 meals and 3–4 nourishing snacks per day



All food and drinks should be high in energy and protein. On your plate, prioritise the protein source first, alongside carbohydrates



If you have a poor appetite, higher energy foods should be prioritised over fruits and vegetables, but you should still try to eat them if you can



Avoid large portions if your appetite is small as this can be off-putting. Eating from side plates can help



Try to eat more on the days when you have more of an appetite



Speak to your doctor or dietitian about the possibility of using fortification supplements – these are usually premade milkshakes or yoghurts that are high in calories and protein



Stay active and practise physical exercise (e.g. walking for at least 30 minutes per day) to maintain your muscle mass and physical fitness



You may want to consider using a food tracking app to help you monitor your calorie, protein, carbohydrate and fat intake

Coping with side effects of treatment



As part of your treatment, you may undergo surgery or radiotherapy, or be given different types of medicine called chemotherapy or targeted therapy. Each of these treatments can cause side effects. Your doctor will be able to advise you on your treatment plan and what you can expect.

The following pages describe some of the more common side effects you may experience and how your diet can help to cope with them.

Nausea and vomiting



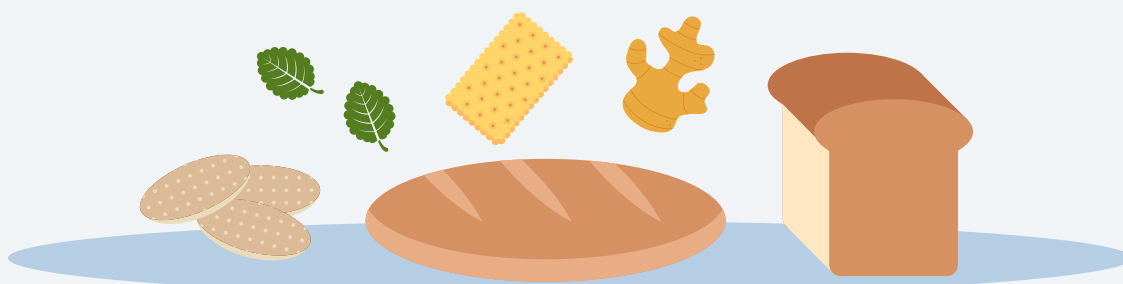
Feeling and being sick (nausea and vomiting) can sometimes occur during treatment.^{4,5}

If you are feeling sick, try to avoid eating your favourite foods in case you develop a dislike for them. You should also avoid spicy foods or foods with a strong smell.⁵

Eating dry, plain foods, such as toast, crackers, and rice cakes, can help to reduce symptoms of nausea and vomiting. Foods containing ginger and peppermint (especially peppermint tea) can help to relax stomach muscles and reduce nausea.⁵ You may find that you feel less sick at certain times of the day, so try to eat at these times if you can.



If you are struggling with nausea and vomiting, your doctor may be able to give you medication to help.



Coping with side effects of treatment



Diarrhoea



Diarrhoea can be a symptom of your cancer or the treatments you are taking.^{4,5} If you are experiencing severe diarrhoea, please speak to your doctor as they may be able to give you medicine to help.

If you are experiencing diarrhoea, you should avoid eating high-fibre foods (e.g. wholegrain bread, cereals, and raw vegetables) as this can make you need the toilet more often. You should also avoid caffeine, and fatty or spicy foods for the same reason.⁵



Make sure you are drinking plenty of fluids to replace those lost during the day. As well as water, try to drink juices, sports drinks, or herbal teas to replace salts and sugars that have also been lost.⁵

Sore mouth or throat



Certain types of chemotherapy can cause you to experience a sore or dry mouth and throat. Some people may also get a mouth infection called thrush.^{4,5}

If you have a sore mouth or throat, try to eat cold, soothing food and drinks, such as yoghurt, milk, or ice cream. You should avoid salty, spicy, and acidic foods (such as lemon) as these may make your symptoms worse.⁵



Using antiseptic mouthwashes or sprays can help to cope with symptoms. If you are struggling, speak to your doctor who can refer you to a dietitian for advice on a soft or puréed diet.

Coping with side effects of treatment



Changes in taste



Your treatment can change the way that some foods taste to you, they may taste metallic, bitter or bland.⁵

If you are having taste changes, try:⁵

- Preparing foods that look and smell appetising to you, for example colourful fruits and vegetables
- Try adding herbs and seasoning to your food to make it more palatable



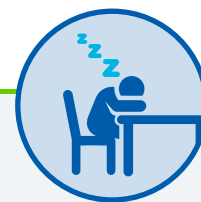
Avoid foods that don't taste good for a few weeks before trying them again to see if your taste has returned to normal⁵



Coping with side effects of treatment



Fatigue



Feeling tired (also known as fatigue) is a common side effect of many cancer treatments. For many people, feelings of tiredness worsen the longer they are on treatment and can continue for many weeks.^{4,5}

Eating a balanced diet should help you reduce these feelings of tiredness. However, there are other practical things you can do, such as:^{4,5}

- Using an online food shopping delivery service
- Keeping your cupboards well stocked with easy-to-prepare foods
- On days you are feeling more active, trying to cook extra meals and freezing them for a later date
- Allowing family and friends to help do the shopping and cooking for you

Hyperphosphatemia



Hyperphosphatemia (*pronounced HY-per-FOS-fa-TEE-mee-uh*) is a condition which occurs when the levels of a mineral called phosphate in your blood are too high. This can sometimes happen as a side effect of certain medications.⁹



If you have hyperphosphatemia, your doctor may ask you to make some changes to your diet. One of the best ways to do this is to reduce your intake of foods containing added phosphate (phosphate additives), such as processed foods. You may also need to reduce your intake of foods naturally high in phosphate, such as meat, eggs, and dairy.¹⁰

Nutritional considerations following surgery



If your cholangiocarcinoma can be operated on and removed, you may experience long-term side effects from the surgery. These side effects may need to be managed differently to those associated with cholangiocarcinoma treatment.^{5,11}

Surgery for cholangiocarcinoma



Recovery time following surgery will vary for each individual depending on the extent of their surgery and general level of fitness before their operation. Most people will need to stay in hospital for several weeks so that doctors can make sure they recover as expected.¹¹

Following surgery your bowels may not work as they normally would and you may find eating and drinking difficult. Your doctor will be used to managing this and will help you to gradually reintroduce water followed by small and frequent meals.¹¹

It is normal to experience some pain following surgery and your doctor or nurse will be able to give you medications to manage this if needed. Getting up and moving once it is safe to do so can help to speed up your recovery.¹¹

The following pages provide more information on the nutritional considerations for people who have had surgery for their cholangiocarcinoma.



Nutritional considerations following surgery



Whipple procedure



Some people who have cholangiocarcinoma will have a type of operation commonly called a Whipple procedure (pancreaticoduodenectomy).⁵

The purpose of this surgery is to remove the tumour but surgeons may need to remove other healthy parts of the body (organs) that are located nearby. This includes parts of your pancreas, gallbladder, bile ducts and intestines.⁵

After performing the Whipple procedure, the surgeon will reconnect the remaining organs to allow you to digest food after surgery, but the procedure can have a long-term effect on your nutrition. Some of the symptoms you may feel include poor appetite, feeling sick, feeling full when not eating enough (early or prolonged satiety), bloating, cramping and wind, weight loss (even when eating enough), diarrhoea or fatty/oily stools.⁵



If you have had surgery, your doctor may recommend that you receive pancreatic enzyme replacement therapy (PERT).^{5,11} This medication would replace the enzymes that your pancreas would normally make. These enzymes help you to digest your food by breaking down carbohydrates, fats and proteins in your food.^{5,11} Your doctor or dietitian will provide you with more information on this.



Nutritional considerations following surgery



Bile acid malabsorption (BAM)



Bile acid is a substance produced in your liver which is released into the small intestine when food is eaten to help digestion. In some people who have had surgery as part of their treatment, bile acid is not reabsorbed properly back into the blood, causing a condition called bile acid malabsorption (BAM), which can lead to diarrhoea and weight loss.^{5,11}



BAM can cause stomach issues, such as bloating, cramping, stomach pain, and excessive wind. Changes to your diet, such as reducing the amount of fat, can help to reduce symptoms. You may also be given medication to help reduce bile acid and prevent further irritation.^{5,11} If you have BAM, you should work closely with your doctor and dietitian to cope with your symptoms and treatment plan.

Small intestinal bacterial overgrowth (SIBO)



Changes in your small intestine from surgery may cause your natural gut bacteria to grow abnormally or to unusually high levels. This can lead to significant symptoms, such as bloating, excessive wind, diarrhoea, weight loss, nutritional deficiencies, and osteoporosis (weak bones).⁵



Depending on the type of bacteria growing, treatment usually involves a course of antibiotics and supplements to return nutrients in your body back to their normal levels. You may also be advised to follow a specific diet called the low-FODMAP diet. Your doctor or dietitian will be able to provide you with more information on this.⁵

Use this space to take notes if needed. You can take this booklet with you to your next doctor's appointment to help discussions about your individual nutritional needs.

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If you require further support or information, please speak to your doctor, nurse or dietitian.

They will be able to advise you on the right type of diet for you.