



Adapting to cholangiocarcinoma (CCA)

A guide for people living with CCA and
their caregivers



INTRODUCTION

Welcome to Adapting to Cholangiocarcinoma (CCA), part of the Support Harmonized Advances for better Patient Experiences (SHAPE) program.

This guide aims to help people living with CCA. It has been developed for you with input from people living with cancer, patient advocates, and cancer experts.

This guide is part of the SHAPE initiative that is supported by an unrestricted grant from Servier.

HOW CAN THIS GUIDE HELP YOU?

When you are diagnosed with CCA, you start a new part of your life. You are unlikely to have experienced anything like this before, and may feel like there is a lot of information to take in.

This guide can give you a clearer idea of what to expect along the way. It has been designed to guide and support you, your family, and caregivers as you experience the different steps of CCA.

You can use this guide to help you better understand the information you receive from your health care team. The guide also provides advice on questions you may ask yourself, your loved ones and your health care team, which can help you to feel more at ease.

As you move forward, this guide will support you to adapt to life with CCA.

DEVELOPED WITH SPECIAL INPUT FROM:



Steve Holmes

Founder – Chief Executive
Patient Navigator and Survivor,
Cholangiocarcinoma Foundation Australia



Claire Holmes

Founder – Chief Operations Caregiver
Navigator, Cholangiocarcinoma
Foundation Australia



**and members of the
Cholangiocarcinoma
Foundation Australia**

“The SHAPE program is really working on providing information for patients and other healthcare providers...especially in rare malignancies like cholangiocarcinoma.”

Angela Lamarca, Institute Fundacion Jimenez Diaz University Hospital, Spain.

“As patients, we must first equip ourselves with knowledge to become empowered. The SHAPE program helps us achieve this”

*Steve and Claire Holmes,
Cholangiocarcinoma Foundation Australia.*

THE ADAPT PATHWAY

Every person living with CCA is unique. Your experiences and those of your family will be individual to you. However, there are key steps that are important for everyone.

The ADAPT pathway brings together information that can help you to understand how your life will change after your diagnosis. It can also point you in the direction of resources that provide information in more detail.

Key steps following diagnosis are shown below. However, your pathway may not run in this order. You might have treatment more than once, or you may want to plan for the future straightaway. Whether you are reading this just after being diagnosed, during treatment or afterwards, you can use the ADAPT pathway to take you to the information that is most important to you right now, and you can return to earlier sections or jump to later ones whenever you need.



Diagnosis

Awareness

Information to help you know more about CCA, understand your diagnosis and guidance on how to find more information online

This will be the beginning of your CCA pathway where you receive a diagnosis and find out more about what this means for you.



Discussions with loved ones and your health care team

Dialogue

How to talk about your diagnosis, including:

- Sharing the news with family, friends, and peers
- Preparing for conversations with health care professionals (including shared decision-making)

Dialogue is important throughout the whole pathway and may be relevant whenever you need to speak to your family, loved ones or health care team about your cancer and how you feel.



Treatment

Access

Information to help and support you before, during and after treatment, including:

- Getting the most information and support from your health care team
- Clinical trials information

Treatment will usually happen for a period of time and then stop, but you may need to have treatment several times to help you feel better.



Living Well

Psychological and physical well-being

Guidance to help you look after your psychological and physical well-being, including:

- Emotional health
- Nutritional health
- Physical health

Living well is important at all times during your pathway, especially during and after treatment.



Future Planning

Take care

Guidance to help you take care of different aspects of everyday life and plan for the future, including:

- Relationships
- Work-life balance
- Finances
- Palliative care

You can choose to plan whenever you wish. You might prefer to think about the future early or after your treatment.



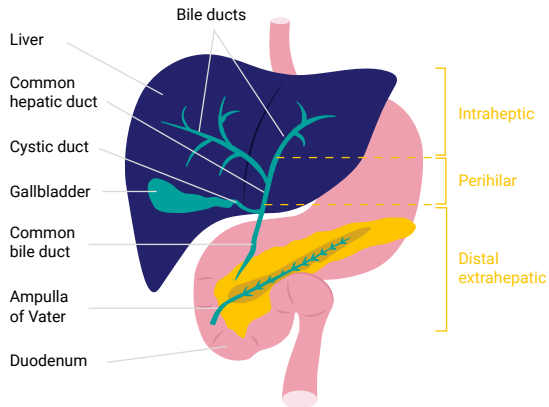
AWARENESS

This chapter focuses on what CCA is - the symptoms, disease staging, tests for diagnosis, introducing the health care team, and guidance on how to find trustworthy information.

UNDERSTANDING CCA

WHAT IS BILE AND THE BILE DUCTS?

Bile is a liquid produced inside the liver that is used to help digest fats. It passes out of the liver through small tubes called bile ducts that drain the bile to the gallbladder, where it is stored, through to the small intestine.¹



WHAT IS CCA?

CCA, also known as bile duct or biliary tract cancer, is a rare cancer that occurs in the bile ducts.¹

WHAT ARE THE DIFFERENT TYPES OF CCA?

There are three main types of CCA, which depend on where the tumor is situated:¹

- **Intrahepatic** CCA that occurs in the smaller bile ducts within the liver
- **Perihilar** CCA that develops just outside the liver
- **Distal or extrahepatic** CCA that starts in the bile ducts near the bowel

WHAT ARE THE EARLY SYMPTOMS OF CCA?

CCA usually doesn't cause symptoms early on. When it does cause symptoms, they can be vague and difficult to spot, such as nausea and loss of appetite.²

HOW IS CCA DIAGNOSED?

After you have noticed any symptoms and spoken to your health care team, they may do some tests to see if you have CCA. These tests may include:

TYPE OF TEST	WHAT HAPPENS DURING THE TEST?
Blood test	Your doctor will order a blood test to check your bilirubin levels. Bilirubin is a substance in your blood that may be a sign that something is wrong with your liver or gallbladder. Your doctor may also look for liver enzymes in your blood, called a liver function test. ³
Imaging	Your doctor will use imaging scans such as ultrasound, CT, MRI, and X-rays to look at where the tumor is and how big it is. ⁴
Biopsy	Your doctor will do a biopsy, taking a small sample from the tumor with a needle and studying the cells from the sample under the microscope to see what kind of tumor it is. ⁴
Endoscopy	A long, thin tube with a small camera inside, called an endoscope, is passed into your body through a natural opening such as your mouth. ⁵ In CCA, an endoscopy might be used to take a sample of your tumor. ⁴
Molecular testing (also known as biomarker testing)	Your doctor will have to take samples from the site of your tumor or, if your cancer has spread, your first tumor that developed. This is often done by taking a biopsy. Your doctor will be looking for biomarkers. ⁶ Biomarkers can tell your health care team whether you have cancer and help determine: the type and form of your cancer (diagnostic biomarkers); the chance of your cancer coming back after you've finished treatment (prognostic biomarkers); and which therapies might work for you (predictive biomarkers). ^{6,7}

WHAT HAPPENS AFTER A DIAGNOSIS?

Once CCA has been diagnosed, the cancer is staged. Staging is a way of describing where the cancer is in your body, the size of the cancer, if or where it has spread to, and whether it is affecting other parts of the body.^{4,8}

Staging includes further tests. Knowing the stage of the cancer helps decide the best treatment for it, and in some cases, whether a clinical trial may be a treatment option.^{4,8} To stage your cancer, your doctor may arrange a PET (positron emission tomography) scan which helps to find out how big the cancer is and whether it has spread.⁹



praetorianphoto © Getty Images

WHAT ARE THE DIFFERENT STAGES OF CCA?

The stages of CCA are based on the location and size of the tumor and how far it has spread:⁸

STAGE 1/I

The cancer is small. The cancer cells are in the bile duct and have not started to spread into the surrounding tissue. Or they have grown into the bile duct wall.

STAGE 2/II

The cancer is larger. There might be one or more tumors. It may have grown into the surrounding tissues, and there may be cancer cells in the lymph nodes nearby.

STAGE 3/III

The cancer has spread to nearby:

- tissues
- blood vessels
- lymph nodes
- organs such as the gallbladder and pancreas

STAGE 4/IV

The cancer has spread to body parts further away, such as the lungs.

This stage is known as **metastatic CCA**, **advanced CCA**, or **secondary CCA**.



METASTATIC CCA (MCCA) DIAGNOSIS

WHAT ARE THE POSSIBLE SYMPTOMS OF MCCA?

CCA that has spread to another part of the body is called mCCA.¹⁰ Symptoms of mCCA will vary for each person but can include:^{11,12}

- Tiredness (fatigue)
- Yellow skin and eyes (jaundice)
- Abdominal (tummy) pain
- Feeling or being sick
- Unexplained weight loss
- Mood changes

WHERE CAN CCA SPREAD TO?

CCA most commonly spreads to the lungs, bones, the lining of your abdomen (where your organs are contained) and your brain.¹⁰

Being diagnosed with a rare cancer like CCA can be overwhelming and confusing. It is normal to want to find more information online, but this information is not always correct. If you want to do your own research into CCA, the Cholangiocarcinoma Foundation: <https://cholangiocarcinoma.org/> and the Cholangiocarcinoma Foundation Australia: <https://cholangiocarcinomaaustralia.org/> provide trustworthy information online.

Speak with your doctor about any information you find online, and they can help you to understand it correctly.





MOLECULAR TESTING

GENE MUTATIONS AND CANCER

Genes are coded messages that tell cells how to behave. They control how our bodies grow and develop.

A change in a gene is called a mutation. These changes can make a cell stop working properly. If a gene mutation encourages a cell to divide and grow uncontrollably, it can lead to cancer.¹²

WHAT IS MOLECULAR TESTING?

No two CCA tumors are exactly the same. Even when they start in the same place, one person's cancer cells can be very different from another person's. In part, this depends on which gene mutations are present. These changes can alter the way the cancer cells look, behave and react to different treatments.^{13,14}

Molecular testing, also called 'molecular profiling', 'biomarker testing', 'genomic testing' or 'mutation testing',¹³ gives a detailed map of your tumor.¹⁵ Your health care team can use this information to select the best treatment options for your individual tumor,¹⁵ this is called 'personalized' treatment, or 'precision' medicine.¹⁶

Since molecular testing can help direct your treatment, it is important to be tested soon after your diagnosis. Don't be afraid to tell your doctor early on that you are interested in molecular testing.





HOW IS MOLECULAR TESTING DONE?

In molecular testing a small sample of tumor (tissue biopsy) or blood (liquid biopsy) is tested to find specific biomarkers which 'drive' the tumor.¹⁴



A small sample of your tumor is taken using a long needle. Occasionally, a blood sample can be used instead.^{13,17}



The sample is sent to a laboratory where tests will be performed to find unique characteristics of your tumor, called biomarkers. These biomarkers can be mutated genes or other molecules that signal if disease is present.^{13,17}



The results are sent to your health care team; they will discuss the findings with you, explain which treatments might work well for you and why, and you will agree a treatment plan together.^{13,17}

WHAT DO THE RESULTS OF MY MOLECULAR TESTING MEAN?

Knowing which biomarkers are driving your tumor could help you and your health care team to pick a treatment option that is most appropriate for you (see the [Access section](#) in this guide to see your treatment options).⁷

If your treatment stops working, or your tumor comes back or spreads after successful treatment, you may need to have further molecular testing to look for new biomarkers.⁷

WHAT IF I DON'T HAVE ANY KNOWN BIOMARKERS?

There is a chance that you might not have any known biomarkers that can help your health care team decide which treatment will be most effective.⁶

However, not having a biomarker doesn't necessarily mean the tumor is any more aggressive or there aren't any treatment options. In those cases, your health care team may use standard treatment options like chemotherapy, immunotherapy, or a combination of both.⁶



QUESTIONS TO ASK YOUR HEALTH CARE TEAM ABOUT CCA

There may be lots of information to take in when you are diagnosed with CCA. The following questions may help you better understand what this diagnosis means to you and your family:

What stage is my cancer, and what does that mean?

Do I need other tests before we consider treatment options?

Will you be carrying out molecular testing?

How long until we know the test results?

How will the test results affect my treatment options?

Do I need to see any other healthcare specialists?

Could you share your experience in treating this type of cancer?

How will CCA affect my daily life?

Don't worry if you feel something has already been covered by your health care team and you need to ask a question again. You might want to bring someone with you to your appointments for support and to help you remember key points or record your appointment on your phone (remember to ask permission from your health care team to record).





HOW LONG WILL I LIVE AFTER A CCA DIAGNOSIS?

Outlook, or prognosis, will vary for each person with CCA. Most people with CCA already have advanced cancer when they are diagnosed.¹⁰

However, in recent years the understanding and treatment of CCA have improved, meaning more patients are getting better results.¹⁸

Your doctor will be able to give you an approximate idea of what to expect. You may also not wish to know your outlook; instead, you may want only your loved ones to know your outlook.

COULD I PASS MY CANCER TO MY CHILDREN?

It is unlikely that CCA can be passed from a parent to their children, although there is not enough clear evidence currently to be sure.¹⁹

CCA often develops without any obvious cause.¹⁹ There are some things that may increase your risk of developing CCA, like getting older or having certain illnesses.¹⁹ However, CCA is rare, so it is important to remember that the risk of developing it is very small.¹⁹

MEET YOUR HEALTH CARE TEAM: THE PROFESSIONALS WHO WILL SUPPORT AND GUIDE YOU

Although you may feel at times on your own, you'll have the support of a team of highly specialized and expert doctors, nurses, and other health care staff. These will differ depending on where your CCA has spread to and what type of treatments you have.

This team is sometimes called a multi-disciplinary team (MDT), and their goal is to decide on the best treatment for you and support you through your CCA pathway.

TEAM MEMBER	THEIR ROLE	TEAM MEMBER	THEIR ROLE
Case manager	Your first point of contact who knows your case well.	Gastrointestinal (GI) cancer clinical nurse specialist	A nurse who specializes in caring for GI cancer patients. They may also be your case manager.
Clinical psychologist	An expert who specializes in supporting you emotionally. Other experts with a similar role are psycho-oncologists who focus on the cancer experience for patients and their loved ones.	Hepatobiliary surgeon	A doctor who specializes in surgery of the liver, bile ducts and pancreas.
Dietician and nutritionist	Experts who focus on supporting you to eat and drink well and maintain a healthy weight.	Hepatologist	A doctor who specializes in liver, bile duct and pancreas medicine.
Gastroenterologist	A doctor who specializes in investigating, diagnosing, and treating diseases of the bile ducts, stomach, intestines, pancreas, etc.	Occupational therapist	A HCP who has expertise in helping you regain independence after treatment.



TEAM MEMBER	THEIR ROLE	TEAM MEMBER	THEIR ROLE
Oncologist	A doctor who specializes in treating cancer patients.	Physiotherapist	An HCP that helps you regain strength and mobility after treatment, particularly surgery.
Palliative care team	A team of health care professionals who work together to organize the care of people living with an incurable illness.	Psychiatrist	A doctor who specializes in diagnosing and treating mental illness.
Pathologist	A doctor or a clinical scientist who will examine samples of your tumor that were taken during a biopsy or surgery.	Radiation oncologist	An expert who specializes in using high-energy rays (radiation) to treat cancer.
Pharmacist	An expert who provides ongoing support with medication management and advice on additional supportive medicines.		



You and your family are also an important part of this team. While your health care team know about treatments and the risks and benefits, you know your own body and what you want from your life. As much as you are willing and able, you and your family can discuss and work with your health care team to decide on care that works for you.



DIALOGUE

This chapter aims to support difficult discussions with your loved ones and improve communication with your health care team to help shared decision-making.

At times, you may need to have difficult conversations with your loved ones. This could be after your diagnosis, during treatment or afterwards. Remember that these discussions should be on your terms. You only need to have them when you're ready and feel prepared. Although difficult, letting people who you trust know about things like diagnosis and treatment decisions can help you feel better supported.

SHARING WITH OTHERS: WHY TALKING CAN HELP

As well as getting more support, talking about your cancer can help you to:²⁰

- Understand your feelings and be reassured that they are normal.
- Feel more in control.
- Make important decisions.
- Feel less anxious.

BEFORE THE CONVERSATION, TRY:²⁰

- Thinking about who you would be comfortable speaking with.
- Taking a paper and pen with you so you can write down any questions.
- Considering how much you would like to talk about your diagnosis. It's fine to revisit the conversation later.

You may also feel like you aren't ready to talk about your CCA diagnosis yet, which is completely normal. At some point, it's advised that you speak to someone about your diagnosis, as this can help you make decisions on your treatment and improve your relationships with family and friends.²⁰

CONVERSATIONS WITH YOUR HEALTH CARE TEAM

Although your health care team will have knowledge of the treatment options, you can still have a say in your treatment, if you wish.

Shared decision-making is the conversation that happens between a patient and their health care team to make health decisions together, taking into account:²¹

- Your preferences, your personal experiences, your goals, and your values.
- Your health care team's knowledge of available treatments, and the potential risks and benefits of those treatments – there may be more than one option.

For example, you may wish to only have certain types of treatment that have fewer side effects than standard treatments. With your health care team's input, you can discuss how this may work for you and come to an agreement together.

You are free to participate in the shared decision-making process if you want to. Some people may decide that they do not want to take such an active role in decision-making. Whatever you choose, positive and open communication with your health care team will help you reach decisions that are right for you.

GETTING A SECOND OPINION

Your diagnosis and treatment plan will involve your experienced health care team. However, you may want a second opinion from a different set of health care professionals.²²

While some health care professionals may encourage you to look for a second opinion, it is not always necessary or possible, so think carefully before asking about a second opinion. Below are some of the advantages and disadvantages of getting a second opinion:²²

ADVANTAGES	DISADVANTAGES
<ul style="list-style-type: none">• Reassurance that different doctors agree on your diagnosis and treatment.• Access to different treatment options.	<ul style="list-style-type: none">• Delays to starting your treatment.• Receiving conflicting information.• Having to travel to different (sometimes foreign) hospitals.

If you decide you would like a second opinion, the following questions for your health care team may help:

If you had CCA, is there another doctor you'd want to talk to about your options? Will you refer me to them?

I'd like to see a specialist for a second opinion. Who would you recommend?

Some useful resources for finding experts/ getting second opinions include: <https://cholangiocarcinomaaustralia.org/second-opinion/>





Speak up if you would like a second opinion

"Having a second opinion allows us as patients to navigate our journey with more confidence, ensuring we are receiving the best practices and feel confident that our team will respect and support our decisions regarding treatment and ongoing care."

CCA patient, Chloangiocarcinoma Foundation Australia



ACCESS

This chapter focuses on treatment options and what these may mean for you.

Starting treatment for CCA is an important moment. Receiving care for your symptoms can be relieving but can also be scary.

Every person with CCA is different. This means that some treatments will be suitable for some, whereas others will not. The best treatment or combinations of treatment for you will depend on:^{23,24}



Size, number, and location of tumor(s).



The characteristics of your tumor(s).



How you have responded to previous cancer treatments.



Your general health and level of fitness.

HOW IS TREATMENT DECIDED?

As part of your diagnosis, you will likely have had numerous tests to find out about your cancer, known as '**staging**'.²³ Molecular testing can help doctors work out what treatment is best for you and your cancer.⁶ Depending on your results, one specific treatment or a combination of different treatments might work best.⁶

HOW CAN I BE A PART OF THE TREATMENT DECISION-MAKING PROCESS?

You may have your own preferences, experiences and goals when it comes to your treatment. Alternatively, you may be happy for your health care team to choose your treatment for you.

Whatever you decide, your health care team should explain potential treatment options to you. While it is important to not take too long to decide so you can be treated as quickly as possible, you should also take some time by yourself or with your loved ones to decide on a treatment plan that works for you.

WHAT ARE MY TREATMENT OPTIONS?

The general aims of treatment are to increase survival, relieve symptoms, stop the tumors growing or spreading further, and improve quality of life.²³

Surgery	<p>If CCA is diagnosed at an early stage and it has not spread elsewhere in the body, you may be able to have surgery.^{23,24}</p> <ul style="list-style-type: none">• Surgery involves removing the bile ducts, or parts of it, as well as other organs or lymph nodes around it.²⁴• However, less than 1 in 3 people are diagnosed early enough to have surgery.²⁵
Chemotherapy	<p>Chemotherapy is a type of medicine that kills cancer cells. You may have chemotherapy for CCA:^{23,24}</p> <ul style="list-style-type: none">• after surgery to remove any cancer left behind after the operation and help stop it coming back.• to help make the tumor smaller and control and improve any symptoms if you can't have surgery.

Targeted therapy	<p>Depending on the results of your molecular testing, you may receive targeted therapy – a type of treatment targeting specific sites in cancer cells that help them grow, divide and spread, with less harm to normal cells.^{7,26,27}</p>
Immunotherapy	<p>A type of treatment that helps your immune system to attack cancer.^{26,28}</p>
Radiotherapy	<p>A cancer treatment that uses X-rays or similar types of radiation to kill cancer cells or keep them from growing.²⁶</p>
Clinical trials	<p>There are clinical trials ongoing for more targeted treatments for CCA.²³ You may be eligible for some of these, so it's worth asking your health care team about any ongoing clinical trials for CCA.²³</p>



Although everyone's treatment experience will be different, the following questions may help you better understand what to expect, and if you wish, help you decide what treatment is best for you:

What treatment would you recommend? Why?

Are there any other ways to treat my CCA?

How long will I need treatment for?

How effective is this treatment? What are the possible side effects?

WHAT IF I CHOOSE NOT TO HAVE TREATMENT?

You may decide not to have treatment for your cancer. This may be because you want to spend as much time as possible with your family and friends without spending lots of time in hospital or having side effects of treatment.

Bearing this preference in mind, your health care team will offer you a treatment that keeps you comfortable and reduces the burden of symptoms. This is called palliative care.²³

You can ask your health care team what not having treatment could mean:

If I choose not to have treatment, what is likely to happen?

If I choose not to have treatment now, could I have treatment later?



HOW WILL MY SYMPTOMS BE MANAGED?

Your health care team will offer support and treatment to help you feel more comfortable. This will include pain relief and treatment to help with sickness and nausea, if you need it. There are also treatments available that can address specific symptoms.²³

You may have nutritional support if you've lost your appetite or lose weight due to CCA or treatment.²³

You may have surgery to remove blockages caused by tumors.²³

- Most often, a stent (a small tube which opens the blockage) is fitted in the bile ducts.
- If a stent can't be fitted, then you may need surgery to bypass the blocked area.

You may have radiotherapy to relieve some CCA symptoms.²³ Radiotherapy uses high-energy rays of radiation to kill cancer cells.²³ Radiotherapy can help shrink tumors that block blood vessels or bile ducts.²³

WHAT ARE THE RISKS OF TREATMENT?

As with any surgery and any treatment, there are risks and side effects which should be considered.²³ However, your health care team will make sure that the possible benefits of your treatment are higher than the potential risks. You can also be a part of this decision-making process. You may wish to ask your health care team:

How could the side effects I experience affect my everyday life?

(For surgery) What are my chances of surviving the surgery?



WHAT IS A CLINICAL TRIAL?

A clinical trial is a study that compares treatments that are currently used with new treatments that aren't currently used to find more effective and safer treatments.²³ Clinical trials show us what works (and what doesn't) in medicine and health care. Your health care team may recommend them to you if they believe that the new treatment has a chance of treating you better than currently used treatments.²³

However, there are both benefits and risks of joining a clinical trial:

BENEFITS:	POSSIBLE RISKS:
Receiving a treatment that is more effective than the current standard treatment.	Receiving a treatment that is no better, or less effective, than the standard treatment.
Free treatment and care.	Having unexpected side effects or side effects that are worse than the standard treatment.
Close monitoring by HCPs and more opportunities for questions.	Needing extra tests, which could be uncomfortable or time consuming.
Contributing to important research that can help other cancer patients in the future.	Not being allowed other treatments after the trial, even if the treatment did not work for you.
	Travelling to different hospitals, or even different countries, to take part in the trial.



HOW DO I GET INVOLVED IN A CLINICAL TRIAL?

Your health care team may already know about clinical trials that might be right for you and may discuss these with you.²³ Or you or your loved ones may find clinical trials yourselves.

The only way to join most trials is if your health care team thinks it is right for you, and you agree. You may wish to ask the following questions to help with your decision:

What clinical trials are available for my cancer currently?

Where are they located?


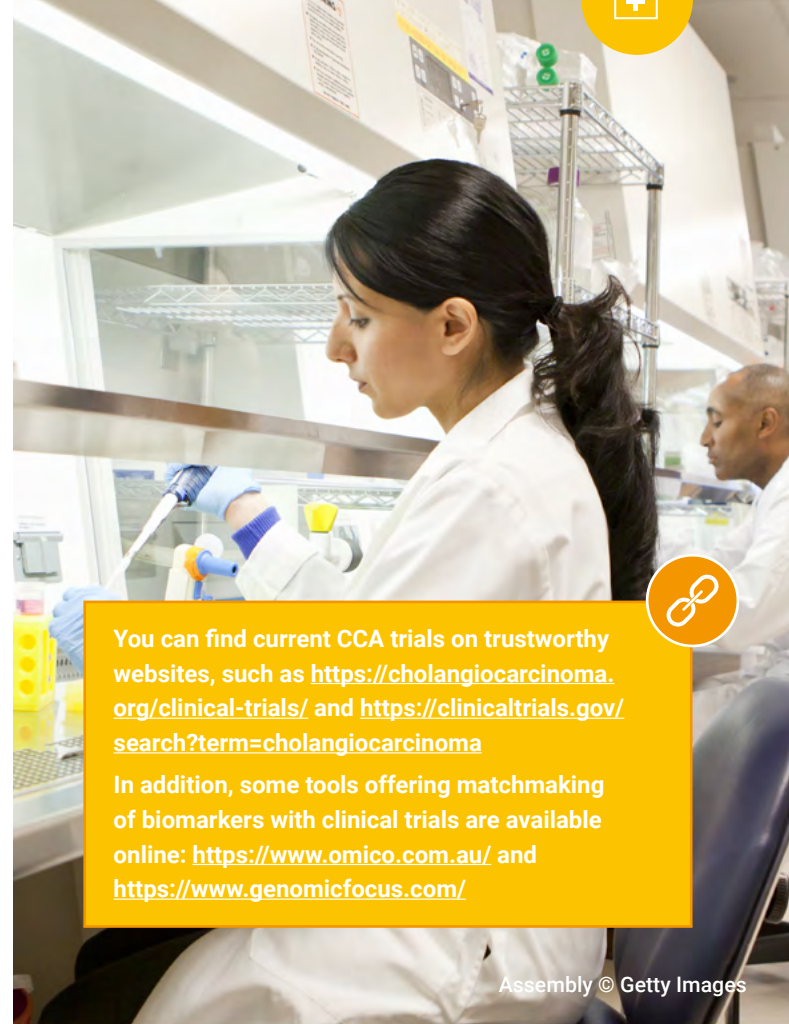
Is there one in my country?

Am I eligible for a clinical trial?

What is involved? How time consuming will it be?

To what extent will you be involved if I choose to participate in a clinical trial?

What treatments will I be allowed/not allowed after a clinical trial?



You can find current CCA trials on trustworthy websites, such as <https://cholangiocarcinoma.org/clinical-trials/> and <https://clinicaltrials.gov/search?term=cholangiocarcinoma>

In addition, some tools offering matchmaking of biomarkers with clinical trials are available online: <https://www.omico.com.au/> and <https://www.genomicfocus.com/>

UNDERSTANDING CARE BEFORE, DURING AND AFTER TREATMENT

HOW CAN I PREPARE BEFORE THE TREATMENT BEGINS?

Your health care team may mention something called **'Prehabilitation'**. This helps you to prepare for treatment, cope with any treatment challenges and potentially improve your recovery after treatment.²⁹

Some things that may help you prepare for treatment are:²⁹



Eating a wide range of foods in the right proportions, also called a varied diet.



Being physically active; even just making small changes to your routine, like walking around your garden can help.



Looking after your mental well-being.

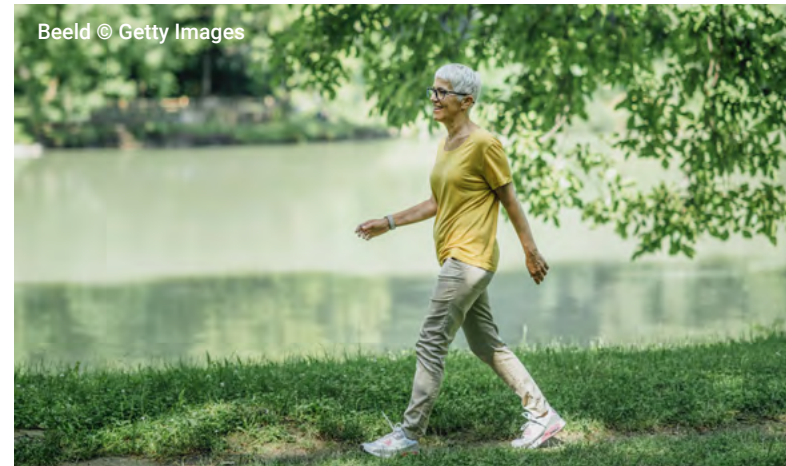
What you can do to help prepare for treatment will be individual to you and your treatment. Speak to your health care team about what you can do to prepare for your treatment with questions like:

Is there anything I should stop or avoid doing before treatment?

Is there anything I can do to help myself before treatment?

HOW CAN I PREPARE FOR SURGERY?

If you are having certain types of surgery, you may need to follow a special diet or take some medicine.²⁹ Your health care team will advise you about this.





WHAT CAN I EXPECT DURING TREATMENT?

The following table gives a simplified description of what you can expect when you have each type of treatment:

TREATMENT TYPE:	WHAT TO EXPECT:
Surgery to remove the cancer	<ul style="list-style-type: none"> Your health care team will give you a general anesthetic (put you to sleep) and remove the cancer or parts of the cancer.²³
Surgery to place a stent	<ul style="list-style-type: none"> You have an injection to make you feel relaxed. The doctor passes a thin, flexible tube with a camera on the end (called an endoscope) into your mouth. A stent is then placed to keep the bile duct open.²³
Chemotherapy, targeted therapy or immunotherapy	<ul style="list-style-type: none"> You will be given medicine as a pill, by injection or through a drip.^{27,30,31} This will happen in hospital/health clinic or potentially at home, and you will be monitored by your health care team (at least the first time you receive treatment).^{27,30,31}
Radiotherapy (for treating the symptoms of CCA)	<ul style="list-style-type: none"> You will lie down on a bed while a radiotherapy machine targets your cancer with high energy waves.²⁶ Members of your health care team will watch you during the process.

WHAT TO EXPECT AFTER TREATMENT?

Different treatments may impact your health in different ways. By understanding the treatments, you may be able to cope with them better.

AFTER SURGERY

- When you wake up after a surgery, you will have some pain and will need medicine for a few days. For the first couple of days, you may not be able to eat or drink much.²⁵
- You may need to stay in hospital for 1 to 2 weeks depending on how well you recover.²⁵

AFTER CHEMOTHERAPY

- Chemotherapy weakens your body's immune system. Hence, after your chemotherapy session, it's advised that you avoid people with colds or other infections.³²
- You may be advised to drink lots of fluids for 48 hours after chemotherapy. This helps move the medicines through your body.³²

AFTER RADIOTHERAPY

- Usually, you will feel ok straight after radiotherapy, but you may begin to feel tired or have side effects in the days or weeks after the session.³³

AFTER TARGETED THERAPY OR IMMUNOTHERAPY

- Depending on the type of targeted therapy/immunotherapy, you could begin to feel unwell in the days, weeks or even months after treatment.^{34,35}

WHAT SIDE EFFECTS CAN I EXPECT FROM MY TREATMENT?

Side effects of CCA treatment are common, and will depend upon many different things, like the type of treatment, where the cancer has spread to and how your body works. Your health care team will notify you of any expected side effects of treatment and help you to manage them. Depending on the treatment you receive, possible side effects may include:^{23,33-35}



TYPE OF TREATMENT:	COMMON SIDE EFFECTS:*
Surgery	<ul style="list-style-type: none"> • Pain and tenderness in the area of the operation.
Chemotherapy	<ul style="list-style-type: none"> • Fatigue. • Diarrhea. • Feeling and being sick. • Loss of appetite, taste changes or a sore mouth. • Increased risk of infection. • Tingling or numbness in fingers and toes.
Radiotherapy	<ul style="list-style-type: none"> • Fatigue. • Mild skin reactions.
Targeted therapy	<ul style="list-style-type: none"> • A rash to the face and upper body, or other skin reactions.
Immunotherapy	<ul style="list-style-type: none"> • Fatigue. • Diarrhea. • Rash or itching. • Dry eyes. • Fever. • Muscle, bone, joint or abdominal pain.

*not an exhaustive list

It is likely that you will get some of the side effects listed above, but you are very unlikely to have them all. Most are temporary and can be managed by medicine or lifestyle changes.²³ **Speak to your health care team as soon as you notice any side effects so they can support you.**



If there are any medical terms you don't understand, the glossary of terms at the end of this guide is a good starting point.

HOW CAN I GET THE MOST OUT OF TREATMENT THROUGH DISCUSSIONS WITH MY HEALTH CARE TEAM?

Staying connected with your health care team during your treatment may help you benefit the most from your care. You may wish to ask yourself some of the questions below to understand if you're happy with how your treatment is going:

BETWEEN APPOINTMENTS:

How well do you feel your last appointment went?

How well is your care plan working for you – given your own preferences, experiences, goals, and values?

What would you like to discuss during your next appointment?

AFTER MY APPOINTMENTS:

Did I ask everything I wanted to?

Is there anything I don't understand?

MY TREATMENT AND CARE PLAN SO FAR:

Do I understand my treatment and care plan?

Does the plan match with my personal goals and preferences?

Is my treatment working for me and do I want to continue it?

Am I experiencing any side effects, and do I know how to manage these?



WHAT IF MY TREATMENT DOESN'T WORK?

Sometimes, your treatment may not work as planned. In these cases, you and your health care team will decide whether you should try a different treatment. This is sometimes known as 'second-line' (or 'third-line' if second-line does not work) treatment and can include any of the treatments mentioned earlier in this chapter. It may also be at this point that you or your health care team consider a clinical trial.

If you have metastatic CCA it might be very hard to treat. Potentially, your health care team may believe that continuing treatment will not be beneficial for you. You can also be a part of this decision, as you know how you feel and whether this fits with your goals. You may also wish to get a second opinion from a different HCP.

If you do decide that you no longer want treatment, you will then begin palliative care to manage your symptoms and ensure you are comfortable.

AFTER TREATMENT – WHAT HAPPENS NEXT?

When you finish treatment, it can be an emotional time. While you may feel glad or relieved, it can feel strange to have fewer hospital appointments and check-ins with your health care team.

Depending on how your treatment went, you will continue to be in contact with your health care team who will provide support to help you manage any side effects. You may also continue to have tests to monitor your cancer and see if more treatment is needed. Remember, there is no right or wrong way to feel. It can take some time to get used to your new-normal.

The following chapters will discuss emotional health, diet and exercise and planning for your future, to help support you in your everyday life.



Maskot © Getty Images



PSYCHOLOGICAL WELL-BEING

This chapter focuses on the importance of emotional health and understanding the different feelings patients might experience. It includes practical tips to help manage different emotions and advice on seeking additional help from a professional, such as a psychologist or psychiatrist.

LOOKING AFTER YOUR EMOTIONAL HEALTH

You may feel many different emotions during your cancer pathway: as you receive a diagnosis, learn to live with cancer and its symptoms, receive different treatments and experience side effects, and as the cancer potentially becomes more advanced.³⁶

It is important to remember that these feelings are normal, understandable, and many people feel the same way.

Your immediate response to diagnosis – or learning your cancer has advanced – may be feeling numb, shock, fear, guilt, or uncertainty about the future.³⁷ Some days, you might feel positive and ready to face your cancer head-on, but in other moments, you may not know what to do next.

Everyone's cancer pathway is different – each person will react differently to the difficult news of a cancer diagnosis, challenges of treatment, life after treatment and thinking of the future. There are no right or wrong reactions or emotions.³⁷

While emotional reactions are natural, they should not impact your daily life in a significant or lasting way. It is important to regularly check in with how you are feeling.



"Fighting cancer can take an immense toll both physically and emotionally. Taking care of both of these puts you in a much better position to face this head on with positivity and hope."

CCA caregiver, Chloangiocarcinoma Foundation Australia

DO WHAT YOU CAN TO HELP YOURSELF

Ask: How do I feel today? **Then ask:** What might I be able to do about this today?

Practical things you could do to positively impact how you are feeling, could include:

TIP:	SUGGESTED ACTIVITIES:	
Staying connected to the people you enjoy spending time with and the things you enjoy doing	<ul style="list-style-type: none">• Talk to your loved ones.• Take part in group classes or activities, such as an art class.	<ul style="list-style-type: none">• Prioritize the things you enjoy doing, such as a hobby.
Being kind to your body	<ul style="list-style-type: none">• Eat what you can, when you can.• Keep moving your body.	<ul style="list-style-type: none">• Focus on getting good quality sleep.
Lowering your stress levels	<ul style="list-style-type: none">• Practice positive self-talk and mindfulness exercises.	<ul style="list-style-type: none">• Keep a journal and write down how you are feeling or any questions to ask your health care team.

ASK OTHER PEOPLE FOR HELP

Talk to your family, friends, and other patients. Talk to a health care professional.

Tell them how you feel and ask for the help you really need.

Ask: Do I need to speak to a mental health professional?

If negative feelings are significantly impacting your daily life, speaking to a mental health professional could help you to cope better.

WHAT KINDS OF MENTAL HEALTH PROFESSIONALS ARE THERE?

A psychologist is a health care professional who helps people learn to cope more effectively with life issues or psychological suffering. Most commonly they use talking therapies. Psychologists help a wide variety of people with many different problems.³⁸

A psychiatrist is a trained medical doctor who specializes in helping people with emotional disorders and mental health problems. They use a variety of treatments, including medications and talking therapy, depending on the person's needs.³⁹

WHAT CAN I EXPECT IF I SEE A PSYCHOLOGIST OR PSYCHIATRIST?

This can depend on the type of mental health professional you see and your own experiences.

You can expect the person to listen to your experiences and help you understand more about how you are thinking and feeling and how you might be able to overcome these thoughts and feelings.⁴⁰

Most mental health professionals will see patients once a week for about 45-50 minutes. Some types of therapy will last for a few sessions, while other types may continue for months or longer.⁴⁰





Join Support Groups

"A CCA diagnosis can be isolating, its rarity makes it hard to relate to other cancer patients. Patient groups are an invaluable resource for patients to connect and relate with others. It helps ease the burden of feeling so alone after such a devastating diagnosis."

CCA patient, Cholangiocarcinoma Foundation Australia

HOW CAN I BECOME MORE RESILIENT?

Psychosocial support, information related to CCA, and learning self-management skills, are essential to improve resilience among adult cancer patients.⁴¹

Some useful tips to calm and replenish yourself and improve resilience, include:⁴²

- Try exercise.
- Visualize calming scenes.
- Listen to a calming recording, music or voice.
- Connect with calming and comforting people.
- Go into predictable calming routines.



Patient organizations like the Cholangiocarcinoma Foundation and the Cholangiocarcinoma Foundation Australia offer the opportunity to find a mentor – someone who has personal experience with the disease – to ask questions and get one-on-one support. For more information, visit: <https://cholangiocarcinoma.org/get-one-on-one-support/> or <https://cholangiocarcinomaaustralia.org/cholangiomentors/>





PHYSICAL WELL-BEING - NUTRITIONAL HEALTH

This chapter focuses on the importance of diet and nutrition with guidance on how to adapt a diet for the different challenges patients may face.

It is important that you maintain a healthy and balanced diet, making sure you have an adequate intake of nutrients and calories to help keep you strong throughout your treatment and recovery.⁴³ This can be a real challenge especially when dealing with cancer and treatment.⁴³

Cancer symptoms or side effects of treatment may affect your appetite, and you may not enjoy eating the way you did before.⁴³ Your weight or bowel movements may change. These effects are common, and there are ways you can overcome these, with the right support.⁴³

Along with staying active, being well-nourished may improve your quality of life and well-being and may also impact your response to treatment or surgery.⁴⁴ You can even find enjoyment from food during your cancer pathway.

DOES MY DIET AFFECT MY CANCER PATHWAY?

With the right guidance and support, changes to your diet and nutrition could impact:⁴⁴



Your response to treatment or surgery.



The symptoms you experience.



Your quality of life and well-being.

Thinking about your nutrition could help you ensure you are eating the food your body needs.

HOW WILL CANCER AFFECT THE WAY I EAT?

Since everyone's cancer pathway is different, the foods you can or want to eat may be affected. It is possible to make adjustments to your diet that help you continue to eat well while you undergo treatments or procedures, or if you experience certain symptoms.

If you have recently been diagnosed with CCA, you can speak to your health care team for advice about your diet. Your dietary needs should be regularly reviewed by your health care team and rebalanced as needed.

Your diet may change in a number of ways:⁴³

- You may need to change your diet because of **symptoms**, which depend on where your CCA has spread to.
- **Treatments** like chemotherapy or radiotherapy may change the way food tastes to you and may affect your appetite.
- You may be preparing your body for cancer **treatment**, which is called '**prehabilitation**'.⁴⁵

- You may adapt your diet because of **procedures** you have had.
- In some specific cases, you may need **oral nutritional supplements** and/or **herbal vitamins** due to your cancer type. Your health care team will explain these to you.
 - Always speak to your health care team before you decide to take additional herbal vitamins, oral nutritional supplements, or probiotics, as these can affect your treatment.⁴⁶
- Your age, body weight, activity levels, mood, and personal likes and dislikes could also affect your diet.

TOP TIPS FOR EATING WELL WITH CCA

Below are some of the common nutritional challenges you may experience, along with some top tips to help you manage. Always ensure you speak with your health care team before making changes to your diet.^{47,48}

ISSUE:	TIP:
Poor appetite/ weight loss	<ul style="list-style-type: none">• Have small frequent meals and snacks (~ 3-4 nourishing snacks per day).• Avoid large portions if your appetite is small.• Choose foods and drinks high in calories and protein.• Prioritize the protein source first, alongside carbohydrates. <ul style="list-style-type: none">• Choose more nutritious types of food to maximize the energy/protein content (e.g., choose full fat foods; add extra cheese to food; use fortified milk instead of regular milk; add lentils, dried beans and peas to soups and casseroles; etc.).
Nausea and vomiting	<ul style="list-style-type: none">• Avoid your favourite foods if you feel sick so you don't start to dislike them.• Avoid lying down for at least 2 hours after eating.• Avoid hot foods, strong smelling foods, excessive fluid during a meal, strong tea/coffee, greasy or high fat foods.• Try plain foods like toast and crackers. <ul style="list-style-type: none">• Ginger or peppermint tea, ginger biscuits, and sprinkling grated ginger on meals can help to reduce nausea and sickness.• If you are vomiting, drink plenty of fluids, particularly sports drinks and fruit juices.



ISSUE:	TIP:	
Diarrhea	<ul style="list-style-type: none"> • Drink plenty of fluids, including sports drinks to replace lost salts and sugars. • Limit fruit juice to less than 150ml or dilute it with water before drinking as it can make diarrhea worse. Instead, you can add frozen fruit (e.g. orange and lemon slices) to water for flavour. 	<ul style="list-style-type: none"> • Caffeine, sweeteners and fatty, spicy or high-fiber foods can make you need the toilet more often, so consider reducing these if diarrhea is a problem.
Sore mouth or throat	<ul style="list-style-type: none"> • Try cold and soothing food and drinks, like ice cream or yogurt. • Avoid acidic, very salty or spicy foods and very hot drinks/ foods. 	<ul style="list-style-type: none"> • Antiseptic mouthwash or sprays can reduce symptoms.
Changes in taste	<ul style="list-style-type: none"> • Make food look and smell appealing. • Add herbs and seasoning. 	<ul style="list-style-type: none"> • Experiment with flavours, mix flavours (e.g. sweet and sour) and different textures of food to make it more interesting and appetizing.
Excessive wind	<ul style="list-style-type: none"> • Foods more likely to cause wind include cabbage, broccoli, cauliflower, brussels sprouts, pulses (e.g., beans or lentils), dried fruit (e.g., raisins or apricots), • Food or drinks containing the sweetener sorbitol, fizzy drinks and beer may also cause wind. 	<ul style="list-style-type: none"> • When eating make sure you are chewing your food well and try to keep your mouth closed while chewing. • When you are feeling bloated try to stay active, sip peppermint tea for relief, and use a warm water bottle for comfort.





SURGERY FOR CCA CAN ALSO LEAD TO NUTRITIONAL CHALLENGES.⁴⁷

If you've had your pancreas removed:

- Your health care team may recommend pancreatic enzyme replacement therapy (PERT).
 - This provides you with the enzymes needed to digest food that your pancreas normally makes.
 - Must be taken with all food, snacks and drinks containing fat, protein and carbohydrate.

You may have something called bile acid malabsorption (BAM):⁴⁹

- This happens when bile acid is not reabsorbed in your body properly, and can cause bloating, cramping, stomach pain and excessive wind.
- Reducing the amount of fat you eat may help symptoms.
 - It's important to gradually try to cut down on the fat you are eating each day and always with your doctor's guidance, especially if you are underweight or losing weight.
- Your health care team can also support you with medication.

You may have something called small intestinal bacterial overgrowth (SIBO):⁵⁰

- Surgery can sometimes cause changes to your natural gut bacteria, resulting in bloating, excessive wind, diarrhea, weight loss, undernourishment and weakened bones.
- Antibiotics, supplements or a special diet, with the support of your health care team, can help reduce symptoms.



For more information and guidance on adapting your diet and eating well with CCA, visit our recommended patient organizations cited at the end of this booklet.

THE IMPORTANCE OF PROTEIN

Protein is particularly important if you are losing weight, as you may be losing muscle mass as well as body fat. Below are some simple ways to include more protein in your diet:⁵¹

- Try to include protein at every meal, the aim is for 1-1.5 grams protein per kilo of body weight.
- Choose yogurts, snacks, and puddings with 15-25g of protein.
- Foods with around 20g of protein include:
 - 100g of nuts
 - 75g of meat
 - 100g of fish
 - 200g of full fat yogurt
 - 225g of lentils
 - 3 eggs



FOOD PLANNING FOR CAREGIVERS

As a caregiver you may be preparing or helping to prepare meals. Here are a few tips to make the process easier:

- **Make meals appealing:** Serve small, colourful meals so people can ask for seconds.
- **Avoid bulk buying:** Taste preferences change, so avoid buying too much of the same food at once.
- **Protein-based meals:** Plan 5-6 small meals or snacks per day with a focus on protein.
- **Encourage eating:** Be supportive without criticizing or being too persistent.
- **Quick options:** Keep ready meals and snacks to hand, like nuts, crackers with dip, flapjacks, and custard pots.



RECIPES TO TRY

Chicken noodle soup

- **Nutritional facts:** 12g protein and 250kcal.
- **Want to increase the calories?** Add 30g grated cheese, 60mls cream, 1-2 tblsp olive oil, 1-2 tblsp dried skimmed milk powder or 30g protein powder.
- **Find the recipe here:** <https://www.wcrf.org/living-well/eating-well/recipes/chicken-noodle-soup/>

Apple and ginger compote with yogurt

- This recipe is great if you are experiencing **taste changes**.
- **Want to increase the calories?** Use full fat yoghurt.
- **Find the recipe here:** <https://www.wcrf.org/living-well/eating-well/recipes/apple-and-ginger-compote-with-yoghurt/>





PHYSICAL WELL-BEING - PHYSICAL HEALTH

This chapter focuses on the importance of physical activity and exercise with guidance on how you can introduce movement into your everyday life.

Treatment for CCA can make you tired and inactive; sometimes for long periods after treatment finishes. It is common to experience fatigue from your cancer or your treatment; 9 out of 10 people living with cancer are affected by this.⁵² Pain is also common.

However, there is good evidence that people with digestive cancers who do some physical exercise have a better quality of life and experience fewer and less severe side effects.^{53,54}

BEFORE YOU START TO CONSIDER PHYSICAL EXERCISE, REMEMBER THE 4 PS:



PATIENCE

Be patient. Everyone is different. Remember, it will take time! Start slowly and invest in rest.



PROGRESSION

Build it up. When you feel you can, try new things. Always listen to your own body and make changes if needed.



POSITIVITY

Focus on the positives. Record what you have achieved: even if you planned a 30-minute walk and you only took one step... that's a step in the right direction.



PERSEVERANCE

Keep going. Even the smallest amount of movement can be beneficial.

HOW CAN PHYSICAL ACTIVITY HELP ME?



POSITIVE EMOTIONS

Physical activity may have a positive effect on your mood, helping with difficulties like depression or anxiety. It can also help you feel more confident and increase your independence.^{53,55,56}



HEART AND MUSCLE FITNESS

Movement can help preserve and improve your heart and muscle fitness before, during and after treatment.^{54,55,57-65}



BONE HEALTH

Resistance training (strengthening activities) can have a positive effect on your bone health.⁷¹



OVERALL WELL-BEING

Physical movement can improve your overall quality of life, which includes your physical, mental, and social well-being.⁵³⁻⁵⁵



REDUCES SIDE EFFECTS

Physical activity may reduce some side effects of cancer treatment, such as tiredness and joint pain.^{54,55,58-60,66-70}

WHAT TYPES OF EXERCISE COULD I DO?

Before starting any exercise plan, speak to your health care team as they can advise on the best activities for you and can confirm if there are any safety issues to keep in mind.⁷²

In general, try to find a type of exercise you enjoy and take it easy. Some days you'll be able to do more than others. Some days you will need to invest in rest.⁷³

Gentle exercise when you feel able to is recommended. If you don't want to exercise alone, you could even ask your loved ones to join you.⁷³

Examples of gentle exercise to try:⁷³



Going for a short walk.



Light housework or gardening.



Walking up and down a few steps.



Sitting down and lifting small weights with your arms.

Your health care team may also be able to refer you to a physiotherapist who can help to tailor an exercise plan based on your cancer and your overall health and wellness.⁷³

For more ideas on how you can exercise, we have provided a **routine** that has been developed by a cancer and rehabilitation specialist.



"Exercise in the morning to get endorphins going"

CCA caregiver, Cholangiocarcinoma Foundation Australia



Pamplemousse © Getty Images

CCA EXERCISE ROUTINE

To help you move more, there is an exercise routine on the next page. This has been developed by Mark Wild, a cancer rehabilitation expert. This routine aims to help improve your quality of life by creating change with kindness, and bringing big benefits to your muscles, movement, and mind.

Before attempting the routine, speak to your health care team and refer to the information below.

HOW TO DO THE ROUTINE?

- **Rounds:** Do the exercises back to back – try to keep a nice rhythm throughout.
- **Repetitions:** Try starting on 6 or 8 repetitions per exercise.
- **Rest:** For 30-60s at the end of the round.
- **Repeat:** When you feel capable - repeat the round once or twice more.

If you would like to **raise the intensity**, you can add more repetitions per exercise (e.g., 10 / 12 / 14).



HOW TO TAILOR YOUR SESSION?

Choose a '**mode**' that suits how you feel.

- **Control mode:** Perform the exercises nice and slowly – keep your breathing soft and stable.
- **Challenge mode:** Perform the exercises quicker – maintain a slight level of breathlessness.



GOLDEN RULE: Listen to your body.

- Listening to your body instills awareness; ensuring safety and elevating effectiveness.
- Do what you're capable of: Start sessions slowly and do what you can. When you feel able to do more – do more!
- Acknowledge how you feel during and after a session: This brings an understanding as to what's best for your body.



SIMPLE SQUAT

1. Stand tall – Feet shoulder width – Hands to side of hips.
2. In one movement – Swing arms forward and squat down.
3. Return by lowering arms and standing tall.

Progression: Squat lower.



STEP BACK WING OUT

1. Stand tall – Feet hip width – Arms forward with palms together.
2. In one movement – Step back and open arms to side – Pulling shoulders back.
3. Return by stepping in and bringing palms together – Switch legs so you're alternating.

Progression: Rather than step – Lunge so your back knee is just above floor.



GOLF SQUAT

1. Stand tall – Feet outside shoulder width – Hands clasped at shoulder height.
2. In one movement – Squat down swinging arms to center of body – Swing arms to the opposite shoulder to stand tall – Head follows hands.
3. Repeat in the opposite direction – Keep head following hands.

Progression: Squat lower.

Restricted range of movement? Start and bring hands into shoulder.

4



SPLIT SQUAT (CHAIR)

1. One hand on a chair – Feet hip width and a big step distance apart – Front foot flat to floor with back foot on the ball/toes.
2. Bend both knees to lower towards floor – Keep shoulders back and head up.
3. Return to upright to repeat all repetitions – Then switch legs.

Progression: Lunge lower so back knee is just above floor.

5



ELBOW OPEN SWING BACK

1. Stand tall – Feet hip width – Finger-tips on shoulders – Elbows forward and up.
2. Open elbows to pull shoulders back – Bring elbows in – Release arms to swing them behind hips whilst bending knees slightly.
3. Return by pushing hips and swinging arms forward to bring finger-tips onto shoulders.

Progression: Bend knees more when swinging arms back.

6



FRONT STEP AND TURN

1. Stand tall – Feet shoulder width – Arms forward with palms pushed together.
2. Step forward bending both knees – Pause – Turn arms over front leg – Head follows hands.
3. Return by bringing arms to centre – Step back to start position – Switch legs so you're alternating.

Progression: Rather than step – Lunge so the back knee is just above floor.

Restricted range of movement? Turn arms only as far as you feel comfortable.



WALL PRESS

1. Stand 3 foot away from a wall – Feet hip width – Hands on wall in line with shoulders.
2. Bend elbows to bring your body towards wall whilst raising heels to bring you onto the balls of the feet.
3. Return by pushing against the wall – Bringing your body back and feet flat.

Progression: Stand further away from wall.



LEG KICKS (CHAIR)

1. Stand tall – One hand on chair – Balance on one leg – Lifted leg has 45-degree bend at knee.
2. Kick lifted foot forward to extend leg – Squeeze muscles in the front of your thigh – Hold for 2-3secs.
3. Return by relaxing leg muscles – Bring foot back to start position – Repeat all repetitions – Then switch legs.

Progression: Take hand off chair.

REST UP FOR ONE MINUTE. IF YOU FEEL ABLE, TRY TO COMPLETE THE ROUTINE AGAIN.

TOP TIPS

- **Consistency creates change:** try your best to do 2+ sessions per week.
- **Move in the morning:** you'll feel the benefits for the whole day.
- **Walking does wonders:** be as active as possible during your days.





TAKE CARE

This chapter aims to provide ‘beyond treatment’ guidance and support for different aspects of everyday life including socializing, sex, work and finances. At the end of the chapter, there is also information on palliative care.

During CCA treatment and afterwards, you may have to change the way you live your life. But, in time, you should try to do some of the things that you enjoyed before. **Remember that cancer doesn't take away your personality.**

MANAGING RELATIONSHIPS WITH CCA

A CCA diagnosis, going through treatment and dealing with the long-term effects is stressful for you and your loved ones. You may have to stop some of the things you regularly did with family and friends for a time. Moving forward, adaptations to the things you once did can make them easier and allow you to slowly bring them back into your life.

HOW CAN I STAY SOCIAL WITH CCA?

Most people say that remaining connected with others can help if you have CCA or are undergoing treatment. A study found that GI cancer patients and their loved ones, who received emotional support from others felt less lonely with possible mental health benefits.^{74,75}



Staying connected with others, talk about how you are feeling and try not to feel embarrassed

SEX LIFE WITH CCA CANCER

CCA and treatment can put your sex life on hold for a time. You simply may not feel like having sex due to:⁷⁶

- physical changes to your body that make sex uncomfortable or painful.
- emotional or mental challenges that make you feel embarrassed or uninterested in sex.

Many changes are temporary, however, in some cases, you may need to make long-term adaptations to your sex life.⁷⁶

Whatever your situation, be reassured you can continue intimate relations, even if you have to make some changes. Try not to be ashamed or embarrassed – communication is key.⁷⁷

WHAT SHOULD I DO IF I'M HAVING PROBLEMS WITH MY SEX LIFE?

If you have a partner, being open and talking about your problems can help. Showing intimacy, even in non-sexual ways such as hand holding and cuddling, can help you to feel close to your partner.⁷⁷

If you are single, consider speaking to a close friend or seek professional help from your health care team or a psychosexual counsellor.⁷⁷

WORKING WITH CCA

How much CCA impacts your life will depend on the type of job you have, how you feel, both physically and emotionally, your treatment and side effects, and your financial situation; including that of those who support you.⁷⁷

MAKING A DECISION ON WORK



BEFORE AND DURING TREATMENT

The physical and emotional impact of treatment will be unclear. While surgery could require long periods of rehabilitation, you might still want to work if you have a different treatment. Speak to your health care team to get a better idea of how your treatment may impact work and consider relaying this information to your employer.⁷⁷



AFTER TREATMENT

Depending on your age and financial situation, working less or not at all may be an option. Often, people see this as an opportunity to retire. You could also choose to switch to part-time working and spend more time doing the things you enjoy.⁷⁷





MANAGING FINANCES WITH CCA?

Living with CCA can have a financial impact with a knock-on emotional effect. Not being able to work as much as you did previously or having to spend more money elsewhere can make you anxious and is linked to poorer health and quality of life.⁷⁸

However, there are ways to stay in better control of your money, including managing your spending and looking into potential financial support (e.g., government grants).⁷⁷

HOW CAN PATIENT ORGANIZATIONS SUPPORT ME?

Patient organizations are readily available to support you and your family and friends. They often employ people or have volunteers with cancer experience and will be trained to talk to you.⁷⁷

WHAT IS PEER SUPPORT?

Peer support means using first-hand experiences to help others.⁷⁹ This typically means meeting other CCA patients and their loved ones to listen, share experiences, and provide useful advice.

CARING FOR SOMEONE WITH CCA?

If you are a partner, family member, or friend of a person with CCA, there are a lot of things to consider, including the many ways you can help.

WHAT DOES BEING A PATIENT CAREGIVER MEAN?

A caregiver is someone who provides voluntary help to a person with CCA who would be unable to manage without them.⁸⁰

You may not immediately see yourself as a caregiver. Your own life and routine will change suddenly because of your loved one's diagnosis, and you might not have had time to reflect on the situation. Once you recognize you are a caregiver, it can become easier for you to provide care and get further support.⁸⁰

If you decide to become a person's caregiver, you should make yourself known to the health care team as soon as possible. This means you can contact them more easily if you or the person with CCA have any concerns.⁸⁰

"Caregivers often feel like they're on a tightrope, they have to advocate for their patient but also don't want to overstep the mark with the patient or the oncologist." - Caregiver

HOW CAN I HELP AS A CAREGIVER?

Things you could do to help include but are not limited to:⁸¹

- attending hospital appointments to take notes and help patients digest the information.
- helping the patient to take their medication correctly.
- managing the patient's self-care needs, ensuring they use the facilities safely and protecting their dignity.
- listening and talking to the patient about their concerns and helping them with decision-making.
- assisting with financial and insurance issues.





HOW WILL MY RELATIONSHIP CHANGE WHEN I BECOME A CAREGIVER?

Having different feelings toward the person you care for is a normal part of the process. To help keep your relationship healthy.^{81,82}

- **Take time to become familiar with your caregiver role.** It can feel strange if the caring relationship has reversed, such as looking after a parent or grandparent.

- **Be open and honest with each other.** You cannot understand one another without talking about any issues.

- **Let the person know they are the one in control.** Try not to take away their role as the key decision-maker for as long as possible.

- **Use humor where and when appropriate.** This can help you both to stay positive and maintain your relationship.

- **Know the boundaries of the care you give.** If the person can do something safely and independently, let them do it.

HOW CAN I SUPPORT MYSELF AS A CAREGIVER?

When you are a caregiver, it's important for you to look after yourself. Staying well means you can provide better care, try to:^{83,84}

- **Take breaks from care and continue to do the things you enjoy.**

- **Eat well.** Try to eat healthily, but also foods you like.

- **Stay active.** Although you will be tired, exercising can help you feel stronger.

- **Get enough sleep.** Night times can be especially difficult, and you may need help from others or social care if you are providing care during the night.

- **Talk about how you feel.** Try not to hold back your emotions – talk to family members, friends or professionals.

PALLIATIVE CARE

WHAT IS PALLIATIVE CARE?

At some point in your CCA pathway, you may **receive palliative care**. This can happen if:⁸⁵

- symptoms or side effects related to your CCA and treatment make it challenging for you to continue your therapy.
- your cancer is incurable, meaning that it will not go away with treatment.

Palliative care is treatment that helps to reduce the impact of symptoms and improve or maintain your quality of life.⁸⁵

WHY AM I RECEIVING PALLIATIVE CARE SO SOON?

Palliative care is often mistaken with end-of-life care. Palliative care can begin at any stage during your treatment to support care, enhance quality of life, and enable you to continue your cancer treatment.⁸⁵ Palliative care can be given for months or years depending on your individual circumstances.





WHAT DOES PALLIATIVE CARE INCLUDE?

As well as pain relief and anti-sickness medication, palliative care includes other treatments to reduce symptoms.

Palliative treatments may include:⁸⁵



Chemotherapy.



Radiotherapy.



Targeted therapy and immunotherapy.




Complementary therapies, like relaxation therapy, massage, yoga and acupuncture.

Palliative care also aims to fulfil your holistic needs, including psychological, social, and spiritual support. You might have some side effects from palliative cancer treatments. However, the aim is to make you feel better, so your health care team will choose treatments that have as few side effects as possible.⁸⁵

WHEN SHOULD I START THINKING ABOUT PALLIATIVE CARE?

Discussions about death can be challenging. They can be perceived as negative or giving up. However, there are benefits to having palliative care discussions when you are well and able, rather than unwell, such as improved symptom control, reduced distress, and care that matches your preferences.⁸⁶



Living with CCA can be a distressing time for you and your family, but it is important not to lose hope. Finding the joy in small, everyday activities can help you to feel better about your situation. This could include making time to visit family and friends, or organizing activities you enjoy. Sharing your hopes with your loved ones can also help them to make sure they are fulfilled, so you can continue living as well as possible.

If you have questions about end of life care, the [SHAPE Managing End of Life Care](#) guide can provide some answers for people living with CCA and their caregivers.

CONNECTING WITH CCA PATIENT SUPPORT GROUPS

Connecting with CCA patient support groups may provide social support and help you to meet other people with or who have had CCA.⁸⁷

A few of the major CCA patient support groups are included in the table below:

ORGANIZATIONS:	LINKS:
Cholangiocarcinoma Foundation	https://cholangiocarcinoma.org/
Cholangiocarcinoma Foundation Australia	https://cholangiocarcinomaaustralia.org/

These organizations provide useful resources for patients in the different stages of disease and treatment. You may even find that volunteering for a patient-oriented organization or becoming involved as an advocate for other patients provides a positive means of engaging with the changes in your life.⁸⁷



GLOSSARY OF TERMS

TERM:	DEFINITION
Biomarker:	characteristic of the body that can be measured and help give doctors more information about your cancer
Biopsy:	a medical procedure where a small sample of tumor is taken and examined under a microscope
Chemotherapy:	a drug treatment used to treat cancer by killing cells, or stopping them from growing and multiplying
Computerized tomography (CT) scan:	an imaging test that uses a series of X-rays to create images of the inside of your body, showing a tumor's shape, size, and location
End-of-life care:	a type of care given to people in the final days, weeks, or months of life
Immunotherapy:	a type of treatment that helps the immune system to fight cancer
Magnetic resonance imaging (MRI) scan:	an imaging test that uses strong magnetic fields to show a tumor's shape, size, and location
Metastatic:	when cancer cells break away from the original tumor, spread to other organs or parts of the body and form a new tumor
Palliative care:	care that aims to improve quality of life, reducing the burden of symptoms, and is typically given when a metastatic GI cancer is incurable, but it can add value at any stage of the treatment pathway as needed

TERM:	DEFINITION
Personalized treatment, or precision medicine:	a way of treating patients by considering their individual characteristics (e.g., genes, lifestyle, and environment)
Prehabilitation:	preparation for cancer treatment
Prognosis:	an estimate of how a disease will progress
Radiotherapy:	a cancer treatment that uses X-rays or similar types of radiation to kill cancer cells
Second-line treatment:	the second treatment recommended for an illness, such as CCA, when the first-line treatment has failed, stopped working, or has side effects that are not tolerated
Side effects:	symptoms experienced following treatment
Targeted therapy:	a type of treatment that targets the changes in cancer cells that help them grow, divide, and spread
Ultrasound:	a test that uses high-frequency sound waves to create an image of part of the inside of the body.

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