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CANCER OF THE BILE DUCTS WITHIN THE LIVER OR HILAR CHOLANGIOCARCINOMA

INFORMATION FOR PATIENTS AND THEIR FAMILIES

*THIS INFORMATION REFLECTS THE PERSONAL PRACTICE OF DR KELLE SLATER ONLY
AND DOES NOT SUBSTITUTE FOR DISCUSSION WITH YOUR SURGEON*

YOUR ADMISSION DETAILS:

Your admission date is: _____

Date of your operation: _____

Fasting time from: _____

Greenslopes Private Hospital Admissions (Phone 1800 777 101) will contact you **the day before** you are due to enter the hospital to confirm the details.

WHAT IS HILAR CHOLANGIOCARCINOMA?

Cholangiocarcinoma is cancer of the bile ducts. Bile is a golden liquid that is made in the liver. The bile ducts are tubes that carry the bile into the bowel. The bile ducts are arranged roughly into the shape of a tree. The trunk of the tree is the only part outside the liver and this carries bile to the bowel where it helps to digest food.

Cancer can occur anywhere in the bile ducts but hilar cholangiocarcinoma is when the cancer occurs in the 'fork of the tree' just as the bile ducts emerge from the liver. It is one of the most challenging problems in all of liver surgery. All patients must be assessed by a unit that specifically specializes in complicated liver surgery and has access to advanced x-ray services and high quality intensive care facilities. There are a limited number of surgeons in Australia who have the expertise to treat this type of cancer.

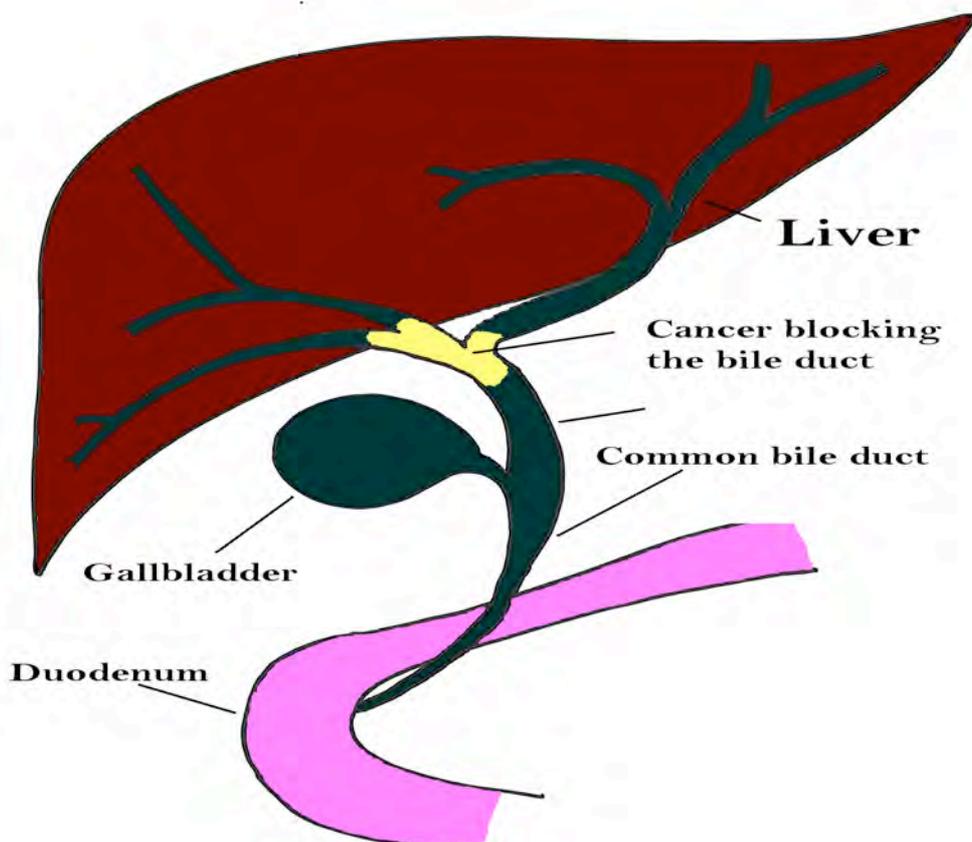


Figure 1. There are several types of bile duct cancer, but hilar cholangiocarcinoma blocks both the right and left bile ducts

WHAT CAUSES CHOLANGIOCARCINOMA?

In most cases of cholangiocarcinoma, the cause is unknown. In a few people it can be due to:

1. An immune disease called Primary Sclerosing Cholangitis
2. Parasites that have lived in the bile ducts for many years
3. Stones forming in the bile ducts
4. Genetic abnormalities of the bile ducts

WHAT ARE THE SIGNS THAT I HAVE THIS TYPE OF CANCER?

Many patients will not know they have this cancer until they develop jaundice or yellowness in the eyes. The cancer may have been there for many months before there are any symptoms at all. Jaundice may be accompanied by:

- severe itch
- dark urine – like tea
- pale or white bowel movements
- fever or shivers and shakes
- pain is unusual and often only occurs when the cancer is advanced

If the blockage is just on one side of the liver then jaundice will not occur. Jaundice develops when there is a blockage of both side of the liver or the main bile duct and bile cannot flow out of the liver. The bile is then forced into the bloodstream and this gives the characteristic yellow colour of the skin. Bile is very important in the bowel to help absorb the fat we eat.

WHAT CAN BE DONE TO TREAT HILAR CHOLANGIOCARCINOMA?

This cancer is one of the most complicated tumours to manage that exists in the body. This is because the area has very important blood vessels that must not be damaged. Sadly, it is very often the case that it is not possible to remove these tumours at all. This is because removing the tumour successfully would result in damage to these blood vessels. This cannot be done without the risk of death. Additionally, cutting out these tumours may mean the removal of up to 80% of the liver and in many people this is not possible.

Surgery is the only option to attempt a cure for this type of cancer. Chemotherapy can be used to help prevent the cancer coming back but is unlikely to be effective by itself.

WHY CAN'T I HAVE A LIVER TRANSPLANT?

Liver transplantation is not a successful treatment option for most cholangiocarcinoma. In fact, transplantation can make the cancer return faster and more aggressively. Patients usually live longer with no treatment at all rather than having a transplant. Transplantation is occasionally suitable for very early cancers and cholangiocarcinoma is very rarely diagnosed early.

HOW DO YOU REALLY KNOW I HAVE CANCER? WHY HAVE I NOT HAD A BIOPSY?

Getting a biopsy of hilar cholangiocarcinoma is exceptionally difficult. This cancer does not usually grow into a large lump that can be easily sampled. There are major arteries and veins supplying blood to the liver that travel alongside the bile duct, taking a biopsy in the majority of patients is dangerous and virtually impossible. This means that there is usually no tissue diagnosis prior to operation. This can be unsettling for both the patient and the surgeon because nothing is 100% for sure unless there is a biopsy. In this area of the body, however, there are virtually no other conditions that can cause this problem and the diagnosis of cancer is correct 99% of the time. Even if the narrowing of the bile ducts is not due to cancer, radical surgery is usually the only solution.

Many people may have heard of a technique called 'brushing'. This is where a telescope (endoscopy) is passed via the mouth down to the region of the bile duct. A brush is then inserted into the bile duct and a sample of the cells is taken. If a cancer result comes back, then this is useful. If there are no cancer cells seen, it is not helpful at all because it is still likely that there is cancer present and the brush has missed it.

WHAT IS IT LIKE TO BE JAUNDICED?

Jaundice occurs when there is too much bilirubin in the blood. Bilirubin is what makes bile yellow. When the bile duct becomes blocked by cancer, the bile that normally passes into the bowel giving the brown colour to your faeces can no longer get there. Bile under pressure builds up in the liver and spills into the blood stream. This causes the whites of the eyes to turn yellow, the urine to become dark and bowel motions to turn white. Eventually the skin turns a deep yellow colour. This may occur gradually and it might be noticed at first by a family member.

In some patients, jaundice is accompanied by a terrible itch. You might not be able to sleep. Nothing will take away this itch until the bile duct is unblocked. As soon as this happens, the itch will disappear quite quickly. Try not to scratch because it will cause skin irritation and bleeding. Sometimes calamine lotion helps to sooth the itch. If it is debilitating, a sleeping tablet can help in getting some rest.

When someone is jaundiced, they are usually admitted to the hospital because jaundiced patients can get infections and become dehydrated very easily. Being jaundiced means you will not be able to absorb Vitamin K and your liver will not be able to make the factors required for blood to clot. You may bruise easily.

In the hospital you will be given intravenous fluids and intravenous Vitamin K. Your blood tests will be checked regularly.

Jaundice needs to be fixed within a few weeks of its onset because permanent liver damage will eventually occur. This will often be done with a test called PTC (see below).

WHAT TESTS WILL I HAVE DONE BEFORE AN OPERATION IS OFFERED?

Planning surgery for hilar cholangiocarcinoma is highly technical and takes a number of weeks. There are many tests both invasive and non-invasive that must be performed before any decision can be made regarding an attempt at curative surgery. After each test, the situation is reassessed. The decision not to offer an operation can occur after any or all of these tests. The final decision about feasibility of surgery is made at the actual time of the operation. You can be sure that your case will be discussed with all the surgeons, oncologists and radiologists on the Hepato-biliary unit and the best course of action devised. You will be included in the decision making.

Frequently, the tests and work up for this operation is almost as difficult as the operation itself. It is a time of much uncertainty and the process is quite slow. It may take 6-8 weeks. You will learn to be very patient and during this time you may not be feeling very well.

You must be quite fit to undergo this type of operation. Generally, we are reluctant to offer this surgery to people over 70 years of age. Even if you are healthy, you may not have enough reserve to survive this operation.

Some of the tests you can expect to have may include but are not limited to:

1. CT scan of the chest and abdomen

This is done to look for cancer outside the area around the bile duct i.e. the distant spread of cancer to the lungs or liver. It also gives information about the artery and vein that supply blood to the liver and their relationship or involvement with the tumour. The computer performing the scan can also help us assess whether you will have enough liver remaining to survive after the operation.

2. Heart and lung tests

This is performed to assess your fitness for major surgery. This will depend on your age and other health problems. These tests may include an ultrasound of the heart (Echocardiogram), lung function tests and exercise tests.

3. MRI

An MRI is performed to get a picture of the bile ducts and the exact site of the blockage. This test is critical to determine which side of the liver is best removed. MRIs involve lying on a bed in a narrow, noisy tunnel. Some patients find this very

claustrophobic. The X-ray Department take great care to make this experience as pleasant as possible.

4. Key hole surgery or diagnostic laparoscopy

This is done under general anaesthesia (fully asleep) in the operating theatre. A small cut is made in the belly button and the tummy cavity is blown up with gas. A camera is inserted. There may be one or more additional cuts made so we can move things around with long instruments. This test is done to look for small lumps of cancer that may have spread around the abdominal cavity. This is relatively common in advanced bile duct cancer and if present, is not curable. This type of advanced cancer is not seen well on scans.

5. PTC (Percutaneous Transhepatic Cholangiogram)

The principle of PTC is to unblock the side of the liver that will be saved during the final operation so it can grow. The blocked side will shrivel away. This provides the best hope that there will be enough liver left at the end of the surgery for you to survive. You can expect to have a PTC tube in your liver for 4-6 weeks after the liver is unblocked to give the liver time to grow. You may be sent home during this time.

If you are jaundiced, this test will be done shortly after you are admitted to the hospital. It is performed in the X-ray Department by specialist radiologists. This can be a very tricky procedure and it is vital that there be good communication between the radiologists and the surgeons. It is very important that the radiologist be very experienced in this type of procedure.

Under local or general anaesthetic, a soft tube is inserted through the skin and into the liver. The surgeon will decide in advance which side of the liver will need to be drained. This tube is passed through the liver and into the blocked bile duct. Instantly, bile will come out of the drain under pressure. The bile may be golden yellow, dark green, bloody or clear like water if the liver has been blocked for a long time. This tube relieves the pressure in the blocked bile duct and allows that section of liver to recover. Taking the pressure out of that section of the liver allows that part to grow and the undrained part to wither. We will be watching carefully for the level of jaundice in the blood to drop. If it does, then this is a good sign that this section of liver will be enough for you to live on after the surgery.

At the end of the procedure, you will have a soft tube coming out of your abdomen emptying into a drainage bag. The nursing staff will monitor how much bile comes out each day. It may drain up to a litre of bile per day. At some point, this tube may be capped off and there will no longer be any drainage. A PTC often involves a number of trips to X-ray for different procedures over a number of days. It can take a week to get right.

Complications Associated with PTC

PTC is an invasive test but is usually performed with very few problems. This is a list of potential concerns.

- a. **Infection (cholangitis):** by its very nature, a PTC will introduce bacteria into a stagnant, blocked system. Infection occurs in 50% of patients. It is expected and you will be given intravenous antibiotics prior to the procedure. Infection presents as a high fever, pain, shivers and shakes. Your blood pressure may be low. Rarely, this type of infection requires treatment in intensive care with special medications to support the blood pressure. You will feel absolutely terrible after an attack of infection of this nature.
- b. **Kidney failure:** being jaundiced is very hard work for the kidneys. You will be given extra intravenous fluids, but kidney failure can occur at any time especially during an infection. This kidney failure may be temporary, may require dialysis and occasionally, it is fatal. Another problem for the kidneys is the large loss of fluid out of the PTC. It can be difficult to drink enough water to keep up with this loss. For this reason patients usually have to stay in hospital for the entire time a draining PTC is in place.
- c. **Bleeding:** serious bleeding is uncommon. There may be bleeding into the abdomen requiring urgent surgery or there may be bleeding into the bowel or PTC tube that will require further x-ray procedures. You may require a blood transfusion. It is perfectly normal for a small amount of blood to come out of the tube from time to time.
- d. **Leak of bile:** bile may leak around the tube and into the abdomen. This can cause pain and infection. It may need another x-ray procedure or uncommonly an operation.

WHAT ARE THE ODDS OF SURVIVAL IF I HAVE THE SURGERY TO REMOVE THE TUMOUR?

There are many factors that go into determining the outcome of a patient who has an operation for cholangiocarcinoma. In general, patients who have a successful operation for cholangiocarcinoma, where the cancer is removed with clean tissue surrounding it have a 1/5 chance of being cancer free in five years.

WHAT CAN I DO WHILE I AM AT HOME WAITING FOR MY OPERATION?

You may be at home for the few weeks before your operation while we are waiting for your future liver remnant to grow. It may be a full month before your jaundice level drops to normal. We recommend the following:

- It is best to try and eat as much and as healthily as possible with a high protein diet. This means lots of meat, fish, eggs, fruit and vegetables. When you are jaundiced you don't feel like eating much, so it is important to pay attention to it. Try and eat as though you were training for a marathon.
- Do not take any herbal preparations or products claiming to be liver cleansers. These occasionally result in liver failure and there is no proof that they are of benefit.
- Take a simple multivitamin daily (purchased from the chemist or supermarket).
- Drink at least 3 litres of water per day. Being jaundiced is very hard on the kidneys and dehydration may cause kidney failure.
- Try to avoid hot weather and use the air conditioner in the summer if possible. Hot weather makes dehydration more likely.
- Try and do some light activity every day, like a short walk in the cool of the morning or evening.
- Try to decrease your intake of caffeine because it is really common to have a caffeine withdrawal headache in the days after the operation.

THINGS YOU NEED TO BE WORRIED ABOUT WHEN YOU ARE AT HOME BEFORE THE OPERATION

- **Fever, shivers:** Means there is an infection in the bile ducts and is very common. You may feel extreme fatigue and have headaches during one of these infections. If it happens you must call us or if you are out of town, go to your nearest Emergency Department. It is likely you will need to be admitted to the hospital and given intravenous antibiotics.
- **Drain dislodgment.** If the drain tube falls out and you are well, there is no need to come to the hospital in the middle of the night. Just contact us the next morning. It will need to be replaced. This is uncommon.
- **Bad pain that is new.** The drain may be leaking. You will need to go to the Emergency Department.
- **Frank blood** that comes out of the drain and does not stop after a few minutes. Go to the Emergency Department.

CARE OF YOUR PTC DRAIN

If your drain is capped off, then the care is very easy. The drain just needs to be coiled under a pad and taped to your tummy. If the bag is left open, then it will drain into a colostomy bag. This bag needs to be emptied each day and the amount recorded. The bag apparatus only needs to be changed every few days. The nurses will show you what to do before you go home. You may notice that the tube will slide in and out of your skin for a few centimeters. This is normal

It is normal for the skin where the drain emerges to be red and a layer of jelly-like material may form around the tube. You may notice an unpleasant odor coming from this tissue. This is normal and is not an infection. You may take the whole bag off and gently clean around the tube with water.

As the liver recovers, you might notice a change in the colour of the bile coming out. This is normal. A small amount of blood may come out from time to time. Even during an infection, you may not notice a change in the colour of the bile.

WHAT IF MY CANCER IS TOO ADVANCED TO OPERATE OR IF I DECIDE I DON'T WANT TO HAVE SURGERY?

This is a very sad situation. There is no chemotherapy or radiation therapy that will cure cholangiocarcinoma. If you are not able to have surgery to remove the cancer, a permanent internal drain tube will be placed inside the liver to fix your jaundice. This process takes more than a week to perform and when it is finished there will be no external tubes to be seen. These stent tubes may become blocked and infected at any time and will require revision.

You may then go home and we will continue regular follow-ups. You may be referred to cancer specialists called palliative care. They look after patients with inoperable cancer.

It is likely that you will feel well for sometime after your jaundice is gone and you may even feel like you don't have cancer. This is great and you should concentrate on eating well and having a happy life.

OPERATING ON THE LIVER FOR CHOLANGIOCARCINOMA

The type of liver operation required for hilar cholangiocarcinoma is very specific to where your cancer is. Up to 70-80% of the liver will be removed. The operation is carried out by tying and stapling hundreds of bile ducts and blood vessels and dividing the liver with a clean cut. In addition to the liver, the upper part of the common bile duct, lymphatic tissue and the gallbladder will also be removed. You can live a perfectly normal life without your gallbladder.

This operation pushes the boundaries of how much liver can be safely removed. It takes enormous surgical judgment to perform this operation. It is a major procedure and should only be performed by a surgeon experienced in liver and bile duct surgery.

After the liver resection is completed, there will be one or more bile ducts emerging from the remaining piece of liver that will need to be joined onto the bowel. The bowel will be slightly rearranged to make this join up (see diagram).

The surgery for hilar cholangiocarcinoma typically takes 5-10 hours.

The incision will be in the upper part of your abdomen and may look either like a hockey stick or occasionally like a Mercedes Benz sign.

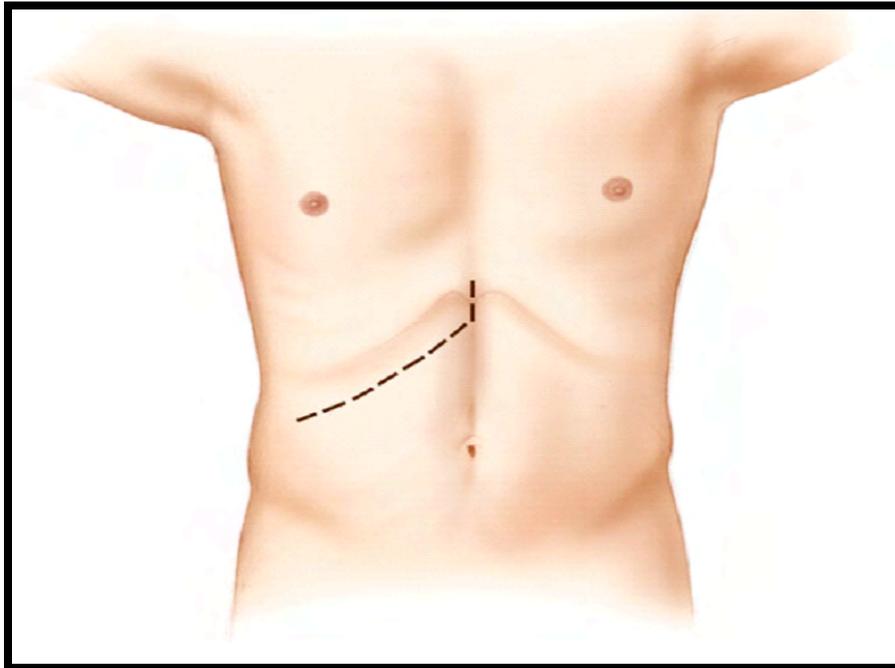


Figure 2. How your incision will look.

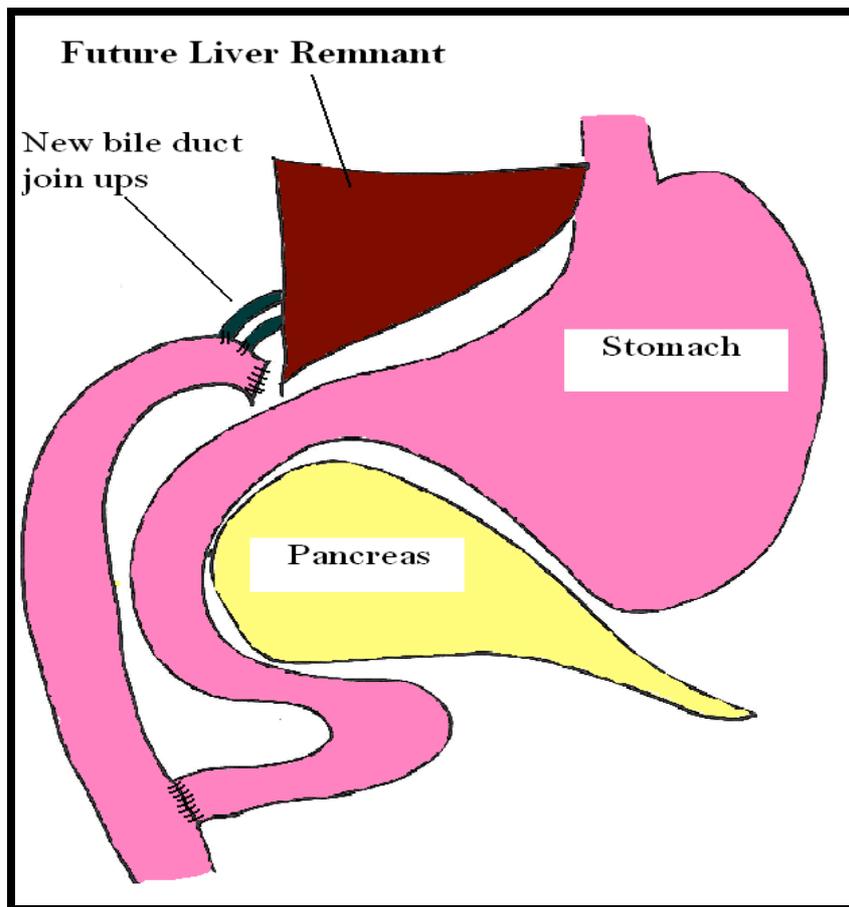


Figure 3. This is a picture of how your bowels and liver will look after the right side of the liver is removed for hilar cholangiocarcinoma. The small bowel is rearranged and the bile ducts are joined on to a loop of bowel. You might hear this referred to as a Roux-en-Y (pronounced roo-on-y).

WHAT TO EXPECT IMMEDIATELY AFTER SURGERY

Intensive Care

After the operation is finished, you will be transferred to intensive care. You may be kept asleep (induced coma) for a short time after the operation. Alternately, you may be woken up straight away. There are many factors that go into making this decision and your family will be told whether you will be awake or left asleep.

Pain Relief

On the first day after surgery, there may be a moderate amount of discomfort at the site of the operation.

You will have some form of pain relief. There are two different options.

- Patient Controlled Analgesia (PCA) and a “Pain buster” - a button you will press that causes strong pain killers (like morphine) to run straight into your IV line, combined with a tiny catheter in the wound providing local anaesthetic. These devices are very safe and have locking mechanisms to prevent overdose.

IT IS VERY IMPORTANT THAT YOUR RELATIVES DO NOT PUSH THE PAIN BUTTON FOR YOU AS THIS WILL RESULT IN AN OVERDOSE OF MEDICATION THAT MAY STOP YOU BREATHING.

- It is very unlikely that you will be offered epidural pain relief for a hilar resection. This is because so much liver is being removed, the blood may not clot well after the operation. This increases the risk of bleeding around the epidural and there is a chance of permanent paralysis.

Every effort will be made to minimize your discomfort and make it bearable. Your nurses will be monitoring your level of pain frequently.

When you are back to eating normal food you will be converted to oral pain relief.

Drain tubes

You will have a number of plastic tubes in your body following surgery. They will vary a little depending on your particular medical need. They will be removed at variable times following your surgery under our supervision.

1. **IV line:** In your arm and in your neck (placed under anaesthesia) to give you fluids and pain relief.
2. **Urinary catheter:** tube placed in your bladder so you don't have to get up to pass urine.
3. **Arterial line:** a fine catheter inserted into the artery at the wrist to monitor the blood pressure.
4. **Abdominal drain tubes:** two or three soft plastic drains coming out of your abdomen that are placed along the cut surface of your liver to drain blood or bile, so it does not collect in your abdomen.
5. **Stomach tube:** you will wake up with a tube in your nose that goes into your stomach to keep your stomach empty. This will usually be removed in the first day or two after surgery.
6. **Bile duct drain:** it is likely the PTC drain you had before the operation will remain in place for a short time after the operation. This enables us to x-ray your bile ducts to make sure the joins are healing properly.

Eating

You will not have anything to eat or drink for the first 2-3 days after surgery. An intravenous infusion will provide you with the necessary fluids.

We will let you know when you will be able to eat. You may not be able to tolerate eating food for several days. If this is the case, we will feed you via a tube in your nose or via an intravenous drip. Nutrition is very important in recovery from this operation.

It is very common to lose your ability to taste food. This will return in the first few months after surgery.

It is normal to have a sore throat from the breathing tube and gastric tube for a few days after the surgery.

Urinating/Bowel Movements

During the first week after the surgery, the tube placed in your bladder will drain your urine. You will probably not have a bowel movement for several days. You will notice that you will pass wind first. You may need laxatives to help you go. It is usual for your bowels to be out of their usual routine for weeks after the surgery.

Daily Activity on the Ward

You can expect your nurse and physiotherapist to help you to get out of your bed even on the first day after surgery. You will be able to walk short distances even with all of the tubes and intravenous lines.

As each day passes your tolerance for walking and sitting in a chair out of bed will increase. This is extremely important to prevent pneumonia, clots in the legs and loss of general condition.

Other Medications and Preventative Measures

You will be given a blood thinner once or twice a day as a small injection under the skin. This helps to prevent clots in the legs (DVT) that may travel to the lungs and be life threatening. If you are in a high risk group for DVT, you may be sent home with this injection for several weeks after surgery. You or a family member will be taught how to give the injections.

You will be asked to wear TED stockings throughout your hospital stay. These prevent clots in the legs.

In most instances you will be given a medication to decrease the acid secretions in the stomach. This prevents stomach ulcers that may occur after major surgery.

You must not smoke at all.

Your Incision

You can expect to have a waterproof bandage over your incision for the first several days. Your dressing will be removed by your doctor at the appropriate time. You will be able to shower with the waterproof dressing on. It is quite common to have a small amount of leakage from the wound.

Other Important Information

You can expect to see your primary surgeon every day. On weekends or in times when we are operating elsewhere, you will see one of the practice partners. All of us are very experienced in this type of surgery and commonly assist each other in the operating theatre.

We will make every effort to keep you informed of your progress. We are always honest and open with you and your family. Feel free to ask questions.

Length of Stay in Hospital

On average, most patients having a hilar resection that experience no complications will expect a 3-4 week hospital stay. This length of stay, however, differs greatly for individual patients. Some will stay less and some will stay much, much longer. You will not be discharged before you can walk unaided and care for yourself.

WHAT ARE THE COMPLICATIONS THAT MAY HAPPEN IMMEDIATELY AFTER SURGERY FOR HILAR CHOLANGIOCARCINOMA?

Liver surgery is a complex procedure with many potential complications. Hilar resection is the pinnacle of liver surgery and the risks are higher than conventional resections.

The most serious and specific complications that may be seen after this operation include:

Bleeding

Bleeding can occur during the course of your surgery. You may require a blood transfusion for this. In addition bleeding can occur at any time after the operation but is more common in the first week. This may require further surgery. Approximately 15 – 20% of patients having hilar resection will need a blood transfusion. The risks of acquiring a viral disease such as Hepatitis B, C or HIV via blood transfusion are exceptionally rare. Bleeding may rarely occur several days and weeks after surgery due to a ruptured artery.

Bile leak

When the liver is cut across, there are hundreds of tiny bile ducts and blood vessels that must be tied and clipped. Occasionally one of these bile ducts opens up after the operation and bile will leak out. This is usually obvious in the soft drains that are left in your abdomen after the operation. These drains may be left in for a prolonged period of time. Sometimes the drain will not be adequate and you will need a new drain placed either in X-ray or in the operating theatre.

In many cases this bile leak will heal itself. If the bile leak is large in volume or becomes infected, you may require further surgery or drains.

Insufficient Liver

Patients having a hilar resection will lose 70 -80% of their liver. Sometimes the remnant piece of liver is not enough to allow the body to function. This is an often fatal condition and is a reality of this surgery. Having a small liver makes recovery from surgery very difficult. Patients with a small liver remnant after liver surgery may become jaundiced and may remain that way for many months. Some patients may never wake up from this operation because of inadequate liver.

Dead and Infected Liver

The blood supply to the remaining liver in this operation is often partially removed in order to clear the tumour. This can result in small sections of dead liver on the surface of the liver. This may liquefy and cause an abscess requiring draining in the X-ray Department or further surgery. It may be a problem for many weeks after the operation and prolong your hospital stay.

Tumour that is not fully removed

It is very common that cancer of the bile duct spreads microscopically much further than we can see with the naked eye. It is only when the pathology result comes back, do we see whether we have removed the cancer with clear tissue around it. Sometimes, cancer comes right up to the margin of the specimen and this means there may be some cancer cells left in your body. It means the cancer has a high chance of coming back. This is a difficult and sad situation because we cannot go back and remove anymore tissue.

Narrowing of the bile duct

Patients having a hilar resection may develop a narrowing of the joins between the bile ducts and bowel. This will usually occur in the first year and may present as altered blood tests, jaundice or fever. It will need further PTC and surgery to correct the problem.

Other immediate complications of hilar resection

Like all major surgery there are a number of serious complications that may occur. These must be dealt with on a case-by-case basis. Some of these complications are:

- Death: approximately 1-5% of all patients having this type of operation.
- Infections: wound, pneumonia, urine, intra-abdominal, epidural related, IV line related.
- Damage to the hand from the arterial line in the wrist.
- A hole in the diaphragm (muscle between lungs and abdomen) that may require a tube in your chest.
- Punctured lung secondary to the IV line in your neck.
- Clots in the legs that may travel to the lungs. Clots in any of the blood vessels supplying the liver. This may be fatal.
- Stomach ulcers that may bleed: this may present as a vomit of blood or black bowel motions.
- Urinary catheter complications: unable to pass urine after catheter removed especially in men
- Permanent or temporary damage to nerves in the arms, legs and neck due to prolonged immobilization on the operating table. This may result in loss of feeling or movement.
- Wound pain and prolonged numbness under the wound.
- Hernia of the wound.
- Bowel obstruction due to hernia or adhesions. This is a lifelong risk.

AFTER YOU GO HOME

Alteration in diet

After a hilar resection there is a significant change in the amount of food people can eat. Most people find they feel full very quickly and will not take in enough calories. This is part of the reason for the weight loss that occurs after this operation. Because the liver is undergoing massive growth in the post-operative period, a large amount of calories and protein is required to fuel this process.

We generally recommend that patients eat smaller meals and snack between meals to allow better absorption of the food and to minimize symptoms of bloating or fullness. This means eating small amounts of food 6-8 times per day.

We also recommend the use of high calorie drinks like Ensure, Sustagen or Resource. They are a relatively low volume and pack in a lot of calories. A dietitian may be involved in your care.

Loss of weight

It is common for patients to lose up to 10% of their body weight after this surgery. Most patients will regain this weight in the six months after surgery.

How you may feel

You will feel completely shattered after this operation. Many people find that it is exhausting to sit out of bed, even for a short time. You will want to nap often and simple tasks may exhaust you. You may lose your taste for food. You might have trouble concentrating or difficulty sleeping. Most people have transient depression and feel that there is no light at the end of the tunnel. You may have temporary memory loss and confusion in the first few weeks after surgery.

These feelings are usually transient and can be expected to resolve but may last many months after this tremendously arduous operation.

Going home

You will not be sent home until you are walking unaided and able to care for yourself. You may need to have help at home to prepare meals and clean because you will be tired for many months. Some people need to go to a rehabilitation unit for a period of time after this surgery. This is a time to rely heavily on family and friends and it is a good idea to have someone at home with you for the first week or two.

Your medications

We will discuss with you, the medications you should take at home. This will usually include some sort of painkiller. You can expect to go home with stomach medication to prevent ulcers and you might have to take this life long.

Your incision

Your dressing will be removed before you leave the hospital and if it is not leaking it will be left open to the air. You may wear clothes over the top of it.

It is very common to have a small or even large leakage of clear fluid from one of the drain sites, several days or weeks after the operation. If this occurs at home, do not panic. Just call the surgery the next day for advice.

It is common to have discomfort, pulling and numbness of the wound for many months after the operation. It becomes more pronounced about a month after surgery. It is not

agonising, but it can be annoying if you don't understand that it is normal. It is common and goes away with time. It takes a full year for a wound of this nature to settle completely.

It is very common to have a prickly end of a stitch poking out of the end of the wound. This happens as the stitches dissolve. If it bothers you, you may snip it off with a pair of scissors. Otherwise it will disappear about 8 weeks after the surgery. If you are very thin, you may be able to feel the deep stitches that are not dissolvable if you push hard with your finger. If this bothers you, it is relatively easy to cut the offending stitch out several months after the operation.

Your incision may be slightly red along the cut. This is normal. Over the next few months your incision will fade and become less prominent.

You may gently wash dried material around your incision and let water run over it. Pat the wound dry with a towel. Do not rub soap or moisturizer into your incision for at least 4 weeks or until it is fully healed. After this you may rub vitamin E cream along the wound.

It is normal to feel a ridge along the incision. This will go away. It is normal to have a patch of numbness under the wound.

You may see a small amount of clear or light red fluid staining your dressing or clothes. If it is minor cover that part of the incision with a pad. If leakage is severe, you should contact our office.

Passing drain tubes in bowel motion

During surgery, we may insert several soft pieces of plastic tubing to hold open your bile duct. These tubes may pass with your bowel motion at any time after your surgery. It is usual to not notice them. If you do see them in the toilet, it is completely normal. DO NOT retrieve the tubing from the toilet bowl. They may be seen on an x-ray and they may stay in your bile duct or bowel for a long time before passing out. Very rarely they may require removal via further surgery or endoscopy.

Activity

Listen to your body, if it is hurting, don't continue with the activity.

Do not drive until you have stopped taking strong pain medication and feel you could respond in an emergency.

You may climb stairs and raise your arms above your head.

You may go outside, but avoid travelling long distances until you see us at your next visit.

Do not lift more than 10kg for 6 weeks. (This is about the weight of a briefcase or a bag of groceries). This also applies to lifting children, but they may sit on your lap.

You may start some light exercise when you feel comfortable.

You may gently swim after 6 weeks.

Heavier exercise may be started after 8 weeks - but use common sense and go slowly at first.

You may resume sexual activity when you feel ready.

WHAT SHOULD I BE AWARE OF IN THE DAYS BEFORE MY OPERATION?

Hospital

The hospital will call you a few days before your operation to confirm your admission time. It is likely you will be admitted the day before. The hospital will also let you know about any excess you may have to pay.

Fasting

You must have nothing to eat or drink for six hours prior to surgery. (You may take sips of water up until 2 hours before the operation and you may take your medications with a sip of water). You must not chew gum or smoke on the day of the operation.

Medications

- If you are on blood thinners such as Aspirin, Warfarin, Plavix, Iscover, Clopidogrel, Pradaxa, Dabigatran, Rivaroxaban or anti-inflammatory drugs (Brufen, Mobic, Voltaren, etc), they can cause bleeding during surgery. We will advise you about what to do with these drugs prior to surgery. You must let us know about these drugs and the decision to stop them is based on each individual patient's needs.
- Diabetic medications: we will give you advice on whether to take your diabetic medications on the morning of surgery or not. Some diabetics will be admitted the night before the operation.
- If you are on Prednisone, you should not stop this drug suddenly.
- Cholesterol lowering medication should not be taken when you are fasting.
- If you are taking any alternative medications e.g. St John's Wort, fish oil or garlic, you should stop these tablets one week before surgery as they may result in excess bleeding.
- You may continue to take a multivitamin.
- Continue to take all other medications, even on the morning of surgery with a small sip of water.

Other things to know

- You must bring all relevant x-rays to the hospital with you. **THIS IS VITAL FOR THIS OPERATION AND WE MAY NOT BE ABLE TO GO AHEAD WITHOUT THEM.**
- If you smoke, it is in your best interests to stop completely as soon as you can. See your GP for alternatives or call Quitline (13 18 48) if you wish to seek advice.
- You should also abstain from drinking alcohol as soon as this problem is diagnosed.
- Bring all your current medications with you to the hospital.
- Bring comfortable pyjamas, personal toiletries, small change for newspapers etc.
- Do not bring large amounts of cash or valuables.

Income Protection Insurance and Centrelink

If you have income protection insurance, start doing the claim paperwork before the operation. Centrelink claims can take many weeks to process. It is difficult to recover well when you are worried about finances. Before any major surgery it is wise to get your affairs in order including an Advance Health Directive, Will and Power of Attorney. Talk to your employer and let them know that you may be away from work for many months.

Queensland Cancer Council

Call the Queensland Cancer Council 13 11 20 as they have a number of general support and financial assistance programs in place if needed.

Family

This is the time to rely on family and friends for support. If you receive offers of home cooked meals and household help, you should accept them happily. That way, you can concentrate on getting better. It is a good idea to bring your family to any consultations you attend as it is often difficult for patient's to remember things at this emotional time.

WHAT WILL THIS SURGERY COST ME?

We largely work as 'no-gap' doctors. This means that the surgeon fee for your operation will be sent to your health fund and there will be no 'gap' or extra money to pay. There are always exceptions and decisions regarding this are made on a case-by-case basis.

If you do not have private health insurance or if you have overseas insurance, you will be given a quotation for surgery, anaesthetic and hospital fees and must pay in full **prior** to the operation.

This surgery is very technically demanding. We are usually assisted by another consultant surgeon from the group. The remuneration for the assistant is very low for the work required and as a consequence there may be an out-of-pocket charge for the assistant.

If your Body Mass Index is >40, i.e. you are morbidly obese, the surgery is far more difficult and the risks of complications including liver failure are much higher. If it is medically suitable, we may recommend a period of weight loss with a program called INTENSIV <http://www.intensivweightloss.com/> before contemplation of this operation, so it can be done more safely. This will incur an extra out of pocket expense.

Outpatient consultations are not covered by the health funds and there will be a charge for these meetings. You will get a proportion of this money back from Medicare. There is no fee to be paid for normal care after the operation.

There may be other out-of-pocket fees from your anaesthetist and any other specialists who are asked to look after you. You should ask them ahead of time about any out-of-

pocket costs. Ask us who will be performing your anaesthetic and you can make enquiries with them about any out-of-pocket expenses.

There may be extra costs for x-ray, pharmacy and pathology. Intensive Care is usually billed straight to your health fund with no more to pay.

You have a right to gain ‘Informed Financial Consent’. Fees from other practitioners are beyond our control and you should ask for the costs from each person who is asked to look after you. Patients have a choice when it comes to paying for their health care and you are fully within your rights to negotiate and shop around.

If you do not live in Brisbane, you will be responsible for all accommodation, hotel, meal and transport costs for you and your family. There is some monetary assistance available for private patients through the Patient Travel Subsidy Scheme (PTSS) providing assistance to patients and in some cases their carers, to enable them to access specialist medical services that are not available locally. Please see Queensland Health’s Patient Travel Subsidy Scheme site for details <http://www.health.qld.gov.au/iptu/html/ptss.asp>. Greenslopes Hospital web site has an extensive list of hotels available in the local area <http://www.greenslopesprivate.com.au/For-Visitors/off-site-accommodation.aspx>.

ABOUT YOUR SURGEON

Dr Kellee Slater MBBS (Hons) FRACS

2006 – Present	Staff Surgeon Hepatopancreatic-Biliary-Liver Transplant Princess Alexandra Hospital and Greenslopes Private Hospital Brisbane, Queensland
2004 – 2006	Hepatobiliary and Liver Transplant Fellowship Princess Alexandra Hospital Brisbane, Queensland
2002 – 2004	Liver and Kidney Transplant Fellowship University of Colorado Hospital Denver, Colorado, United States of America
2002	Fellow of the Royal Australian College of Surgeons (FRACS) General Surgery
1989 – 1994	MBBS (Honours) University of Queensland