CDH1 cancer syndrome our whānau journey

my hospital passport

Jeremy Rossaak, Tauranga Hospital, Department of Surgery (Tauranga, New Zealand)
The University of Auckland, Faculty of Medical and Health Sciences (Auckland, New Zealand)

Parry Guilford, University of Otago, Department of Biochemistry (Dunedin, New Zealand)

Kirsty Harris, Clinical Pharmacist BPharm, a CDH1 mutation carrier & a Gastrectomy Patient, (Brisbane, Australia).

Contents

Stomach (Gastric) cancer and our whānau

Overview of this booklet

This booklet has been written to help patients (urihaumate) and their whānau with familial gastric cancer to understand the reasons for the decisions made around their care so that they can actively participate in those decisions. The aim of this booklet is to inform urihaumate and whānau about their disease (mate) and to ensure good quality care for urihaumate with familial gastric cancer.

This booklet is divided into three parts. Part 1 (green) is information about the whānau with familial gastric cancer and the genetic defect. Part 2 (Blue) is some helpful information and advice for urihaumate about the surgery. The third part (Red) is up-to-date evidence for doctors and caregivers (kaitiaki) who may be unfamiliar with familial gastric cancer and the *CDH1* gene, to ensure that everyone gets the absolute best care.

Part 1 – Background

Stomach cancer is the fifth most common cause of cancer worldwide and the third most common cause of cancer deaths worldwide. One in 110 people will be diagnosed with stomach cancer during their life. The vast majority of these are random. However, in 1 percent to 3 percent of cases, there is a genetic predisposition.

A genetic predisposition increases the chance of developing the cancer because of the genes we have.

Our whānau has one of these genetic predispositions. In our case, inheritance is autosomal dominant (meaning that each child from a parent with the gene will have a 1 in 2 chance of having the abnormal gene, and a risk of developing stomach cancer). If you have the gene, it predisposes you to a particularly aggressive type of cancer called diffuse gastric cancer or linitis plastica.

Carrying an abnormal gene confers a lifetime risk of about 70% in our whānau members of developing stomach cancer.[1, 2]

Lobular breast cancer, a type of breast cancer that may not form a lump is also a risk in our whānau. There is a lower risk than gastric cancer, but still high, at 40% in females over their lifetime.

The *CDH1* Gene and our whānau

Our whānau has a long history of developing and dying from stomach cancer at an early age. However, it was only in the 1990s, with scientists from the University of Otago, that we were able to identify the gene that caused the stomach cancer within our family.[1, 2]

This document has been written to help us have a better understanding of our disease, and to provide information on how we would like to be managed as a whānau and as individuals.

My whānau needs to be in charge of our own health, this is why we have this resource, to help our doctors provide the care we would like. We need to work together to get the best chance of cure from our disease.

Let's P.L.A.N. for better care

Four steps for your next health care visit

Notes:

Genetics

In our family, there is a mutation (abnormality) in the *CDH1* gene. The gene is a type of gene called a tumour suppressor gene, which codes for the E-cadherin protein. This protein controls how cells attach to each other. If this protein is abnormal, from the abnormal gene, the cells in the stomach, or in the breast, do not attach to each other, and therefore cells do not know when to stop dividing. When cells continue dividing, cancers can develop.

Inheritance of this gene is autosomal dominant. This means that each of us in our whānau has a one in two chance of getting the gene, and if we have the gene, a 70% risk of developing stomach cancer and 40% risk of breast cancer in females.

This is a link to a video describing how the gene was found. **https://www.youtube.com/watch?v=iqLPdcvHBvE**

Clinical

In our whānau, when we get diagnosed, we often have multiple (a hundred or more) small spots (foci) of cancer within the stomach, but don't have any symptoms or suspicion of the growths. In fact, if we develop symptoms from our stomach cancer, it's often too late for a cure.

Our whānau

It is important to us, that clinicians realise that we are Māori, and how important the whānau and our culture are to us. As a whānau, we have endured stomach cancer.

A number of close whānau members have died from the disease. However, more recently, a number of whānau members have been treated, and are doing well. We have a few short videos which talk about our journey and can be viewed online:

https://www.youtube.com/watch?v=jsJ0zf9z0s4

https://www.youtube.com/watch?v=EHlRxSXRCU

https://www.youtube.com/watch?v=eIajBtacBbY

How we got to today …

Our family is a close-knit family who live together in Tauranga.

Our story starts back in 1864, at the battle of Gate Pā. In this battle our ancestors from the Ngāi Te Rangi tribe fought against the British.

This battle was famous for two reasons. First, the New Zealand Māori were completely outnumbered in both numbers and firepower yet beat the British. Secondly, on hearing the cries of wounded British soldiers, Heni Te Kiri Karamu performed an act of great mercy and took water to the injured soldiers.

Some years later, a princess of Ngāi Te Rangi married a European man and our family is descended from this union.

Throughout the 20th century, our family lost our young adults to this disease.

In 1996, we felt we had to do something, so believing there was a genetic cause for our stomach cancer we asked Parry Guilford from the University of Otago to look into our family.

Management

Overview

Our whānau is very knowledgeable about familial stomach cancer. After all, we have been living with it for many years. However, we still need to have the information and a plan discussed with us, so that we can participate in our care.

Once we are old enough, and are ready to have genetic testing, we would like to have this with a clinical geneticist.

In general, surgery when performed in time and well, removes all the cancer. However, surgery is a large operation with significant short and long-term complications. Thus, in some circumstances, we may wish to delay surgery for a few years (for example, until after we've completed studies). If this is the case, we would like annual gastroscopies and biopsies.

Some important facts about our cancer are:

- Members of our whānau have developed cancer from the age of 14 years. Most of us will develop cancer when we are in our twenties, thirties or forties.
- We therefore get genetic testing anytime from age 16 onwards. If we have the abnormal gene, we're offered gastroscope screening from the age of 16. A gastroscope is a

telescope test to look at the stomach and to take samples from the stomach.

- At gastroscopy we may have a normal looking stomach, yet have multiple small areas (foci) of cancer.[3]
- A gastroscope can be reassuring, and buys time until we have an operation to remove our stomach. However, a gastroscope is not a treatment, and we will need regular gastroscopies with many biopsies each time, to make sure a cancer is not developing.[4]
- A gastrectomy (removal of the stomach) is the only cure for the cancer.
- The females in our family also develop breast cancer. These are lobular cancers and can be difficult to detect by mammogram or examination because the cells do not form a lump.
- We will need screening for the cancer with an annual MRI starting at 30 years of age, and stopping at 50-60 years depending on breast density, in discussion with the breast clinical team. A mammogram is also advised from around the age of 40 years old, until 70. Breast MRI needs to take place on day 10-14 of a patient's menstrual cycle to optimise sensitivity.
- If we have a strong family history of breat cancer, we may wish to have a bilateral risk reducing mastectomy (with or without reconstruction).

Gastroscopy

A gastroscopy (endoscopy) does not cure the condition. At best, a gastroscope can be used for reassurance, and to buy time so that we can complete our studies or schooling before having the operation. Gastric cancer can be difficult to see in our whānau. Please do not rush the procedure and please follow the protocol at the end of the book.[4]
At the gastroscope, we like to have a whānau member present. We know this is different from the usual practice, however, it is important for us to have this support.

Prophylactic gastrectomy

There are no reliable ways to look for the cancer or watch it before it becomes a problem in our whānau. Therefore, removing the stomach before a cancer is evident (prophylactic gastrectomy) should be considered in our whānau when we are in our early 20s. However, in most cases it is highly individualised.[4]

Since surgery has a major impact on the quality of our lives, we need to be well informed, well prepared, and the timing should be right.

There may be a dormant period in which the signet ring cell adenocarcinoma (the name pathologists give to our type of cancer) does not spread. This may explain why some of our whānau members are found to have *T1a N0* stage tumours at prophylactic gastrectomy.

However, if we develop diffuse stomach carcinoma, the prognosis is poor with less than 10% having curable disease.

Bilateral mastectomy

The option for bilateral risk reducing mastectomy (with or without reconstruction) should be discussed on a case by case basis with the surgical team.

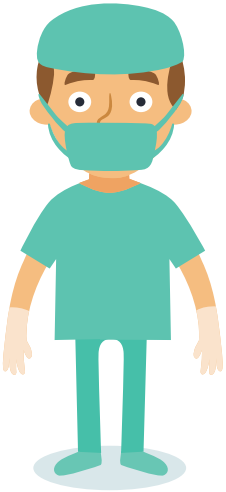
Screening for other cancers

There is no evidence that colorectal cancer is increased in our whānau, so we don't need additional screening for this.

However, we also develop colon cancer, as can anyone else. If we have a history of colon cancer in our whānau, we should be screened following the normal Colonscopy Screening Guidelines for New Zealand. (**https://www.health.govt.nz/system/files/documents/publications/colorectal-cancer-surveillance-guidance.pdf**)

Part 2 – About the surgery

A total gastrectomy



The total gastrectomy is the surgical removal of the whole stomach to ensure all the cancer producing lining is removed. If there is cancer already present, the lymph nodes around the stomach may need to be removed.

The lymph nodes form a filter around the stomach. Fluid that surrounds the cells in the wall and lining of the stomach drains in lymphatic channels, then through lymph nodes, which sieve the lymph and help remove infections or cancer cells before the fluid returns to the blood stream.

The lymph nodes can trap cancer cells, which can then grow in the lymph node. For early gastric cancer it may not be necessary to remove the lymph nodes. The lymph nodes are on the arteries that supply blood to the stomach.

Removing the stomach is obviously a big operation with a number of risks. The risks are divided into risks at the time of surgery, and long-term risks. These will be discussed in detail in the following sections. Being prepared will help you manage the risks or get over any complications more easily.

Preparing for your gastrectomy

As you often have the luxury of some time before surgery, here are some ideas to help you prepare for surgery.

Fitness: Surgery often goes a lot better if you are fit. In addition, if there is a complication or problem after surgery, you will have more kaha to get over the complication. You should walk for 45 minutes each day to build up your kaha. Find a cousin or hoa to do it with you; it's harder to quit if you're both doing it.

Stop smoking as soon as possible to reduce the coughing and mucous in your chest. Auahi kore is hard, but there's lots of good support. Ring the Quitline on 0800 778 778. You also need a quitting buddy, then set the day you're going to stop smoking.

Make sure you plan in one month, three months, six months, even a year later, what you're going to do with all the money you're going to save!

Nutrition: Watch what you eat, and eat plenty of red meat and fruit and vegetables to ensure you have a good reserve of vitamins. Kai moana is great for you, providing it's not drowning in cream. Don't eat white bread, and try not to eat fry bread too much. Rewena is quite good because it's a sourdough. Don't drink fizzy drinks, even diet ones, they just make you want more sugar. Milk and water are what you're after. When you're at a hākari, the trick is to take the things off your plate that you know you shouldn't have before you start. Don't drink the fizzy drinks and give the pudding to your buddy.

We will make an appointment for you to see the dietitian before your surgery. This is important because weight loss following the surgery can continue for up to two years.[5]

Do your research: "This is your tinana and your oranga". You should know what to expect (although everyone is different and there are no rules). There are some great resources for information about living without a stomach (**https://www.nostomachforcancer.org**).

Finally, how you're feeling about life and yourself has been reported as being worse two years after surgery, than it is before surgery.[5] You might need to get some counselling to help you get through the surgery and for the few years following the operation. This can be organised through your GP, your Hauora, or the hospital.
Use this checklist to ensure we have covered everything before your surgery.

Checklist

I have had genetic counselling ☐

I have had a gene test ☐

Result ? _____

I have had my first gastroscope ☐

Future gastroscopes ☐

Dates _____

I will see the surgeon on

Date _____

We discussed
- Smoking ☐
- Fitness ☐
- Nutrition ☐
- Psychologist / Adolescent health ☐
- Managing of other medical illnesses ☐

I will see a dietitian? ☐

Who _____

Date _____

Risks of the surgery

The surgery for stomach cancer is a large operation, that does carry a risk of complications. These can be divided into:

Complications of stomach surgery: The biggest risk is a leak from the join-up. Although this is uncommon, it can be life threatening, and can take 2-4 months in hospital to get over. If you have a leak, you may become very sick and may be in ICU for some of this time.

Other risks include bleeding, which may require a return to theatre. There may be other reasons you may need to go back to theatre such as a bowel blockage for example.

Complications of all surgery: These are things like developing clots in your legs from not moving enough (deep vein thrombosis (DVT), which are managed by thinning your blood and keeping you mobile early after the operation. Pneumonia or heart attacks can happen and are best avoided by being fit. Finally, allergies or side effects to some of the drugs used in anaesthesia can be troublesome. Anaphylaxis, a serious allergy, is rare but can be life threatening.

Long term risks: These generally revolve around your nutrition and your digestion and are discussed next.

If you feel that something is 'not right', don't hesitate to check in with your GP, your Hauora, or the hospital.

Long term problems after surgery

Nutrition following a gastrectomy

Following a gastrectomy, everyone responds differently to how, and how much you can eat. Some may have almost no problems, and others may have ongoing trouble. Don't be afraid to try different things. You may find something that works for you. Share your experience so others can learn from it.

Use the No Stomach for Cancer website (**https://www.nostomachforcancer.org**) to share your stories.

After the surgery, without your stomach, you'll not be able to eat much at all, and it may hurt to eat. Also, it's common not to feel hungry and food doesn't taste good. For these reasons you will need to "learn" how to eat again. Some basic tips are to eat at least 6-8 small meals a day of high energy foods such as protien energy drinks or protein bars, so that you don't drop too much weight. It's important to learn the difference between foods with lots of sugar which are not good and high energy foods which are good.

We will give you protein energy drinks. Try to have 2 every day, between meals. Use the drinks to make a fruit smoothie to vary the taste and to get more energy.

Set an alarm so you don't forget to eat. Have a whānau member who you give the mana to, to tell you when you have

to eat. In time the amount of food you can eat will increase and it will become an enjoyable experience once again.

Some people develop the Dumping Syndrome, which is a feeling of abdominal cramping, sweating, diarrhoea, dizziness and low blood sugars. The syndrome can occur anything from 15 minutes to 3 hours following a meal, and is divided into early dumping and late dumping. Early dumping is the rapid "dumping" of food into the intestine which draws in fluid from your blood. This results in dizziness and abdominal cramps.

Late dumping occurs later and is due to a rapid rise in blood sugar as food is quickly absorbed. Once there is no further absorption, the blood sugar level drops quickly making you feel hypoglycaemic. This may result in sweating, weakness, flushing, anxiety and tiredness. The symptoms of both early and late dumping can usually be controlled with diet. Eat small meals regularly, do not drink fluids with your meals, and do not eat high sugar meals.

Steatorrhoea is oily stool and occurs when the fats we eat are not absorbed in time. Fats come from meals that have too much fat in them like pizza. This results in greasy, oily bowel motions with abdominal cramps. Diet and time often helps with this, however in addition, we can prescribe Creon®, an enzyme replacement tablet to help you digest the food.

We don't know a lot about vitamins and minerals following a gastrectomy. However, some info can be obtained from surgery for obesity, as there are a number of similarities. In both procedures, a large portion of the stomach or all the stomach is removed and the duodenum (the tube that takes food out of the stomach) is bypassed. However, there are some differences, most notably, in obesity surgery some stomach remains.[7]

There are a few well described nutritional problems however.

You may lose a substantial amount of weight following your gastrectomy despite problems such as Dumping Syndrome, or fat malabsorption, which are easily recognised and can be treated.

There are a number of problems which may go unnoticed.

Without a stomach, intrinsic factor (a chemical made in your stomach) is not secreted; therefore Vitamin B12 cannot be absorbed. This is normally found in meat, milk and fish. You will need regular Vitamin B12 injections. This may be anything from monthly to 3 monthly. Recent evidence has shown that some vitamin B12 can be absorbed from under your tongue.

The duodenum is the most important part of the gastrointestinal tract for calcium, vitamins and protein absorption. Therefore, you will need multivitamins morning and evening following the surgery. Please make sure these multivitamins contain Vitamin D to help with your bone strength.

Unfortunately, if you have a problem with calcium metabolism it may only become apparent in 30 years' time, with a hip fracture for example. If you take calcium tablets, it goes to the arteries rather than bones. This seems to be true if you do not need calcium. Most people need calcium after a gastrectomy, so the calcuim will likely go to your bones.

Iron is best absorbed once it has been converted by stomach acid to an easily digestible form. Obviously without a stomach, this conversion cannot take place and therefore you are likely to take in less iron. It's often helpful to replace the iron with liquid replacements or an iron injection. If you don't have enough iron, your blood becomes weak and you get tired easily.

The No Stomach For Cancer website has some excellent information, recipes and people's experiences following a gastrectomy (**https://www.nostomachforcancer.org**).

This table summarises our recommendations for vitamin and mineral replacement after a gastrectomy.

- Take a good multivitamin daily.
- You should have 100% of the RDA (Recommended daily allowance) of at least 2/3 of the listed nutrients in the multivitamin.
- Separate the calcium and the iron with vitamin C by 4 hours:

Calcium citrate (chewable)	1200mg-1500mg a day, try to divide the dose to allow more absorption. For bone strength
Vitamin D (liquid/chewable)	800-1000 international units per day. For bone strength.
Ferrous sulphate (Iron) with Vitamin C	300mg ferrous sulphate a day, increased around pregnancy. For anaemia (low blood count) and brain development. The vitamin C helps iron absorption.
Vitamin B12	1000 mcg by injection 1-3 monthly or under the tongue daily. To prevent anaemia.
Vitamin B1 (Thiamine)	50-100 mg daily if persistent vomiting

It’s not the same without a stomach

Some points about medications:

Use alternatives to tablets / capsules

Tablets and capsules require stomach juices to be broken down into smaller particles and allow for proper absorption Without a stomach these may not be easily absorbed. Liquids or chewable / dispersible tablets may be better. Be aware of sugar in liquids (dumping syndrome) and gas from effervescent tablets may cause abdominal cramps.

Avoid

Controlled release or delayed release tablets - pass through you too fast.

The oral contraceptive – reduced effect without a stomach.

Ongoing use of oral anti inflammatory drugs (brufen or voltaren) – can cause ulcers.

Be vigilant

Assess whether your medications are having the desired effect, and or having side effects and discuss these with your doctor. Remember to remind your doctor you do not have a stomach and show him the booklet for more information.

Other concerns

Breast cancer surveillance

At present, it should be assumed that all women with the *CDH1* mutation are at an increased risk of lobular breast carcinoma. In contrast to ductal breast cancer, lobular breast cancer invades in sheets or cords of cells, typically in single file, and does not form a lump.

Therefore surveillance should start at 30 years old with an annual MRI until you are 50-60 years old. During the MRI you lie on your stomach and it takes about 45 minutes. You will have contrast injected, which will be discussed with you by the surgeon and radiologist at the time.

From the age of 40 you should start having annual mammograms. Sometimes these are offset 6 monthly from MRI, but this depends on local practice. In addition if MRI is not avalible then it is reasnoable to do mammogram and breast ultrasound. Issues aroud this will be discussed by your specialist breast team.

An alternative may be a bilateral risk reducing mastectomy. You may want to talk to your surgeon about the inplications about this surgery. Be sure to ask about the feel and shape of the reconstruction.

Following the procedure you should not need ongoing mammograms and MRI's.

Colorectal cancer

At present, there is no evidence that the risk of colorectal carcinoma is increased in carriers of *CDH1* mutations. However, in families with a *CDH1* mutation, who also have colorectal cancer, enhanced colonoscopic screening should be considered, as per the New Zealand guidelines. **https://www.health.govt.nz/system/files/documents/publications/colorectal-cancer-surveillance-guidance.pdf**

Pregnancy

Although a gastrectomy does not stop you getting hapū, it may be more difficult because of the weight loss.[7] Also, you may not have enough vitamins and iron stores for you and your baby. You need to ensure you have sufficient Vitamin D, folate and vitamin replacement as well as iron replacement before you become hapū.

If you are planning to get hapū, we suggest you increase your vitamin supplements and take folate, iodine and iron supplements. Do this as soon as you start planning to get hapū, don't wait until you're trying! That way you will have built up some stores before you get hapū.

Talk to your whānau about your plans for tamariki. That way they can tautoko you if it goes well or it doesn't go well. It's also good to talk about whether you'd be open to having a whangai if it doesn't happen for you.

Travel

Having a gastrectomy should not stop you from travelling. However there are some precautions you should take.

Take it easy on travelling to kaupapa around the motu. Long hours of car travel are exhausting. For the time just after your surgery, you need to think about your tinana first; your whānau will understand if you can't come to a tangi or go to huritau because you're tired and sore. Just let them know.

Airline travel is dehydrating, drink plenty of fluids.

Going to Australia or Europe is not a problem. Carry extra food around with you in case you get hungry or are not able to get food easily.

If you are going to travel further afield or to more adventurous places, talk to a travel doctor first. You may need vaccinations. You are more susceptible to gastroenteritis (Delhi belly) and you can fast become dehydrated. It may be useful to carry antibiotics with you to treat gastroenteritis early in its course. Your travel doctor can explain how and which antibiotics to take, depending on where you intend travelling.

Part 3 – Advice to health care professionals

The current guidelines for diagnosis and management of Hereditary Diffuse gastric cancer can be downloaded from PubMed (PMC4453626). This covers diagnosis, screening and management of patients with the *CDH1* mutation.

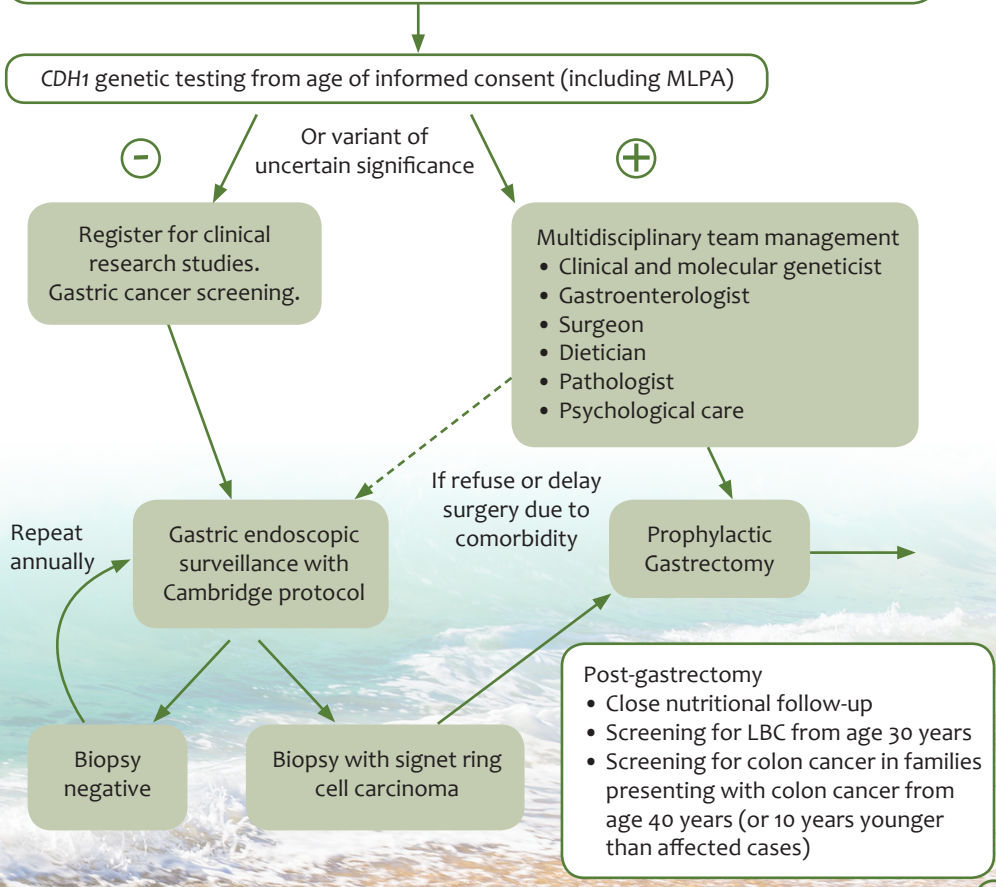
Established criteria*

- 2 gastric cancer cases regardless of age, at least one confirmed diffuse gastric cancer
- One case of diffuse gastric cancer <40
- Personal or family history of diffuse gastric cancer and lobular breast cancer, one diagnosed <50

Families in whom testing could be considered*

- Bilateral lobular breast cancer or family history of 2 or more cases of lobular breast cancer <50
- A personal or family history of cleft lip/palate in a patient with diffuse gastric cancer
- In situ signet ring cells and/or pagetoid spread of signet ring cells

*Including 1st and 2nd degree relatives



Post-gastrectomy

- Close nutritional follow-up
- Screening for LBC from age 30 years
- Screening for colon cancer in families presenting with colon cancer from age 40 years (or 10 years younger than affected cases)

Diagnosis

Genetic testing is offered in the context of a genetics service, with adequate counselling from the age of 16 years.

Gastroscopy

Early gastric cancer is very difficult to see at gastroscopy. The gastroscope should be performed annually with white light and narrowband imaging, with a high definition endoscope. Please examine the mucosa on both inflation and deflation.[4,5]

The majority of our cancers are found in the body but can be anywhere.[5] The small foci of cancer appear as tiny white spots, perhaps 1 mm across. There may be very few of them (if any), and hence can be easily missed. It is therefore important to take five random biopsies from each of the following zones, pre-pyloric area, antrum, transitional zone, body, fundus and cardia, making at least 30 biopsies in total.[6]

The protocol for the gastroscope is on page 365.[4] (**https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4453626/**)

If H. pylori is present, treat it, as it may be a carcinogen in *CDH1* carriers.

Whānau member support is important at the gastroscopy, as the diagnosis of stomach cancer for a member of the whānau is devastating.

Operative details

The requisite operation is a total gastrectomy with a Roux-en-Y reconstruction, ensuring a 50 centimetre Roux limb to the oesophagus to prevent bile reflux.[4]

The proximal resection must be within the distal oesophagus to ensure that no stomach mucosa is left behind. There is generally no need for a radical lymph node dissection as the majority of tumours are *T1a N0*. If the stomach looks abnormal on gastroscopy, a more radical operation may be needed.

There is significant morbidity associated with the operation. This includes the need to eat little and often and patients require support from a dietician. Eating too much or too quickly can cause abdominal pain.

Dumping Syndrome can be troublesome as is lactose intolerance, fat malabsorption and steatorrhoea. Each patient is different following the surgery. However in most cases the symptoms resolve over the first six months to a year following the surgery.

The operation can be performed both open (the usual) and laparoscopically. The laparoscopic procedure may have some advantages in the immediate post-operative period, with less pain and early mobility.

However, the anastamosis between the oesophagus and the small bowel

is technically demanding. In addition, before, one should biopsy the end of the oesophagus to make sure there is no stomach mucosa left behind. This is a difficult biopsy to take laparoscopically. It can be surprising how far the stomach mucosa can be seen going up the oesophagus. Leaving some stomach mucosa behind, runs the risk of developing a cancer in the remaining tissue. The long-term nutritional problems and risks are not altered by the laparoscopic approach.

Currently an open operation is the gold standard and ensures all the stomach lining is removed. In time, as techniques are developed and improved, a laparoscopic approach may become more mainstream.

Nutritional advice following surgery

Following a gastrectomy, there are a number of nutritional problems that can occur. Some of these will be discussed below.

1) **Volume.** The amount of food someone can get in post gastrectomy is reduced considerably. We recommend 6-8 small meals a day as well as snacks.

2) **Vitamins.** Vitamin B12 is absorbed with intrinsic factor secreted from the stomach. Without intrinsic factor, no Vitamin B12 is absorbed, which would result in anaemia. This needs to be injected every 1-3 months (Hydroxy cobalamin 1000 mcg IMI). There is some evidence vitamin B12 can be absorbed sublingually 1000mcg daily s/L may be an option.

   Fat soluble vitamins. (Vitamins A, D, E, K) are generally easily absorbed, however if the patient has steatorrhoea (fat malabsorption with greasy stools) deficiencies of these vitamins can arise. They can manifest as night blindness (Vitamin A) and bruising (Vitamin K). If these occur, consider adding Creon® 25000 2 with each meal and 3 with a fatty meal, taken at the beginning and mid-way through the meal to aid fat digestion. Open the capsule and sprinkle the Creon® on food to ensure adequate absorption.

3) **Minerals.** Iron in our food is poorly absorbed without a stomach as iron needs to be converted to Fe2+ by stomach acid. Oral iron supplements are easily absorbable, but are often not well tolerated. Injectable iron may be an alternative every 6 months to yearly. Take vitamin c with iron to aid the absorption of iron.

4) **Calcium.** This is usually absorbed in the duodenum, which is bypassed. Calcium deficiencies only become apparent in later life. There is some evidence that replacing oral calcium appears to deposit in the arteries.

However this seems to be the case if you do not need calcium. Most people are calcium deficient post gastrectomy so calcium deposits in the bone. We recommend a walk in the sun each day and multivitamins containing Vitamin D. (800-1000 iu/d) and calcium citrate 1200-1500mg/day in divided doses.

In summary, we treat all our patients with a multivitamin BD and oral iron or injectable iron to prevent deficiencies. Be sure to increase these in pregnancy.

This table summarises our recommendations for vitamin and mineral replacement after a gastrectomy[8].

- Take a good multivitamin daily.
- You should have 100% of the RDA (Recommended daily allowance) of at least 2/3 of the listed nutrients in the multivitamin.
- Separate the calcium and the iron with vitamin C by 4 hours:

Calcium citrate (chewable)	1200mg-1500mg a day, try to divide the dose to allow more absorption. For bone strength
Vitamin D (liquid/chewable)	800-1000 international units per day. For bone strength.
Ferrous sulphate (Iron) with Vitamin C	300mg ferrous sulphate a day, increased around pregnancy. For anaemia (low blood count) and brain development. The vitamin C helps iron absorption.
Vitamin B12	1000 mcg by injection 1-3 monthly or under the tongue daily. To prevent anaemia.
Vitamin B1 (Thiamine)	50-100 mg daily if persistent vomiting

Possible problems

Steatorrhoea. Fat is the most difficult nutrient to absorb and following a gastrectomy there is reduced time that food is mixed with bile and pancreatic juice. This may lead to fatty oily stools. This is diagnosed on history, with a layer of oil in the toilet pan, diarrhoea, post prandial loose bowel motions, and cramping abdominal pain. This may lead to overall nutritional deficiency and vitamin deficiencies. Treatment is with Creon® 25000, 2-3 tablets with each meal, taken at the beginning and during the meal.

Dumping Syndrome. The Dumping Syndrome is characterised by diarrhoea, fullness, abdominal cramping and vomiting occurring 15-30 minutes after a meal. Weakness, flushing, dizziness and sweating may also be present.

Simple guidelines include:

Eat small, more frequent meals.	Try to eat 6-8 small meals throughout the day.
Eat more slowly.	Consciously chewing food well.
Eat a source of protein with each meal.	Poultry, red meat, fish, eggs, tofu, nuts, milk, yogurt, cheese, and peanut butter are good choices.
Soft, ground or pureed foods may be better tolerated.	Solids may not be digested well enough without stomach acid.
Limit concentrated sugars.	Avoid candies, sodas, juice and syrups.
Eat more complex carbohydrates.	Whole grains, pastas, potatoes, rice, breads, bagels, and unsweetened cereals are excellent choices.
Choose foods high in soluble fiber.	This includes apples, oats, beets, Brussel sprouts, carrots, spinach and beans.
Try adding a small serving of fat to meals and snacks.	Fats slow emptying and may help prevent Dumping Syndrome. Butter, margarine, gravy, vegetable oils, salad dressings and cream cheese are good choices.
Don't drink to much liquid with meals. A sip to help swallowing is ok.	Instead drink 30 - 60 minutes before or after meals.

Post gastrectomy syndromes include a series of problems that can occur as a result of the surgery. These include vomiting after a meal, vomiting bile after a meal or pain. These may require a specialist appointment as they are uncommon, but can be helped with surgery.

Further information is available at

https://bpac.org.nz/2018/gastric-cancer.aspx

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4453626/

https://hereditarydiffusegastriccancer.org/

Notes on Medication

Absorption of medications can be altered by a gastrectomy. As data is scarce for gastrectomy patients, the following is a list of commonly affected medicines, as seen in patients who have had a very similar surgery (Roux-en-Y Gastric Bypass)[9].

Medications which may increase absorption post gastrectomy.

- Ethanol
- Linezolid
- Metformin
- Morphine
- Moxifloxacin

Variable absorption

- Atorvastatin
- Citalopram*
- Duloxetine*
- Escitalopram*
- Sertraline*
- Venlafaxine*
- Warfarin

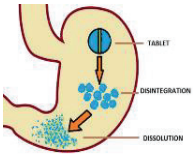
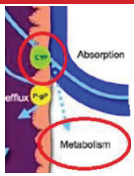
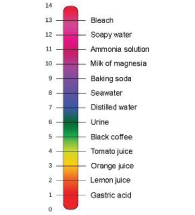
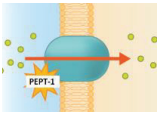
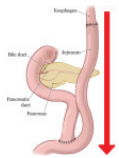
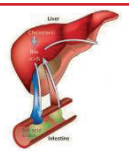
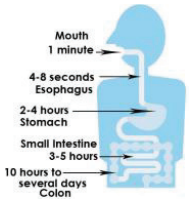
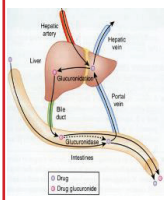
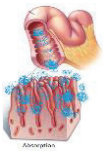
* Displayed an initial decrease in oral absorption but usually normalised at 6 to 12 months. Close monitoring with/without dose adjustment may be needed.

Medications with decreased absorption post gastrectomy

- Amiodarone
- Amoxicillin
- Antituberculosis medication
- Azithromycin
- Carbamazepine
- Cyclosporin
- Enalapril
- Erythromycin
- Imatinib
- Isoniazid
- Itraconazole
- Ketoconazole
- Lamotrigine
- Metoprolol
- Mycophenolic Acid
- Niacin (Vitamin B3)
- Nitrofurantoin
- Olanzapine
- Oral contraceptives
- Phenytoin
- Quetiapine
- Posaconazole
- Propranolol
- Ramipril
- Selegiline
- Simvastatin
- Sirolimus
- Tacrolimus
- Tamoxifen
- Zolpidem

Medications post gastrectomy – it's not the same without a stomach

Removal of the stomach to result in significant changes in the way the body deals with both nutrition and medications. This should be considered when prescribing medications to patients. The following table outlines some of the differences removing the stomach makes[10].

Reason	Consequence	Reason	Consequence
 1. Bypass stomach	• No gastric mixing to break down capsules. • Some medications absorbed through the stomach. ⇨ Less medication entering the bloodstream e.g. aspirin.	 6. Intestinal enzymes	• Enzymes metabolise some medicines within the wall of the intestine. • Number of enzymes altered due to surgery. ⇨ More medication may cross into bloodstream e.g. some cholesterol medications.
 2. No stomach acid	• Strongest acid present in the stomach. • Significantly affects the amount of medication absorbed. ⇨ Can decrease or increase the amount of medication e.g. iron, calcium and anti-inflammatory medications.	 7. Intestinal transporters	• Proteins which transport medication from intestine into bloodstream. • Number of transporters altered due to surgery. ⇨ Less medication entering blood stream e.g. penicillins via PEPT – 1 transporters.
 3. Faster onset	• Medication deposit immediately into the small intestine. ⇨ Faster absorption e.g. alcohol and caffeine.	 8. Bile acid secretion	• Delayed mixing of bile acids with medicines. • Changes solubility of some medicines. ⇨ Less medication entering blood stream eg. some heart medication.
 4. Faster transit	• Medications bypass part of the GI tract (stomach, duodenum and, proximal small intestine). • Less time for absorption. ⇨ Less medication entering the bloodstream e.g. controlled/extended release medications.	 9. Cycling of medications	• Some medicines cycle continuously between intestine and liver to maintain drug levels. ⇨ Less medication entering blood stream e.g. oral contraceptive pill.
 5. Decreased surface area	• Less GI tract. • Less absorptive area. ⇨ Less medication entering the bloodstream e.g. potentially all medications.	 10. Weightloss	• Medications can readily distribute into fat cells. ⇨ Altered drug levels e.g. some antidepressants.

My journey

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