

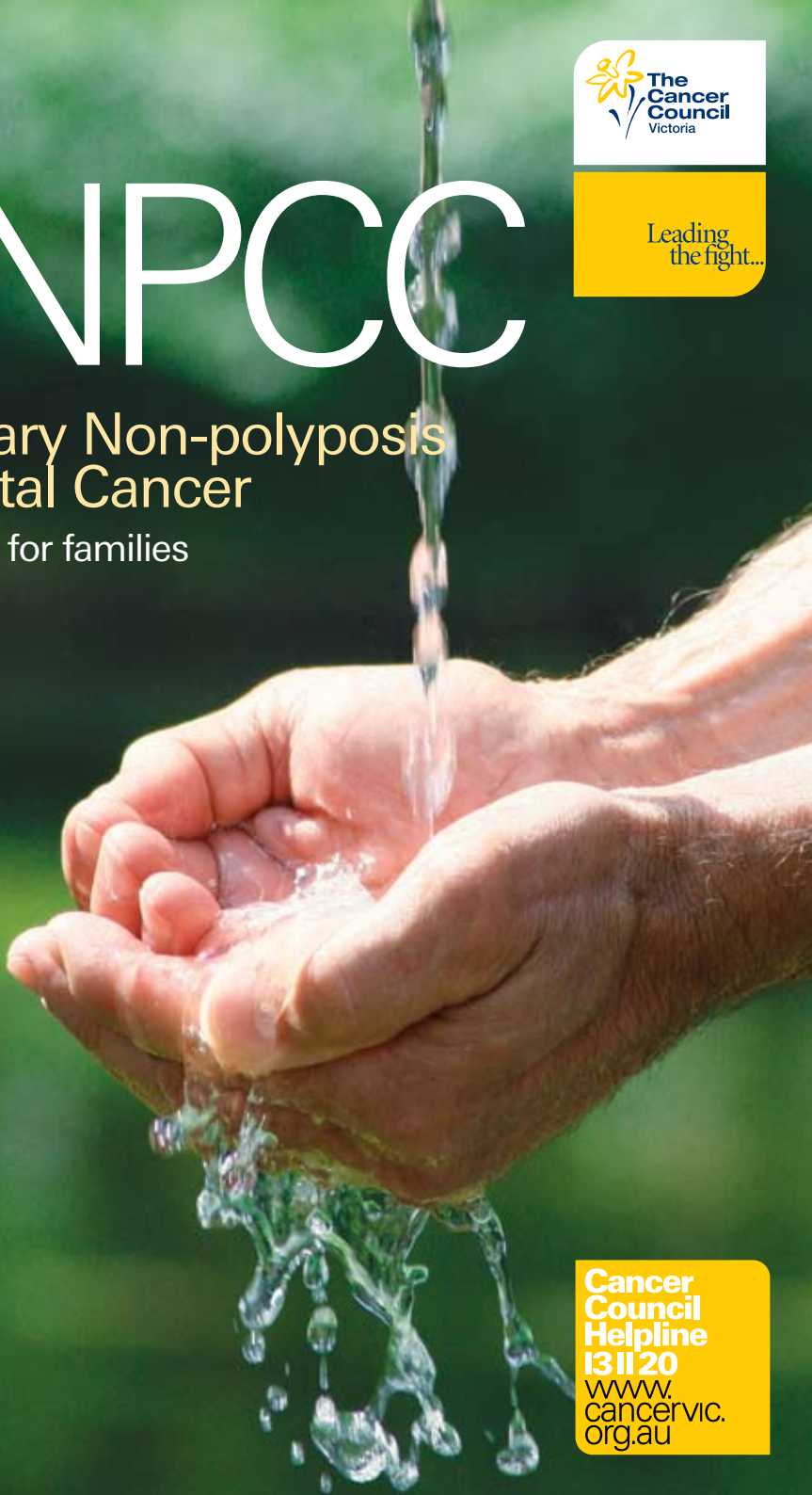


HNPPCC

Hereditary Non-polyposis Colorectal Cancer

Information for families

Leading
the fight...



**Cancer
Council
Helpline**
1311 20
www.cancervic.org.au

Hereditary Non-polyposis Colorectal Cancer (HNPCC)

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Introduction

This booklet has been written for people who have, or are at risk of, **hereditary non-polyposis colorectal cancer (HNPCC)**. It explains what HNPCC is and what can be done about it.

You may choose to read all of this booklet at once, or only some parts. Choose the parts that are helpful to you now.

The words in **bold** are explained in the glossary.

 Are you reading this for someone who does not understand English? Tell them about the Multilingual Cancer Information Line. See the inside back cover for details.

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Hereditary non-polyposis colorectal cancer (HNPCC)

Hereditary non-polyposis colorectal cancer is often shortened to HNPCC.

- ‘Hereditary’ means that a changed gene which causes HNPCC is passed on within families.
- ‘Non-polyposis’ tells us that you don’t have FAP (**familial adenomatous polyposis**). This is another family condition which leads to **bowel cancer**. People with FAP may have hundreds of **polyps**, which can become bowel cancer. People with HNPCC can still develop polyps in the bowel; however, they do not get such high numbers of polyps over their lifetime.
- Colorectal cancer means cancer of the colon or rectum. It is another name for bowel cancer. Bowel cancer is the cancer most common in families with HNPCC. There can be other types of cancer.



The Cancer Council has a booklet about FAP. Telephone 13 11 20 for a copy or visit www.cancervic.org.au

What is HNPCC?

HNPCC is a condition that increases the risk of bowel and certain other cancers. HNPCC is also called Lynch syndrome.

HNPCC runs in families. If one of your parents has HNPCC then you are at risk.



What causes HNPCC?

HNPCC is caused by a change in a gene. This gene's normal job is to protect against **bowel cancer**. The gene is an MMR gene (or **mismatch repair gene**). It helps repair mistakes in **DNA**. There are four different MMR **genes**: MLH1, MSH2, MSH6 and PMS2 (see glossary). In this booklet, we call any of these changed genes an **HNPCC gene**.

About half of all HNPCC families have a change in one of these four genes. The other half is probably affected by gene changes that are not yet known.

How does an HNPCC gene get passed on?

Genes are like a set of instructions. They tell our bodies how to grow and work. We have thousands of genes in each cell of our body. Each gene has two copies. At conception, we get one copy of each gene from our mother, and another copy from our father. If one of these copies has the change then **HNPCC** is passed on from the mother or father.

How does the cancer develop?

Normal MMR gene pairs work together to repair damage to cells in the bowel. If you inherited an **HNPCC gene** from one parent, then repairs do not take place. The damaged cells can develop into cancer. Cancer occurs mainly in the bowel, but sometimes in other parts of the body.

Does an HNPCC gene always cause cancer?

Having an **HNPCC gene** does not mean you will definitely get cancer. Between 10% and 20% of all people with an HNPCC gene do not develop a cancer related to **HNPCC**.

Who is at risk?

Am I at risk?

If you have a parent with **HNPCC**:

- you have a 50:50 chance (or one chance in two) of having HNPCC
- your brother or sister also has a 50:50 chance of having HNPCC.

Are men or women more likely to inherit HNPCC?

The risk of inheriting an **HNPCC gene** is the same for men and women. The risk of developing cancer if you have HNPCC is slightly higher for men.

Are my children at risk?

Remember that you have a pair of **genes**. This means that:

- a parent who has an **HNPCC gene** will also have a normal copy of the gene
- a parent will pass on one or other gene to a child, but not both.


If you are a parent with an HNPCC gene, each of your children has a 50:50 chance (one chance in two) of inheriting that change.

If one of my children has an HNPCC gene, does that mean the other will not?

Having two children does not mean one will get the HNPCC gene and the other will not. One child might inherit the HNPCC gene, both might, or neither might.

Can HNPCC not be passed down within a branch of the family?

If a child does not inherit an **HNPCC gene**, the gene cannot be passed on to their children in the next generation. This branch of the family will no longer be at risk of **HNPCC** (unless a new genetic change occurs).



What are the signs that HNPCC could be in my family?

In a typical **HNPCC** family, there are three or more cases of **bowel cancer** across two or more generations in a row. These bowel cancers often occur at a young age (before 50).

If people have HNPCC, how old are they when they get cancer?

Cancer due to **HNPCC** usually occurs when people are in their 30s or older. Sometimes people may develop cancer in their 20s, or, rarely, as teenagers.

Remember that not all people with an **HNPCC gene** develop cancer.

Are other cancers linked to HNPCC?

An **HNPCC gene** can cause cancers other than **bowel cancer**.

Women with **HNPCC** are at higher risk of getting **endometrial cancer**. Endometrial cancer is also called cancer of the womb, cancer of the **uterus** or cancer of the lining of the womb. It is not cervical cancer. More rarely, cancers can also occur in the **ovaries**, the kidney and the ureter (the ureter is the tube from the kidney to the bladder). Sometimes cancers can happen in other parts of the **digestive system**. They can occur in the **small bowel**, the stomach or possibly the pancreas. Brain and skin cancers are also linked with having an HNPCC gene.

Finding out if HNPCC is in the family

HNPCC is highly suspected when:

- at least three people in a family have had **bowel cancer**, and at least one is a parent, sibling or child to the others. (This is called a **first-degree relative**.)
- at least two successive generations are affected
- at least one person is diagnosed before they are 50
- the cancer is known not to be due to FAP (**familial adenomatous polyposis**).

Tissue testing


Cancer **tissue** taken from a **tumour** can be tested. The tests are called **microsatellite instability** (MSI) and **immunohistochemistry**. These tests do not give definite results. They give clues about whether **HNPCC** is present. If the test is normal, HNPCC is unlikely. The results can be added to a family history to help diagnose HNPCC.

Cancer tissue is often stored by laboratories, having been taken for various tests. It may be tested for **HNPCC**, if needed. This can be years after a person has had **bowel cancer** or even after a person has died.

Genetic testing

What does it involve?

Four common **HNPCC genes** are known: MLH1, MSH2, MSH6 and PMS2. (There may be more.) The change in an HNPCC gene usually differs from one HNPCC family to another. This is what is meant by 'family-specific gene change'.



Genetic testing can:

- look for a family-specific gene change
- check individual family members to see if they have the changed gene.

Scientists can find out which HNPCC gene is changed. They do this by testing a blood sample. The blood is taken from someone in the family who has had a cancer due to **HNPCC**, preferably a cancer diagnosed when the person is young.

Searching for a family **HNPCC** gene is difficult. It can take some time and may not be successful. Sometimes several tests are needed.

When the family-specific HNPCC gene is found, genetic testing can be offered to other family members. This is called **predictive DNA testing**. It is done by testing a blood sample.

Genetic counselling

Before you have a genetic test, you will meet a genetic counsellor at the **familial cancer centre**. They will talk about what the test may mean to you and your family. You will be able to discuss how you may feel about finding out if you have an **HNPCC gene**. You may feel relieved to have a definite answer or you may feel angry, depressed or frightened.

You can discuss questions such as: Will I get cancer? How would I cope with surgery? What about my children?

The genetic counsellor can help you think about these issues. If you decide to have testing, they can prepare you for the results. They can explain the results and give you any more information you need.

I'm not sure if I want to know

This is a normal response. It is frightening to think you may have an **HNPCC gene**. Genetic testing has many benefits. However, it is not a good choice for everyone.

- If a family-specific HNPCC gene is found and a test shows you do not have it, you know you won't develop a cancer due to **HNPCC**. Your children will not inherit an HNPCC gene from you. You will not need the frequent check-ups that people with HNPCC should have. It does not mean you will never get **bowel cancer**. You still have the same risk as the rest of the population.
- If the test shows you do have an HNPCC gene, you have a higher risk of developing some cancers. Cancers of the bowel and **endometrium** can be treated very successfully, if the diagnosis is made early. There are screening and preventive options, should you find that you have an HNPCC gene.

Some people feel it is just not worth knowing. Others do not want testing now but may want it later.

Talking with your doctor or a genetic counsellor may help you decide what is right for you. You can also talk to a professional counsellor or someone else you trust and respect. This could be a family member, friend or religious adviser.

You may decide not to have testing, or to delay testing. In this case, it is important to have regular check-ups. If a close relative has an HNPCC gene, ask your doctor if you should have more frequent check-ups and from what age.

You may find a counsellor through your local hospital or community health centre. The Cancer Council Helpline (13 11 20) or genetic coordinator (9635 5176) can put you in touch with counselling services.

Where is the testing done?

Genetic testing in Australia is done at **familial cancer centres**. These also give advice and help to people having genetic testing.

In Victoria, contact the Victorian Family Cancer Genetics Service. For advice about contacting a familial cancer centre, telephone the Cancer Council Helpline (13 11 20) or the HNPCC coordinator (9635 5176).



When can the testing be done?

If an HNPCC gene is identified in your family, you can have a genetic test any time from the age of 18.

What does the testing cost?

There is no charge for genetic testing. In Victoria, costs are covered by a special grant from the Victorian Department of Human Services.

How long do the results take?

Genetic testing is complex. Finding an **HNPCC gene** in a family can take many months. It takes less time for **predictive DNA testing**, which means testing if an individual has a known family-specific HNPCC gene.

Ask the person arranging your test when you can expect your test results.

What if I do not have an HNPCC gene?

If the test is normal it will be called ‘negative’. This means you do not have an **HNPCC gene**. You cannot pass the gene on to your children. Therefore, they are not at risk. They do not need to have genetic testing.

Note that a negative result does not mean you will never get **bowel cancer**, or any other type of cancer. It simply means you do not have an HNPCC gene. You will not develop cancer due to **HNPCC**. However, like anyone else, you could still get ‘ordinary’ bowel cancer. This affects about one person in 20 at some time during their life. It usually occurs after the age of 50.

What if I do have an HNPCC gene?

If the test is positive, this means that you have an **HNPCC gene**. You have a high risk of developing cancer at some stage in your life. The risk is higher for men (about 80–90%) than for women (about 70–80% or lower).

You need to have regular check-ups. With check-ups, if a cancer develops it can be found and removed at an early stage. There is a very good chance of a successful treatment if the cancer is detected early. You could also discuss preventive surgery with your doctor.

If you have a positive test result, other members of your family could be at risk of carrying an HNPCC gene. It is important they are told about HNPCC and **predictive DNA testing**. It is mainly up to family members to pass on this information.

Can all families have the gene test?

No, not always. Testing for **HNPCC** is difficult and not perfect.

In some families thought to have HNPCC, it is hard to find a family member who definitely has had bowel cancer or a related cancer. They may be hard to contact, or may have died. The search needs to begin with someone who is affected and living.

Sometimes testing may not find a family-specific **HNPCC gene**. This could be because testing cannot detect all changes. Also, a gene other than the presently known HNPCC **genes** could be involved. This means that gene testing is not yet available for these families. It does not mean that there is no genetic cause for the cancers occurring in the family.

What happens if I cannot be gene tested?

If your family-specific HNPCC gene cannot be found, then you will need to have regular bowel check-ups. Women also need regular **gynaecological** check-ups.



Privacy

Familial cancer centres ask a lot of questions about you and other members of your family. All your information is confidential. Information that identifies you will not be passed on to any other person or organisation without your consent.

Who will know my test result?

With your permission, your test result will be sent to the doctor who referred you to the **familial cancer centre**. If you have joined it, your test result will also be sent to the Victorian Family Cancer Register. It could help in the future medical care of you and your family.

Two things are needed to give correct advice to other family members:

- knowing your family's **HNPCC gene** – what your family HNPCC gene 'looks' like
- knowing whom in the family has HNPCC, which reveals whether or not others are at risk.

The Victorian Family Cancer Register

People with **HNPCC** may join the Victorian Family Cancer Register. The register helps HNPCC families and others with an increased risk of developing cancer due to an inherited change in a gene.

The Victorian Family Cancer Register is kept at The Cancer Council Victoria. The HNPCC coordinator looks after registered HNPCC families.

The Victorian Family Cancer Register can:

- send you reminder letters when your bowel examinations are due
- inform you about support services
- send you a regular newsletter
- send you updates of this HNPCC booklet
- provide information on HNPCC diagnosis, treatment and the HNPCC genetic test
- be a point of contact for people and families with HNPCC
- contribute to research that may help you and your family in the future
- work with doctors, **familial cancer centres** and other family cancer registers looking after you and your family. Medical advice and care are available to people at risk of HNPCC.

What information will be kept if I join?

With your consent, the following information will be kept:


- your name and date of birth
- your relationship to other family members (parent, child, sibling)
- your contact details.

The following information will also be kept (if it applies, and with your consent):

- HNPCC gene test results
- whether you have had cancer and at what age
- details of cancer treatments and their results
- cancer screening tests and results.

Protection of personal information

Written information that identifies you can only be seen by Victorian Family Cancer Register staff. Electronic records that identify you are stored on a password-protected computer system.



You have access to your own information. No information about you is given to your family members. If you have agreed, the genetic coordinator may give information to doctors, genetic counsellors or **familial cancer centres** involved in the care of your family.

Joining the Victorian Family Cancer Register

The HNPCC coordinator (9635 5176) at the Cancer Council can tell you more about the Victorian Family Cancer Register and how to join. The coordinator works with doctors, hospitals and **familial cancer centres**, and patients and their families in Victoria.

Insurance policies and genetic testing

If you are planning to have genetic testing, it is best to discuss personal insurance policies first. Life insurance and disability insurance can be affected. Note that an individual's health insurance is not affected by a family history of cancer.

Your family history of cancer and results of genetic testing may influence whether life and/or disability insurance are available to you. They can also affect the cost of premiums. Application forms for these types of insurance usually have a series of questions. These include whether you have had genetic testing for any condition. They may ask about your family history of inherited conditions, whether you have been tested or not.

Australian insurance companies will not ask applicants to have genetic testing purely for insurance purposes. **Familial cancer centres** and the Victorian Family Cancer Register will not give your genetic test results to an insurance company without your written consent.

Regular check-ups

If you are at risk of HNPCC, talk to your doctor about having regular check-ups.

Bowel check-ups

If you are in one of the following groups, see your doctor regularly.

If you have an HNPCC gene and have not had bowel surgery

See your doctor and have regular bowel check-ups with a **colonoscopy** from about the age of 25. Do this every one to two years. You can discuss this with your **gastroenterologist** or surgeon.

It would be very unusual for a cancer to develop in the one to two years between colonoscopies. Even if this did happen, it would very likely be at an early stage (especially if the examination is yearly). There would be a very good chance that it could be removed and cured.

If you are at risk and have not had genetic testing


To be on the safe side, you should assume that you have an **HNPCC gene**. It is recommended that you have a **colonoscopy** every two years, and a **faecal occult blood test** (FOBT) in alternate years.

If you have had surgery (colectomy) for HNPCC

To ensure any remaining bowel is clear, you will still need yearly check-ups by **sigmoidoscopy** or **colonoscopy** after surgery for HNPCC.

What does a bowel check-up involve?

A bowel check-up can involve one or more of a **colonoscopy**, **sigmoidoscopy** and a **faecal occult blood test** (FOBT).



At colonoscopy, the lining of the **large bowel** is inspected using a flexible tube and assisted by television technology. The tube is passed through the **anus**. It is gently moved around to enable the doctor to see the full length of the large bowel. The examination takes 20 to 30 minutes. It is done in hospital as a day procedure. You will have a sedative before the colonoscopy and be sleepy during the procedure. If any **polyps** are seen, they will be removed. These growths in the bowel wall are mostly harmless, but may occasionally go on to form a cancer. You should not drive for the rest of the day after the procedure.

Sigmoidoscopy is a quicker and easier procedure than colonoscopy. It does not require any sedation and takes only a few minutes. This procedure is for people who have had a **colectomy** to remove the upper part of the large bowel. Only the **rectum** and lower part of the large bowel are examined.

You may have a bowel preparation to clean out your bowel before these tests. You may have an **enema** and/or oral medication.

Faecal occult blood test (FOBT) looks for traces of blood in the faeces. This test works on the basis that cancers often bleed a little. The test does not always indicate cancer but it can help with early diagnosis of **bowel cancer**.

Additional check-ups for women

Women with **HNPCC** are more likely to get **endometrial cancer** and **ovarian cancer**. Women can have regular testing from about the age of 25.

- A **transvaginal ultrasonography** is a pelvic ultrasound used to give a clear picture of the inside of the **uterus** and the **ovaries**. The procedure is very much like a gynaecologic examination. The patient lies on her back, with feet raised. A probe is gently inserted into the vagina and rotated to examine the pelvis. This procedure takes approximately 30 minutes and should not be painful or significantly increase discomfort.

- If **endometrial sampling** is needed, an instrument is inserted into the uterus to remove a small sample of the **tissue**. This tissue is tested for abnormal **cells** that suggest cancer might be present. The procedure is uncomfortable, but it only takes a few minutes.
- A blood test may be done to check for a substance known as CA 125. The level of this may be raised if there is an ovarian cancer. This test works better for women who have been through menopause. (A regular Pap test for cancer of the **cervix** does not replace these check-ups.)

Check-ups for other HNPCC cancers

Some families have unusually high numbers of other HNPCC cancers. Special tests may be needed if these cancers appear to ‘run’ in a family. Tests may include gastroscopy (examination of the stomach) and urine testing.

Symptoms to report to your doctor

Women and men with **HNPCC** should see their doctor if they have:

- bleeding from the bowel
- indigestion
- pain in the stomach or area around the stomach
- urinary symptoms such as blood in the urine.

Women should also note

- any changes in periods, bleeding between periods or bleeding after menopause.



Preventive surgery

Preventive surgery aims to reduce the risk of cancer. It does this by removing organs in which cancer may develop. If you are at risk but have no sign of cancer, preventive surgery is something you need to think about carefully. You can discuss it with your doctor or the team at the familial cancer centre. You need to be sure that the benefits of preventive surgery outweigh any risks of surgery and long-term effects of having the organ(s) removed.

Preventive surgery is not best for all people who have or may have **HNPCC**. However, doctors may recommend preventive surgery for some people.

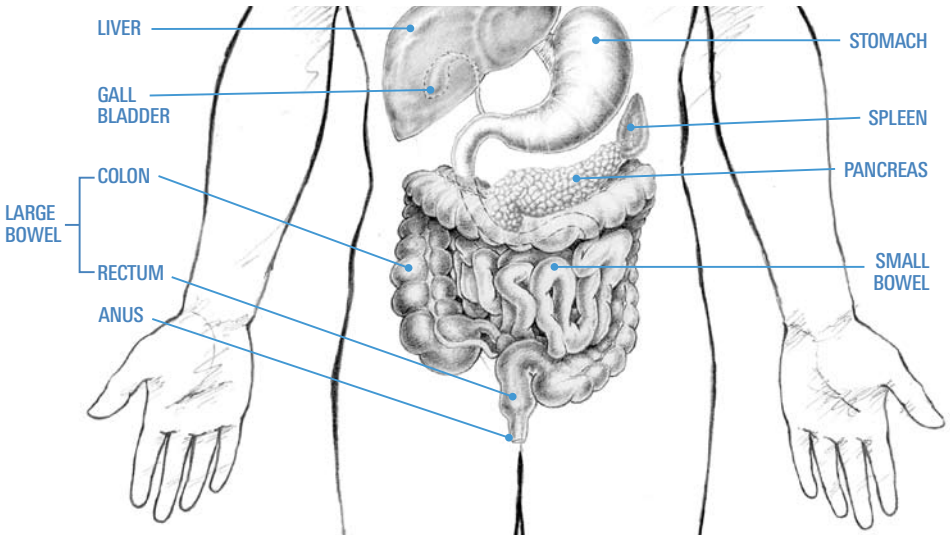
Surgery does not usually affect fitness, social or sexual activities. People who have jobs are usually back at work after about six weeks.

Surgery aimed at preventing bowel cancer

People with an **HNPCC gene** may choose to have bowel surgery. The aim is to prevent cancer while keeping your **digestive system** working as normally as possible. It does not affect how your body absorbs food.

The bowel

The bowel is the longest part of the **digestive system**. The digestive system includes the long tube that runs from the back of the mouth, forms the stomach and bowel, then ends at the **anus**. It winds around inside the body. Food passes through it and is broken down and absorbed. Waste products are passed out as bowel motions.




The bowel has two sections. The **small bowel** (the **duodenum**, **jejunum** and **ileum**) is where food is absorbed. The small bowel leads into the **large bowel**, where only water and salts are absorbed. The large bowel has two parts: the **colon**, which is about 1.5 m long, and the **rectum**, which is about 15 cm long. The rectum leads to the outside of the body through the anus.

Types of bowel surgery

There are two bowel surgery options for people with **HNPCC**. Each has advantages and disadvantages. If you wish to have preventive bowel surgery, talk to your doctor about the best option for you.

Total colectomy and ileorectal anastomosis (colectomy and IRA)

The surgeon removes the **colon** (total **colectomy**). They then join the end of the **small bowel** (**ileum**) to the **rectum** (ileorectal anastomosis).



The advantage of this operation is that the rectum and **anus** remain. You continue to go to the toilet to pass bowel motions in the usual way. The change to the bowel means that most people need to have two to three bowel actions a day.

The disadvantage is that there is still a small risk of cancer in the rectum. You will need regular check-ups by **sigmoidoscopy**.

Restorative proctocolectomy

This is a bigger operation. The main difference between this and **colectomy** and IRA is that the surgeon also removes most of the **rectum** and all of its lining. A 'new rectum' is made at the end of the **small bowel**, and joined to the **anus**. You will need a temporary **stoma**. You will have more surgery after about three months to close the stoma and ensure that you can go to the toilet normally. Discuss this option with your surgeon.

After bowel surgery, you will still need regular check-ups with your doctor.

Surgery aimed at preventing endometrial and ovarian cancers

Some women with **HNPCC** are advised to have their **uterus** and (sometimes) **ovaries** removed to prevent cancer developing at these sites. Removing the uterus is called **hysterectomy**. Removing the ovaries is called **oophorectomy**.

If you have your uterus and ovaries removed you will no longer menstruate or be able to become pregnant. Removing the ovaries in premenopausal women brings about immediate menopause. You will have menopausal symptoms, such as hot flushes and vaginal dryness. You can talk to your doctor about ways to deal with this.

Preventive surgery: talking it over

For most people, the idea of surgery is frightening. Talk to your surgeon, gynaecologist or **gastroenterologist** about what is involved. Seek a second opinion if you wish.

You may find it helpful to talk with someone who has had a similar operation. Your surgeon could arrange this, or call the Cancer Council Helpline (13 11 20) or the Cancer Council's genetic coordinator (9635 5176). In **HNPCC** families, there may be someone who has had the operation who could be very helpful.

You may also wish to talk over the social and emotional impact of surgery. A social worker or professional counsellor can help. The Cancer Council Helpline can put you in touch with counsellors.

What if I don't want bowel surgery?

You need to continue having a **colonoscopy** every one to two years. Colonoscopy is a very good way to look at the bowel. However, it is not perfect: a very small cancer may be missed, or a cancer could start between colonoscopies.

Some people prefer to have the reassurance that surgery can offer. Others prefer to avoid surgery if at all possible and are prepared to have regular colonoscopies.

Participating in research

HNPCC cancers and other family **bowel cancers** are being investigated by scientists. You may be offered an opportunity to participate in a research project. With help from **HNPCC** families, researchers can better understand and treat people with **HNPCC**.

Resources

You may wish to contact the following services for further information.

The Cancer Council Victoria

For information, advice and links to other websites, see www.cancervic.org.au

For information about HNPCC, preventive surgery and other matters related to cancer call the **Cancer Council Helpline** on 13 11 20

Cancer Council Genetic Coordinator

Telephone: 9635 5176

Genetic Health Services Victoria

Telephone: 8341 6201

Victorian Family Cancer Register

The Peter Mac Familial Cancer Centre (FCC)

Peter MacCallum Cancer Centre

Telephone: 9656 1199

Familial Cancer Centre

Monash Medical Centre

Telephone: 9594 2026

The RMH Familial Cancer Centre

Royal Melbourne Hospital

Telephone: 9342 7151

Glossary: what does that word mean?

Most of the words listed here are used in this booklet; others are words you are likely to hear used by doctors and other health professionals who will be working with you.

anus The opening of the bowel through which bowel motions are passed.

bowel cancer Cancer that begins in the bowel. Also called colorectal cancer.

cells The 'building blocks' of the body. A human is made of billions of cells, which are adapted for different functions.

cervix The neck of the uterus (womb).

colectomy Surgical removal of the colon.


colon The part of the large bowel between the end of the small bowel (ileum) and the rectum. It is about 1.5 m long.

colonoscopy Examination of the large bowel using a colonoscope. This is a thin flexible tube with a light and a camera at the end.

digestive system The organs that are responsible for getting food into and out of the body and for making use of food to keep the body healthy. These include the mouth, oesophagus, stomach, liver, gall bladder, pancreas, small bowel, colon and rectum.

DNA Deoxyribonucleic acid. The molecules inside cells that carry genetic information and pass it from one generation to the next.

duodenum The first 30 cm of the small bowel. The stomach empties into the duodenum.



endometrial cancer Cancer affecting the lining of the uterus.

endometrial sampling The removal of a small sample of tissue for testing from the lining of the uterus, using an instrument inserted through the vagina.

endometrium The inner lining of the uterus, above the cervix.

enema Fluid is passed into the bowel via the anus (back passage), in order to cause a bowel action and empty the bowel.

faecal occult blood test (FOBT) A test for blood in a person's bowel motion.

familial adenomatous polyposis (FAP) A genetic disease, in which many polyps grow in the bowel and cancer often develops.

familial cancer centre An organisation that provides services including genetic counselling, genetic testing, medical advice, psychological support and the opportunity to take part in research to people concerned about their risk of cancer due to their family's cancer history.

first-degree relative The parents, children or siblings of an individual.

gastroenterologist A specialist who diagnoses and treats people with diseases of the digestive system.

genes The tiny factors that control the way the body's cells grow and behave. Each person has a set of many thousands of genes inherited from both parents. These genes are found in almost every cell of the body.

gynaecological Related to women's reproductive organs, including the uterus and ovaries.

HNPCC (hereditary non-polyposis colorectal cancer) Cancer of the colon or rectum known, or strongly suspected, to be due to an inherited fault (change) in a gene – in particular, in one of the mismatch repair (MMR) genes. Other undiscovered, familial genes may be involved in hereditary bowel cancer.

HNPCC gene A change in one of the MMR (mismatch repair) genes that increases the risk of developing certain types of cancer.

hysterectomy The surgical removal of the uterus and the cervix.

ileum The lower half of the small bowel, which joins up with the colon.

immunohistochemistry A laboratory test on tissue samples to help identify characteristics of the cancer.

jejunum The part of the small bowel below the duodenum and leading into the ileum.

large bowel The lower part of the digestive system, which consists of the colon and rectum. Also called the large intestine.


microsatellite instability (MSI) A test for a genetic pattern in tumours potentially caused by a HNPCC gene change.

mismatch repair genes The set of genes, including MLH1, MSH2, MSH6 and PMS2, that correct mistakes made when the DNA of cells divides. In HNPCC, one of these genes is changed and does not work normally.

oophorectomy The removal of the ovaries.

ovarian cancer Cancer that begins in cells in an ovary.

ovaries The female sex organs that secrete important hormones and contain the ova (eggs).



polyp An abnormal growth that grows from the inside wall of a hollow organ and may occasionally form a cancer.

predictive DNA testing Testing of a person's DNA that can tell whether or not they have inherited a change in a gene.

rectum The last 12 to 15 cm of the large bowel, which opens to the outside at the anus. The faeces collect in the rectum before they are passed as a bowel motion.

restorative proctocolectomy The surgical removal of the colon, most of the rectum and all of its lining. A 'new' rectum is made from the end of the small bowel and joined to the anus.

sigmoidoscopy Examination of the rectum and part of the colon using a sigmoidoscope. This is a narrow lighted tube. It is inserted gently through the anus, and gives a view of the lining of the bowel.

small bowel The part of the digestive system that consists of the duodenum, jejunum and ileum. Also called the small intestine.

stoma An 'exit' for bowel motions if the bowel can't be joined properly after surgery.

tissue A collection of similar cells.

transvaginal ultrasonography Taking an ultrasound of the uterus and ovaries using an instrument inserted into the vagina and through the cervix.

tumour A new or abnormal growth of tissue in or on the body.

uterus The hollow, muscular organ in which a fertilised egg can grow and the foetus can be nourished until birth. Also called the womb.

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