

Total abdominal hysterectomy - bilateral salpingo-oophorectomy and pelvic node dissection

(for endometrial cancer)

*We dedicate this book to all of the women
who have entrusted their care to us.*

*By allowing us to take part in their surgery and after care,
they have shared an important time in their
lives with us and taught us a great deal.*

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The purpose of this booklet is to help prepare you for your surgery and recover at home. Our Gynecologic Oncologist (the type of surgeon who will be doing your surgery) will explain the surgery in detail with you.

This book will not replace talking with your caregivers, but may make it easier. It contains answers to common questions women have about this surgery. Please share your concerns with us.

We encourage you to write down questions you wish to ask your health care team.

Questions:

Learning about the surgery

Who is a Gynecologic Oncologist?

Your doctor is a specialist called a Gynecologic Oncologist. Gynecologic Oncologists have extra training in gynecologic cancer surgery. Your Gynecologic Oncologist will coordinate with other medical specialists so you get the best possible care. These specialists include other doctors, nurses, social workers and dietitians.

At the Juravinski Cancer Centre (JCC), the Gynecologic Oncologist reviews your medical history to get a full picture of your situation. Before your surgery and depending on your needs, you may need to see other doctors to make sure that you are fit for surgery. These doctors are from: Anesthesia, Respiriology, Cardiology, Internal Medicine or the Thrombosis Team. Other doctors may need to assist with your surgery including General Surgery, Plastic Surgery or Urology. Sometimes this is known before surgery, other times this is not known until the time of surgery.

Who does my surgery?

A Gynecologic Oncologist does the surgery with the assistance of gynecologic residents (doctors in training to become gynecologic specialists). Sometimes, the surgeon may be different than the one that you first met at the JCC. All the gynecologic oncologists are equally trained and qualified to do your surgery.

Who looks after me following surgery?

While you are in the hospital you will be seen by members of the Gynecologic Oncology team who will review how you are doing and plan your care. Your recovery is evaluated and managed by doctors and nurses with the assistance of social workers, dietitians and physiotherapist to make sure you get all the care you need.

When you leave the hospital, a Gynecologic Oncologist will see you in follow up to review the results of your surgery and if any further treatment is needed.

Why do I need surgery?

This surgery is needed because there is evidence of cancer or possible cancer in the uterus. This was likely determined before surgery by a biopsy done in your gynecologist's office.

The most important reason for surgery is to remove the uterus which may be cancerous and to take samples of other tissues in your abdomen and pelvis.

During the surgery, the surgeon will check the liver, spleen, diaphragm and surfaces in your abdomen. This is to see if these organs are healthy. For this reason, your incision may go from the pubic hairline to several inches above the belly button. For those having a panniculectomy the incision is from hip to hip.

After the surgery a doctor called a pathologist examines all of the tissues that were removed under a microscope. This is done to determine the extent of any cancer found. The pathologist needs to look at the tissues very carefully to give your oncologist all the information that is needed. This can take up to 3 to 4 weeks.

Your doctors and other health care providers will discuss the results of these tests and any treatment plans with you as soon as possible after the surgery.

Sometimes surgery is the only treatment that is needed. Other times, further treatment such as chemotherapy, radiation, or both may be needed. Each woman's treatment plan is designed for her type of disease in order to provide the best possible results.

What is a total abdominal hysterectomy – bilateral salpingo-oophorectomy and pelvic lymph node dissection?

There are several parts to this surgery:

- **A total abdominal hysterectomy (TAH)**, is the removal of your uterus or womb and the cervix through an open incision.
- **Bilateral salpingo-oophorectomy (BSO)**, is the removal of both fallopian tubes and ovaries.
- **Pelvic lymph node dissection** is the removal of lymph nodes in your pelvis. Lymph nodes are pea sized structures that are found all over the body. There are chains of lymph nodes – they move and filter lymph fluids and help prevent infection. Cancer cells can travel through these lymph nodes and spread to other areas of the body. As part of the surgery and figuring out whether the cancer has spread, a sampling of lymph nodes are removed and sent to the lab for testing.

After pelvic lymph node dissection, there is a small possibility that you may develop a condition called **lymphedema**. Lymphedema is a build up of fluids in the tissues. This can cause permanent swelling to the legs. This does not occur in everyone, however, if identified early, can be managed with massage and/or compression stockings.

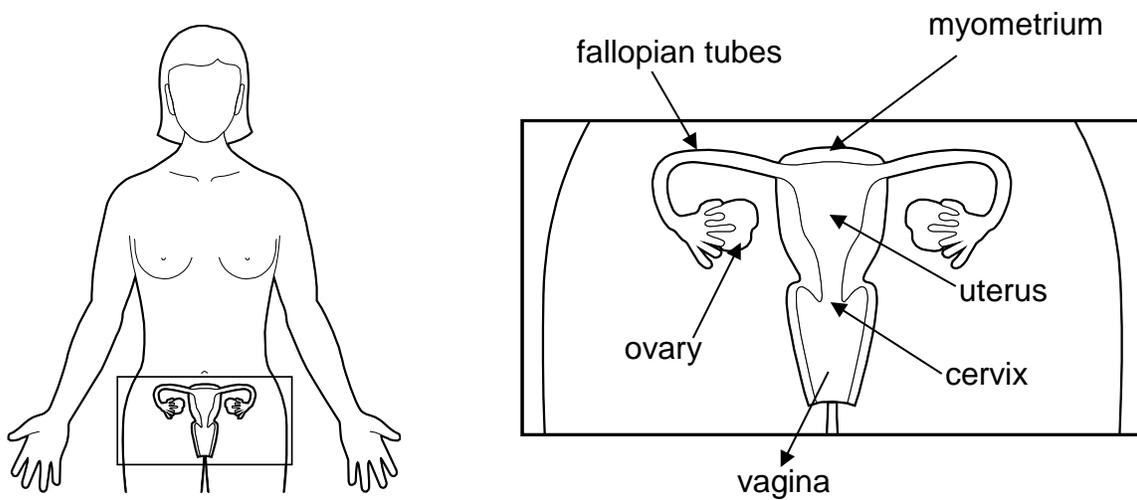
Some women may have a **sentinel lymph node biopsy**.

This procedure involves injecting the cervix and sometimes the body of the uterus before starting the operation. The substance in the injection helps to identify the first lymph nodes that drains the uterus and this lymph node is representative of the whole region. If it does not contain cancer cells, it means none of the others do. Once this lymph node has been identified, it is removed for testing.

- After a sentinel node procedure you may have a transient (less than 24 hours) change in the colour of your urine and skin.
- **Sampling of para-aortic lymph nodes** may also be done. These are lymph nodes that travel near the large artery within the upper abdomen.
- Some women may have a **panniculectomy** at the time of surgery. This is the removal of a large fat pad and skin which allows the oncologist to perform the surgery more safely.

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- **Omentectomy**—Some women will also have the omentum removed as part of their operation. The omentum is a fat pad that drapes over the intestines; it is a place cancer cells can travel to. Removal of the omentum allows it to be tested for cancer cells.



How long will I be in the hospital?

A usual hospital stay is around 2 to 3 days. This is just an estimate. Your hospital stay may be longer or shorter than this. When the doctors feel you are ready, you will go home. Typically you are ready to go home when you are tolerating pain pills by mouth, eating food, walking and passing urine and gas freely.

Will I have a lot of pain?

This is a common concern. During your pre-op visit the anesthesiologist will talk to you about pain control.

There are 2 main types of pain control used after surgery: Patient Controlled Analgesia, or PCA, and Epidural Analgesia. You will most likely have one of these types of pain control when you wake up after surgery.

Patient Controlled Analgesia, or PCA

PCA consists of a mechanical pump that delivers medicine by intravenous (IV) when you push the button. There is a dose and time limit set on the pump so you do not have to worry about giving yourself too much or becoming addicted to it. You will find that you may use it a lot the first day or so and then less each following day. Patients usually have a PCA for 1 to 2 days after surgery.

Epidural analgesia

Epidural analgesia consists of a small tube placed in your back by the anesthesiologist during your surgery. The tube is taped to your back and over your shoulder. A special pump delivers medication continuously so that you will feel less pain in the surgical area. Some patients have slight numbness or heaviness of one or the other thigh/leg. This is normal and will be closely watched by the nurses. Your strength and sensation will return once the epidural is taken out.

You will still be getting up and walking with the epidural in place after surgery. Patients usually have an epidural in for 2 to 3 days after surgery.

Once the PCA or epidural is removed you will receive pain medication pills by mouth, including:

- Acetaminophen (Tylenol)
- anti-inflammatories such as naproxen
- an opioid such as hydromorphone

Preparing for surgery

Planning ahead

It is important to plan for your healthy recovery before surgery. Be sure to get groceries and banking done a few days before your surgery.

Rest is very important for the first few weeks after surgery. Arrange help with meals, child care, pets, gardening and housework.

Be sure you have someone to drive you where you need to go.

After surgery your doctor may not advise driving for a few weeks, especially while on prescription pain medications. Once you are off these and comfortable with twisting movements, you may slowly resume driving. You must wear your seatbelt as a passenger or driver. We also advise that you have someone with you for the first few times you drive to take over if you become tired or have pain.

Always make sure that you are safe!

What should I expect before surgery?

Your surgeon may require that you have more tests done before surgery to help plan your care. These may include:

- Bloodwork
- CT scan

- Ultrasound
- MRI
- Sleep studies — tests to see how well you breathe while sleeping
- Pulmonary function tests (PFT's) — tests used to measure how well the lungs are working
- ECHO (echocardiography) — a procedure that uses ultrasound to view the size, shape and function of the heart

Pre-op Clinic

You will be seen in the Pre-op Clinic at McMaster Hospital before your surgery. There, the team will review your surgery and ask you specific questions about your health. You will have blood taken as well as other tests. An ECG (electrocardiogram) may also be done to check your heart. The team needs this information to plan your care. The information is also helpful to see your progress as you heal.

They will also review with you:

- the consent form you signed at the doctor's office
- how to clean your bowels out before surgery
- when to stop eating and drinking before surgery
- what medications you take the night before or the morning of your surgery
- what medication you stop before surgery

After surgery you will not be as active as you are now because of drowsiness and discomfort. In order to prepare yourself to help lessen complications after surgery, it is important to learn and practice deep breathing and coughing as well as leg exercises that are vital to keeping you healthy after surgery.

Doing these will help you keep your lungs healthy and reduce the risk of pneumonia and blood clots (see page 18).

Practicing these exercises before your surgery helps you prepare and do them after surgery.

The day before your surgery

Only drink clear fluids the day before your surgery. A clear fluid is anything you can see through when poured in a glass.

Do not eat or drink any food or fluids after midnight the night before your surgery. Even if your surgery is planned for the following afternoon, sometimes there are unavoidable cancellations which might move your surgery forward. By fasting after midnight, this allows your surgery to proceed in the event of a last minute cancellation.

Morning of surgery

- have a shower or bath
- remove nail polish from fingers and toes
- remove all rings, jewelry and piercings. Keep them at home for safekeeping.

Day of surgery, arrival to the hospital

On the day of surgery, you will check in at Patient Registration and then go to the Same Day Surgery Unit at the Juravinski Hospital.

There they will take your belongings and put your name on them and take them to the area you will be staying after surgery. It is important not to bring anything of value (money or personal).

You will change into a hospital gown, empty your bladder and remove your dentures and contact lenses if you wear them. An intravenous (IV) will be started to give you fluids and some medications that are needed before, during and after surgery.

Once these preparations are completed, you will go to the holding area about 30 minutes before your surgery. Usually, one person may stay with you at that time.

We cannot be sure of the exact time of your surgery. The time may be slightly earlier or later than planned.

Once you go into the operating room, your family members or friends can wait in the waiting room to talk to the surgeon after the surgery or they can leave a contact number on the chart or with the volunteer. It is best for your family to get coffee/snacks when you go into surgery. The surgery may be done earlier than expected and the surgeon cannot wait to speak with family if they are not in the waiting room as he or she needs to prepare for the next patient.

After the surgery, you will go to the recovery room where the nurses will look after you. When you are fully awake, you will go to the ward to complete your recovery. Some women go to the Intensive Care Unit (ICU), Cardiac Care Unit (CCU) or observation unit, after the surgery. Your doctor will tell you if any of these are necessary.

Your hospital stay

What should I expect after surgery?

The goal of care is to help you recover and to prepare you for going home. A number of people will be involved in your care. They are all part of your health care team. The most important person on the team is “you”.

The health care team plan your care according to your individual needs. We encourage you to help us plan your care. Please ask us any questions regarding your care and hospital stay. Your care involves:

Pain control

- Pain control options will be offered to help you maintain a level of comfort. Remember, pain is an individual experience and cannot be compared to others.

Intravenous (IV)

- IV fluids are needed until you are drinking enough to meet your body's needs. As well, an IV provides a way to give you medications to help prevent or treat nausea, heartburn, itching or if antibiotics are needed.

Vaginal bleeding

- Check for vaginal bleeding. A pad is worn to check for this as well as for comfort. A small amount of vaginal bleeding can be normal for a few weeks after surgery.

Incision

- It is not unusual to have the dressing removed the day after surgery and left uncovered. Usually there is only a small amount of reddish pink drainage from your incision. Some women may have drains along the incision, especially after a panniculectomy. These help prevent a fluid collection which may develop under the incision. These drains usually remain in for a few days. If you are ready to go home before the drains are ready to come out, home care will be set up for you to help you care for them at home.
- There may be numbness around your incision. This is normal and will get better over the next few months. If this worsens over a few days, contact your surgeon's office for what to do.

Urinary catheter

Your bladder catheter tube will be cleaned and cared for until your bladder can work normally again. The catheter is usually in place for 24 to 48 hours.

Bowel activity

- You will be offered ice chips soon after surgery to keep your mouth moist and to help prevent nausea. Your diet will gradually increase from fluids to solids as your bowel function returns to normal.
- Your bowel activity will be slow at first. Many women feel bloated and have “gas pains”. Pain medication helps but walking is most effective to help get the gas moving and ease the discomfort.
- Chewing gum can help get the gas moving after surgery. You can chew gum if you don’t have dental problems or dentures. If you want to chew gum after surgery, bring this with you from home, since the hospital does not provide it.
- Stool softeners will be provided so your bowel movements will be soft and easy to pass so as not to put added strain on the incision area.

Blood thinners

You will receive a blood thinning medication by needle in your upper thighs to help prevent blood clots from forming.

This medication will likely be stopped when you leave the hospital, however, in some situations your doctor may recommend using it for a longer period of time after the surgery.

Activity, walking and moving

- Getting up and walking, starting the day after surgery is the most important thing you can do to have a good recovery from your surgery. Our recommendation is that the day of surgery you sit at the edge of your bed. The first day after surgery we encourage you to walk, with assistance from staff, in the hallway 3 times each day and spend time sitting in a chair rather than staying in bed most of the time.
- Once you are steady on your feet, you must walk several times a day to regain your general strength. Aim to walk around the nursing station at least 3 times each day. Staff or a family member can help you push the IV pole.
- Increase the number of times you walk as well as the distance each day. Your goal for walking after surgery should be to walk around the hallways at least 3 times per day.

Breathing and leg exercises

- For several days after your surgery, your activity will be less than normal. During this time, your breathing is more shallow at rest. Fluid build up may occur in the lungs. This could lead to complications, therefore it is very important to do your breathing and leg exercises as described on the next page.
- Do leg and breathing exercises every 1 to 2 hours while awake. On the day after surgery, you will be helped with getting out of bed and into a chair. You will be shown how to support your abdomen when getting out of bed so you do not put any stress on your incision.

Breathing exercises

1. Take a slow deep breath and fill your lungs. Hold the breath for a count of 3. Slowly blow out.
2. Repeat 8 to 10 times each hour.
3. Cough 3 times after your finish deep breathing.

Remember to hold your incision with a pillow or folded blanket.

Change your position every 2 hours.

Lie on each side, change the height of the bed or sit up in a chair.

Leg exercises

These need to be done every 2 hours while awake.

1. Tighten the buttocks. Hold for a count of 5. Relax.
Repeat 10 times.
2. Lie with legs straight. Tighten your right leg muscles and push knee down into the bed. Hold for a count of 5. Relax.
Repeat 10 times. Now repeat the exercise with the other leg.
3. Turn your ankle in a circle 10 times in one direction then 10 times in the opposite direction. Do this first with the right foot, then the left. Flex your foot up and then point your toes down.
Repeat 10 times each foot.

How important is nutrition?

Nutrition plays a major role in your recovery.

Good nutrition can help give you energy and strength. A balanced diet of protein, fruit, vegetables and whole grains will help your body heal. Your diet can also prevent problems with constipation. Eat foods high in fibre such as bran, whole grains, fruits and vegetables to keep your bowels healthy and regular once your bowels have returned to normal.

If you have any questions about your diet, please write them down and ask your nurse or doctor.

How can a Social Worker help?

A new diagnosis of cancer and treatment can be frightening. Patients and families often have very strong and upsetting feelings at this time. The social worker can help you recognize and express those feelings.

Sometimes the illness and recovery can affect your role in the home, either as breadwinner, spouse or caretaker of older parents, or dependent children. The social worker is aware of the turmoil this creates in the family and can support you in finding other sources of help.

During your hospital stay and recovery, you may be entitled to sick benefits either from your employer plans or other sources. The social worker can help you sort out your benefits.

A social worker is available on request from yourself, your family or your health care team and are located at both the cancer centre or hospital.

When you go home ...

Most patients are ready and eager to go home 3 to 4 days after surgery. Some women heal more slowly than others. If you need nursing care for your incision or your bladder is still slow to function, home care may be provided.

Pain

- Your surgeon will give you a prescription for pain pills. Prescription pain medications can cause constipation. When you have less pain, you should take only plain or Extra Strength Tylenol. This will give you pain relief and allow your bowel function to get back to normal. If you find that an activity gives you pain, stop and rest. Wait a few days before trying that activity again.

Incision

- If you go home with staples in your incision, you will need to go to your family doctor's office, or walk in clinic if you have no family doctor, to have them removed about 7 to 10 days after your surgery. Your health care team will advise you if this is needed and provide you with a staple remover for you to take to your family doctor's office.
- Your incision should be a clean, dry and closed line. Look at your incision before you leave the hospital so that you will be able to see if there are any changes to it when you are at home.

Shower

- You may have a shower to help keep your incision clean and to help it heal. You may have a bath once any discharge from the vagina stops. For the first few weeks, patients usually prefer showers as it is easier to get in and out of the shower than a tub. Be sure to completely and carefully pat dry your incision after washing. It is very important to keep your incision clean and dry. Use a clean cloth and towel each time you bathe.

Urinary catheter

- After the catheter comes out, you may feel a little discomfort (burning or stinging) when passing urine. Be sure to drink 6 to 8 glasses of water or other clear liquids, such as cranberry juice, each day to help prevent infections or other problems. If you notice worsening burning or stinging when passing urine, contact your surgeon's office.

Activity

- Once home, you can continue to increase your activity. Remember that your need for rest will still be more than usual. For the first 6 weeks after surgery you should avoid heavy lifting (5 to 10 pounds or more). Activities such as lifting your children, vacuuming, or grocery shopping (lifting heavy bags should be avoided for 4 to 6 weeks). Do stairs slowly and with help for the first few days. If you feel tired, stop and rest.
- Exercise can help your recovery as well. Walking is an excellent exercise that is tolerated by most patients. You can gradually walk farther and faster each day. You may also gradually return to the gym. Start slowly with activities such as the treadmill, stationary bike and elliptical and increase your activity over time.
- You use a lot of emotional energy following a cancer diagnosis and surgery. Rest and relaxation will help your recovery. Activities you enjoy will also renew your energy and sense of well being. It is important to try and resume your normal activities and routines as quickly as possible. These things help you feel normal again and generally recover more quickly.

Follow-up visits

You will be given an appointment for a follow-up doctor's visit before you leave the hospital. If not, contact your surgeon's office 905-389-5688 to book an appointment for 3 to 4 weeks after your surgery.

Regular follow-up appointments are in the cancer centre. You will be seen a few weeks after your surgery and your Gynecologic Oncologist will determine how often you need to be seen. These visits may vary from a single visit to a few times per year or yearly, depending on your personal situation.

At the first follow-up visit your surgeon will review with you the pathologist's report and may examine you to make sure your incisions are healing properly.

What fills the empty space when everything is removed?

Normally, the uterus, ovaries and fallopian tubes fill a space in your pelvis about the size of your hand. The small bowel or intestines are just above. After surgery, the intestines will dip down to fill the space.

Will I have to take hormones after my ovaries are removed?

There is no single answer to this question.

During the years when you can have children, you produce hormones each month. They prepare your body for pregnancy and also maintain the health of your bones, vagina and breasts.

If the ovaries stop working early either through surgery or in menopause, you will no longer produce the same amount of hormones. This may lead to side effects such as hot flashes, thinning of the bones or dryness in the vagina. Changes made to diet and lifestyle can help lessen some of these side effects or you may choose to take hormones.

There are times when a doctor would not recommend hormones. There is some evidence (proof) that certain cancers or medical conditions get worse when taking hormones.

There are some medications that are not hormones that can be taken to ease the symptoms of menopause if you need them.

It is very important to discuss all these issues openly with your nurse and doctor to make the best decision for yourself.

If you cannot or choose not to take hormones:

- To keep your bones strong, walk or exercise briskly for 20 minutes – 3 times a week. Be sure to maintain a healthy well balanced diet including vitamins such as Calcium and Vitamin D and limit salt, alcohol and caffeine to help keep your bones healthy and strong. Also, talk with your family doctor about having routine bone density exams.

How long does recovery take?

Total recovery has 3 parts: physical, emotional and sexual.

These 3 parts of the recovery period may happen at different times.

Physical

Physical recovery includes healing of the skin and abdominal incisions, and a return to your normal energy level. This can take 6 to 8 weeks.

At the end of this time, most women will be back to their usual work and social activities.

Emotional

Emotional recovery means perhaps adjusting to the shock of having cancer, being away from home and believing you can become well again. It also means feeling comfortable with yourself and the changes in the appearance of your body after your surgery. Emotional recovery may happen at the same time as physical recovery, or it may take longer.

Sexual

Sexual recovery involves a return to your previous patterns of intimacy, or making changes that fit with you and your partner's needs.

Absence of the uterus and cervix should not alter your ability to engage in sexual activity. The other sexual organs, the vagina and the brain remain the same. So does your normal human need to feel loved and cared for.

If you would like, we can talk with you about positions and activities that can help you and your partner enjoy a comfortable relationship.

The length of time for this recovery varies, but it is possible with patience and care. It is recommended that you not attempt intercourse for 6 to 8 weeks after surgery to allow the tissues to heal completely at the top of the vagina.

Women may notice the following changes:

- The vagina may be shorter in its relaxed state if the top section has been removed with the uterus. As the vagina is very stretchy, most people cannot tell the difference during lovemaking. In the "aroused" state, the vagina naturally lengthens.
- The operation should not affect your ability to have an orgasm or sexual climax. However, a climax causes muscle contractions in the uterus as well as other parts of the body. Since the uterus is no longer there, some women have said there is a slight difference in their orgasms.

- If menopause had not previously started, it will now. Many women find the vagina is not as lubricated as it was before menopause. It is therefore a good idea to spend more time becoming aroused before lovemaking so the vagina can lubricate. It also helps to use a water-soluble lubricant such as K-Y Jelly. Oil based lotions and Vaseline will not flow freely out of the body and should not be used.
- There are a number of over the counter products available to women that provide hormone free moisture replacement to the vagina. These include Replens, Repagyne, Gyne Moisterin, Lubrin and others. These products are inserted into the vagina at night (but not before intercourse) and help plump up the water content of the cells lining the vagina to reduce vaginal dryness and discomfort with intercourse. A prescription is not required for these products as many of them are not covered by insurance plans. You do need to use them fairly consistently to see any benefit.
- A cancer diagnosis and surgery is stressful. If you are tired, anxious or worried, you may find that your interest in sex is decreased. Talking with your partner or health care providers along with time and patience will often help your sexual feelings return. By 6 months, most women report a return to their usual lovemaking.

Why does it take so long after surgery to get results?

After the surgery a doctor called a pathologist examines all of the tissues that were removed under a microscope. This is done to determine the type and extent of any cancer found. The pathologist needs to look at the tissues very carefully to give your oncologist all the information that is needed. It can take up to 3 to 4 weeks to process the sample and give your oncologist a detailed report.

What is CCAC?

CCAC stands for Community Care Access Centre. CCAC is a program, which arranges nursing, physiotherapy, nutrition and social services when you go home, **if needed**. Other services which the program provides include:

- drugs, dressings and medical supplies
- hospital and medical equipment

If needed, the CCAC case manager will meet with you to review your needs so that the appropriate services can be provided once you are home. If you are not eligible for the program, the case manager can help find other sources of care or you may wish to pay for services privately. You may need to make arrangements with friends and family to help you during your recovery. Not all patients will need CCAC once they go home.

How does CCAC help?

CCAC helps the healing process continue in your own home. If you need professional care when you get home, the doctor will ask the home care coordinator to see you. If you think you will need more help and it has not yet been mentioned, tell your nurse or doctor of your needs and concerns.

Sometimes it may be difficult to go home if you have no supports to help you the first few days after surgery. This may require “Respite care”, which means that you would stay at a retirement home for the first few days after discharge from hospital until you are strong enough to go home alone. There is a cost associated with this and needs to be arranged ahead of time. Should you think that you would like to explore this option, please inform your health care team as soon as possible to try and arrange.

When to call the surgeon

Call if you have:

- **any bright red bleeding or clots (size of a walnut or larger) from your vagina that looks like a period or soaking more than one pad (regular maxi pad) every hour or passing clots of blood from your vagina**
- fever 38.3°C (101°F) or higher
- chest pain, cough, difficulty breathing or coughing up blood
- pain, swelling or tenderness in your calf or thigh
- dizziness that does not get better or fainting
- concerns about your incisions such as:
 - incision coming apart
 - swelling, hardness or leaking
 - redness, bleeding or drainage of pus
 - pain, which does not get better with pain pills
 - increasing abdominal pain or bloating
- burning or bleeding when you pass urine, passing urine often or difficulty starting flow
- foul smelling discharge from the vagina, an increased amount of discharge
- nausea and vomiting that lasts more than 24 hours
- change in bowel habits

Phone numbers

Office: 905-389-5688

Surgeon (Gynecologic Oncologist): _____

Nurse: _____

Follow-up appointment: _____

Questions to ask at my follow-up visit:

Total abdominal hysterectomy
- bilateral salpingo-oophorectomy and pelvic node dissection
(for endometrial cancer)



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