Information Leaflet

NHS
Liverpool Women's
NHS Foundation Trust

Ovarian Cancer Pathway

Introduction

Diagnosis and treatment of any type of cancer can be frightening for most people due to the uncertainty involved. This Ovarian cancer pathway leaflet aims to ease your mind by answering commonly asked questions. However, it will not replace a one-to-one discussion between you and your doctor.

Diagnosis

Diagnosis can take time and it can be stressful and emotional, which is one of the difficulties with ovarian (fallopian tube or peritoneum) cancer. However, the time taken for these tests is very important in deciding the appropriate treatment for you. We understand your frustration but remember it is important to do everything correctly, not just quickly.

Who is involved in my treatment planning?

A multidisciplinary team (MDT) meeting takes place at Liverpool Women's Hospital (LWH) every Wednesday where a group of people come together to discuss and make recommendations for your treatment. This multidisciplinary team (MDT) will include:

- **Gynaecology- oncologists from Liverpool Womens'**- surgeons who are specialised in the surgical management of gynaecological cancer.
- **Medical and Clinical oncology Consultants from Clatterbridge Cancer Centre**- specialists in cancer treatments such as radiotherapy, chemotherapy, and targeted therapy drugs.
- **Consultant Radiologists from Clatterbridge Cancer Centre and Liverpool University Hospital-** specialist doctors who analyse X- rays, CT, PET, and MRI scans and are crucial in the ovarian cancer treatment decision.
- **Consultant Pathologists from Liverpool University Hospital** - doctors who examine cancer cells under a microscope and advise on the type and extent of cancer.
- **Surgical Oncologists from Aintree Hospital**- These oncologists work together with gynae oncology surgeons to perform extensive surgeries (Cytoreductive or

interval Debulking surgery), which may be recommended for the treatment of some ovarian cancers.

- **Gynaecology- oncology nurse specialist (Liverpool Women's hospital, Clatterbridge Cancer centre, Local Hospitals)** - You may have already met one of the specialist nurses and they will be your point of contact for communication and support throughout your journey.

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. This will be based on the biopsy results, scan findings. There are several routes and combinations for the treatment of ovarian cancer.

What are the combinations of the treatment?

Combination 1	**Combination 2**	**Combination 3**
● Surgery* ● Chemotherapy – 6 cycles	● Chemotherapy- 3 cycles. ● CT scan to reassess. ● The decision not for surgery. ● Chemotherapy – 3 more cycles.	● Chemotherapy – 3 cycles. ● CT scan to reassess the next part of the plan. ● The decision for surgery* ● Chemotherapy – 3 more cycles.

***Operation sites**

Liverpool University hospital (Royal Liverpool)– if you need ITU support after operation.

Liverpool Women's hospital – if you are unlikely to need ITU support after operation.

How is treatment planned?

The decision of your cancer treatment will depend upon many things such as the type of cancer, where it is, your current symptoms, how strong your body is, and your thoughts and wishes. Usually, the first decision is whether we look to start with chemotherapy or start with an operation.

1. Surgery first

Surgery can be important for the treatment of ovarian cancer, to remove as much visible cancer, as well as to help with the symptoms. On the original scan, if we feel all the disease can be removed by the surgery, we will talk to you about surgery as the first treatment.

If you require any further treatment, it is usually chemotherapy. We aim to start this approximately 6-8 weeks after your surgery, as you may take some time to recover from surgery, to receive a better effect from chemotherapy. The aim would be to complete 6 cycles of chemotherapy without any interruption if possible.

2. Chemotherapy first

On the original scan, if we feel the disease cannot be removed by the surgery, we will talk to you about chemotherapy as the first treatment. This is because chemotherapy helps to shrink cancer and make surgery easier and more effective (neoadjuvant chemotherapy). Then a medical oncologist from Clatterbridge Cancer Centre will assess you and discuss the options of the treatment and drugs. The risks and benefits of treatment will also be discussed with you in detail to help you make decisions about your treatment.

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. This treatment is often used to treat cancer that starts in the ovaries, fallopian tubes, or peritoneum. The drugs are usually given into a vein (Intravenously). Chemotherapy is given as one or more sessions of treatment. Each session takes a few hours, and it can be done as an outpatient, and you do not need a stay in the hospital. After the session, you will have a rest period of a few weeks. The chemotherapy session and the rest period are called a cycle of treatment.

The length of a cycle depends on the chemotherapy drugs you have. But most cycles are 1 to 3 weeks long. Chemotherapy drugs may cause unpleasant side effects. But these can be well controlled with medicines and usually go away once treatment has finished. Not all drugs cause the same side effects, and some people may have very few. The main side effects of chemotherapy are risk of infection, anaemia (low number of red blood cells), bruising and bleeding, feeling sick, muscle or joint pain, hair loss, numbness or tingling hands or feet, sore mouth, and loss of appetite. Information regarding side effects will be provided at your discussion of chemotherapy with the medical oncologist.

You usually have three cycles of chemotherapy followed by a CT scan to check how effective the treatment has been. This will then be discussed in the MDT who will make a recommendation as to and if surgery is recommended a surgeon will then talk to you about whether surgery is possible depending on the response of cancer to chemotherapy on a CT scan. If you have surgery, you will have three cycles of chemotherapy after you have recovered from surgery. If you do not have surgery, you will have another three cycles of chemotherapy (maximum of 6 cycles in total).

Is there any maintenance treatment available?

Yes, there is a maintenance treatment with PARP inhibitors and Bevacizumab (Avastin) available in the treatment pathway. These are a type of targeted cancer drugs. The goal of maintenance therapy is to ‘maintain’ a remission or prevent or delay the cancer’s return if the cancer is in remission after initial treatment. This therapy can be used for the treatment of some women with ovarian cancer, fallopian tube cancer or peritoneal cancer. The medical oncologist will be able to tell you more about maintenance treatment.

What is BRCA? Do I need to consider Tumour Next- HRD (Homologous recombination deficiency) testing?

The name ‘BRCA’ is an abbreviation for ‘BReast CAncer’ gene, and everyone has these genes. BRCA 1 and BRCA 2 are two different genes normally play a big role in preventing breast cancer. However, in some people these genes become altered and does not function correctly and is called a gene mutation. A woman’s lifetime risk of developing breast and/or ovarian cancer is markedly increased if she inherits a mutated BRCA 1 or BRCA 2. TumorNext- HRD is a paired tumour and germline analysis of BRCA 1, BRCA 2 and 9 other genes in the homologous recombination care pathway. Looking at both the tomour and germline can help to identify ovarian cancer patients who are at an increased risk for other cancers and guide targeted treatment such as with PARP inhibitors. Your medical oncologist will be able to tell you more about this.

Will I get support with my symptoms?

Ovarian cancer treatment can take several months to finish and during this period you may experience different cancer symptoms and treatment side effects. The team can help you to reduce the side effects and difficulties during this journey.

- Treatment of cancer symptoms or treatment side effects- you may experience nausea, vomiting, loss of appetite, fatigue, bladder, or bowel symptoms during the treatment itself. Please speak to your doctor or nurse when the side effects impact your quality of life.
- Treatment for anaemia- Illness caused by cancer can make you anaemic and that can make your recovery more difficult. As a result, we will take blood tests lookout for anaemia and advice will be given for iron treatment if required. If there is time for this to work, it is a better and safer treatment for anaemia than a blood transfusion.
- Clinical nurse specialist support- Throughout the whole journey, the clinical nurse specialists are there to help physically and emotionally whenever you are struggling.
- Advice on chemotherapy- Triage line at Clatterbridge Cancer Centre.

What is a CA 125 blood test?

This blood test checks for raised levels of a protein called CA125. It is normal to have some CA125 in the blood, but the level may be higher in women with ovarian cancer. The level of CA125 can also be raised by non-cancerous conditions and by other types of cancer. In early Ovarian cancer, CA125 levels may be normal.

What is cytoreductive or debulking surgery (IDS)?

Debulking is a type of abdominal surgery to remove as much cancerous tissue from a patient’s abdomen as possible. This is because ovarian cancer often is not confined to just one area. During this surgery, your surgeon will cut your abdomen. This can be from the top of your abdomen down to your pelvis. This type of surgery allows the surgeon to explore the pelvic and abdominal area for cancer and remove any tumour masses.

Since surgery aims to remove all sites of disease, we have developed the surgery in conjunction with the Oncology surgeons at Aintree to give us the best chance of removing all sites involved with cancer.

During the operation, the surgeon will remove your uterus (womb), cervix, fallopian tubes, and ovaries. The surgeon may also need to remove other organs such as the Omentum (fatty lining of the abdomen), peritoneum (filmy covering the abdominal wall), spleen, lymph nodes, sections of the diaphragm (the muscle underneath the lungs) but never the whole diaphragm, lymph nodes (glands), and part of your bowel which may require a stoma.

As mentioned before, the whole point of surgery is to try to remove all visible cancer remaining. Sometimes this is not possible, there are more areas involved than could be seen on the CT scan, or it involves crucial organs in the body that cannot be removed. If this is the case, we would have to decide at the time of the operation what is the right thing to do. It can be to remove what we can or stop the operation and not to continue. Whilst it is uncommon it can happen.

Diagram A- Internal abdominal Organs

*****Omentum- A piece of fatty tissue that lies over the abdominal organs
*Peritoneum- A lining of the abdominal cavity

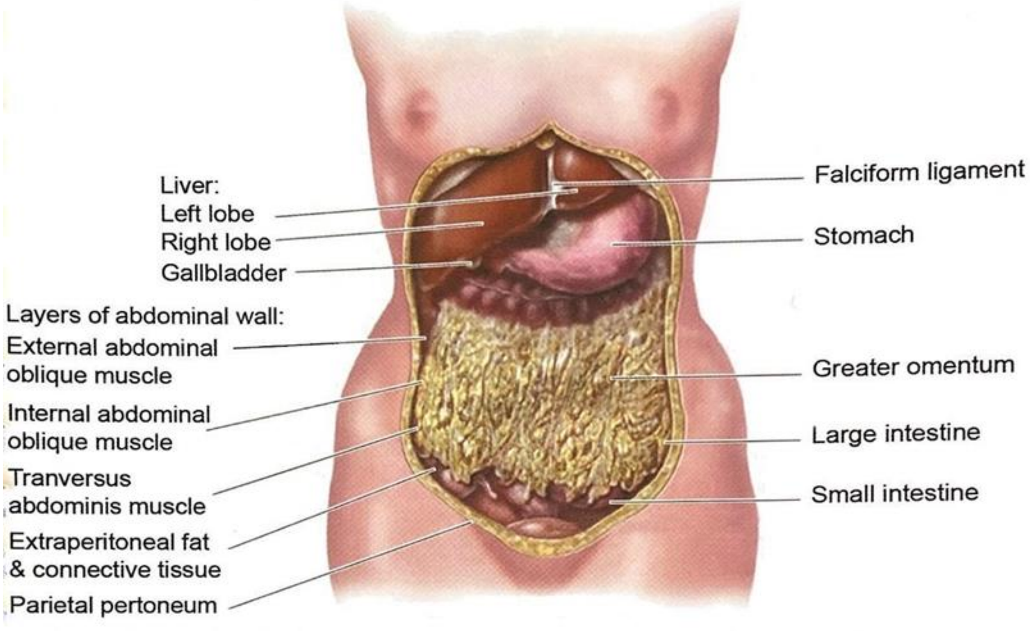


Diagram B- Internal abdominal organs

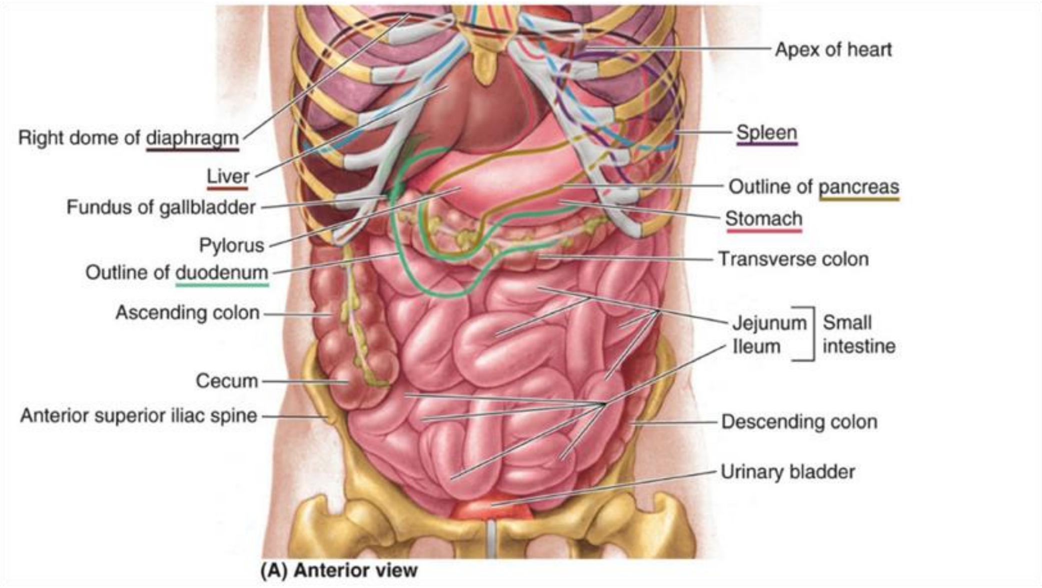
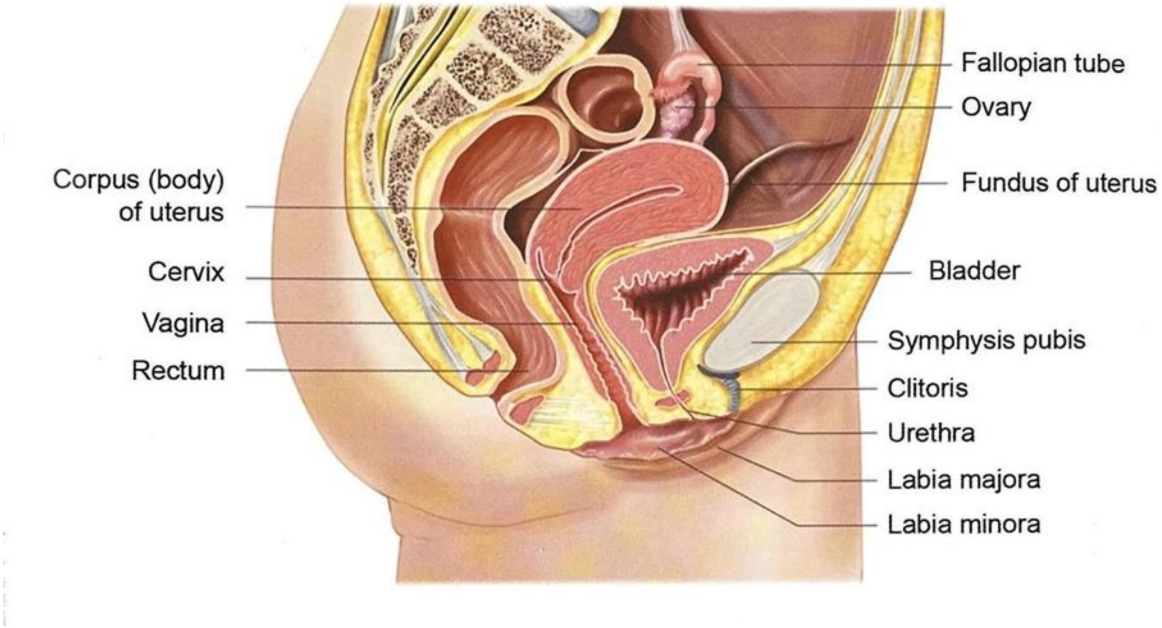


Diagram C- Side view of reproductive organs



(Images sourced from the book called Yes doctor. But what does that mean?)

Will I need a stoma?

When ovarian cancer is more advanced at the time of diagnosis it will have spread to the surface of the bowel (intestine). In these cases, to make sure that as much of cancer as possible is removed, your surgery may include removing a part of the bowel. Sometimes the affected area of the bowel can be removed, and the two ends joined back together. But if it is not possible, your body will need a new way to get rid of faeces (poo). In these cases, the surgeon will make an opening through your abdominal wall and bring the end of the bowel through the skin. This is called the creation of an ostomy or stoma (an artificial opening). The faeces (poo) are then collected in a stoma bag which is attached to your abdomen (tummy). This may well be temporary (several months).

Before your operation, a stoma nurse or a consultant will mark your abdomen with a skin marker pen (known as siting). This is to guide your surgeon to the best possible place to bring out the stoma if it is necessary. Your stoma nurse will also discuss with you, in more detail, what having a stoma will involve and answer any questions that you may have.

If a stoma is created in your case, you may get an appointment with a Surgical Oncologist at Aintree hospital for follow up.

Is a stoma permanent?

In many cases of ovarian cancer, a stoma is intended to be temporary. This means that in the future you may be able to have further surgery that means you no longer have the stoma. It is important to remember that all cases are different, and you would need to discuss your case with your surgeon and the team.

Before surgery

You should carry on taking your usual medications unless told otherwise. We strongly advise that you stop smoking before your surgery. If you develop an illness before your surgery date or have any questions, please contact your Nurse specialist.

Pre-Operative assessment

You will have a pre-operative assessment before your surgery at Liverpool University Hospital (RLUH). During this assessment, your fitness for general anaesthetic and surgery will be checked. This will include recording a full medical history, any current medication, and arranging any investigations needed. Please tell the nurse if you have had problems with any previous surgery, anaesthetic or if you have any allergies- this is very important.

You will also meet the pre-habilitation team at Aintree University if surgery is possible. Pre-Habilitation- Being fit physically and mentally can help reduce the side effects of all treatments, therefore, speeding up recovery. The pre-habilitation team will offer advice and support about maintaining fitness if you are having surgery at Liverpool University hospital.

Will I have to sign a consent form?

You will be asked to sign a consent form giving your consent to the surgery. The consent form is a written record of the consent discussion you have with your doctor and makes it clear what operation you have consented to. Your surgeon will only perform surgery for which you have specifically consented. The only exception being if a further procedure becomes necessary to save your life or save you from serious harm. The medical terms commonly used on the consent form are:

- Total abdominal hysterectomy- removal of the womb which includes the cervix (neck of the womb).
- Oophorectomy- removal of one ovary
- Bilateral- oophorectomy- removal of both ovaries
- Salpingectomy- removal of one fallopian tube
- Bilateral salpingectomy- removal of both fallopian tubes
- Bilateral salpingo-oophorectomy- removal of both ovaries and fallopian tubes
- Splenectomy- removal of the spleen
- Omentectomy- removal of part or all of the omentum
- Diaphragmatic striping- removal of part or all of the lining of the diaphragm muscle
- Peritoneal stripping (removal of the peritoneum)
- Lymphadenectomy (removal of lymph nodes)
- Bowel resection- removal of part of the large or small bowel
- Stoma formation- bringing the bowel through the abdominal wall to form an opening on the tummy.

Day of your surgery

An anaesthetist and your surgeon (or a member of the team) will explain to you what will happen during your operation and check if you have any questions or if anything has changed.

We want you to fully understand why you are having the surgery and the possible risks involved. You will be asked to sign a consent form if you have not already done so, and you will have the opportunity to ask any questions that you may have.

During the surgery

All surgeries are carried out under a general anaesthetic (while you are asleep). A narrow plastic tube called a cannula will be inserted into a vein in your arm or hand using a needle. This is used to give you fluids and medications. Before having the general anaesthetic, your anaesthetist may give you an epidural (small plastic catheter) into your spine (backbone) to help control pain after your surgery. And also, an arterial line (a plastic tube) will be introduced into one of your radial arteries (vessel supplying blood to arm) to monitor your blood pressure continuously while you are in ITU/HDU after the surgery. After you have been given a general anaesthetic and you are asleep, a catheter (a tube to drain urine) will be inserted into your bladder.

While under general anaesthetic your surgeon will make a cut on your abdomen which can be from the top of your abdomen down to your pelvis.

At the end of the surgery, rectus sheath catheters (plastic tube) will be inserted into each side of your abdominal incision to provide continuous pain relief after the surgery.

All the organs and cancer removed during your operation will be sent to the laboratory for examination to assess your response to chemotherapy.

The wound will be closed with dissolvable stitches or staples. The procedure can take 4-6 hours, but you should expect to be in the theatre and recovery for longer.

After the surgery

You will normally wake up in the operating theatre recovery area, but you may not remember much. You will then be transferred to the department of critical care (ITU/HDU). You will be moved to the ward once you are stable, and the critical care team is happy with your recovery.

Risks

Minor risks

- Infections (such as wound, chest, or bladder)
- Bruising to any wound on the abdomen
- Haematoma (blood collecting in the wound)
- Hernia
- Adhesions (tissues sticking together)
- Constipation
- Delay in chemotherapy.

Major risks

- **Pain-** Pain after surgery is common but can be managed and controlled. A particular issue after surgery for ovarian cancer can be painful breathing. Commonly the peritoneum (the internal skin) overlying the diaphragm (the muscle beneath the lungs) is involved in the cancer that needs removing. The diaphragm itself can often need removal as well, and both of these surgeries can mean breathing is difficult and painful after surgery. It does get better but can slow your recovery.
- **Nausea/ vomiting**- surgery and anaesthetics and many of the medicines used can make you feel sick. Please tell your anaesthetist if it has been a problem for you in the past, and they can try to reduce the nausea the treatment causes.
- **Ileus**- Surgery in the pelvis and bowel can lead the bowel to stop functioning for some time after the surgery. If this goes on for several days, we may need to drain the stomach with a tube through the nose (NG tube- nasogastric tube) and consider feeding you through a vein. This normally resolves within a few days but can go on for a couple of weeks or more.
- **Poor appetite**- As a response to everything else that has happened (pain, nausea, sickness, etc) it is not surprising your appetite may not be normal for some weeks.

  We will commonly ask the Dietician to talk to you about how to get your appetite back and also about the best foods to eat whilst you are recovering.

- **Blood clots (DVT/PE)-** Cancer, surgery, and immobility after the surgery all put you at risk of a blood clot either in your leg or lung. The support stockings and the injections we give you after the surgery reduce the risks of a blood clot but not remove it entirely. Please tell your doctor if you get a swollen leg or sudden onset of breathlessness.
- **Slow recovery**- The healing after a major surgery takes time. This can be very frustrating. Allow yourself time to recover; it will happen. But if you rush and push your body too hard, you may well go backward. Listen to your body and try to make your progress gradually.

How long will I be in Hospital?

Recovery from such a major surgery takes time; the length of hospital stay can be between 4-14 days depending on your surgery. And steady recovery after this at home. Most people feel very tired and lacking in energy after the operation and this may take several weeks to slowly improve. A lack of concentration is also common and can take some time to come back.

After surgery, it is crucial to get you fit again as soon as possible either for the remainder of your chemotherapy or to start the chemotherapy. The fitter you are before the surgery and the fewer the complications you get after the surgery, the quicker you will recover and get on to the next phase of your treatment. We will encourage you to move around as early as possible to help you to recover quickly.

Going home

You may still have some discomfort when you leave the hospital, but you will be given a supply of pain relief medication regularly for the best effect. And also, you will be given a supply of daily anticoagulant (blood-thinning medication) to reduce the risk of a blood clot (DVT/PE). A nurse will show you how to inject yourself. If you are not able to inject yourself, they will show a relative or friend how to do this. Or they will arrange for a district nurse to do it for you.

You may have some light vaginal bleeding (spotting) for up to 6 weeks after the surgery. This is normal but if the bleeding becomes heavy and has an offensive smell or if you are concerned, please contact your GP and let your oncologist know during your chemotherapy assessment.

Next Appointments

Around three weeks after your surgery a post-operative check will be undertaken either by telephone or face to face with the surgical team. At this time results will be discussed following your surgery and an update sent to the Clatterbridge Cancer Centre on your progress. Following this appointment you will have an appointment, either face to face or on the telephone, with the Clatterbridge team to discuss resuming your chemotherapy and any further treatment.

You will also have a follow up holistic assessment by your surgical nurse specialist, on the telephone. You may also receive a follow up from Mr Skaife if you have a stoma or if this is indicated.

Returning to normal

You may feel more tired in the weeks following your surgery. Further chemotherapy treatment can also make you feel tired. You might experience slight aching discomfort at the wound site. This can persist for some months, but most women can resume light daily activities and tasks within 6-12 weeks.

What about my sex life?

The area at the top of the vagina, where the cervix was, will have had stitches. The wound will need about 12 weeks to heal before intercourse is resumed. You will tend to know when you feel ready to resume intercourse. You should find that there is no alteration in the sensation, but there may be slight discomfort if you are over-enthusiastic. Please ask your specialist nurse or GP for advice if you experience any pain.

When can I drive?

You will be able to travel as a passenger, but if you are travelling long distances, please make sure that you stretch your legs regularly.

You should not drive until you feel able to perform an emergency stop comfortably and are not taking regular pain medication. This usually means 6 weeks without driving. We recommend you discuss this with your insurance company.

Once treatment is complete

After your treatment, you will have regular check-ups, which are usually every 3- 6 month to start with. Your doctor and nurse will ask you how you are recovering from the treatment. They will ask if you have any new symptoms. If needed, you may have scans or blood tests. You can talk to your doctor or nurse about any problems or worries at these check-ups. But if you notice new symptoms or have problems between appointments, contact them for advice sooner.

- CA 125- CA 125 (ovarian tumour marker) blood tests are sometimes done as part of your follow up, but this is not always needed. A rising CA 125 level may be a sign that cancer has returned and help us to consider further tests such as a CT scan. But for most people, it is just as effective to wait for symptoms of cancer to develop and then start treatment again.

- Supported self-management- Coming into the hospital for an appointment for a blood test, is a very ineffective way to assess you. However, this method has been developed to keep you out of the hospital but still keeping you under proper review. Please talk to your specialist nurse about this.

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Liverpool Women's NHS Foundation Trust
Crown Street
Liverpool
L8 7SS

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