

Ovarian cancer and stomas



A guide to help you prepare
for surgery and stoma care



Welcome to our guide on ovarian cancer and stomas.

The information inside will help you to find out more about what a stoma is, how it works and what it's like to live with one. This guide has been written with experts in ovarian cancer and stoma care – so you can trust that it's reliable, accurate and up to date.

▶ Welcome	2
▶ When will I find out if I need a stoma?	5
▶ What does a stoma look and feel like? Does it hurt?	8
▶ Is there just one type of stoma?	9
▶ How does it actually work?	9
▶ How do I learn to cope with a stoma?	10
▶ How do I look after my stoma?	13
▶ What if I'm having problems with my stoma?	14
▶ Common stoma questions answered	16
▶ Where can I find out more?	22

Along the way, you'll also hear from different women with personal experiences of living with ovarian cancer and a stoma, including Helen and Pauline:



Helen

“I was diagnosed with stage 3C high grade serous ovarian cancer in 2016. I had three rounds of chemotherapy followed by surgery and then more chemotherapy. I was told that I had a 7 in 10 chance of having a stoma (a colostomy). My consultant said she wouldn't know until she was doing the surgery.

When I came round after my operation, my stoma was the first thing I saw. I wouldn't accept it at first and was so upset. It took me a long time. But today – almost seven years later – I'm so grateful for the procedure, as I wouldn't be here otherwise.”



Pauline

“I was diagnosed with stage 2 high grade serous ovarian cancer in 2014. I had surgery followed by chemotherapy. During surgery, I had a stoma formed (an ileostomy), which was reversed 13 months later.

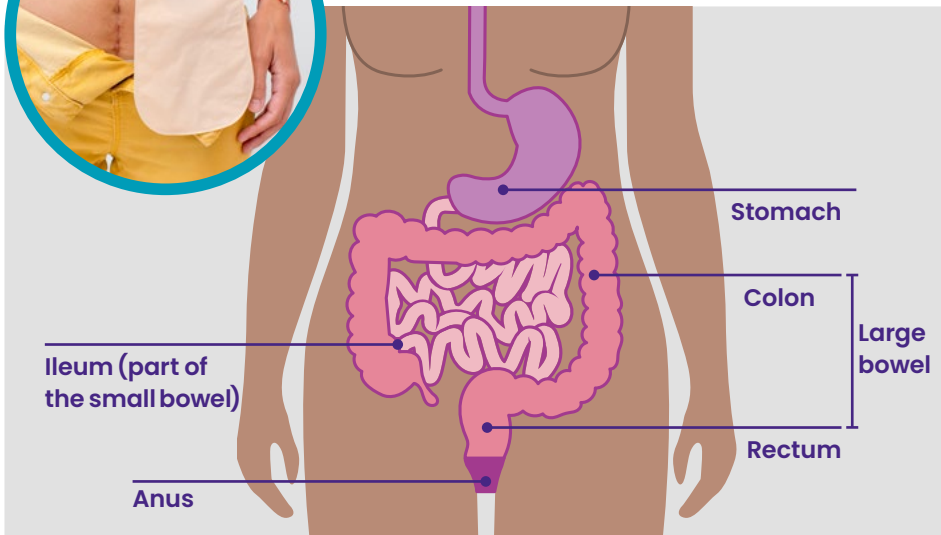
Before surgery, I remember that I talked to my surgeon and medical team, who said that I may need an ileostomy. And that's what happened. I'm fortunate that – just over a year later – everything had healed perfectly, and I was able to have a stoma reversal.”

Introduction

When ovarian cancer is more advanced at the time of diagnosis it will sometimes have spread to the surface of the bowel (part of the digestive system).

In these cases, in order to make sure that as much of the 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 this isn't possible your body will need a new way to get rid of faeces (poo).

To do this the surgeon will make an opening through the wall of your abdomen (tummy) and bring the end of the bowel through the skin. This is called the creation of an **ostomy** or **stoma** (an artificial opening). The poo is then collected in a stoma bag which is attached to your tummy.



When will I find out if I need a stoma?

Before your operation takes place your surgeon should talk to you about all of the possible outcomes (results) of your surgery, including the creation of a stoma.

During this conversation you will be asked if you give permission (consent) for a stoma to be formed if you need one.

It's normal to feel overwhelmed or anxious about your operation so don't be afraid to ask your surgeon to explain things more than once or in a different way to help you understand. If you know that your operation will involve creating a stoma (because it's clear that the cancer is affecting your bowel) you will also talk about where the stoma will be on your body.

This is usually on the left-hand side of your tummy for a **colostomy** and the right-hand side for an **ileostomy**. You can find out more about these types of stoma in the **Is there just one type of stoma?** section on page 9.

Your surgeon will explain things to you based on your individual circumstances. You should then be able to speak to a Clinical Nurse Specialist (CNS), sometimes called a stoma nurse, and ask questions about what to expect.

These nurses are experts in this area and take lots of people through this surgery so they will understand your concerns and want to help you prepare.

They will be able to explain in detail what's involved and how you look after a stoma. They may also be able to help choose a position on your tummy for the stoma which suits your body shape, life and the clothes you wear.

Although it can be worrying at first, learning about your stoma and talking to a professional about how you feel before the operation will make it easier to cope. Knowing what to expect reduces the fear of the unknown.

Sometimes a surgeon won't know that you need a stoma until they're operating. In these cases a stoma may be formed as part of an emergency procedure.

These unexpected and unplanned stomas can be particularly difficult to cope with and may come as a shock. You can speak to your surgeon about this before the operation if it's something you're worried about.

Your CNS or stoma nurse will help you cope after the operation and show you how to look after your stoma and get used to having one.



Good to know

"A nurse came to mark my tummy with a permanent marker on both the left and right sides. When doing this she asked how I wore my clothes – high waisted or low – so some consideration could be given to where the stoma was sited."

Sally

"There will be stitches to hold the stoma in place at first. But these aren't permanent and your stoma nurse will remove these when they're ready or, if they're dissolvable stitches, they will dissolve on their own."

Annette



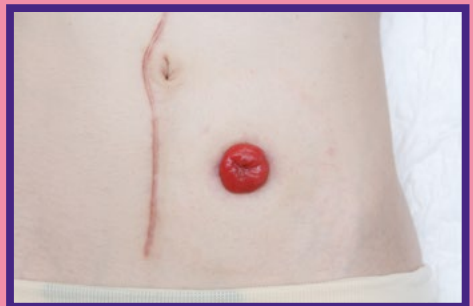
My stoma and me

“At my appointment with my surgeon I was told that there was a 7 in 10 chance of having a stoma bag. She said she would do all she could to avoid it but was very keen to make sure that I understood all possibilities. She advised me to speak to my Clinical Nurse Specialist who would arrange for me to speak to the stoma nurses at my local hospital.

The stoma nurses were fantastic. I wasn't rushed and they explained everything to me even though I kept reminding them it wasn't definite!

I was shown a model and found it difficult and even cried at this stage. So another meeting was arranged and I was given a leaflet to read through and write down my questions. Two days before my surgery I went to have markings put on my left side at waistband level, so the surgeon could see where to put the stoma. **The easiest way to describe it is, do an 'ooh' shape with your lips and look in the mirror!**”

Helen



What does a stoma look and feel like? Does it hurt?

Most stomas will be a pinkish-red colour and feel a bit wet when you touch them (like the inside of our mouths) but everyone's will be different in size and shape. Some are quite short and sit flat against the tummy, while others stick out a little. There are no nerves in a stoma so it won't hurt to touch. Unlike going to the toilet through your bottom, with a stoma you won't feel when you're pooing. So it's important to regularly check your stoma bag to make sure it's not full.

A new stoma will be swollen (larger than usual) for six to eight weeks after the operation but the swelling will go down and the stoma will normally get smaller. The outside edge of the stoma where the stitches have been can bleed a little when being cleaned, especially at the beginning. This is normal and should stop soon afterwards. If you have any concerns you should speak to your stoma nurse or CNS.



Good to know

Your stoma nurse will show you how to empty and change your stoma bag and will make sure you're supplied with the bags that are right for your stoma.

"I found that after about six months my bowel routine hadn't changed too much from before. I change my bag at different times during the day but not because it needs changing – I do it more for hygiene."

Helen

"It does seem strange for a while not to perform a normal bowel habit, but you soon adapt."

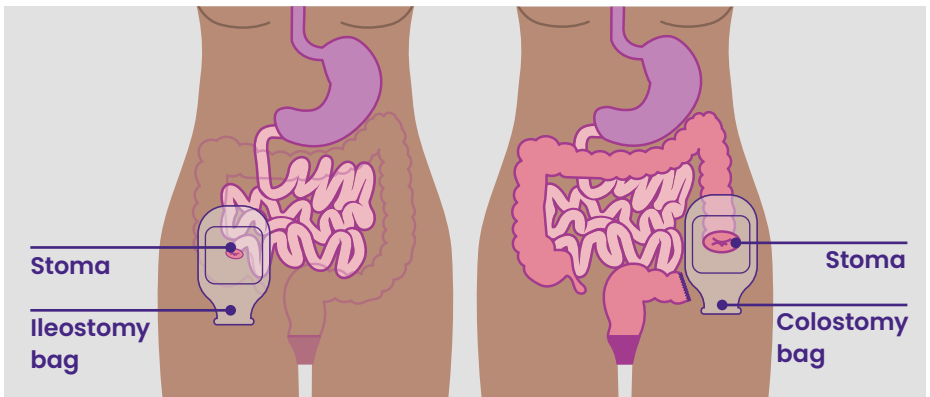
Pauline

Is there just one type of stoma?

There are two different types of stoma that you might have after ovarian cancer surgery. The type that you have and the name it's given depends on which part of the bowel your surgeon needs to use. A **colostomy** is formed from the large bowel (colon) and produces a more solid poo. An **ileostomy** is formed from the small bowel (ileum) and produces poo that is more like porridge. In both cases the open end of the bowel is sewn onto the skin and called a stoma.

How does it actually work?

Your bowel will still work as normal but the poo will come out of the stoma into the stoma bag. Your stoma just means your bowel opening is in a different place from before. A removable bag (**stoma bag**) will be fitted snugly around your stoma and this will keep the poo contained as it leaves your bowel. The stoma bag will need to be emptied and/or changed regularly. There are lots of different stoma bags and the type you have will depend on the type of stoma you have. You will pass urine (have a wee) as usual.



How do I learn to cope with a stoma?

Although having a stoma isn't uncommon, having a stoma as well as an ovarian cancer diagnosis is a huge event for anyone. Sometimes the thought of having a stoma can be more difficult to cope with than the ovarian cancer diagnosis.

You're not alone: there's help and support available. Your stoma nurse will support you after the surgery to help you get used to your stoma and how to care for it.

They will be happy to answer your questions and will help you to feel as comfortable and confident as possible. You might also find it helpful to get in touch with your community hospital (a small hospital that provides a range of services to the people living in your area) to ask if there are **community stoma nurses** in your area.

Community stoma nurses will be able to help and support you with your stoma when you're at home.

You may find it helps to talk to others who understand what it feels like to have a stoma. You can ask your stoma nurse about support groups in your area.

You can also find lots of online support (including stories from people who have stomas) through the organisations in the **Where can I find out more?** section at the end of this guide.



My stoma and me

“My first day on the ward, I met my stoma nurse who was a very calm lady. We clicked immediately and despite me saying, “I’m never going to be able to deal with this,” she still helped me lots over the next few days. When I got home, my local stoma nurse visited me the next day. She was so lovely and supportive too.

Usually your hospital or stoma nurse will send you home with your initial pack which will contain all you need – wipes, new bags and disposable bags for the old ones. Sometimes they will also arrange with the manufacturer to deliver your order direct to you, you can just phone them when a new supply is needed.

I treated having a stoma as just part of my daily routine.

As soon as I felt strong enough my husband would drive me for coffee with my buddies. This gave me such a boost to start socialising again. Then I would sit in, not always participating, at my craft class. This, along with my granddaughter, my little rock, really helped to push me back into some kind of normal life again.”

Pauline



“I woke up to a lovely nurse smiling at me but I was inconsolable. I really gave everyone a hard time. No way was I dealing with that! When I was moved to a ward downstairs I met a young nurse who gave me a bit of tough love (I’d met my match).

I was desperate to go home but couldn’t until I could prove to the stoma team I could change my bag. The young nurse set me a challenge and I did it! Through tears and a few expletives I changed my first bag on day four. I was quite proud of myself and it wasn’t that bad. That was my acceptance of my future.”

Helen



How it felt for me

“Where I had my surgery, the hospital won’t discharge you until they’re happy your stoma is working as it can take several days for your system to get moving again after major surgery. In my case it was nearly two weeks and I had several further days in hospital to make sure there were no issues. But we must not be afraid to ask for help in the hospital – on a gynae-oncology ward they’ve seen it all before!”

Annette

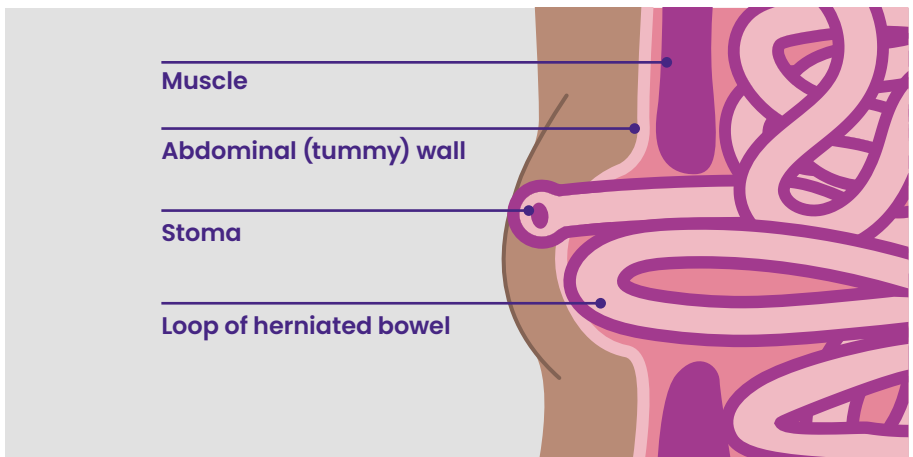
“The enormity of it all came to a head when a friend visited hospital a few days after the surgery and she announced in an upbeat tone that I would ‘be fine’. I was so angry and upset. After she went (with my apologies ringing in her ear!) I realised I had to get on with it. From that moment on, I took to changing my own bag and reading the booklet they had given me. My stoma nurse told me she was proud of me and even hugged me before agreeing that I could go home.”

Janet

How do I look after my stoma?

Your stoma nurse will show you how to look after your stoma including changing your stoma bag and getting rid of used bags. They will also talk to you about how to reorder the supplies that you need to manage your stoma. Remember to ask questions if you're unsure about anything: no question is too silly or too small. Be patient with yourself as you get used to your new routine and take your time to clean your stoma carefully. It may feel like a mountain to climb but you will soon become confident in how to manage it yourself. You may also be given written instructions or photographs showing how to change your stoma bag which some people find helpful.

For some people with a stoma it will be important not to lift heavy things because doing so increases the risk of causing a hernia around the stoma. A hernia is when a part inside of your body pushes through a weakness in your muscle or tissue. This is because there's a potential weakness in the area around the stoma which means the tummy muscles can bulge out and form a lump or swelling. Hernias are very common and don't tend to cause symptoms but your stoma nurse will talk to you about whether this is a risk for you.



What if I'm having problems with my stoma?

It can take some time to get used to having a stoma but it's important that you feel as comfortable as possible when wearing the bag. If you have any problems or concerns you should always speak to your stoma nurse. These may include:

- Changes in the size and shape of your stoma or how it works
- Unusual symptoms including bleeding or tummy pains
- Concerns around changing your stoma bag or stoma care



How it felt for me

"From a practical point of view I haven't had many issues. My product supplier has been great, the stoma nurses have been great if I've had to call them (which fortunately hasn't been often) and I've had the occasional blockage, which is awful, but I've managed."

Janet

"A new stoma is noisy while it settles – you can't hide the noise and you have no idea it's on its way! I just told my friends that I had a bag and when it blew raspberries, we all laughed and moved on."

Annette



Good to know

“I had a stoma nurse visit me regularly at home for the first few weeks to check how I was coping, how the stoma was healing, whether I’d got the best bags for my needs and how to set up ordering supplies for myself.”

Annette

“Many of the stoma product companies also employ stoma nurses. Obviously they have their products in mind but these nurses are professional and can be a great help.”

Irene

“It’s quite a culture shock when you initially start dealing with the whole process yourself. But you get quicker with the cleaning and changing process and it just becomes part of you.”

Natalie

Common stoma questions answered

I'm worried it will smell. What can I do?

Stoma bags are odour-proof so your stoma won't smell as you go about your day-to-day activities. There will be a smell when you're emptying or changing your stoma bag – but everyone makes smells when they go to the toilet! If you're still worried about smell there are odour neutralisers available which can be put inside your stoma bag and can help you feel more confident. These are drops or granules that help to reduce any smell.

How can I be sure the stoma bag is watertight? What if it leaks?

Stoma bags are watertight and once you find one that suits you, you should have very few problems with leaking. While you're getting used to your stoma it's normal to have worries about how watertight your stoma bag is and the thought of it leaking can be embarrassing and upsetting. But there are lots of different types of stoma bags and all of them are specially designed for their purpose.

Your stoma nurse will work with you to find the right bag for you. As you recover from your operation, or if you change weight, you may need to adjust the fit of your stoma bag as your stoma may change size. But your stoma nurse will be able to help with all of this.



“On the second day I had a disaster: I was sitting in the chair beside my bed when I was aware of the most awful smell and I felt extremely wet. My bag had completely opened and leaked! I felt so embarrassed and sorry for the nurse looking after me. I don't think she knew where to start – me, the chair or the floor! But she was so relaxed and kind: she had seen it all before. And that was my only extreme experience of a leakage.”

Pauline



Good to know

“You'll be encouraged to shower as normal while in hospital, with the bag on. This can seem daunting but the adhesive copes well with water, and once your surgery wounds have healed you can bathe at home with it on too.

One of the biggest things is the worry of an accident in public – it can really hold you back at first but once I had the right bags there was no holding me back. I've been swimming, I go to exercise classes twice a week and I went on almost every ride at Disneyland Paris. I've never worn any “special” garments for those or any other activities.”

Annette

Is there anything I should or shouldn't eat or drink?

You should be able to eat and drink lots of the same things as before your operation, but everyone reacts to food and drink in different ways.

There may be certain things you're told not to eat or drink depending on the type of stoma you have. In general you should aim to eat regular well-balanced meals and drink lots of water, particularly in the first few weeks and months after your surgery. Remember that the consistency of your poo can change and you can still become constipated (find it difficult to poo) or have diarrhoea (loose, watery poo).

Some drugs, including painkillers, can cause constipation so you may be told to eat more fibre (such as wholemeal and wholegrain breads, cereals and pasta) to help with this. You might also find that certain foods or drinks (such as alcohol) produce more wind from your stoma than others. Some foods are also harder to process (such as apple peels or nuts). It might help to keep a food diary to look for patterns and symptoms so that you can work out the best balance of food and drink for you.



“My stoma nurse advised me of the dos and don'ts but I told them I was going to try what I'd normally eat and drink with a food diary and extra stoma bags (I'm not one for rules!) We've had a few giggles! When I tried fizzy drinks, my bag popped with the gas (it was empty!) and nuts are not the best. I struggle with white bread and foods that cause wind as everyone can hear! But everyone reacts to foods differently. I can eat salads and fruit, which others can't.”

Helen

Irene's top tips

1

Most people think they drink lots of water when in fact they don't! I kept count of the number of glasses I drank and aimed for a daily target.

2

I found that eating soft apricots or drinking prune juice were simple ways to ensure that the poo stayed soft enough to pass easily.

3

I was very conscious of it causing a problem with my clothing but it was fine. At first tunic tops were a blessing, with stretchy leggings!

Do I have to wear different clothes?

No. You may find that tight clothing is uncomfortable for a little while after your operation but most stoma bags are quite small and are designed to be worn under normal clothes. There are also smaller stoma bags which may be suitable for when you're swimming, playing sport, for intimate moments or when having sex.



“As my stoma opening is on my waistband I feel more comfortable in elastic waistbands. I wear longer t-shirts when going to Zumba or the gym so when I reach upwards I'm covered and confident.”

Helen



What else do I have to consider?

It can take time to get used to having a stoma and there will be some days when you find it easier to cope than others. Be kind to yourself. Allow yourself the time you need to rest and recover from your operation and to learn about caring for your stoma. There will be changes to your day-to-day routine when you have a stoma but with time these will become second nature. For example, at first it may be worrying to go out and meet up with other people but you will soon know how many extra supplies to take with you and where you feel comfortable changing your bag. Remember that this is a new experience for you and learning new skills takes time.



“For a while I did feel quite alien to my friends knowing I was the only one wearing a bag. I had no hair, no eyebrows, no eyelashes, massive weight loss, wearing a bag... But it wasn't going to hold me back. They were all great and said, “Nobody would know it was there!”

Pauline

Is a stoma permanent?

In many cases of ovarian cancer a stoma is intended to be temporary (only for a limited amount of time). This means that at some point in the future you may be able to have more surgery that means you no longer have the stoma. It's important to remember that all cases are different and you would need to discuss your situation with your surgeon and healthcare team.



How it felt for me

"Yes, there were dark days but once I recovered from the surgery, every day was a step closer to getting my life back on track.

Later on, my surgeon felt I was strong enough to have a reversal performed – no more bag! The surgery went ahead and once I was awake and aware, the thought kicked in that I must retrain my brain and body to realise 'I have to use my bowel again in the normal manner'. It was terrifying! What if it didn't work or I had damaged what the surgeons had done?

It took a few days to get everything functioning and it was very up and down: it was a case of being patient. I was very poorly for a month and I thought I'd made a big mistake having the surgery. But suddenly it all changed and I've never looked back."

Pauline

Where can I find out more?

- Colostomy UK provides support, information, reassurance and practical advice to anyone who has had or is about to have stoma surgery in the UK. They also have a free to call 24-hour Stoma Helpline, which offers experience-based support from volunteers (all of whom have or have had a stoma), and a private Facebook support group. Call **0800 328 4275** or visit **colostomyuk.org**
- The Ileostomy and Internal Pouch Association supports people living with an ileostomy and their families, friends and carers. Visit **iasupport.org**
- Your CNS or stoma nurse will be able to help you find further information including stoma support groups in your area.

More support from Target Ovarian Cancer

- Target Ovarian Cancer's nurse-led support line offers confidential information, support and signposting for anyone with questions about ovarian cancer. You can call us on **0808 802 6000** (Monday – Friday from 9am to 5pm) or visit **targetovariancancer.org.uk/supportline**
- Our guides for anyone with ovarian cancer offer expert advice, practical information and emotional support on a wide range of issues at all stages. You can order or download your copies online for free at **targetovariancancer.org.uk/guides** or by calling **0808 802 6000**
- We also run regular information and support events as well as online communities where you can speak to others affected by ovarian cancer: **targetovariancancer.org.uk/support**

“ I’m coming up to seven years with my stoma. **Be kind to yourself and give yourself time**, you’re not on your own. I can’t believe how many people are living with stomas.

Use your stoma nurses for support. Be prepared for friends not to understand how it works and have questions for you. I answer them and show them my spares that I take out!

I’m now at the stage where **I do everything I did before my ovarian cancer and my stoma.** It doesn’t have to be a negative experience.”

Helen




When you need information, friendly support or someone to talk to that understands, our specialist nurses are here.

**We're open 9am–5pm, Monday–Friday.
Call us on 0808 802 6000**



Get in touch for more information, support and signposting for anyone affected by ovarian cancer:

 0808 802 6000

 info@targetovariancancer.org.uk

 targetovariancancer.org.uk

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