



Ovarian cancer and stomas

When ovarian cancer is more advanced at the time of diagnosis it will sometimes have spread to the surface of the bowel (intestine). 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 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) is then collected in a stoma bag which is attached to your abdomen (tummy).

"Just before going into theatre for my ovarian cancer surgery, my consultant and her anaesthetist came to discuss things with me. Here came the first news of, 'You may wake up with a stoma bag attached.' Because I was concentrating on going into theatre for hours I'm sure my response to this statement was just, 'OK!'"

Pauline



"I was only told the potential risk of having a stoma in my pre-op meeting. I was quite taken aback and distressed, particularly as my doctor went through the list of all potential risks just like a shopping list, without explanation."

Janet

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 is 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 (usually 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 6.) It is not unusual to need one stoma but some people may need two stomas if their cancer has spread to different parts of their bowel. 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

"At my appointment with my surgeon I was told that I was told that there was a 70 per cent 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! When I was shown a model I was horrified. I did find 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."

Helen



through this surgery so they will understand your concerns and want to help you prepare. They will be able to explain in detail what is involved and how you look after a stoma. They may also be able to help choose a position on your abdomen (tummy) for the stoma which suits your body shape, life and the clothes you wear. Although it can be daunting 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 that can be so hard.

Sometimes a surgeon will not know that you need a stoma until they are 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 is something you are worried about. Your Clinical Nurse Specialist (CNS) or stoma nurse will help you cope after the operation and show you how to look after your stoma and adjust to having one.

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

Annette



"It's worth mentioning that the new stoma is anchored with big stitches which can be quite disconcerting to see for the first time. But your stoma nurse will remove these when they're ready."

Annette

"It can be quite frightening when you first see it."

Pauline

What does a stoma look and feel like?

Does it hurt?

Most stomas will be a pinkish-red colour and moist to touch (like the inside of our mouths) but everyone's will be different in size and shape. There are no nerves in a stoma so it won't hurt to touch. A new stoma will be swollen for six to eight weeks after the operation but the swelling will go down and the stoma will normally get smaller.

"The easiest way to describe it is, do an 'ooh' shape with your lips and look in the mirror! The shape and pinkness is about correct."

Helen

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 is given depends on which part of the bowel your surgeon needs to use. A **colostomy** is formed from the large bowel (colon) and an **ileostomy** is formed from the small bowel (ileum). In both cases the open end of the bowel is sewn onto the skin and called a stoma.

"After my operation I woke in critical care to be met by a colorectal surgeon who told me that he had had to remove my intestine and I now had a permanent ileostomy."

Janet

How does it actually work?

Your bowel will still work as normal but the faeces (poo) will be diverted 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 faeces (poo) contained as they are expelled from your bowel. The stoma bag will need to be emptied and/or changed from time to time. 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.

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

Pauline

"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



How do I learn to cope with a stoma?

Although having a stoma is not uncommon, having a stoma in addition to an ovarian cancer diagnosis is a huge event for anyone. Some people find the prospect of having a stoma more difficult to cope with than their ovarian cancer diagnosis.

You are not alone: there is help and support available.

"I'd suggest finding out lots of information about stomas by looking at the various websites from the expert stoma organisations. I also joined Facebook groups but didn't find them helpful. When I learned more I realised that some of the advice given by Facebook members wasn't right."

Irene

"I cried for a long time. I kept trying to accept that they had to remove the intestine to remove the cancer, but it was so difficult."

Janet

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 pleased 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.

"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

Some people find it helps to talk to others who understand what it feels like to have a stoma.

You might want to 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 booklet.



"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."

Pauline

"No, I didn't enjoy having my stoma. Especially wearing the bag in the heat of summer. But I treated it 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

"Where I had my surgery, the hospital won't discharge you until they are 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 mustn't 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'. 'Fine!' I screamed, "How would you like to s*** out of a hole in your tummy?!" I was so angry and upset but that release of anger helped me. 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



“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.”

Pauline



How do I look after my stoma?

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Your stoma nurse will show you how to look after your stoma including changing your stoma bag and disposing of used bags.

Remember to ask questions if you are unsure about anything: no question is too ‘silly’ or too small. Be patient with yourself as you adapt 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 (when an internal part of your body pushes through a weakness in your muscle or tissue) around the stoma. This is because there is a potential weakness in the area around the stoma which means the abdominal (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.

“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. I had a complete muck up with my supplies on discharge from hospital and was fortunate enough to have a supplier nurse nearby who came to my assistance.”

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. At the end of the day, you have to get on with it.”

Pauline

What if I'm having problems with my stoma?

It can take some time to adjust 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 (such as changes in the size and shape of your stoma or how it works; unusual symptoms including bleeding or abdominal (tummy) pains; concerns around changing your stoma bag or stoma care etc.) you should always speak to your stoma nurse.

"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

"It took three attempts with my nurse to find the right size bag in shape and length. I also became extremely raw and stinging around the stoma so she gave me an additional ring to add to the bag and some powder to dry the area up. This worked well most times."

Pauline

"I think people also ought to know that a new stoma is noisy while it settles – you can't hide the noise and you've 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



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 are emptying or changing your stoma bag – but everyone makes smells when they go to the toilet! If you are still worried about smell there are odour neutralisers available which can be put inside your stoma bag and can help you feel more confident.

"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."

Annette

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

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Stoma bags are watertight and once you find one that suits you, you should have very few problems. While you are getting used to your stoma it is normal to have worries about how watertight your stoma bag is and for many women, the thought of a leakage 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

"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 are 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 or have diarrhoea.

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, and some foods are 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.

"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."

Irene



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

Irene

"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

"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!"

Pauline

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 are 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 inevitably 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 too daunting to go out and socialise but you will soon know how many extra supplies to take with you and where you feel comfortable changing your bag. You may even surprise yourself with how confident you become. Remember that this is a new experience for you and learning new skills takes time.

"Psychologically I still struggle with having a stoma and I can honestly say I've cried more over that than my continued battle with ovarian cancer. I cannot talk about my stoma without tearing up. My Clinical Nurse Specialist (CNS) has recommended things to help manage my emotions; I still feel I have pent up feelings which hopefully one day will subside."

Janet

"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

"My surgeon felt that 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

Is a stoma permanent?

In many cases of ovarian cancer a stoma is intended to be temporary. This means that at some point 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 individual case with your surgeon and healthcare team.

"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."

Pauline

Where can I find out more?

- Target Ovarian Cancer's nurse-led Support Line provides confidential information, support and signposting for anyone affected by ovarian cancer – **020 7923 5475** or **targetovariancancer.org.uk/supportline**
- 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 24-hour stoma Support Line which offers experienced-based support from volunteers, and a closed Facebook group – **0800 328 4275** or **colostomyuk.org**
- The Ileostomy and Internal Pouch Association supports people living with an ileostomy and their families, friends and carers – **iasupport.org**
- Your Clinical Nurse Specialist (CNS) or stoma nurse will be able to help you find further information including stoma support groups in your area so don't be afraid to ask.

"I'm coming up to three years with my stoma. Be kind to yourself and give yourself time, you are not on your own. I can't believe how many women and men 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

Find out more

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



Support Line: 020 7923 5475



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targetovariancancer.org.uk

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