Living with an Ileostomy
Essential advice for before and after your operation

The Coloplast story began back in 1954. Elise Sørensen is a nurse. Her sister Thora has just had an ostomy operation and is afraid to go out, fearing that her stoma might leak in public. Listening to her sister’s problems, Elise creates the world’s first adhesive ostomy bag. A bag that does not leak, giving Thora – and thousands of people like her – the chance to return to their normal life.

A simple solution with great significance.

Today, our business includes ostomy care, urology and continence care and wound and skin care. But our way of doing business still follows Elise’s example: we listen, we learn and we respond with products and services that make life easier for people with intimate healthcare needs.
Your ileostomy…

Having any operation can be an emotional experience but being well prepared can help you to know what to expect. Whether your operation was planned or an emergency, this booklet has been specially written to answer some of the questions often asked about having an ileostomy and can also act as a quick reference guide for later on.

...we’re here to help

The first thing you can be assured of is that you will have lots of support. Your care team includes your surgeon, your Stomal Therapy Nurse and many other healthcare professionals. We are all here to give you, your family and carers, help and advice both before and after your operation, while you are in hospital and when you go home.

It’s natural to have lots of questions so, no matter how small it may seem, if you have any concerns please ask a member of your care team. They will be more than happy to help.

The information contained in this booklet is general and some of it may not apply to you. Inevitably there will be some issues that this booklet doesn’t address or that you would like more information about.

So in addition to this booklet, at Coloplast we’ve developed a number of other resources to help you through your experiences. For complimentary copies please call us on:

Australia - 1800 653 317
New Zealand - 0800 265 675

This booklet has been produced by Coloplast with content reviewed by Bowel Cancer Australia’s Stomal Therapy Nurse.

Coloplast is a proud supporter of Bowel Cancer Australia, a national charity working to reduce the impact of bowel cancer in our community through advocacy, awareness, education, support and research. To do all this Bowel Cancer Australia relies on public support. If you would like to get involved or make a donation, please visit bowelcanceraustralia.org
Understanding your digestive system

Having any type of surgery can feel daunting. So, to help you understand what is involved in your operation, we’ll first take a look at your digestive system and describe how it works.

Have a look at the diagram of the digestive tract and starting at the mouth follow it all the way down to the anus.

When you eat or drink, the food travels down a long, narrow tube called the oesophagus (food pipe) into your stomach. Once here, the food is churned into smaller pieces and liquidised by the digestive juices in the stomach. The journey continues as the contents of the stomach move into the small bowel (ileum). Here digestion finishes and your body begins to absorb, via your bloodstream, the nutrients it needs for energy, growth and building new cells.

The residue from digestion, very importantly, leaves waste and roughage behind. This is the initial making of faeces or stools. This material then moves forward into the large bowel (colon) where your body absorbs more fluid to make the faeces more solid. The muscles in your colon wall then push any faeces forward into your rectum where it passes out of your body through your anus.

What is an ileostomy?

The type of stoma you will be having is called an ileostomy. During your operation, part of your small bowel will be brought to the surface of your abdomen to form a stoma (opening). If possible, you may be able to agree on a site for your stoma with your Stomal Therapy Nurse before your operation. This is usually made on the right-hand side of your body, but may in some circumstances be on the left-hand side.

What difference will having an ileostomy make?

When an ileostomy is made on your abdomen it alters the usual way you go to the toilet to pass faeces. After surgery, instead of coming out through your anus, your faeces will pass through the stoma instead. The traditional way you pass faeces is controlled by a special sphincter muscle in the anus. However, the main difference you will notice when you have a stoma, is that you will no longer be able to hold on to or have control over, when you pass faeces. You will also not have any control over when you pass wind or flatus.

Ileostomy bags are specially designed to help you with these challenges, so that you can live life to the fullest!

“Your surgeon and Stomal Therapy Nurse will explain the type of surgery you’ll be having and why you need to have a stoma”
What will the stoma look and feel like?
The stoma will be moist and pinkish red in colour and will protrude slightly from your abdomen. It may be quite swollen to begin with but will reduce in size over time – usually after 6-8 weeks. Despite being red, there is no sensation in the stoma and it’s not painful.

Why do I need an ileostomy?
Your surgery may need to be performed for a number of different reasons and your surgeon and Stomal Therapy Nurse will explain all of this to you. An ileostomy may be an end or loop ileostomy.

End ileostomy
An end ileostomy is formed when part of the large bowel (colon) is removed and the end of the small bowel is brought out as a stoma. This can be temporary or permanent. An end ileostomy can also be formed due to a disease in the last part of the ileum.

A pan-procto colectomy involves removing the colon, rectum and anus and forming a permanent end ileostomy.

A total colectomy is where the whole colon is removed. The rectal stump is retained and an end ileostomy is formed. This can be temporary or permanent.

Formation of an end ileostomy
1. An artificial opening is created in the abdomen and the end of the intestine is pulled up through the abdominal wall and layers of skin.
2. The intestine is folded back to form a cuff.
3. The cuff is stitched to the abdomen to keep the intestine in place.
4. An end stoma is formed.

Loop ileostomy
A loop ileostomy is created when a loop of the small bowel (ileum) is brought out as a stoma. This allows the colon to heal after part of the colon (due to disease or obstruction) is removed and the two ends of the colon are joined together.

Faecal material comes out of the active end of the loop ileostomy and if it is particularly watery it may spill over into the adjacent inactive end, therefore you may pass some faecal matter from the anus from time to time.

This can be a temporary stoma and may be able to be closed/reversed at a later operation.

Formation of a loop ileostomy
1. An artificial opening is created in the abdomen and a loop of intestine is pulled through the abdominal wall and layers of the skin. A bridge is placed through the loop to rest on the skin and keep the intestine in place.
2. The intestine is cut, folded back and stitched to the skin.

Your operation is called
Your Stomal Therapy Nurse can show you on the diagram which part of your digestive system will be affected by your operation.
Why do I need to wear a bag?
After your operation your faeces will pass out through your stoma instead of your anus. However, unlike your anus, there is no sphincter muscle around the stoma, so you’ll have no control over your bowels or when you pass wind or flatus and you will need to wear an ileostomy bag (or pouch) to collect the output.
Initially after your operation you will find that the output from the stoma may smell stronger and will be more liquid, or looser, than you are used to. However it will never be any thicker than ‘toothpaste’ consistency and may become more watery depending on your diet.
It is important to avoid dehydration particularly if the output is watery so adequate fluid intake is essential especially during the summer when you perspire more.
There are several different types of ileostomy bags and your Stomal Therapy Nurse will show you ones that are most suitable for you.

How does an ileostomy bag work?
The bag is designed to stick onto your abdomen where it will collect the faeces and flatus from your stoma.
A ileostomy bag has several special features including a filter. This filter works by releasing wind so your bag doesn’t inflate (which is called ‘ballooning’). The filter also has a deodorising action which makes sure that the smell is minimised, the one thing that people often worry about the most.
The bag is waterproof so you can wear it whilst you are in the shower or bath.

How can my Stomal Therapy Nurse help?
Your Stomal Therapy Nurse is a qualified nurse with additional training in all aspects of stoma care who will be able to help you and your family before, during and after your operation.
Depending on your circumstances, your Stomal Therapy Nurse may be able to help you to decide on a suitable site for your stoma before your operation. This is important as it can affect the care of your ileostomy and issues such as the type of clothes you wear.
Your Stomal Therapy Nurse, along with many other healthcare professionals, will provide you with as much help as you need, for as long as you need it – not only while you are in hospital but also after you have gone home.

“I felt quite emotional before going into surgery, but knowing what to expect and that there would be a whole team taking care of me really helped”
How will I feel after my operation?
Following surgery it’s not surprising that you will feel weak. You may go through a whole range of emotions and this will vary from person to person. It’s important to remember, emotionally and physically, it may take a while for you to recover and to get back to feeling like yourself again.

What should I know?
When you wake up after the operation you’ll be wearing your first bag. This will probably be a clear one so that your nurses will be able to check on your new stoma easily. At first your stoma may be swollen but it will gradually decrease in size over several weeks.
You may also have drips and drains attached to your body and there may be a ‘bridge’ (supporting rod) which goes underneath the stoma to support it for the first few days. Please don’t be alarmed as these are all routine procedures and will be removed with very little discomfort when appropriate. Your doctor will advise you when you will be able to eat and drink as usual.

When will my stoma begin to work?
Your stoma will begin to work shortly after your operation, usually within a few days. At first the output will be watery and may have a strong smell given your bowel hasn’t been working for a while. Occasionally the output may be mixed with a little blood. Initially, it is also likely that a certain amount of noisy wind (or flatus) will come from the stoma, again this is perfectly normal and will settle.
It is not uncommon for patients who still have some lower bowel (rectum) to feel the need to go to the toilet as they did before. This is normal and should reduce with time. You may pass some old blood and mucus. It may help to sit on the toilet to help pass the mucus.

“Please ask about anything that may be bothering you, particularly in these early days. You can be sure that your concerns would have been raised before”
What happens when the bag needs emptying?
In the first few days after your operation you’ll wear a clear bag, but you can then move onto an opaque bag. The faeces are often quite watery when the stoma first starts to work after the operation. Your nursing staff will help with emptying the bag, and other tasks, until you are ready and have learnt how to do it for yourself.

Will I always have to wear a bag that needs emptying?
Yes. The output will never be thicker than a toothpaste consistency.

How do I change my bag?
It’s a good idea to begin to establish a routine for changing your bag and to try and keep this as simple as possible. As you get used to your stoma you will find that at certain times of the day it’s more active than others, for example shortly after a meal. Don’t choose this time to change the bag but select a time when it’s relatively inactive – perhaps first thing in the morning. Before starting to change the bag make sure you have everything to hand that you will need. Just like everything else in life, a little bit of forward planning can help a lot – you may find our ‘Changing guide’ on page 13 a useful reminder.

How often do I need to empty or change my bag?
This will vary from person to person. The stoma bag only needs to be changed when required – generally an ileostomy bag needs to be changed every other day and emptied an average 5-6 times per day, but this depends on the amount of faeces and how often you open your bowel.

“Your Stomal Therapy Nurse will teach you how to look after your stoma and change your bag – it really is quite simple when you get used to it”
What sort of bag should I choose?

Generally, with an ileostomy you will need to use a drainable bag. There are many different drainable bags available and your Stomal Therapy Nurse will be able to help you choose the most appropriate one for you.

For example, you may wish to move away from the clear bag fitted immediately after your operation to an opaque bag.

Stoma bags

There are two main types of systems:

One-piece system

This consists of the collection bag with an integrated baseplate attached which firmly fits around your stoma.

Two-piece system

This has the collection bag separate from the baseplate and the two parts are securely clipped or sealed together. This means that you don’t have to remove the baseplate from around the stoma every time you change the bag.

How should I dispose of used bags?

If you are using a drainable bag, it’s recommended that you empty the bag before you remove it. Then seal the bag inside a disposable bag and place in the bin.

DO NOT flush it down the toilet, as it will cause a blockage.

If you are using public disabled toilets they should have suitable facilities. You can also use nappy changing bins or sanitary bins if available.

Both systems will be kind to your skin, lightweight, leak-proof and odour proof which means that they will be virtually undetectable to anyone else so you can carry on with life as normal. The bags are available in a variety of sizes to suit your specific needs.

“Be careful not to store your bags in direct sunlight or near heat, as this can make them deteriorate”
Changing guide
Before you start, check that you have everything you need:
• soft wipes • warm water • a plastic disposable bag • a new stoma bag • scissors (if required)

Cutting
Trace the size and shape of the stoma and cut the hole to fit the stoma. To reduce the risk of leakage and skin problems it is important that the hole fits perfectly around the stoma.

Closing the outlet
Place the bag on a table with the baseplate pointing downwards. Bend the lower, small plate over the upper, large plate of the outlet. Fold the outlet twice until the velour plate is in line with the velcro ears. Seal the outlet by folding the velcro ears onto the velour plate and press firmly.

Removing protective film
Ensure that the skin is clean and dry before you apply the bag. Place a thumb on the white tab on the baseplate and pull the blue release tab away from the baseplate to remove the protective film.

Application
To ensure a perfect fit around the stoma fold the bag backwards, press firmly against the skin starting at the bottom and smoothing upwards with your fingers.

Emptying the bag
Open the outlet in the position where you want to empty the bag. Allow the contents to run out while you control the emptying with your fingers.

Cleaning the outlet
With a tissue or dry wipe clean the tip of the outlet in one sliding movement away from your body. Next you need to clean the edge of the outlet. Fold the small plate backwards so that only the large plate is visible. Clean the edge of the outlet with a tissue or dry wipe. The outlet is now clean and ready to be closed again.

Removal
Take hold of the white tab on the baseplate and gently pull the bag away from the skin. With your free hand apply light pressure on the skin as you peel the baseplate downwards.

Applying a two-piece system
Apply the baseplate as described above.

Bags with mechanical coupling - SenSura® Click
Ensure the mechanical coupling is open. Press the bag and the baseplate together starting at the bottom. Make sure the bag is securely positioned on the coupling and lock the mechanical coupling, when locked correctly you will hear a ‘click’ sound.

Bags with adhesive coupling - SenSura® Flex
Gently place the bag at the bottom of the baseplate without any pressure or pulling. Then apply light pressure on the bag and baseplate with your fingers to ensure a perfect fit around the stoma.

“It’s advisable to carry a spare changing kit with you when you go out”
What else should I know?

The baseplate and your skin

The adhesive baseplate is the most important component of an ostomy appliance. Its primary role is to help maintain healthy skin around the stoma. Coloplast worked together with Stomal Therapy Nurses and ostomates when developing this latest ostomy appliance, SenSura®. In this collaboration, Stomal Therapy Nurses and ostomates identified the five *must have* parameters in a baseplate. These are:

1. **Flexibility** to ensure the baseplate follows the natural movements of the body, so it does not loosen from the skin
2. **Ease of removal** to be able to remove the baseplate without damaging the skin or causing pain
3. **Erosion resistance** to prevent the baseplate from dissolving, so that the skin is protected from output
4. **Absorption** to absorb excess moisture from the skin and prevent the baseplate from loosening
5. **Tack and adhesion** to make the baseplate stick securely and protect the skin from output

SenSura is the first ostomy appliance scientifically proven to maximise all of these benefits. This means you live life to the fullest. Please ask your Stomal Therapy Nurse if SenSura is suitable for you.

Where necessary, Brava accessories are available to reduce the risk of leakage. Your Stomal Therapy Nurse can advise you which if any accessories are appropriate for you.

* Please note: some products may not be available in New Zealand.
How do I obtain supplies?

In Australia
After leaving hospital, your local Ostomy Association will supply your ostomy products. You have the option of having the products mailed directly to you or visiting the Ostomy Association and picking up the products personally. Your Stomal Therapy Nurse will register you with your local Ostomy Association and order your products.

In New Zealand
Your Stomal Therapy Nurse will discuss with you how to organise your ongoing supply of ostomy appliances after being discharged from hospital.

Do I need a special diet?
No. Just like everyone else, you should eat a well balanced diet, and this can include all of your favourite foods.
You may find that if you eat large meals within the first 2-4 weeks following surgery you may feel bloated. Initially you should try to eat little and often and then gradually build this up to 3 meals a day. This is because regular meals will help you have a more predictable bowel movement.

Your Stomal Therapy Nurse may also recommend a high-energy protein drink for you.
You will find that certain foods may produce more wind than others, and if this bothers you then simply cut down on these foods. Alcohol is fine in moderation, although beer and lager can produce wind and cause the output from the stoma to become more liquid. With a little experimentation you will soon find a balanced diet that's right for you. It is particularly important to remember to chew the food properly in order to give a good start to the digestive process. Foods such as peanuts, are notoriously difficult to digest and should be avoided, or at least eaten in moderation and thoroughly chewed.

Just like anyone else you can pick up a stomach bug which can increase your ileostomy output and cause dehydration. If this happens and you are unable to tolerate oral fluids you will need to seek medical assistance. As you are losing more fluids and salts these will need to be replaced.

Please speak with your Stomal Therapy Nurse if you require additional information on nutrition.
Bowel Cancer Australia provides the services of a dietician to answer any further questions you may have regarding your diet.

“When you go home there is no reason why, with time, you will not be able to resume the life you were leading before the operation”
Will I still be able to travel?
Consult with your surgeon when ready to fly due to the increased risk of Deep Vein Thrombosis (DVT), and it’s also important to check your travel insurance. However, apart from that, there is no reason why having an ileostomy should restrict your ability to travel in any significant way – whether in your country or abroad, for business or pleasure. Just remember to pack all of the things you will need for the journey and make sure that you have enough supplies for the duration of your time away. If you are flying, don’t forget to divide up your supplies between your main and hand luggage to allow for lost luggage or delays.

Should I still exercise?
Exercise is good for everyone and just because you’ve had a ileostomy you are no exception. It is very likely that any exercise you enjoyed before the operation will also be suitable to continue afterwards. Special small bags/mini caps are available for use when swimming and playing sport so there is no reason to feel like you can’t join in.
Obviously you will need to start with gentle exercise at first but you will soon be able to do just as much, if not more, than before.

What about sex?
This very much depends on the nature of the operation you’ve had. Generally, a normal loving relationship can be resumed although impotence and/or discomfort may result from the removal of the rectum and may affect women as well as men.
It’s important to talk to your partner and try not to feel self-conscious because of the operation. It’s also important to talk to your Stomal Therapy Nurse who is used to discussing such issues and will be able to help in many ways.

Who can I turn to for support?
After having a ileostomy the main aim is to get you back to enjoying life. That means being at home, or at work, or on holiday – not in hospital – and not ‘ill’.
But this doesn’t mean that your specialist care team is no longer there to help once you leave hospital – in fact quite the opposite.
Your Stomal Therapy Nurse, and his or her colleagues, will always be on hand to help you with any problems or questions that you might have.
“Sometimes it’s nice to be able to ask questions of people who have had similar experiences... and the anonymity of the internet has given me the confidence to do just that.”

“Do you have questions regarding ostomy care?  
“Do you have experiences that may benefit others?  
“Would you like to expand your support network?  

Ostomates.com.au is an online support network for people with a stoma. Share your story, find support and talk to others online.

Join our conversation
Coloplast Customer Care
At Coloplast we pride ourselves on continuing our long tradition of partnering with Stomal Therapy Nurses and ostomates. An example of this collaboration is the development of SenSura, the first scientifically proven ostomy appliance that maximises all the key features of a superior baseplate.

For ostomates we have a vast array of resources including websites, product information booklets, instruction leaflets, stoma sizing guides... to name a few!

If you would like more information on the resources available please give us a call.

Australia - 1800 653 317
New Zealand - 0800 265 675
au.care@coloplast.com

Your local Stomal Therapy Nurse is

_____________________________________________________________________________

_____________________________________________________________________________

Your ostomy association is

_____________________________________________________________________________

_____________________________________________________________________________

Your local support groups are

______________________________________________________________________________

______________________________________________________________________________

Notes

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

A big thank you to all of the people with a stoma who helped us by sharing their experiences.

Body shapes change over time exposing you to an increased risk of leakage and skin irritation.

In fact, over 60% of people report leakage whether they have had their stoma for 6 months or 6 years.**

That’s why it’s important that you regularly check the fit of your ostomy appliance.

Now with BodyCheck you can take control and stay sure of your ostomy solution...

Developed in collaboration with Australian Stomal Therapy Nurses, BodyCheck is an innovative online resource that enables you to assess your individual profile and find the products that best suit you. By answering 8 simple questions, confidence in your ostomy appliance is just a few clicks away.

Easy to understand language and diagrams
BodyCheck animations will help you to select and use products that are appropriate for your body profile.

www.bodycheck.coloplast.com.au

*Coloplast market research 2010

**Coloplast market research 2010