



YOU AND YOUR ILEOSTOMY SURGERY

Essential advice for before and
immediately after your operation



Ainscorp



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INTRODUCTION

You have been given this booklet because it is likely that you are soon to have an ileostomy formed. The booklet has been written to help explain what an ileostomy is and what it will mean to you once you have had your operation.

- ▶ SECTION 1: **INFORMATION TO READ PRIOR TO YOUR SURGERY**
- ▶ SECTION 2: **HELPFUL INFORMATION FOR YOUR RECOVERY PERIOD**
- ▶ SECTION 3: **OTHER HELPFUL ADVICE**
- ▶ SECTION 4: **STOMA NURSE – YOUR BEST RESOURCE**

Everyone is different and will want to read what they feel is most useful to them. We recommend you read the first section and perhaps have a look ahead to what you can expect when you wake up after your surgery. You may want to leave the remaining sections until you are at home and feeling a bit better. It is completely up to you.

This booklet has been written by a team of Stoma Nurses, who have many years of experience in looking after people living with an ileostomy.

There are a number of **Frequently Asked Questions**, which may not have been covered in the two sections of this booklet. These are included on page 30. If you can't find the answer to any of your own questions in the booklet, please contact your Stoma Nurse.

At the back of the booklet you will find a **Glossary of terms**. This includes a number of words, some of which are medical terms, along with their meanings. We have also included alternative words that you might hear to describe some of the terms.





SECTION 1

YOUR STOMA AND SURGERY

Information to
read prior to your surgery

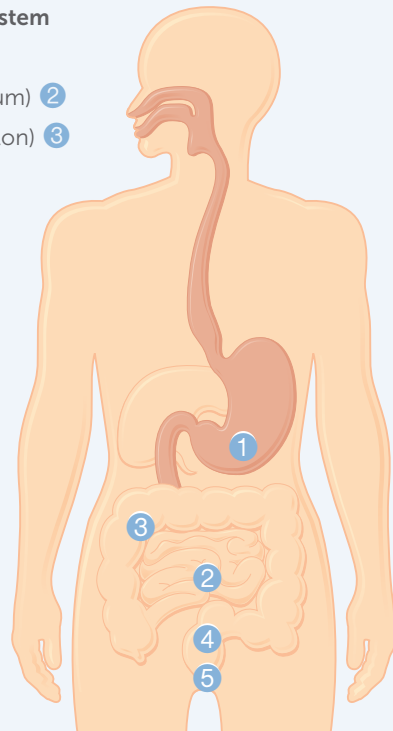
1. YOUR STOMA AND SURGERY

Your digestive system

Your digestive system, also known as the gastrointestinal system, is part of your body that absorbs and digests food, as well as eliminating the body's waste. Anything you eat or drink is chewed in your mouth before travelling down your oesophagus into your stomach where the food is further broken down by gastric juices. This is then pushed along your digestive system into the small bowel, where the digestion and absorption process continues and your body obtains the necessary nutrients it needs. The waste from this process, along with any fluid, moves into the large bowel. This is then absorbed, turning the waste material into a solid stool. The solid stool is then stored within your rectum and excreted via the anus when appropriate.

The digestive system

- Stomach ①
- Small bowel (ileum) ②
- Large bowel (colon) ③
- Rectum ④
- Anus ⑤



1. YOUR STOMA AND SURGERY

What is a stoma?

Stoma is a Greek word meaning 'opening' or 'mouth'. There are generally three types of stomas:

- ▶ **Colostomy:** from the large bowel
- ▶ **Ileostomy:** from the small bowel
- ▶ **Urostomy:** urinary stoma

A stoma can be either temporary or permanent, depending on the reason for its formation.

What is an ileostomy?

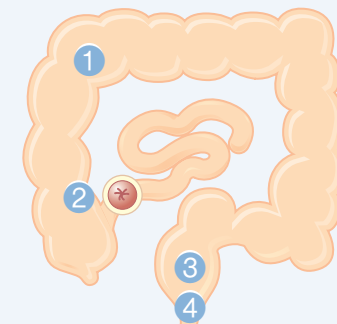
An ileostomy is a surgically created opening from your small bowel to the surface of your abdomen. An ileostomy provides a new path for waste material to leave your body after part of the bowel has been removed. It can produce output varying from liquid stool to a thick, porridge-like consistency. You will either have an end ileostomy or a loop ileostomy.

End ileostomy

This is formed when all or part of the large bowel and/or the rectum are removed. Part of the small bowel is brought out to the surface of the abdomen to create a stoma.

End ileostomy

- ① Large bowel (colon)
- ② Ileostomy
- ③ Rectum
- ④ Anus



The bowel and where an end ileostomy may be formed

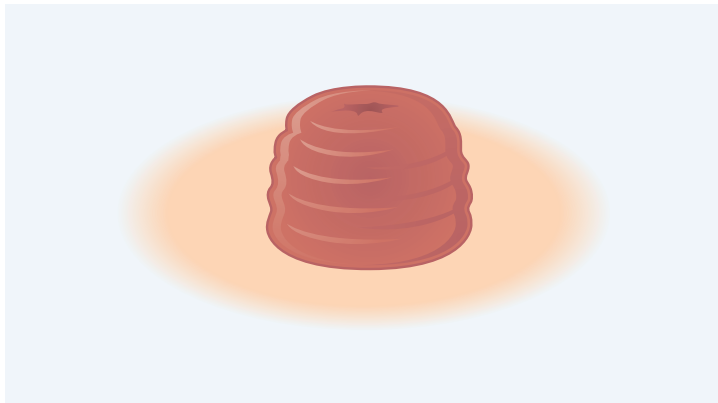


An ileostomy is usually on the right-hand side of your body, but in some circumstances may be formed on the left-hand side.

1. YOUR STOMA AND SURGERY

An end ileostomy can be temporary or permanent. If a temporary end ileostomy is created, a diseased section of large bowel is removed, but the remaining bowel cannot be re-joined at the same time as it is unsafe or inappropriate for your surgeon to do this at this time.

However, it may be possible to re-join your small bowel in the future, and this can be discussed with your surgeon.



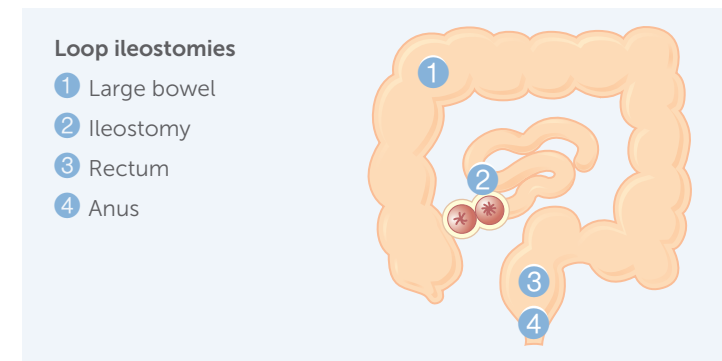
End ileostomy

1. YOUR STOMA AND SURGERY

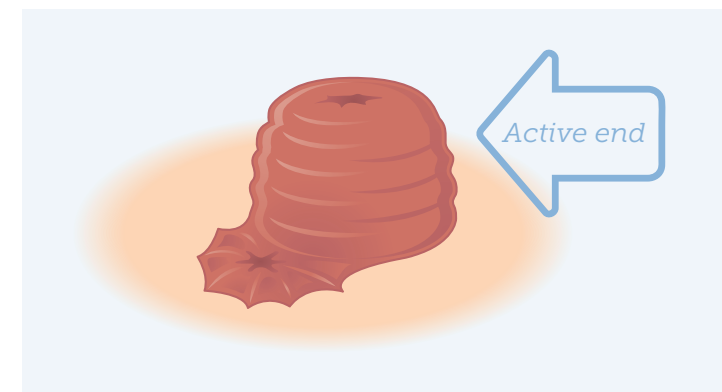
Loop ileostomy

A loop ileostomy is usually created to protect a surgical join in the large bowel or to divert the flow of stool from an obstruction. It is formed when a loop of the small bowel is brought to the surface of the abdomen and opened to form a stoma. This can be temporary or permanent. A loop ileostomy can also be formed to protect the join following reconstruction surgery, such as an ileo-anal pouch.

A loop ileostomy has two openings; only one of these will pass stool. The other may produce mucus.



A diagram of the bowel and also where a loop ileostomy may be formed



Loop ileostomy

1. YOUR STOMA AND SURGERY

Why am I having an ileostomy?

Your operation may need to be performed for a variety of reasons and your Surgeon and Stoma Nurse will explain these to you. There are a number of different diseases and conditions that can result in the need for an ileostomy, such as:

- ▶ Ulcerative Colitis
- ▶ Crohn's Disease
- ▶ Diverticular Disease
- ▶ Faecal incontinence
- ▶ Cancer
- ▶ Trauma
- ▶ Familial Adenomatous Polyposis
- ▶ Radiation damage
- ▶ Congenital abnormalities

Before surgery

You will have the opportunity to meet with the Colorectal Surgeon and Stoma Nurse on one or two occasions before your surgery. This is usually in clinic or at your pre-operative assessment appointment where you will be told about all aspects of your surgery, given written information and most likely be shown ileostomy products. You will be able to take samples home, so that you can familiarise yourself with items you may be using. During your pre-operative appointments you should have time to ask questions and discuss any aspect of your care. You might want to start making a list of things to discuss prior to your appointments to take with you so that you do not forget to ask anything.



It is recommended to take a member of your family or carer with you to your pre-operative appointments, as there is a lot of information to take in.

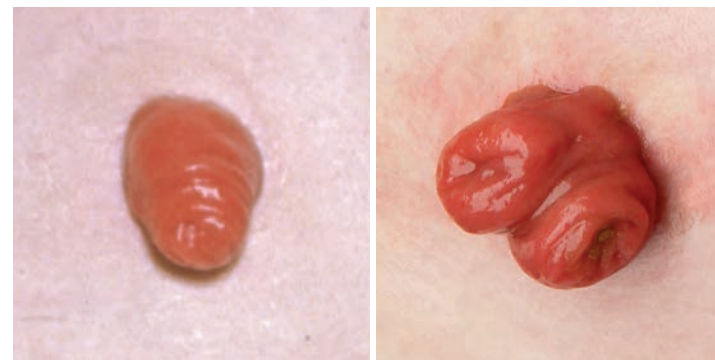
1. YOUR STOMA AND SURGERY

The stoma nursing team will be key throughout your journey and will be available to advise and support both you and your family/carers.

Where possible, your Stoma Nurse will involve you in marking the ideal site for your ileostomy as a guide to the surgeon, taking into consideration your individual needs. However, at the time of surgery, it may not always be possible to put the stoma in the exact position your Stoma Nurse has marked.

What will my ileostomy look and feel like?

Your ileostomy should protrude from your abdomen, like a spout, and this can vary depending on how it is formed by your surgeon. It will be soft to touch, pinkish-red in colour and moist; rather like the inside of your mouth. There is no sensation in the stoma so it is not painful. However, it has a rich blood supply and it is normal for it to bleed a little from time to time, especially when cleaning. Your ileostomy is likely to be swollen at first and will take a few weeks to reduce in size. There will be small stitches around the edge of your ileostomy, which will either be dissolvable or your Stoma Nurse will remove them 1–2 weeks after your operation.



End ileostomy

Loop ileostomy

A young woman with long, wavy brown hair, wearing a light blue V-neck top, is leaning over an elderly woman. She has her hands on the elderly woman's shoulders and is smiling warmly. The elderly woman has short, wavy white hair, is wearing a pearl necklace and a light-colored floral patterned top, and is also smiling. They are in a bright, indoor setting, possibly a hospital or care home.

SECTION 2

AFTER YOUR SURGERY

Helpful information
for your recovery period

2. AFTER YOUR SURGERY

Waking up after your surgery

When you wake up after your operation, you will feel tired. It is possible that you may experience a range of emotions during this time and for some time afterwards. This will vary as we are all different.

Remember that it may take a while for you to recover, both physically and emotionally.

Initially you will be wearing a drainable pouch, which will most likely be transparent or have a viewing window, so that your nurses can check on the colour and size of your stoma easily. The nurses will empty your pouch until you are feeling well enough to do this yourself.

You may have drips and drain tubes attached to your body, but there is no reason to be alarmed – this is quite normal. These will all be removed when appropriate and with very little discomfort.



Drainable pouch and cover

2. AFTER YOUR SURGERY

When will my ileostomy start to work?

Your ileostomy will usually start to work shortly after your operation, and the output will be watery. This will start to thicken to a brown, porridge-like consistency when you start to eat normally. Your output will stay like this as it is no longer passing through the large bowel, where fluid is reabsorbed to create a formed stool.

You will have no control over when your ileostomy works and may not be aware of it happening. Your ileostomy may produce wind, sometimes noisy! All of this is normal and is to be expected.

It is recommended that people with an ileostomy wear a drainable pouch, which would need emptying approximately 6–8 times in 24 hours. It is important to empty your pouch regularly, to ensure that it does not get too full. If a pouch is full, it can be more difficult to empty and may also be more noticeable under clothes. Most people will change their drainable pouch every 1–2 days, but it is up to you.

You may still feel like you need to go to the toilet via your anus if your rectum has not been removed. This is perfectly normal. When you do sit on the toilet you may well pass some old stool and/or possibly some mucus.

If you have had your rectum removed and anus closed, there is a possibility you may experience 'Phantom Rectum'. This is a sensation of wanting to open your bowel in the usual way. It may help to sit on the toilet until the sensation has passed.

2. AFTER YOUR SURGERY

Wearing a stoma pouch

Your Stoma Nurse will usually help you decide which pouch is the most suitable for you. There are a range of different sizes which are designed to be worn under your normal clothes. Drainable pouches have integral filters to allow wind to flow from the pouch very gradually. The filter also contains a charcoal material which will absorb any odour. Pouches are waterproof, so you can choose to have a bath or shower with it on or off. It is up to you, but remember, you will have no control over when your stoma is likely to function.

After a while, you will establish a routine for changing your pouch and it's a good idea to keep this as simple as possible.

Your stoma will work at different times of the day; for instance, it could be active shortly after a meal. It may be easier to change your pouch at an inactive time.



One-piece pouch and cover

Two-piece pouch

2. AFTER YOUR SURGERY

Changing your stoma pouch

Ensure you have everything to hand before changing your pouch:

- ▶ A clean stoma pouch
- ▶ Scissors and template (if required)
- ▶ Dry wipes or plain kitchen roll (not cotton wool, tissue or toilet paper)
- ▶ Adhesive remover (if required)
- ▶ Water
- ▶ Disposal bag
- ▶ Cup
- ▶ Mirror



TIP: It is advisable to wash your hands before and after changing your pouch.



To change your pouch

- ▶ Draw the template of your stoma onto the adhesive of the pouch, then cut it out. Pouches are also available in pre-cut sizes.



Cutting the hole

TIP: It is most important that this hole fits snugly around the stoma to prevent the risk of leakage and irritated skin. Your Stoma Nurse will show you how to do this and it will become easier with practise. However, if you would like your pouches to be cut to size, this will be possible once the initial post-operative swelling has reduced.

2. AFTER YOUR SURGERY

- ▶ Close the outlet of the new pouch so it is ready to apply.
- ▶ Drain the pouch you are wearing into the toilet.
- ▶ To empty your drainable pouch:
 - Once you are in your preferred position for emptying the pouch, undo and unroll the outlet to open it.
 - When empty, clean the outlet with toilet tissue or a dry wipe.
 - Roll the outlet back up to its original position and secure.
 - Some pouches allow you to tuck the outlet up into the pouch for extra discretion.



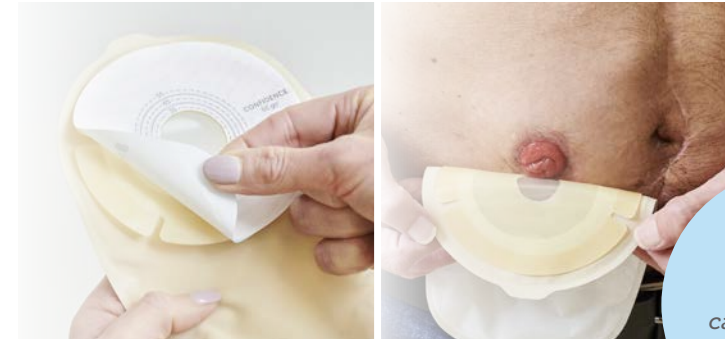
TIP: To clean your stoma and skin, water is considered adequate and acceptable.



Pouch removal

- ▶ To remove the pouch, carefully release the adhesive, working from the top down whilst supporting the skin. You may choose to use an adhesive wipe or spray as you peel away the adhesive to help with removal.
- ▶ Once removed, fold the adhesive section of the used pouch to seal.
- ▶ Place your pouch into a disposal sack.
- ▶ Use dry wipes (kitchen roll is an alternative) and water to clean around the stoma. Place these in the disposal sack (do not put them in the toilet as they may block it!)
- ▶ Ensure the skin around the ileostomy is dry.
- ▶ Remove the backing film from the adhesive of the new pouch.
- ▶ Be attentive that your stoma does not work while the pouch is off, have a disposable cup ready to catch any output.

2. AFTER YOUR SURGERY



Peel

Position



TIP: If you cannot see your stoma, a mirror might assist.

- ▶ Fold the top half of the adhesive back, then position it around the stoma, working from the bottom and smoothing upwards with your fingers. Take time to ensure there are no creases in the adhesive and use the warmth of your hands to mould the pouch to your skin, making sure it is well stuck!
- ▶ Fold the cover in half so that the blue tang can be used freely. Direct the blue tang into the tang pocket. Use your hand to gently press up and down the bag to secure the hook and loop fastening material.
- ▶ Securely close the disposal sack and put in the normal household rubbish bin. DO NOT flush a used pouch down the toilet, as it will cause a blockage.



The tang



Attach the cover

Press

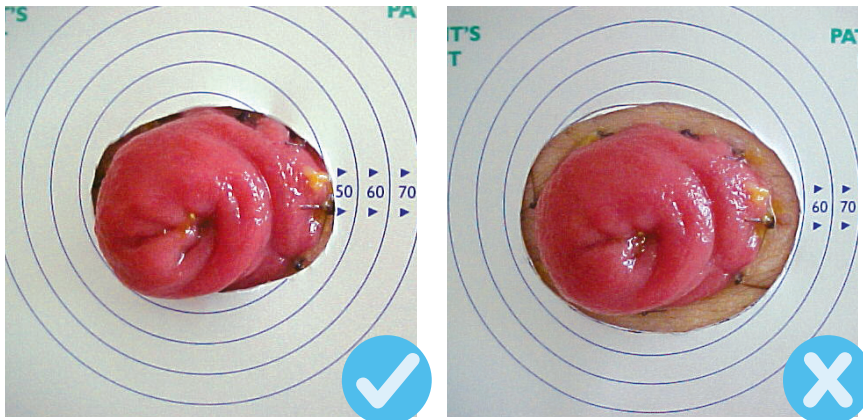
2. AFTER YOUR SURGERY

Caring for your skin

Caring for your skin is an essential part of looking after your ileostomy.

Immediately after your surgery, your stoma will look swollen and even a little irritated. This is all to be expected post operatively and with good care it should improve in appearance over time.

You may find that your product requirements may alter due to the changes in your stoma size and shape. Your ileostomy template will alter and should be checked at least weekly for the first 8 weeks, or particularly if lots of healthy skin can be seen through the hole.



The area of skin around your stoma needs ongoing care and attention to prevent and reduce the risk of soreness and bleeding.

2. AFTER YOUR SURGERY

If you start to develop sore, irritated or even broken skin, do not delay in contacting your Stoma Nurse for appropriate advice on treatment and the need for alternative products.

Aim to keep your skin in optimum condition by considering:

- ▶ **Good nourishment and hydration** – Ask your Stoma Nurse for a copy of our *Living with an ileostomy* booklet for more information on food and drink that aid healing and promote hydration.
- ▶ This could be an excellent opportunity to **stop smoking** – smoking effects how nutrients and oxygen might get to your skin and so results in a drier, dull skin that is at more risk of breakdown.
- ▶ **Regular gentle walking** increases your body's metabolism and encourages oxygen to reach your skin cells quicker and in greater supply.
- ▶ Care for your skin on a daily basis; keeping it **clean and dry** as adaptation to life with a stoma depends largely on the health of the peristomal skin (skin around your stoma).
- ▶ **Remove any hair** from the skin around your stoma. This is so the adhesive does not pull at the hair shaft causing inflammation and trauma to the skin. How often you need to remove hair from around your stoma is very individual, and you will get to know when removal is necessary.



TIP: To remove the hair around your stoma you might find it helpful to use a plastic deodorant lid or empty toilet roll cardboard to place over the stoma, for protection, and shave around it.



SECTION 3
OTHER HELPFUL ADVICE

Additional help and support

3. OTHER HELPFUL ADVICE

Support

Stoma Nurse

Your Stoma Nurse will support you throughout your surgery and recovery, and will continue to be there to offer advice in the future.

Don't be afraid to contact your Stoma Nurse if you have any questions.

You can note the name and contact details of your Stoma Nurse opposite, so that you can refer back to them in the future.

Stoma care training app

Salts Healthcare has a helpful and supportive stoma care training app that can be downloaded onto your smart phone or tablet. It contains lots of useful information and downloadable content, including a comprehensive list of Frequently Asked Questions (FAQs) written by Stoma Nurses. A number of animated videos take you through the steps of removing your stoma pouch, cleaning your stoma and applying a new pouch. Scan your QR code (opposite) to download the app for FREE.

Alternatively:

1. Tap your preferred app store icon to launch the app store
(App Store for Apple, Play Store for Android)
2. Search directly for: **'Stoma Training App'**
3. Download and install the desired app, accepting any permissions
(this may not be necessary)
4. Launch or open your new app

My Stoma Nurse:

Contact Details:

Email:

Stoma product codes:



Scan your QR code to
download the app for FREE






3. OTHER HELPFUL ADVICE

National Directory of Ostomy Associations




AUSTRALIAN CAPITAL TERRITORY:

ACT & Districts Stoma Assn Inc.

 (02) 5124 4888
 stoma@actstoma.net.au
 actstoma.net.au




NORTHERN TERRITORY:

Cancer Council of the Northern Territory Inc.

 (08) 8944 1800
 ostomy@cancernt.org.au
 nt.cancer.org.au




WESTERN AUSTRALIA:

WA Ostomy Assn Inc.




 (08) 9272 1833
 info@waostomy.org.au
 waostomy.org.au

NEW SOUTH WALES:

NSW Stoma Limited




 (02) 9565 4315 or 1300 OSTOMY
 info@NSWstoma.com.au
 nswstoma.org.au

Ostomy NSW Ltd:




 (02) 9542 1300
 orders@ostomynsw.org.au
 ostomynsw.org.au

QUEENSLAND:




Gold Coast Ostomy Assn Inc.

 (07) 5594 7633
 assoc@gcostomy.com.au
 goldcoastostomy.com.au




NTH QLD Ostomy Assn Inc.

 (07) 4775 2303
 admin@nqostomy.org.au
 nqostomy.org.au



QLD Ostomy Assn Inc.

 (07) 3848 7178
 admin@qldostomy.org.au
 qldostomy.org




QLD Stoma Assn Inc.

 (07) 3359 7570
 admin@qldstoma.asn.au
 qldostomy.org.au

Toowoomba & South-West Ostomy Assn Inc.




 (07) 4636 9701
 admin@tswoa.asn.au

Wide Bay Ostomates Assn Inc.




 (07) 4152 4715
 wbstomy@bigpond.com
 wboa.org.au

SOUTH AUSTRALIA:

Ostomy Assn of SA

 (08) 8235 2727
 orders@colostomysa.org.au
 ostomysa.org.au




Ileostomy Assn of SA Inc.

 (08) 8234 2678
 orders@ileosa.org.au
 ileosa.org.au

3. OTHER HELPFUL ADVICE




TASMANIA:

Ostomy Tasmania Inc.




 (03) 6228 0799
 admin@ostomytas.com.au
 ostomytas.com.au

VICTORIA:




Bendigo & District Ostomy Assn Inc.

 (03) 5441 7520
 benost@bigpond.com
 bendigo-ostomy.org.au




Colostomy Assn of Vic.

 (03) 9650 1666
 info@colovic.org.au
 colovic.org.au




Geelong Ostomy Inc.

 (03) 5243 3664
 goinc@geelongostomy.com.au
 geelongostomy.com.au

Ostomy Assn of Melbourne Inc.



 (03) 9888 8523
 enquiries@oam.org.au
 oam.org.au

Victorian Children's Ostomy Assn.

 (03) 9345 5325
 edc@rch.org.au
 rch.org.au/edc

Warrnambool & District

Ostomy Assn Inc.

 (03) 5563 1446
 warrnamboolostomy@swh.net.au

Local Support Groups

Your Stoma Nurse will be able to advise you about support groups that are local to your area. You can note the details below for safe keeping.

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.....
.....
.....

3. OTHER HELPFUL ADVICE

Frequently Asked Questions (FAQs)

If you are worried about anything before or after your operation, please consult your Stoma Nurse who will be happy to help you. Below are some brief, but useful, answers to a range of common questions.

I find odour a problem with my stoma, what can I do?

Most stoma pouches are now designed with integral filters, so odour should not be apparent apart from when you are emptying or changing your pouch. However, deodorising air fresheners are readily available in supermarkets.

Can I bath/shower without the pouch on?

It is entirely up to you. Whether you find bathing or showering most convenient, both can be done either with your pouch on or without it. However, you will have no control over when your stoma may work, so it could work during your bath or shower if you choose to leave your pouch off.

Do I need to pay for my pouches?

If you have a stoma of any type, then no, you do not need to pay for your pouches. You will however, need to sign a Medicare form from a Stoma Nurse. Your products will be available from your Ostomy Association.

Who can I ask for advice?

Your Stoma Nurse will continue to be available should you have any problems with your stoma, or if you need help or advice.

How often do I need to see my Stoma Nurse?

After you have recovered and are feeling more confident with your stoma care routine, you will not need to see your Stoma Nurse as often. However, it is advisable to see your Stoma Nurse for an annual review.



TIP: Some people find that an Extra Strong Mint placed inside their pouch helps to effectively mask odour.

3. OTHER HELPFUL ADVICE

Glossary of terms

Abdomen:

The part of the body that contains the pancreas, stomach, intestines, liver, gallbladder, and other organs. This may also be referred to as: "tummy", "belly" or "stomach."

Adhesive:

The sticky part of a one-piece pouch that sticks to your abdomen. This may also be described as: "wafer", "flange", "base plate" or "hydrocolloid".

Anus:

The natural exit where stool leaves the body.

Pouch: (External):

A term used to describe a stoma appliance worn over a stoma to collect urine or stool/output.

Ballooning (of stoma appliance):

Occurs when a pouch that is being worn fills up with wind.

Baseplate:

The part of a two piece system that sticks to the abdomen. This may also be described as "wafer", "flange", "base plate" or "hydrocolloid".

Cancer:

A term for diseases in which abnormal cells divide without control. Cancer cells can invade nearby tissues and can spread through the bloodstream and lymphatic system to other parts of the body.

Chemotherapy:

A drug treatment for cancer.

Colitis:

Inflammation of the large bowel (colon).

Colon:

Large bowel, consisting of caecum, ascending, transverse, descending and sigmoid colon.

Colorectal:

Referring to the colon and the rectum.

Colostomy:

An opening from the colon to the outside of the body. A colostomy provides a new path for stool to leave the body after part of the colon has been removed.

Congenital abnormalities:

A birth defect or abnormality existing at or before birth.

3. OTHER HELPFUL ADVICE

Glossary of terms (CONTINUED)

Constipation:

Irregular and infrequent stool, usually accompanied by hard, dry stools which can be difficult to pass.

Convexity:

A specialist shape of wafer with an outward curve. The convex shape is most often used with a retracted or flush stoma.

Crohn's disease:

An inflammatory bowel disease affecting any part of the gastrointestinal tract, from mouth to anus.

Diarrhoea:

Loose, watery stool.

Diverticular Disease:

A condition where small sacks or pouches form in the wall of the large bowel.

Diverticulitis:

When the small pouches or sacks mentioned above become inflamed or infected.

Hydrocolloid:

The sticky part of your pouch or base plate.

Ileostomy:

An opening from the small bowel or Ileum to the outside of the body.

Ileum:

The final and longest segment of the small bowel.

Inflammatory Bowel Disease:

A broad term used to describe the three conditions, Crohn's Disease (CD), Ulcerative Colitis (UC), and Familial Adenomatous Polyposis (FAP or Gardeners Syndrome).

Loop Stoma:

A loop of bowel is brought out through a surgical opening made in the abdominal wall.

Mucocutaneous junction:

Sutured join of any stoma between the bowel and the skin.

Muco-cutaneous separation:

Breakdown of the suture line between the bowel and the skin securing the stoma to the abdominal surface.

Oncologist:

A specialist doctor who is trained in diagnosing and treating cancer.

3. OTHER HELPFUL ADVICE

Oncology Nurse Specialist:

A nurse who specialises in oncology and sees patients following a cancer diagnosis.

Ostomist/ostomate:

A person who has a stoma.

Parastomal:

Around/behind the stoma.

Peristomal skin:

The area of skin immediately surrounding the stoma.

Rectum:

Lowest part of the large bowel ending in the anus (bottom).

Stoma:

Stoma is a Greek word meaning 'opening' or 'mouth'. There are generally three types of stomas:

- ▶ Colostomy: from the large bowel
- ▶ Ileostomy: from the small bowel
- ▶ Urostomy: urinary stoma

A stoma can be either temporary or permanent, depending on the reason for its formation.

Stoma Nurse:

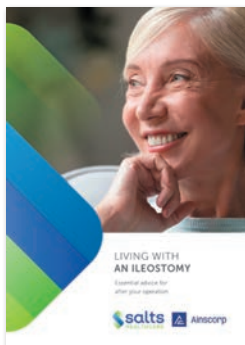
A nurse trained in the care and support of people with ileostomies, colostomies and urostomies.

Ulcerative Colitis:

A disease that causes long-term inflammation of the lining of the large bowel.

Urostomy/ileal conduit:

A urinary stoma.



We recommend that you request a copy of the follow-up booklet – *Living with an ileostomy* – for lots of helpful advice as you adjust to life with your ileostomy. It covers everything from the early days at home following your surgery to diet, hydration, exercise and travel. Please speak to your Stoma Nurse or contact Ainscorp via the one of the options below.

With thanks to Stefan Demur, CNC Stomal Therapy, for his help with content creation.

For free samples, please contact:



TOLL FREE 1300 784 737 (Australia)



TOLL FREE 0800 100 146 (New Zealand)

ostomy@ainscorp.com.au



www.saltshealthcare.com

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@ainscorpmedical