

Essential advice for before and after operation · User

# Your guide to living with an ileostomy



# 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'll have lots of support. Your care team includes your surgeon, your specialist stoma 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.

Inevitably there will be some issues that this booklet doesn't address or that you would like more information about. Similarly, the information is general and some of it may not apply to you. So in addition to this booklet, we've developed a useful guide to help you through the first year following your operation. If you haven't been given this by your nursing team, please call

## [INSERT LOCAL DETAILS]

for a complimentary copy. And don't forget, 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.

## Your operation

Understanding your digestive system	2
What is a colostomy?	4
What difference will having an ileostomy make?	4
What will the stoma look and feel like?	5
Why do I need an ileostomy?	5
Why do I need to wear a bag?	8
How does an ileostomy bag work?	8
How can my specialist stoma nurse help?	8

## In hospital

How will I feel after my operation?	11
What should I know?	11
When will my stoma begin to work?	12
What happens when the bag needs emptying?	12
How do I change my bag?	12
How often do I need to empty or change my bag?	14
What sort of bag should I choose?	14
Stoma bags	15
How should I dispose of used bags?	15
Changing checklist	16
What else should I know?	19

## Going home

How do I obtain supplies?	22
Do I need to eat a special diet?	23
Will I still be able to travel?	24
Should I still exercise?	24
What about sex?	25
Who can I turn to for support?	25

## Sources of help and advice

Useful resources	26
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## Understanding your digestive system

Having any type of surgery can feel a little 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.

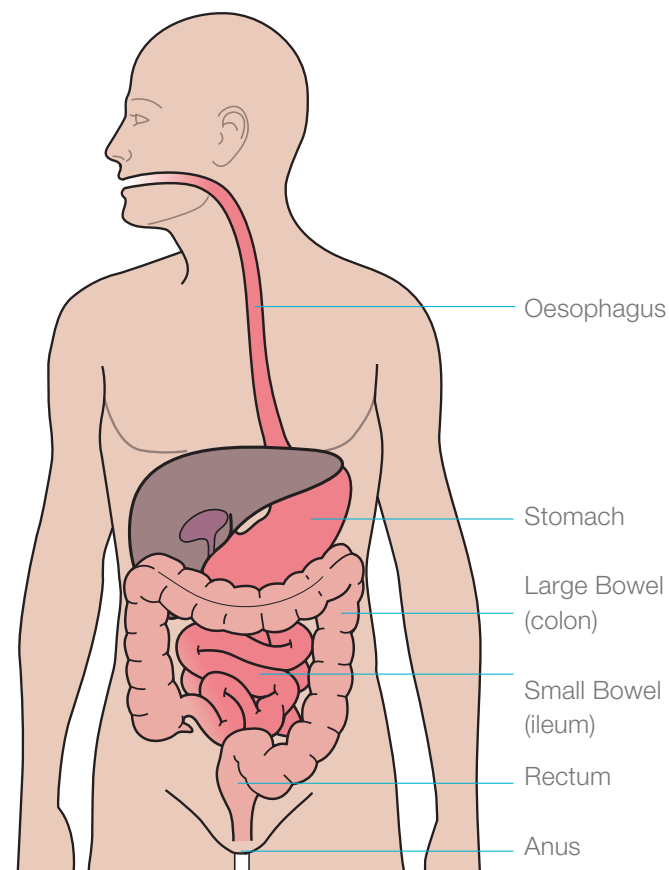
When you eat or drink, the food travels down a long, narrow tube called the oesophagus (food pipe) into your stomach.

Once here the food is churned into smaller pieces and your digestive juices begin to liquidise it. 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 blood-stream, the nutrients it needs for energy, growth and building new cells.

The residue from digestion, very importantly, leaves waste and roughage behind. This then moves forward into the large bowel (colon) where your body absorbs more fluid to make the waste more solid.

The muscles in your colon wall then push any waste forward into your rectum where it passes out of your body through your anus as faeces.



“Your surgeon and specialist stoma nurse will explain the type of surgery you’ll be having and why you need to have a stoma”

### 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 specialist stoma 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.

### What will the stoma look and feel like?

The stoma will be moist and pinky red in colour and should protrude from your abdomen. It may be quite swollen to begin with but will reduce in size over time – usually 6-8 weeks after surgery. Despite being red, there is no sensation in the stoma and it’s not painful.



Ileostomy – just after operation



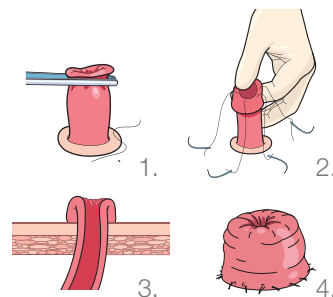
Ileostomy – some time after operation

### Why do I need a ileostomy?

Your surgery may need to be performed for a number of different reasons and your surgeon and specialist stoma nurse will explain all of this to you. An ileostomy may be an end or a 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 disease in the last part of the ileum.

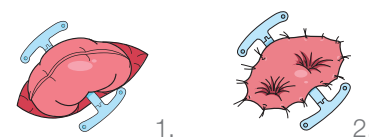


### Formation of an end colostomy

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.

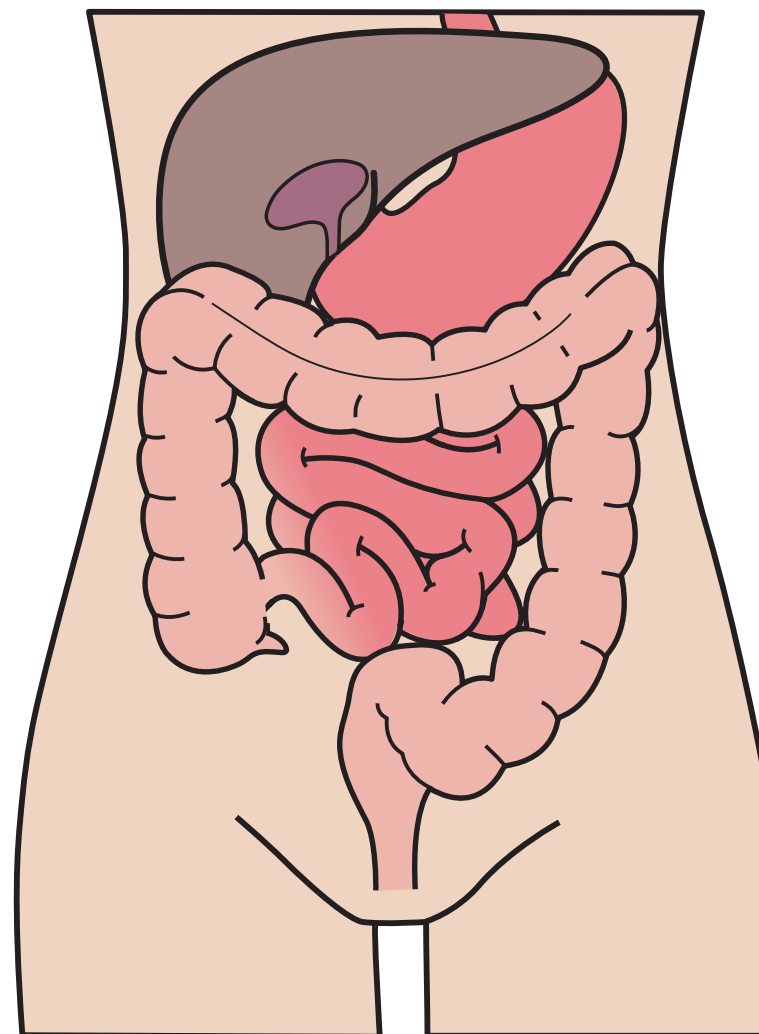
### Loop ileostomy

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.



### Formation of a loop colostomy

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 specialist stoma nurse can show you on the diagram which part(s) 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 will need to wear an ileostomy bag (or pouch) to collect it.

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. After some time the output will become more like a porridge-like consistency but may change or fluctuate depending on your diet. There are several different types of bag and your specialist stoma nurse will show you ones that are 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. An 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 there is no smell, which is one of the things that people often worry about the most.

The bag is waterproof so you can wear it whilst you are showering or bathing.

## How can my specialist stoma nurse help?

Your specialist stoma 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 specialist stoma 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 specialist stoma nurse, along with many other health-care 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”



“Please ask about anything that may be bothering you, particularly in these early days. You can be sure that your concerns will have been raised before”

### 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 to recover and get back to feeling like your old self 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 perfectly routine 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 a watery liquid and may be strong smelling as your bowel hasn't been working for a while. Also your bowel motions may be mixed with blood. However, please be reassured that the consistency will thicken slightly and the smell will settle as you resume a more balanced diet. Initially, it is also likely that a certain amount of noisy wind (or flatus) will come from the stoma – again this is perfectly normal.

It is not uncommon for patients who still have a lower bowels/rectum to feel the need to go to the toilet as they did before. This is normal and should reduce with time. If your anus is still present there may be some mucus discharge from it. Again this is expected but it may help to sit on the toilet to help pass the mucus.

## What happens when the bag needs emptying?

In the first few days after your operation you may wear a clear bag, but you can then move on to 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.

## 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 checklist' on page 13 a useful reminder.



## How often do I need to empty or change my bag?

This will vary from person to person. Your specialist stoma nurse will be able to advise you how often you'll need to change your bag but you'll have to empty it several times a day.

## 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 specialist stoma 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 version that could be smaller.



One-piece



Two-piece  
Mechanical coupling



Two-piece  
Adhesive coupling

## Stoma Bags

### There are two main sorts of system

Both types of system 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. Bags are available in a variety of sizes to suit your specific needs.

### One-piece system

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

### Two-piece system

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

## How should I dispose of used bags?

It's recommended that you empty the bag before removing it. Then seal it inside a disposal bag and place in the dustbin. DO NOT flush it down the toilet, as it will cause a blockage. Some local authorities provide a collection service for used bags. Your specialist stoma nurse will be able to tell you more about this for your particular location. If you are using public disabled toilets they should have disposal facilities. You can also use nappy changing bins or sanitary bins if available.

## Changing guide

Before you start, check that you have everything you need, soft wipes, warm water, a plastic disposal bag and a new bag.

### Closing the outlet

Place the bag on a table with the adhesive pointing downwards. Bend the lower, small plate over the upper, large plate of the outlet.



Fold the outlet upwards twice, until the velour plate is in line with the hook (Velcro) ears.



### Cutting

Trace the size and shape of the stoma on the stoma guide. Cut the hole to fit the size and shape of the stoma. To reduce the risk of leakage and skin problems it is very important that the hole in the adhesive fits perfectly around the stoma. Cutting is easier if you use a curved pair of scissors.



### Removal of clear backing

Ensure that the skin is clean and dry before you proceed with the application of your bag. Place a thumb on the white tab on the adhesive and pull the blue release tab away from the adhesive to remove the clear backing.



### Application

Apply the adhesive around the stoma. To ensure a perfect fit around the stoma, press firmly against the skin starting at the bottom and smoothing upwards with your fingers.



### Opening of the bag

Take hold of the end of the hook (Velcro) ears. Lift both hook (Velcro) ears off the velour plate. Unfold the outlet in the position where you want to empty the bag.



### Emptying of the bag

Allow the contents to run out while you control the emptying with your fingers.



### Cleaning of the outlet

Fold a tissue or dry wipe in your hand and put it around the outlet tip. Clean the outlet in one sliding movement away from your body.



Fold the small plate backwards so that only the large plate is visible to clean the edge. The outlet is now clean and ready to be closed again.

### Re-closing of the outlet

Bend the lower small plate over the upper large plate. Fold the outlet upwards twice, until the velour plate is in line with the hook (Velcro) ears. Seal the outlet by folding the hook (Velcro) ears onto the velour plate and press firmly.



### Removal

Take hold of the white tab on the adhesive and gently pull the bag away from the skin. Apply light pressure on the skin with your free hand as you peel the bag downwards.



“It’s advisable to carry a spare ‘changing kit with you when you go out”

### What else should I know?

One of the most important things to remember is to take good care of the skin around the stoma. Here are some tips that you may find helpful:

#### The adhesive plate needs to fit snugly around your stoma

If the hole in the adhesive plate is larger than your stoma, your skin will become exposed to the harmful effects of the faeces and become sore. Additionally, if the adhesive plate is cut too small, it may cause damage to your stoma. Therefore it's important to regularly check your template size and ensure the adhesive plate is a snug fit around your stoma. A good tip is to position your template over your stoma and see if any skin is showing.

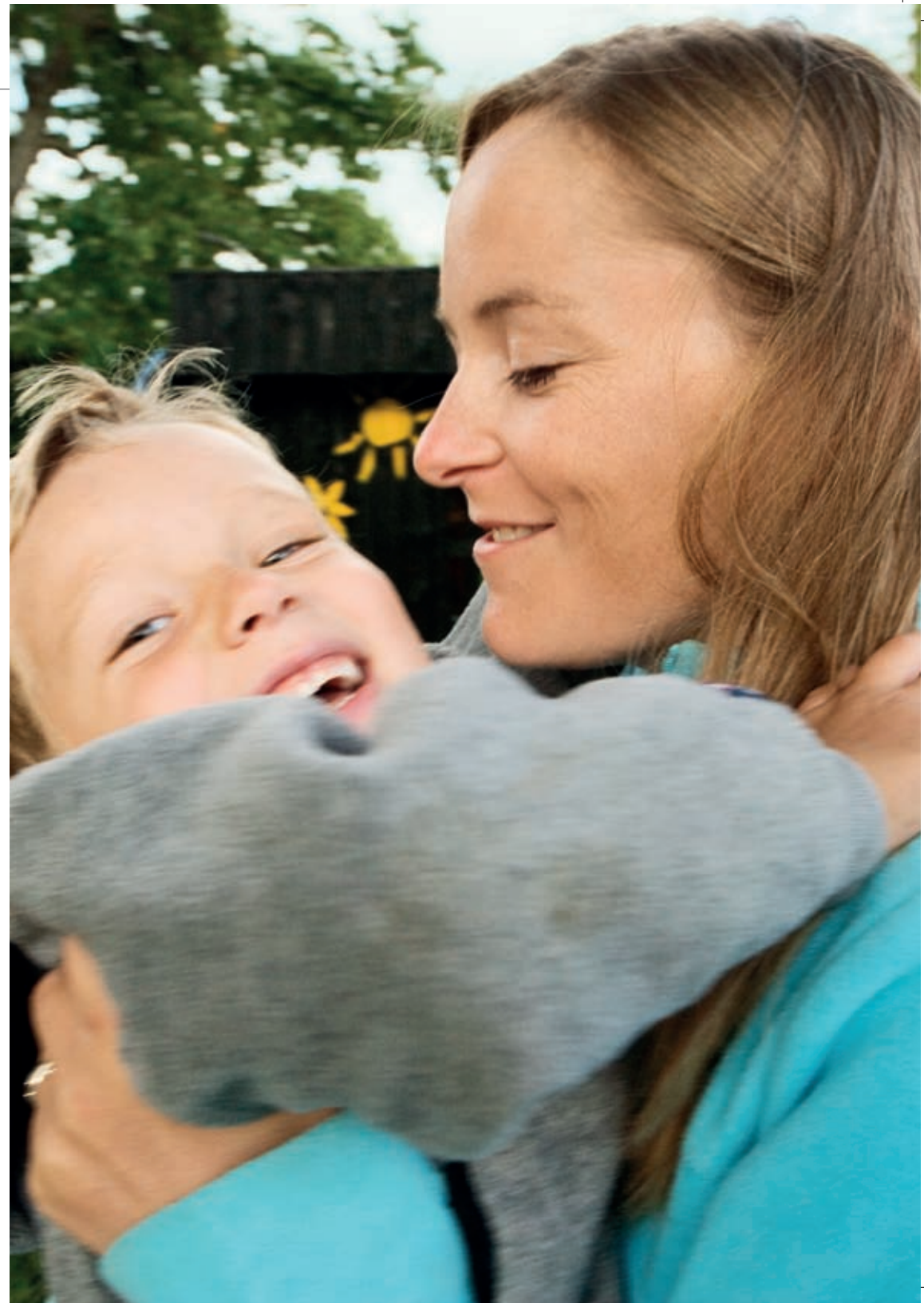
#### Watch out for irritants

Leakage on to the skin, excessive removal of the adhesive plate and harsh skin cleansers can all cause some irritation of the skin.

### Bleeding

It's usual to experience a small amount of bleeding around your stoma when cleaning. This is not a cause for alarm. However, if bleeding comes from inside the stoma you should see your doctor urgently.

“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”



## How do I obtain supplies?

[National procedure should be inserted here]

## Do I need to eat 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 specialist stoma nurse may also recommend a high-energy protein drink for you.

You will find that certain foods may produce more wind than others (just like everyone else this can be noisy), 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 for someone with an ileostomy to

remember to chew their food properly in order to give a good start to the digestive process. Foods such as peanuts, which are notoriously difficult to digest 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 give you diarrhoea. If this happens, treat the condition exactly the same as before. For more information on dealing with diarrhoea please see the 'Early days' section of our 'Things you need to know' guide.

### Want to know more?

For more information on diet for people living with a stoma see our 'Things you need to know' guide.

## Will I still be able to travel?

Generally it's not advisable to fly within the first 6 weeks following any operation because of the increased risk of Deep Vein Thrombosis and it's 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 to make sure that you have enough supplies for the duration of your time away. Plus, 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.

### Want to know more?

For more information on travelling abroad please see the 'Life' section of our 'Things you need to know' guide.

## Should I still exercise?

Exercise is good for everyone and just because you've had a colostomy 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 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 feel able to do just as much, if not more, than before.

### Want to know more?

For more information on exercise please see our 'Things you need to know' guide.

## 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 is 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 specialist stoma nurse who is used to discussing such delicate issues and will be able to help in many ways.

### Want to know more?

For more information on intimacy following a colostomy see the 'Life' section of our 'Things you need to know' booklet.

## Who can I turn to for support?

After having an ileostomy, the main aim is to get you back to enjoying life and that means you are 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 specialist stoma nurse, and his or her colleagues, will always be on hand to help you with any problems or questions that you might have.

[Please insert descriptions/details for national services such as:

- Ileostomy/Ostomy associations
- Cancer associations/helplines
- Healthcare delivery service
- Coloplast contact]

Your local specialist stoma nurse is

Your local support groups are

Notes

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.

Ostomy Care  
Urology & Continence Care  
Wound & Skin Care



Coloplast develops products and services that make life easier for people with very personal and private medical conditions. Working closely with the people who use our products, we create solutions that are sensitive to their special needs. We call this intimate healthcare. Our business includes ostomy care, urology and continence care and wound and skin care. We operate globally and employ more than 7,000 people.

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