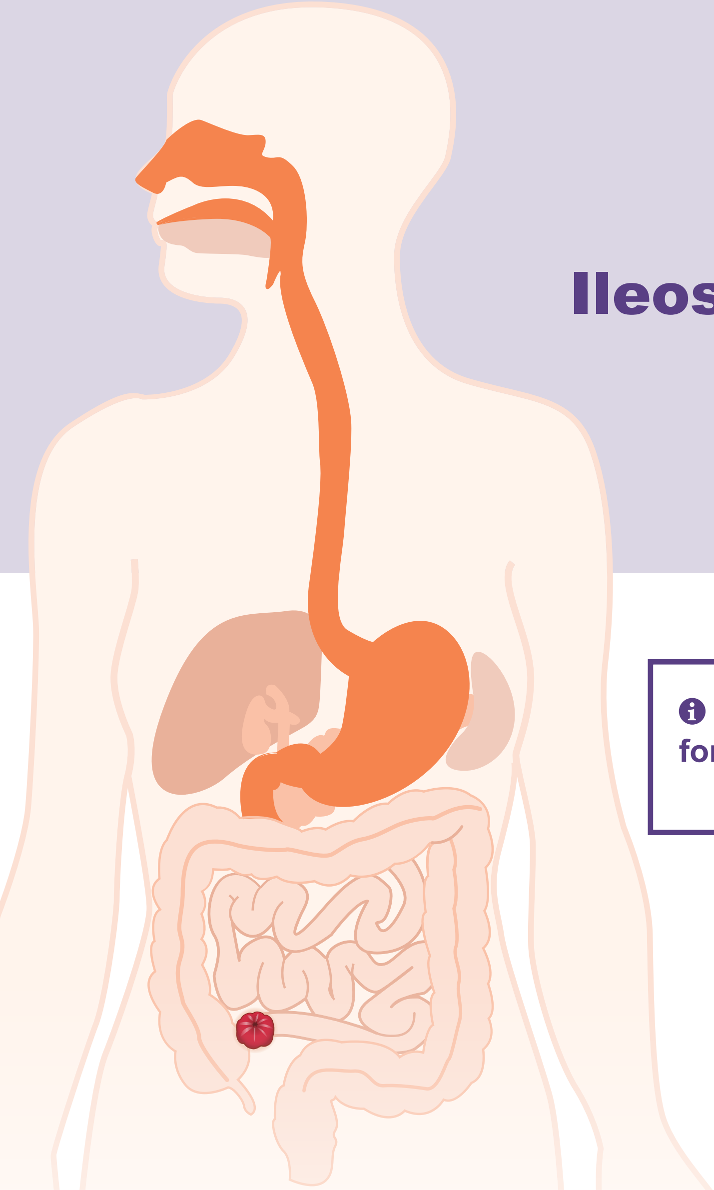
Patient information

NHS
Golden Jubilee



Ileostomy

ℹ Important information for all ileostomy patients

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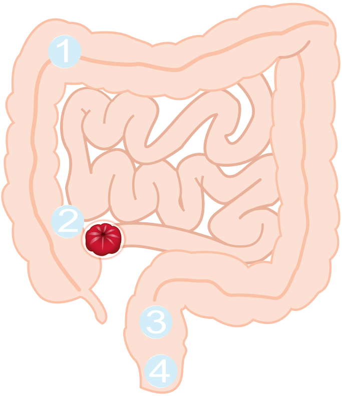
About this booklet

This booklet tells you about what to expect before, during, and after surgery to create an ileostomy formation.

About ileostomy

An ileostomy is a surgically created opening from the small bowel to the surface of your abdomen. This creates a way for waste material to leave the body after part of the large bowel has been removed.



End ileostomy

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

Why do you need an ileostomy?

There are many reasons you may need an ileostomy.

The most common reasons are:

- Ulcerative Colitis
- Crohn's disease
- Cancer
- Trauma
- Familial Adenomatous Polyposis
- Radiation damage
- Congenital Abnormalities
- Faecal incontinence

Ileostomy surgery

Types of surgery can include:

- Anterior Resection
- Right Hemicolectomy
- Formation of Defunctioning Ileostomy
- Panproctocolectomy
- Total Colectomy
- Sub-Total Colectomy
- Proctectomy

An ileostomy can be temporary or permanent and can be formed in 2 ways.

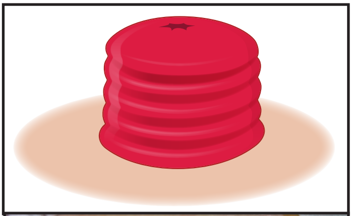
Loop ileostomy

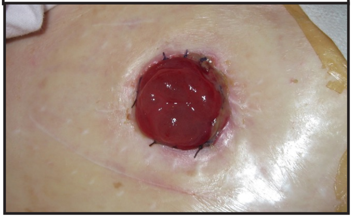
A loop ileostomy is usually created to protect a surgical join the bowel or to divert stools away from an obstruction.

It is formed when the loop of the large bowel is brought to the surface of the abdomen and opened to form a stoma.

The loop has 2 openings – 1 to pass stools and 1 may produce mucus.

End ileostomy





An end ileostomy is formed when part of the large bowel and/or rectum is removed. The remaining large bowel is brought to the surface of the abdomen to create a stoma.

In both loop and end ileostomy, the large bowel will be stitched in placed at your abdomen.

The stitches will dissolve on their own within 6 weeks.

Can ileostomy surgery be reversed?

If your stoma is temporary, it may be able to be reversed at some time in the future.

The length of time you will have your stoma will vary depending on your circumstances.

Your surgeon may be able to estimate how long that is likely to be at the time of your surgery.

Before surgery

Pre-assessment

You will have an appointment with a Stoma Nurse from NHS Golden Jubilee or your local hospital.

You will have a separate pre assessment appointment where you will have bloods and an ECG done.

This appointment may be in person, online, or over the telephone

During this appointment we will:

- discuss what a stoma is and how to manage one,
- discuss lifestyle, diet, exercise concerns,
- give you a chance to discuss the emotional impact of stoma formation, and
- give you a chance to ask questions you may have.

Enhanced Recovery

NHS Golden Jubilee provides an ‘enhanced recovery’ pathway for ileostomy surgery, which will help you recover faster.

We will give you a separate booklet about this to help you prepare for surgery by:

- exercising,
- stopping smoking,
- reducing alcohol,
- making changes to your diet.

You can view the booklet via in the general surgery section on our Hospital website at: **https://hospital.nhsgoldenjubilee.co.uk/patient-information/patient-information-booklets/** Alternatively, scan the QR code on your device.

Day of surgery

You will normally be admitted the day before surgery in order to have bowel preparation. You will also be given carbohydrate energy drinks to prepare your body for surgery.

The Stoma Nurse, either before admission or on admission will put a mark on your abdomen to help guide the surgeon where to place your stoma. This is not the definite position of the stoma but will be an indication to the surgeon of the preferred position as decided by you and the Stoma Nurse.

Your estimated length of stay will depend on the type of surgery you are having and this will be advised before your admission.

Immediately after surgery

Ileostomy site

Your ileostomy should normally protrude a little from the abdomen, like a small spout. This can vary in shape or size depending on how it is formed and how it heals.

It will be soft, warm, pink or red in colour and is often described similar to the tissue inside your mouth. It has no nerve endings so there is no sensation on the stoma itself. It also has a rich blood supply so often will bleed a little when cleaning it.

You may find the stoma is a little swollen to start with and will reduce in size as you heal from your surgery.

Sometimes a loop stoma with have a bridge or rod in place to help it heal in place after surgery. This is removed soon after surgery by the nurse on the ward or Stoma Nurse.

It can often take some time for your ileostomy to begin to pass stool after surgery. This is due to the bowel being quite swollen from the surgery and so the usual peristalsis movement (the movement which pushes your waste through your bowel) stops working properly.

The bowel will usually start working again naturally but sometimes we give you something to get started.

You may find the stoma output will be quite liquid to start with. You can help to thicken the output to more of a paste or ‘porridge’ consistency by eating carbohydrates (e.g. white pasta, potatoes, white bread and white rice). If it does not start to thicken on its own, you may be advised to take some medication to help with this and you will be advice on managing your hydration as well.

You will find that the stoma itself will be swollen to start with and the size will reduce down with time.

Diet

You will be advised initially to eat a light, low fibre diet after surgery.

You should take plenty of carbohydrates to help thicken your output, things like potatoes, pasta, white bread, and white rice.

You should eat plenty of protein-rich foods, such as full fat dairy products, fish and chicken, as this will help with healing after surgery.

Extra snacks can help to increase your intake when you may not be hungry enough to manage full meals.

You may find rich or spicy food will upset your stoma output for a while after surgery. You should also avoid fruit and vegetables, especially those with skins.

What is a low fibre diet?

A low fibre diet means avoiding foods high in fibre that could cause your bowel to become more irritable and work harder to digest your food.

The table on the next page will help you to choose suitable foods from the hospital menu. You can ask the nursing and catering staff to help with this.

	Foods to choose	Foods to avoid
Breakfast cereals	• Rice Krispies • Cornflakes • Ready Brek • Sugar Puffs	• Weetabix • Shredded Wheat • Porridge • All Bran • Bran Flakes • Muesli
Bread and rolls	• White bread • White rolls	• Wholemeal • Granary • Wheatgerm • High fibre white (e.g. Mighty White)
Soup	• Creamed soup	• All other soup
Vegetable	• Peeled potatoes • Crisps • Peeled and well-cooked root vegetables (e.g. turnip, carrot, parsnip, spinach, beetroot)	• All other vegetables

	Foods to choose	Foods to avoid
Fruit	• Fruit juices • Melon, • Skinned peaches and pears. • Citrus fruits with pith removed • Tinned fruit • Ripe bananas	• All other fruit, including dried fruit
Fats and diary	• Milk • Cheese • Butter • Margarine • Cooking fats and oils • Plain and flavoured yogurts	• Yogurts containing fruits to avoid
Eggs, meat, poultry and fish	• All meat and fish, including fish paste	• Pre-prepared dishes containing vegetables, pulses or wholemeal products (e.g. chilli con carne)
Cereals and pulses	• White pasta • White rice • Tapioca • Custard	• Brown rice • Wholemeal pasta • Barley • Peas • Beans • Lentils
Miscellaneous	• Sugar • Chocolate • Boiled sweets • Jelly • Ice cream • Jelly-type jams • Marmalade • Lemon curd • Honey • Syrup • Seasonings	• Nuts • Seeds • Peanut butter • Chutney • Pickle • Jam with seeds and pips

Exercise

Gentle exercise is important, even in the early days after surgery.

You will be encouraged to sit up into your chair and if able, to begin short walks as soon as possible after surgery, ideally in the first 24 hours. Research shows us that this can reduce complications.

Mobilising (moving about) early and every day can also help your bowels to start working and to continue working well. It can also help with your mental wellbeing and make you feel that you are progressing back to normal.

Building up your exercise tolerance can improve your core strength and help to prevent hernias and other complications later in the recovery process.

Remember: It is important to not over-exert yourself. Do not do any heavy lifting, bending or over-stretching in the first 6 weeks after your surgery.

Feelings

It is normal to have mixed feelings when you first see your stoma.

You may feel angry that you have had to have this done, you may feel happy that you had the surgery and will no longer have the symptoms you were experiencing, you may feel upset, you may feel scared.

Whatever your feelings, it is importance to recognise them and accept that all feelings are normal and can change over time and once you are able to manage the practical care of your stoma.

It is important to participate in your stoma care as soon as possible after surgery. The more you look at and care for your stoma, the easier it will be to adjust to the feelings you are having and work through them.

If you are struggling with any of these feelings, please discuss this with your ward nurse or Stoma Nurse.

Stoma self care

What is normal?

Your ileostomy should appear pink and warm. The skin around your stoma should appear healthy and intact without redness or broken skin. It is normal to get a small amount of bleeding from the stoma surface when wiping it.

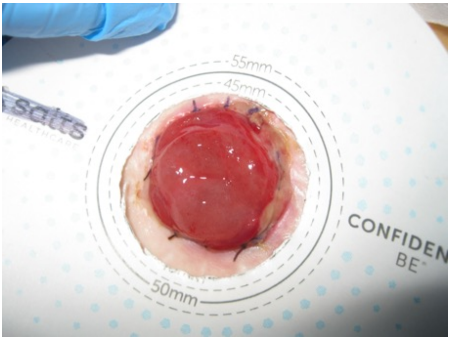
This section details things which you may encounter out of the ordinary and give a brief description of how you might deal with them or who to contact for advice. If you are in any doubt, contact your Stoma Nurse for further advice.

Maintaining healthy skin

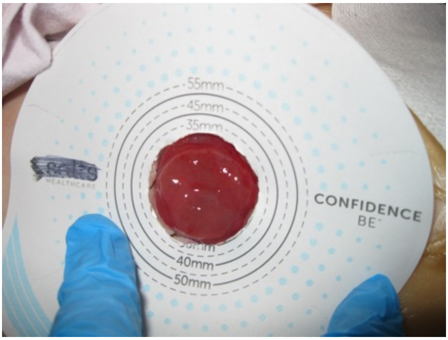
Sore skin can occur around the stoma if the template (hole in the bag) is too big.

Your stoma may be swollen and will shrink in the first few weeks after surgery. It can also reduce or increase with changes to body shape.

It is therefore important to regularly check that your template fits well and that the skin is protected. Your Stoma Nurse will advise you how to do this.



Bad template



Good template

If you have hair on your abdomen, you may find it useful to shave the skin regularly to ensure the adhesive can get a good seal on your skin. We recommend using a clean and new disposable razor each time to prevent infection of the hair follicles.

Some people use an empty toilet roll tube or a clean deodorant lid to put over their stoma and protect it while shaving.

Bathing and showering

You can bathe and shower as normal when you have a stoma.

To begin with you will likely feel more comfortable to bathe and shower with the bag on.

You can take your bag off when showering and let the warm water run over the stoma and skin. You should avoid using harsh shower gels or soaps, but it is okay to let soap suds run over it.

You must ensure that your skin has a chance to dry and cool down before applying a new bag.

Remember: Your stoma can be active when the bag is off, so keep some wipes handy.

Changing your ileostomy bag

As there is no control over when a stoma is active, you will wear a drainable ileostomy bag over it to collect waste and allow you to empty it when it is one-third to half-way full.

Most people change their bag completely every 1-2 days. Initially we will suggest changing it once a day until you get used to it and the stoma size settles.

Most people empty their bag 4-6 times a day, but this can be more or less depending on how much waste you produce.

You will also pass wind into your bag which is usually passed through a small filter in the bag but sometimes you may need to empty this too.

Equipment

Prepare all the equipment you need before you start and have it close to hand.

- A clean stoma bag
- Scissors and template (if cutting your bags)
- Dry wipes
- Warm tap water
- Disposal bag
- Adhesive remover (if required)

Step 1

Prepare your bag by cutting the template. Your nurse will show you how to draw this onto the bag.

Roll up the outlet at the bottom of the new bag and fix with Velcro.

Step 2

Loosen the Velcro at the bottom and unroll the bag. Do this standing or sitting over the toilet and empty the contents straight into the toilet. Sometimes after surgery, you may need to empty this into a waste bowl to allow the nurses to measure it. Remember to fold the bag back up and fasten with Velcro.

Step 3

Remove the bag by peeling the adhesive part (baseplate) from the skin gently. You may be shown to use an adhesive remover to help prevent damage to the skin. When removing the bag, start at the top and work it downwards.
Place the old bag into the disposal bag.

Step 4

Clean the stoma and surrounding skin thoroughly with warm tap water and the soft dry wipes provided. You can also use kitchen roll for this. You must not use tissues or cotton wool as fibres can stick to the surface of the stoma. Once clean, dry the surrounding skin thoroughly with a clean dry wipe to ensure a dry surface for the new bag to stick to.

Step 5

Peel the backing paper/plastic from the new bag.Fold the top half of the baseplate down and position the bottom of the bag underneath the stoma, ensuring that the hole in the bag is close to the stoma edge. Once you fix the bottom half of the baseplate to your skin, the upper half can then be brought up over the stoma and fixed into place.
Use your fingers to smooth the baseplate to the skin and smooth out any wrinkles or creases. Once you are happy it is in the correct place, put your hand over the surface to warm the glue and help it stick (this is often referred to as 'giving it a cuddle'!).

Remember:
Double check you have closed the outlet of the bag if you have a drainable bag.

Step 6
Double tie the disposal bag with all of the rubbish inside. This can be placed into household waste bin.

Clinical waste

Remember: Do not flush the rubbish down the toilet, as it can block your plumbing.

Some local authorities have special uplifts for medical waste or the facility to apply for an extra or larger general waste bin. It is worth contacting them to find out especially if your stoma will be permanent.

Problems you may experience

Sore Skin

Skin can become pink, red or broken if your stool makes contact with the skin surface. This is because the enzymes in your stool will break down the proteins in the skin.

Sore skin is usually due to an ill-fitting bag. You should check that your template fits well and adjust this if required. Speak to your Stoma Nurse about the type of bag you are using, as a different shape of bag may get a better seal.

Sometimes it is possible to become sensitive to the product you are using. Your Stoma Nurse can advise on an alternative product.

There are some protectors which can be applied to the skin such as barrier films, pastes and powders. Ask your Stoma Nurse for advice.

Mucocutaneous Separation

This happens when the stitches and skin separate during the healing process. It usually happens in the recovery period after your surgery.

It can look unpleasant if this happens but your body is a good healer and this will heal in time. You should report this to your Stoma Nurse who can advise on ways to promote healing.

Pancaking

This is the term used when soft formed stool sticks at the top of the bag and doesn’t drop down into the bag.

If this happens, you should check your template and bag fit. You can add a little drop of oil (something like baby oil or cooking oil) to lubricate the inside of the bag.

Blowing a little air into your bag before applying it can prevent a vacuum inside the bag. Using the filter cover/sticker can also help to prevent a vacuum.

Your Stoma Nurse can give further advice on this as changing the type of bag can help too.

Ballooning / wind

Wind is something we all produce as part of the digestive process.

When you have a stoma, it will pass out of the stoma and into the bag.

There is a carbon filter built into stoma bags which helps to release the wind, while neutralising the odour.

We all produce different amounts of wind and if you produce a lot, sometimes the bag can become full with wind – this is referred to as “ballooning”.

Peppermint tea after meals can help to reduce wind.

Reducing foods which cause more wind can also help. Examples are:

- Onions
- Cabbage
- Peas
- Spicy food
- Beans
- Fizzy drinks
- Chewing gum

We are all different and through trial and error, you can adjust your diet to see what works best for you.

Parastomal Hernia

This is a complication which can occur after stoma surgery.

It appears as a large bulge or mound in the abdomen underneath the skin where the stoma has been formed. This is due to the weakness in the muscle caused by the surgery, allowing the bowel to push forward under the skin.

Factors which may put you at a higher risk include age, weight, smoking, multiple surgeries and heavy lifting. You should discuss this with your Stoma Nurse, who can assess your risk.

You can help prevent hernia by doing the exercises in the “Exercise” section of this booklet.

You may be advised to wear a hernia support belt if you are in the high risk category.

If you do develop a hernia, it is rarely dangerous and would be treated conservatively with the use of a hernia support belt. You may experience a dragging or heavy sensation in your abdomen.

If your hernia gets larger or starts to cause you any problems, surgery to repair it may be required. This is usually only done as a last resort and decision on this would be taken between yourself and your surgeon.

Blockages

There are a few foods that you should avoid as they can cause blockages:

- Fruit and vegetables with skin on (peel it first)
- Nuts and seeds
- Sweetcorn
- Mushrooms
- Celery
- Coconut
- Dried fruit
- Bean sprouts
- Bamboo shoots
- Pith, pips and stones
- Popcorn

You can tell you may have a blockage if you get little or no output after eating. Sometimes people get a lot of watery output when that is not expected.

You may experience some cramping, tummy pain, nausea, vomiting and swelling in your stoma or abdomen.

If you suspect you have a blockage, you should:

- Stop eating solid foods
- Drink plenty of water
- Massage your stomach
- Walk or move around
- Warm compress (not too hot)
- Have a hot drink

If this does not help after a couple of hours, you should contact your Stoma Nurse, NHS 24 or your GP for further advice.

You must not let a blockage go on for more than a few hours without getting medical advice.

High Output / Diarrhoea

High output is a term used when ileostomy output becomes watery and the amount is above 1.5 litres within 24 hours.

If you suspect this is the case:

- Report it to your GP or Stoma Nurse as soon as possible.
- Continue to drink 1.5 to 2 litres of fluid per day. Do not exceed this amount.
- Increase your electrolyte intake by adding extra salt to your diet or taking isotonic drinks as part of your 2 litres of fluid.
- Increase your carbohydrate intake (potatoes, white pasta, white bread)
- Reduce your fibre intake.

Your doctor may prescribe medication to help thicken the output and may suggest a special electrolyte drink.

Retraction

This occurs when the stoma surface is below skin level and can occur due to difficulties with the stoma formation, healing after surgery, weight or the shape of the abdomen.

You should report this to your Stoma Nurse as you may require a different bag to get a good fit.

Bleeding

As previously stated, the bowel has a good blood supply and it is normal to get a small amount of blood when cleaning your stoma.

Taking blood thinners such as Warfarin, Aspirin or Apixaban will put you at a higher risk of bleeding. You may see a little more blood when cleaning the stoma.

If you see blood inside the bag/stool or the bag is filling with blood, it is important to get medical advice urgently. If you can’t speak to your Stoma Nurse quickly, call your GP or NHS 24 on 111.

Prolapse

Sometimes a stoma can become extended in length, similar to a telescoping effect. Usually this is not dangerous, although it can be frightening when it happens.

You should report the prolapse to your Stoma Nurse who can give you advice about encouraging the prolapse to go back in.

Your stoma should still be pink, warm and active.

If it is not, this should be reported to your Stoma Nurse, GP or NHS 24(111) urgently.

Granulomas

Granulomas as small red lumps/bumps which usually appear around the edge of the stoma and skin.

They can sometimes be a little sore and can bleed quite a lot due to the small blood vessels in the bumps.

They are not dangerous and can usually be treated quite easily by your Stoma Nurse. They are often caused by ill-fitting templates so this is another reason to try to keep your template fitting neatly.

Ulcers

Ulcers can develop as sore, red broken skin. They can occur as a result of pressure, tears on the skin or due to medication. They can be treated and you should contact your Stoma Nurse for review.

Stenosis

Stenosis is a term describing a stoma which has become very small and tight at the opening. Sometimes it can be difficult for your stool to pass and may become more watery as your body tries to make it easier to pass.

You should contact your Stoma Nurse for assessment and treatment,

A dilator can be inserted into the stoma on a daily basis to help keep the opening a little wider. Your Stoma Nurse will tell you how to do this.

In some circumstances, you may need referral back to your surgeon.

Necrosis

This is the term used to describe tissue which has limited or no blood supply. This is extremely rare.

You would see the tissue on the stoma becoming darker in colour, often dark red/purple or even grey or black in some circumstances. You may notice the tissue feeling cold to the touch and harder than usual.

If you notice any of these things, you should seek medical attention immediately.

Living with a stoma

Getting stoma supplies

You will be advised by your local Stoma Nurse how to obtain stoma supplies.

In Scotland, supplies are free via NHS prescription. You will either get them from a pharmacy or stoma delivery company. Each NHS Board has different protocols, but this will be explained to you.

You should be supplied with free dry wipes and disposal bags. It is also sometimes possible to get your bags pre-cut.

Diet and Nutrition

After your surgery, you may need to eat a low fibre and easy digestible diet. This will be advised by ward staff and your Stoma Nurse.

Once you are able, you should be able to get back to a normal balanced diet. There are not usually any restrictions on your diet with a ileostomy.

If you have been advised to change your diet for other medical reasons, please ask for individual advice or a Dietitian review.

Hydration

You should try keep hydrated by drinking between 1.5 and 2 litres of fluids each day.

To keep hydrated it is a good idea to reduce or stop caffeine and fizzy drinks as they do not help if you are dehydrated.

Exercise

You will be encouraged to get up and move around soon after surgery. Having a short walk each day will help to reduce complications and enhance your recovery.

You should gradually increase your exercise over time, setting yourself realistic goals each day. Once you are back home, you can continue to walk each day to increase your stamina.

Remember: However far you walk, you need to do the same on the way back. Listen to your body and if you experience any pain then stop.

For the first 4-6 weeks, you should avoid heavy lifting or anything with extreme exertion. You can build up your core muscles with some gentle exercises. You could start with 1 exercise for a week, increasing the repetitions as able then add in another exercise each week until you are managing them all.

Exercises can be done on a carpeted floor, yoga mat or even on the sofa/bed, as long as you can lie flat. If you have problems with lying flat, speak to your Stoma Nurse about how to change the exercises to suit your abilities.

1. Tummy Tightening Breathing

This exercise can be starting within the first couple of days after surgery. Provided you are feeling well enough and you have no complications. You should be able to start this exercise while still in hospital.

What to do

- Lie on your back with your head supported by a pillow and bend your knees as far as your feel in comfortable. You can start off doing this on a flat bed.
- Take a deep breath in and slowly exhale through your mouth.
- As you exhale, gently tighten up the deep muscles in your lower abdomen (tummy).
- You should feel a gentle “tightening”.
- It is important at this stage not to lift your bottom or press your back into the bed.
- Hold this “brace” feeling for 3-5 seconds and then release.
- Breath and relax between each repetition.
- Repeat 3-5 times.

Progression

- As you progress, you can do the exercise on the flour without a pillow and begin to aim for a “stronger” tightening sensation.
- Begin to hold the brace for a longer count of 10-15 seconds and breathe deeply 2-3 during each tightening.
- Repeat 5 times.
- Try placing your hands on your lower tummy and you will feel the muscles tightening.

How often

- Aim for 2-3 times per day.

2. Pelvic Tilt

This exercise can also be done in the first few days after surgery. However, start gently and ensure that you are pain free. If you are sore – STOP!

What to do

- Lie on you back with your head supported by a pillow and your knees bent up as far as feels comfortable.
- Very gently rock your pelvis upwards and flatten your back down into the bed or floor.
- You should feel your abdominal and bottom muscles tightening a little.
- Rock back to your “neutral” or starting position and repeat.
- Start with 5 repetitions and just very slight, gentle movements (the movements are so small, they may not be apparent to someone looking on).

Progression

- As you progress, allow your back to arch up a little more and tighten your abdominal muscles more strongly as you push your back into the floor.
- Build up towards 20 repetitions.

How often

- Aim for 2-3 times per day.

3. Hip Lift/Bridge

Provided your recovery is going well, introduce this exercise around 7-10 days post-op. Initially it should be a gentle, small movement and only going as high as you feel comfortable.

What to do

- Lie on your back with your head supported by a pillow and your knees bent up as far as feels comfortable.
- Very gently tilt your pelvis backward and tighten up your pelvic floor muscles (the muscles you use to hold on when you need the toilet).
- Lift your bottom off the bed/floor and slowly lift up vertebrae (back bone) by vertebrae until your bottom is off the bed/floor.
- Lift your bottom as high as you can comfortably hold, if you feel pain – STOP!
- Hold this position for a moment then slowly lower your spine and pelvis back down.
- Imagine you're lifting a string of pearls off the floor and back down again.
- Repeat 3-5 times.

Progression

- Build up gradually to 10-15 repetitions and lifting higher as you feel more comfortable.

How often

- Aim for 2-3 times per day.

4. Knee Rolls

Introduce this exercise 7-10 days after surgery as long as you are feeling well enough and there are no complications. Always work within a pain free range and keep the movements small and gradually increase them.

What to do

- Lie on your back with your head supported by a pillow and bend your knees up as far as feels comfortable.
- Arms out to the sides.
- Keep your knees and ankles together and gently let your knees begin to drop over to one side.
- Only move your knees as far as feels comfortable.
- Then carefully tighten your tummy muscles and roll your knees over to the other side.
- Try to keep your shoulders down and your head relaxed, looking upwards.
- Aim for 5 rolls each side.

Progression

- As you progress, increase the range so your knees drop lower.
- Build up towards 20 repetitions.

How often

- Aim for 2-3 times per day.

You should be able to build up to doing your normal level of exercise after 6 weeks. However, recovery can take longer for some people, so listen to your body.

It is possible to recommence all exercise activities with a stoma. Many people enjoy swimming as this is low impact and helps to strengthen the core muscles. However, it is possible to do a range of sports and exercise including the gym, team sports, running and cycling, among others.

Contact sports and some team sports may require the use of a stoma guard. Speak to your Stoma Nurse if you are unsure or want more information about this.

Some sports which involve lifting or overstretching may require the use of a hernia support belt to prevent hernias. Again, speak to your Stoma Nurse for information about this.

Driving

You should not drive for 4-6 weeks after abdominal surgery.

You must be able to carry out an emergency stop, turn to look over your shoulder and turn the wheel without pain.

If you are in doubt you should speak to your Stoma Nurse, doctor and car insurance company for advice.

Travelling

It is possible to travel as normal with a stoma.

Long journeys with any medical supplies can be daunting but you should not let it put you off.

When travelling in a car for a long distance:

- Prepare by taking plenty of supplies and ensuring you can access these easily during the journey.
- Plan regular toilet breaks.
- Make sure to keep well hydrated.
- Eat snacks to help thicken your output just in case it gets watery on the journey.

When travelling abroad, especially on a plane, contact your airline and airport special assistance desk to ask advice. They can usually offer special assistance and even sometime extra baggage allowance for medical supplies. They can also advise what needs to go in your hand/hold luggage (like scissors/aerosols).

When travelling, it is important to take double the supplies you expect to need. Put half of those supplies in the hand luggage and half in the hold luggage.

Your Stoma Nurse can give you a travel certificate to help getting through security with your medical supplies.

Remember: Your stoma may behave differently when abroad and eating different foods and in a different climate. Stay hydrated and take plenty of supplies.

Using the toilet when out and about

You should always take a small kit with supplies to change your bag when you are out if required.

If you need to empty or change your bag when out and about, you should try to use an accessible toilet with the sink, toilet and waste bin all in one place. These may also have a shelf to place your equipment.

You can ask your Stoma Nurse, delivery company or local council about getting a RADAR key, which can give you access to locked accessible toilets in the UK. These are often found in shopping centres, council buildings and service stations.

Medication

Some medication and other therapies may have an impact on the output from your stoma, e.g. it may cause constipation or diarrhoea.

If this happens, ask the health care provider who prescribed the medication if there is an alternative or for something to treat the side effects.

Rectal discharge

If you still have your rectum in place, it is normal to get some rectal mucous/discharge from time to time. Most people can sit on the toilet to pass this once they get the sensation.

Sometimes, soon after surgery, you may even still pass stool through your rectum but this should stop once it is cleared.

If you have had your rectum removed, it can be possible to get phantom rectal pain/sensations. If you get this, it will usually settle with time. If you are concerned, please report it to your doctor or Stoma Nurse.

Emotional wellbeing support

Although we endeavour to make it as good an experience as possible, it can be a traumatic experience going through abdominal surgery.

You have had to deal with your diagnosis (whatever it might be), you may have had to deal with the symptoms of your health condition and you are having to deal with the impact of getting a stoma formation. There are many feelings which you may experience including relief, happiness, anger, sadness and grief, among others.

Learning to live with your stoma emotionally and practically will be a major part in dealing with what is happening to you. No matter what your feelings, it is good to share them with your Stoma Nurse.

You may also find it useful to talk about these feelings with someone close to you, like a partner, loved one or friend.

We have provided details of support groups at the back of this booklet.

Sex/intimacy

In the immediate post-operative recovery period you may not feel ready to be intimate. This is absolutely natural as you and your body will need time to recover.

If you have a partner, speak openly about your feelings and experiences as they may feel anxious themselves and be worried to bring the subject up. They may be worried that they would hurt you or cause harm to the stoma if they are intimate with you. Encourage closeness and intimacy through hand holding, kissing and cuddling. Try to be relaxed and feel comfortable and the rest will follow in time.

If you don’t have a partner at the moment, get to know your own body again before introducing it to someone new.
Once you feel comfortable yourself, you will feel more confident to be intimate with someone. Be open and honest with the other person about your stoma before the time comes for intimacy but do this only when you feel ready.

To help make things easier, you can ensure your bag is empty or change it before.

Speak to your Stoma Nurse if you would prefer to try a smaller bag/cap or find out how to tape it up to make it less obvious. Some people also prefer to cover the bag either with lingerie, a cummerbund (waistband) or a vest.

Some types of surgery can affect sexual function. This can be due to physical changes as well as psychological changes. If it is psychological, time can often help. But if the difficulties persist, counselling or talking to someone can help too.

The stoma must never be used as a point of entry for sex. This can damage the stoma and usually leads to further surgery.

Women

Sometimes women can experience vaginal dryness or tightness after surgery or medication, which can make intercourse difficult. Lubricants, different positions or non-penetrative stimulation may be more comfortable.

Men

Some surgeries can cause erectile dysfunction. There are many ways to solve this including medications and medical devices.

Ask your doctor or Stoma Nurse for advice or referral to a specialist service.

Contraception

Absorption of birth control pills may be more difficult with some stomas. Ask your doctor for advice on alternative methods of contraception.

Same-sex relationships

Sex via the rectum is not possible if the rectum is removed as part of their surgery.

Please discuss this with your surgeon at an early stage before your surgery.

Pregnancy

Women with a stoma can get pregnant, although there are some surgeries which can affect fertility but this will be discussed at the time of surgery.

If you get pregnant, you should expect that the stoma will change shape and size as your abdomen grows.

You will need to work with your Stoma Nurse to ensure that you change the type of bag regularly to ensure a good fit.

Your skin may be more sensitive so it is important to check this and maintain good skin health.

You may have more bag changes of blockages and watery output as the pregnancy puts pressure on your bowel. **If you are concerned that your bowel is blocked, you should contact a medical professional straight away.**

You also will need to be careful to avoid dehydration.

Sometimes, a caesarean section is required at the time of birth, depending on the surgery you had. Your doctor will discuss this with you.

Body image

It can be hard to come to terms with your new body image.

You may have scars from surgery and your abdomen shape may look different after it heals.

It is normal to feel negatively (or positively) about the change in your body image. With time you will adjust and feel less self-conscious about it.

People looking at you will be unaware of your stoma unless you chose to tell them or display it.

You will feel more aware of it because you know it is there.

Clothing

You do not need to change your normal clothing but should make sure that you feel comfortable.

You may find comfortable, stretchy clothing feels best after surgery. Once you have healed, you should be able to get back to wearing the clothes you would normally wear.

Your Stoma Nurse can provide advice on changing to higher waist or specialist clothing.

Swim wear

You can wear any swim wear you want to.

If you want to cover your bag more, many people find swimsuits with patterns better to hide their bag or clothing with higher waists and abdominal support can also help.

Your Stoma Nurse can give advice on this.

Useful contacts

Oganisation	Telephone	Name
NHS Golden Jubilee Stoma Nurse	0141 951 4743	
Your local hospital Stoma Nurse		

Oganisation	Telephone	Website
Beating Bowel Cancer	020 8973 0011	www.beatingbowelcancer.org
British Dietetic Association	0121 200 8080	www.bda.uk.com
CANCERactive	0300 365 3015	www.canceractive.com
Crohn’s and Colitis UK	0300 222 5700	www.crohnsandcolitis.org.uk
Ileostomy UK	0800 018 4724	www.ileostomyuk.org
Food to Glow (Nutrition)	N/A	www.kelliesfoodtoglow.com
Get your belly out	N/A	www.getyourbellyout.org.uk
Healing Well Forum Ostomies	N/A	www.healingwell.com
Inside Out Stoma Support Group	N/A	www.iossg.org.uk
Living with a Stoma	N/A	www.living-with-a-stoma.co.uk
Macmillan Cancer Support	0808 808 0000	www.macmillan.org.uk
Marie Curie	0800 090 2309	www.mariecurie.org.uk
Ostomy Land	N/A	www.ostomyland.com
RADAR (key)	0207 250 8191	www.disabilityrightsuk.org
Stomawise	N/A	www.stomawise.co.uk

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