



## LIVING WITH AN ILEOSTOMY

Essential advice for  
after your operation



Ainscorp



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# INTRODUCTION

If you are reading this booklet it is likely that you have had an ileostomy formed at some point recently, and are getting used to life with your stoma pouch. This booklet has been written to provide some advice on living with your ileostomy.

▶ SECTION 1: **ADJUSTING TO LIFE WITH YOUR ILEOSTOMY**

▶ SECTION 2: **OTHER HELPFUL ADVICE**

▶ SECTION 3: **STOMA NURSE – YOUR BEST RESOURCE**

Everyone is different and might find different sections of advice more helpful than others. We recommend you read whichever sections are most relevant to you at this stage in your journey, and you can leave other sections until later if you wish. 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** on page 38. 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.



1

## LIVING WITH A STOMA

Adjusting to life with your ileostomy



2

## OTHER HELPFUL ADVICE

Additional help and support



3

## STOMA NURSE – YOUR BEST RESOURCE

Get to know your local Stoma Nurse



SECTION 1

**LIVING WITH A STOMA**

Adjusting to life  
with your ileostomy

## 1. LIVING WITH A STOMA

### Early days at home

When you are first discharged from hospital you will feel tired and find everyday tasks such as having a shower exhausting. This is normal and will improve over time. You should not need to stay in bed when you get home, but you will need plenty of rest, and should make time for a nap during the day.

You may experience some pain and discomfort initially whilst recovering from your surgery. This is a normal part of recovery and you may need to take regular pain relief. There is no need to suffer! Avoid tight fitting clothing during this period as your abdomen may be sore and swollen.

It is normal to feel emotional after major surgery, so don't worry if you have 'down' or 'teary' days to begin with. Talking to family and friends can be helpful – don't feel you need to cope alone. Your Stoma Nurse is there to support you, and there are patient support groups who can help too. Don't forget to visit your GP. Don't be frightened to ask for help.

Changing your stoma pouch will be slow at first, but with practice and as you gain confidence, this will become part of your normal daily routine.



#### **AVOIDING A HERNIA**

*There are steps you can take to help prevent a hernia, and it is important to be aware of these after your surgery. There are exercises you can do to help prevent a hernia: please speak to your Stoma Nurse about these. For more information on what a hernia is: refer to page 28.*

#### **Tips for early recovery**

- ▶ It is advisable to go for a short walk daily.
- ▶ You should be able to manage stairs.
- ▶ Spread tasks over the day and rest in between, but remember you are likely to feel more tired as the day goes on.
- ▶ Do not lift anything heavier than a half-full kettle.
- ▶ You will be able to eat small light meals.
- ▶ You must not drive in the early days after your surgery because you are still sore and may have restricted movement. Certain medication can affect your ability to drive.

#### **Tips for ongoing recovery**

Over the next few weeks, increase the amount of activity that you are doing as your body allows.

- ▶ Continue to rest when you get tired.
- ▶ Continue to avoid any lifting due to the risk of developing a hernia.
- ▶ Household activities such as ironing can be done sitting down.
- ▶ Continue to walk on a daily basis.
- ▶ Avoid any stretching up to reach high cupboards.
- ▶ You should be able to drive after 3–6 weeks, depending on your type of surgery but you **MUST** check with your insurance company.

### Obtaining your supplies

You will be discharged from hospital with a small supply of pouches and any additional equipment you will need. You will be signed up to an Ostomy Association near you. Your Stoma Nurse will help you order your first supply of pouches.

The stoma appliance scheme means that your pouches are supplied free of charge through your Ostomy Association. There will be a small fee to join your Ostomy Association.



**DO NOT LIFT  
DO NOT TWIST  
YOUR BODY  
DO NOT  
REACH**

## 1. LIVING WITH A STOMA

### Diet and hydration

After your surgery you may find your appetite is reduced, but it is still important to eat little and often to help your recovery. You should be able to eat normal foods and return back to the food you enjoyed before your surgery. You may find that some foods can upset your stoma but this may be a one off and we would advise you to try them again in a couple of weeks. Certain foods will alter the consistency of your output, therefore what you eat plays an important part in controlling the output. You should aim for a porridge-like consistency, which can be easier to manage. Some foods can cause blockages, so should be avoided or eaten with caution.



#### Dietary tips for the early days

You are likely to have lost weight following your surgery. It is important to increase your intake of calories, fat and protein to aid your body's healing process. In addition to your normal diet, you should look to include the following foods:

- ▶ Full fat milk and cheese
- ▶ Double cream (add to soup, mashed potato and puddings)
- ▶ Snack on biscuits and cakes
- ▶ Foods high in protein each day such as fish, tender meat and eggs
- ▶ Drink regularly to avoid dehydration

#### Ongoing dietary advice

- ▶ Eat and drink regularly
- ▶ Include fruit and vegetables daily
- ▶ Have foods high in protein each day such as meat, fish, eggs, cheese, milk or yoghurt
- ▶ Include carbohydrates with each meal such as bread, potatoes, pasta, rice and breakfast cereals
- ▶ Include milk and dairy foods two to three times per day as they are rich in calcium – choose lower-fat varieties as a healthier option



*Eating little and often will help regulate your output.*

## 1. LIVING WITH A STOMA

- ▶ Experiment and try everything in small amounts, gradually increasing quantities. If something disagrees with you, avoid it for a couple of weeks and then try a small amount again

People with an ileostomy will experience the same common digestive issues that they may have had before their surgery, such as wind, odour and loose output.

#### Maintaining hydration

Maintaining adequate hydration is important for everyone. It is advisable to drink 6–8 glasses/cups of fluid a day, but limiting caffeine.

#### Loose output

This can be caused by many things including diet, medication and your emotions. Common foods that can cause loose output:

- ▶ Green vegetables
- ▶ Raw fruit
- ▶ Spicy foods
- ▶ Fruit juices
- ▶ Alcohol
- ▶ Wholemeal varieties of foods

#### Solutions to thicken output

- ▶ Starchy foods such as: white rice, pasta, white bread and potatoes
- ▶ Cheese
- ▶ Ripe banana
- ▶ Noodles
- ▶ Marshmallows or jelly babies
- ▶ Tapioca and other milk puddings
- ▶ Natural yoghurt
- ▶ Smooth peanut butter

If you take anti-diarrhoeal medication, such as Imodium/ Loperamide, ask your Doctor for tablets or syrup rather than capsules, as these may not be broken down in the small bowel and so may have a limited effect. If you experience loose/higher output that is unusual for you, please contact your Stoma Nurse for advice.

#### Dehydration

Dehydration is a condition that occurs when the loss of body fluids, mostly water, exceeds the amount that is taken in. When we lose



*Cooking fruit breaks down the fibre in it, so you could try stewing fruit.*



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too much water, our bodies may become out of balance or dehydrate. Severe dehydration can be life threatening. If your output loosens and you find you are emptying your pouch more frequently, you may be at risk of dehydration. Please contact your Stoma Nurse if you are at all concerned.

### Sign & symptoms of dehydration

- ▶ Increased thirst
- ▶ Dry mouth
- ▶ Weakness/headache/lethargy/tiredness
- ▶ Confusion, sluggishness, or fainting
- ▶ Decrease urine output
- ▶ Dark coloured urine

Salt helps your body to absorb fluid and keep hydrated so it is advisable that you include an extra teaspoon of salt in your diet every day to help prevent dehydration, unless you have been advised to avoid salt or limit your intake because of another underlying medical condition. If this is the case please discuss with your Stoma Nurse and/or GP.



### Tips to avoid dehydration

If you experience any of the symptoms of dehydration, firstly be aware of your daily fluid intake (see *Maintaining hydration* on page 11), but you could also try any of the following:

- ▶ Vegemite either spread on toast or as a drink
- ▶ Salted chips
- ▶ Full sugar fizzy drinks (allowed to go flat)
- ▶ Isotonic sports drinks

### Treatment of dehydration

- ▶ Contact your GP or Stoma Nurse

### Food blockages

Some foods can swell in the bowel and may cause a blockage. This will cause your ileostomy to stop working normally. You should seek urgent advice from your Stoma Nurse or GP if you think this may be happening to you.

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### Signs and symptoms

- ▶ Your output will decrease, stop altogether or may contain large amounts of watery fluid
- ▶ You may experience pain
- ▶ You may feel or be sick
- ▶ Your abdomen may swell
- ▶ Your stoma may swell and look bigger
- ▶ You may experience reduced wind or it may stop altogether

### Tips to avoid food blockages

It is important to **chew** your food really well. The following foods are known to increase the risk of food blockages, so extra care should be taken:

- ▶ Nuts
- ▶ Coconut
- ▶ Celery
- ▶ Mushrooms
- ▶ Sweetcorn
- ▶ Raw fruit skins
- ▶ Bean sprouts and bamboo shoots
- ▶ Dried fruit such as currants and raisins
- ▶ Pith, pips and stones
- ▶ Popcorn

### Treatment of food blockages

If you suspect a food blockage, stop eating solid foods. You could also try the following:

- ▶ Increase your fluid intake
- ▶ Take pain relief
- ▶ Massage your abdomen
- ▶ Go for a walk and move around
- ▶ Contact Stoma Nurse/GP



*Leafy green vegetables can cause more wind in the early days. Try root vegetables such as carrots, parsnips and sweet potatoes.*



*Everything in MODERATION*



*Chew Chew Chew  
Your food  
thoroughly!*

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### Wind

Sometimes certain foods can give you wind. The following foods may increase wind:

- ▷ Cabbage
- ▷ Beans/lentils/pulses
- ▷ Cauliflower
- ▷ Sprouts
- ▷ Spicy foods
- ▷ Onions
- ▷ Fizzy drinks
- ▷ Chewing gum

### Solutions to reduce wind

- ▷ Avoid talking and drinking whilst eating and keep your mouth closed whilst chewing
- ▷ Avoid drinking with a straw
- ▷ Eat regularly and avoid long gaps between meals
- ▷ Allow fizzy drinks to go flat
- ▷ Try drinking peppermint drinks such as cordial or tea
- ▷ Eat natural yoghurt
- ▷ Keep mobile
- ▷ Avoid smoking and chewing gum

### Odour

The following foods can sometimes cause odour:

- ▷ Fish
- ▷ Eggs
- ▷ Onions
- ▷ Cabbage
- ▷ Garlic
- ▷ Asparagus

### Solutions to reduce odour

- ▷ Eat natural yoghurt
- ▷ Peppermint tea

If you have any concerns about the effect of your diet or medication on your ileostomy, please seek the advice of your Stoma Nurse or GP.

## Exercise

### In hospital

You will usually be seen by a Physiotherapist who will give you breathing exercises and tell you how to cough supporting your stoma and wound.



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The best exercise immediately following surgery is to get up and walk. You may need the help of a Nurse or Physiotherapist at first but this should become easier. Sitting out of bed is also advised to reduce the chance of a chest infection. You may be taken for a stair assessment prior to discharge.

### In the early days

It is important to keep mobile when you return home, and walking is ideal, but remember – however far you walk you will need to get back again. You may find it helpful to set yourself realistic goals that gradually increase over time. Listen to your body and if it feels too much, don't do it!

### Exercise

After stoma surgery it is important that you get back to a healthy lifestyle as soon as you feel able. Your recovery period may vary and will depend on your age, type of surgery, level of fitness before surgery and time spent in hospital. Strengthening your abdominal muscles is beneficial for your general recovery. Swimming, walking, yoga and pilates will help to do this, but **stop if it hurts**.

Whatever activities you enjoyed before your surgery, you should be able to get back to when you have recovered. Speak to your Stoma Nurse or Surgeon before starting anything strenuous. It is also advisable to speak to your Stoma Nurse about a support belt before returning to any exercise and activities. This will support your abdominal muscles, helping to prevent the development of a hernia around your stoma.

If you go to a gym it is advisable to see a personal trainer before commencing activities as they should be able to offer a tailored exercise programme. Activities such as gardening and bowls can be commenced again but it is advisable to wear a support belt when doing these. Ensure that you drink plenty of fluids when exercising to avoid dehydration.



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### Travel

#### Planning your holiday

If you are planning your first trip, it is only natural that you may be feeling apprehensive about travelling for the first time following your operation. It is sensible to start with short trips away from home to build up your confidence. Once you feel reassured, and as your confidence builds, you can start to venture further afield.



*If you have recently had surgery, check with your consultant or GP prior to booking your holiday to ensure you are able to travel. You should seek medical approval for the trip if you have been in hospital during the last 6 months.*

#### Plan ahead

- ▶ Make a checklist of equipment you need to take with you.
- ▶ Go through your pouch change routine to remind yourself of exactly what you use.
- ▶ Calculate the number of pouches you would normally need for each day of your holiday – and double it, with a few extras! The change in climate and environment may mean more pouch changes are needed.
- ▶ Having extra supplies can only add to your peace of mind.
- ▶ It may be useful to take different size pouches with you for different activities. Most companies make a range of different size pouches. You may want a larger capacity for a long flight, or a smaller pouch for swimming. Ask your Stoma Nurse for advice.
- ▶ In general, it is advisable to keep most of your supplies in your hand luggage so that it remains with you at all times and is within easy reach. However, in case your hand luggage is misplaced, extra supplies should be kept in your suitcase or companion's luggage as a precaution.
- ▶ Contact your Stoma Nurse for details of a Stoma Nurse in the location or country you are visiting.

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- ▶ A separate small travel kit containing items needed for a pouch change should be kept close at hand to make visits to the toilet simple and discreet.

#### Travel insurance

When you have decided on your destination, you must ensure you have adequate holiday insurance cover. Before insurers agree to provide cover, you will have to go through the insurer's screening process. This may involve completing a medical questionnaire or perhaps a telephone call with a medical advisor. You must disclose any medical history, surgery and any pre-existing conditions.

- ▶ Shop around for insurance cover as it is likely to be more expensive than previously.
- ▶ Contact your Ostomy Association as they may have names of reputable insurance companies.

#### Air travel

Remember that the International Air Transport Association (IATA) regulations forbid passengers to take dangerous items on board an aircraft and scissors should be packed in hold luggage. Restrictions also apply to carrying liquids on board. Check with your airline a few weeks before departure. When you check in at the airport, make sure you arrive early so you are at the front of the queue. This way, you can request an aisle seat near the toilet. You may also be able to request this in advance with your travel agent.

Air travel can make some people a bit 'windy'. It is a good idea to avoid foods which you know may cause excessive wind; have frequent small meals for 24 hours prior to flying; and try to avoid spiced or fatty foods and fizzy drinks.

#### Road travel

If you are travelling by road, try to plan your breaks around places that have adequate toilet facilities. Most roadside cafes, restaurants, service stations and hotels have toilet facilities. Do not be afraid to ask if you need to use them.



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### Food and drink

When abroad, the general advice on food and drink is the same for anyone:

- ▶ Be wary of the water supply in some countries
- ▶ Use bottled water or boiled water, including when cleaning your teeth and your stoma
- ▶ Avoid food that has been standing for long periods
- ▶ Don't have ice cubes in drinks
- ▶ Wash salads and fruit before eating them

### Tummy upsets

A change in climate, water or food can upset your bowels, so be prepared. As a precaution for diarrhoea, it is advisable to take with you Loperamide (Imodium) which slows down the bowel's activity, and sachets of rehydration powder, which easily dissolves in water to replace lost body salts, reducing the risk of dehydration.

All of these medications are available on prescription or over the counter from the pharmacist or local supermarket. Always read the instructions very carefully before taking these medications. If your symptoms do not settle after 24 hours, seek medical advice.



*If you have an ileostomy, Loperamide (Imodium) capsules may not be absorbed adequately as they are designed to be absorbed in the large bowel. It is a good habit to open the capsules and sprinkle them on your food.*

### Fluids

Drink plenty of fluids. In hot, humid countries, we perspire much more and need to replace lost body fluids. This applies to all the family, not only those with a stoma. Make sure you have plenty of fluid stops and always carry a bottle of water. Isotonic sports drinks such as Lucozade Sport or equivalent are excellent for combating dehydration. Allow fizzy drinks to go flat first, to reduce wind.



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*Remember that too much alcohol will accelerate dehydration as well as giving you a hangover in the morning – so don't overdo it! MODERATION is always advised.*

### Storage of stoma products

If you are holidaying in a hot climate, your stoma pouches should not be allowed to get too warm. It is advisable to keep your appliances in a cool bag or box and choose the coolest part of your accommodation to store them.

### Swimming

Most people are apprehensive when going swimming for the first time. Some people are worried that the water will affect the adhesion of the pouch. Your stoma pouch will be very secure while you're swimming. Once the pouch is wet, the adhesive tends to become 'tacky' and sticks even better. If you want to change your pouch after swimming, you may find the adhesive is still 'tacky' and, when you try to remove it, it may peel off like chewing gum and leave residual adhesive. It may be better if you dry the pouch well and leave the pouch for a few minutes. The adhesive should then return to normal.



You may want to change your pouch to a smaller size for swimming and going to the beach. If you like spending a lot of time in the sun, it is best to ensure your pouch is covered as the plastic of the pouch magnifies the heat. Chlorine found in swimming pool water and salt from sea will dry out the adhesive on your pouch, so it may be advisable to change the pouch more frequently.



*Don't forget sun protection lotions, avoid periods of intense UV radiation.*

### Swimwear

The type of swimwear that can be worn depends on your personal preferences and the position of your stoma.

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### Female

- ▶ If you are happy to wear a bikini – great!
- ▶ If you choose to wear a more discreet bikini style, a high-legged style may cover your stoma. A good swimsuit lining or double layer fabric will support your abdomen and help hide the pouch
- ▶ When choosing swimwear, try and choose a boldly patterned costume which will camouflage any bulges
- ▶ You could choose to wear a sarong on the beach and at the side of the pool. It can be easily removed when you fancy a dip



### Male

- ▶ If you are happy wearing your Speedos – great!
- ▶ Alternatively, swimming shorts are a good choice as they can be worn above the stoma and are generally loose fitting. Choose a swim-short with a mesh lining which will support your pouch.



**Remember** *Holidays are to be enjoyed! Plan ahead, relax and enjoy your trip.*

## Coping with the emotional challenges of having a stoma

Your stoma may have been formed for a variety of reasons including cancer, trauma or inflammatory bowel disease. The reason your surgery was necessary may have a bearing on how you adapt to life with your stoma. Some people will see their stoma as a welcome relief after many years of experiencing a reduced quality of life, as a result of their illness. Others may feel a sense of loss and look to their stoma as something they do not wish to have. This is a common and understandable reaction.

Learning to cope with your stoma emotionally as well as practically will not come to you overnight. We all learn to accept changes in our lives at different speeds and for some this will take longer than others. It is important to know that you may go through periods of sadness and

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grief, and feel anxious at times. Don't be too hard on yourself, allow your emotions to surface. It is OK to feel angry, sad or want to cry.

It is helpful to talk about these feelings with anyone who you feel comfortable with; your partner, family, friends or your Stoma Nurse. They will be there to offer support and help along the way. There are also support groups and associations offering help and advice from people who are already living with a stoma.

### Who should I tell?

You may be anxious about how other people will treat you now you have a stoma. Only you can decide who to tell and when. Some individuals choose to tell family and friends from the beginning and this can help with adapting to life with a stoma.

## Sex, intimacy and relationships

Initially you will be recovering from your surgery and getting used to the practicalities of living with a stoma so may not feel ready to be intimate. This is fine – give yourself time to recover from surgery first. Speak openly with your partner regarding your feelings and experiences as they may be more anxious about it than you. Promote intimacy through closeness, holding hands and kissing. The main thing to remember is to try to relax and feel comfortable.

Some types of surgery can impact on an individual's sexual function. This could be due to physical changes to this area of your body, or you are simply just not ready yet. You may need to experiment to find the most comfortable position for intercourse. You should discuss this with your Stoma Nurse when you feel ready, to find out what impact (if any) your surgery could have.

### When the time is right

You do not need to wear a special pouch for intimate times, but if you choose to there are smaller sized pouches and caps available. If possible, change or empty your pouch before intercourse – having an empty pouch will be more discreet.

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Cummerbund (wide support bands) help to conceal and support the pouch. Women may wish to wear lingerie and there are several companies that make a variety of underwear styles for women living with a stoma.



### Women

Some women may experience loss of sensation, pain or dryness following some types of surgery. This can be helped with the use of lubricants, change of position and avoiding deep penetration. If you experience difficulties, your Stoma Nurse will be able to offer advice. You should speak to your doctor regarding contraception if you require it, as it is still possible to conceive following stoma surgery. If you do want to become pregnant, please speak to your Consultant or GP as they are best placed to advise you. During pregnancy you may experience changes in the size of your stoma and consequently your template will require adjustment.



### Men

Men may experience difficulties in getting and maintaining an erection and ejaculation. This is because the nerves and blood supply involved with this may become bruised or damaged during surgery. This may improve with time, however if problems continue it is advisable to speak to your Stoma Nurse, as drugs and treatments such as Viagra, penile injections, implants or mechanical erectile appliances are available and can be very effective.



*"Your stoma is a small part of your overall body and it's important to remember that and not let it dominate everything – it will from time to time – but don't let it all the time."*

**Carole living with a stoma**

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### Body Image

Whether male or female, we all have our own personal perception of our bodies – our likes and dislikes. Your surgery will involve a physical change to your body and this may, in turn, affect how you feel about yourself. This is normal and it may take time to adjust to these changes.

*Regardless of surgery, we all come in different shapes and sizes and often find it comforting and helpful to talk about our body image worries.*

You may want to speak with another person who has a stoma. Speak with a Stoma Nurse and they can arrange this for you.

### Clothing choices and tips

When it comes to choosing clothing, people have very individual styles and preferences. There is no reason why you can't wear a variety of different clothing that is comfortable and fashionable. The most important rule with clothing, is to ensure that belts or waistbands are not worn over your stoma or restrict the pouch too much.

There are specialist stoma underwear, swimwear and clothing companies that produce clothing for people with stomas but this is not necessary to purchase or wear – your usual clothing should be suitable.

You can wear anything you like, but here are a few suggestions that may help you to choose your clothing.

## Suggestions from people living with a stoma:

### Women

"In the early days after your surgery opt for loose tops and palazzo type pants, baggy leggings that are kind to your waist area. If you have to buy new stuff get some colourful things as you'll be looking and feeling washed out."

*"Experiment – big scarves, pashminas, soft fabrics are kind. Draw attention to great legs, nice neck lines, earrings, snazzy shoes and boots."*

"Opt for patterned support swimwear. Not only will you look good, you will feel more confident in water with the added support that nothing is coming adrift. Pareos and kaftans are useful too."

*"Trousers or leggings with a deep waistband are the most comfortable as they don't cut across my ileostomy. The same goes for underwear: a deep lace band at the top also holds the pouch in place."*

"I go swimming but don't think there is any need to buy special swimwear – either go for a tankini top and straight leg bottoms, with support pants underneath or an ordinary swimsuit with 'tummy control' panels for support, maybe in a patterned fabric. If you angle the pouch slightly towards the centre of the body when applying it doesn't show."

*"Remember people aren't generally looking for a 'bump,' it is more obvious to you because you know what's there."*

*"High waisted knickers, jeans and skirts are best for me. I like the skinny stretch jeans, but the boyfriend style is good too as they are roomy at the top then taper down. I wear these with a longer jumper or shirt over the top."*

"In the summer wear any tops or t-shirts with linen type trousers as they often have plenty of room for the pouch to expand."

*"Dresses with suitable styling, e.g. gathers, loose waisted, fitted and flared can be more forgiving than skirts and tops."*

"Waistcoats, jackets, a loose cardigan or top – whatever suits the occasion, smart, sporty, casual worn over a more fitted top work well for me."

### Men

*"I find there is a need to unload my pockets to reduce the supported weight. Because of the need to carry emergency supplies with me I use a leather reporter style 'man bag.'"*

"I tend to wear patterned or striped shirts and jumpers which help to deflect the eye from any irregularities in body shape caused by the pouch. I also buy a larger than usual size around the waist so that it offers more space and for the natural folds of the material to distract the eye."

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### Medication

Some medicines are known to cause side effects and having an ileostomy does not exclude you from these. The symptoms will be exactly the same:

- ▶ Antibiotics can cause a change in the usual consistency of your output
- ▶ Iron tablets can cause black and sticky stools

*Despite experiencing these symptoms, it is important to continue to take any prescribed medication and discuss any side effects with your GP.*

Some medications, such as capsules/enteric-coated and slow release tablets, may not be absorbed in the small bowel and therefore will not be effective. Please discuss this with your GP or Pharmacist.



*Elixir is recommended rather than tablets for iron.*

### Chemotherapy

Chemotherapy is drug therapy and there are a number of different types that can be used to treat cancer. Some of these drugs can have an effect on your stoma and output. Speak to your Stoma Nurse or Oncology Nurse Specialist.

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### Problems you may experience with your stoma

#### Sore skin

Good skin care is vital to prevent sore skin. Sore skin is a common problem and is often seen but easily treated. There are a number of reasons why this may be happening. This isn't a complete list, so please contact your Stoma Nurse for further guidance if your symptoms persist.



*A yearly visit to your friendly Stoma Nurse can help you avoid these problems.*

#### ▶ Ill-fitting pouch:

Following surgery you may find that your abdominal shape changes, especially if you gain or lose weight. This means the skin close to your stoma may not sit evenly against your pouch, exposing healthy skin and allowing sore skin to occur or leakage to take place.

It is therefore important to regularly check your template size and suitability of your pouch.

#### ▶ Change in output:

A change in output from your stoma could contribute to sore skin. It is essential that the adhesive wafer fits well to offer good protection to the surrounding skin.

#### ▶ Trauma to stoma or skin:

Your stoma and the surrounding skin is at risk of damage and so should be well cared for. An incorrectly sized template may rub and cause injury to the side of the stoma, which may include small ulcers. It may be that the shape of the stoma remains the same but the size has altered. Get into the habit of checking your stoma, template and surrounding skin regularly.

#### ▶ Product sensitivity:

Sensitivity to the adhesive on your pouch is rare, but can occur even if you've been using it for a long time. It may begin as a slight irritation and become progressively worse if left untreated.

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#### ▶ Folliculitis:

This is an inflammation of the hair follicles. It appears like small pimples, occasionally pus-filled, that can be painful and is often seen after shaving the skin around the stoma.

As soon as you notice any changes to the skin immediately around your stoma, please contact your Stoma Nurse for advice about treatment.

#### Muco-cutaneous separation

To form the stoma, the bowel will be stitched to the skin. Occasionally, following surgery the stitches and skin can separate. This can sometimes look unpleasant but, like any other wound, it will heal over time. It is important to contact your Stoma Nurse who can advise you on treatment to aid healing.

#### Pancaking

Pancaking is relatively uncommon for individuals with an ileostomy. Pancaking occurs if the internal layers of the pouch stick together causing a vacuum which prevents the contents from dropping to the bottom.

#### Ballooning

Ballooning occurs when your stoma pouch blows up with wind. This can cause the pouch to come away from the body.

If you are using a filter cover, try removing it.

If your stoma pouch has a filter and you are still experiencing problems, it may be that you are suffering from excess wind. Spicy foods, some vegetables (onions, cabbage, peas, and beans) and fizzy drinks have been known to increase wind, so try to avoid these.

Also avoid drinking with your meal as this can cause you to swallow excess air. Eating regular meals will reduce the build-up of wind.

## 1. LIVING WITH A STOMA

### Parastomal hernia

A hernia is seen as a bulge in the abdomen. Surgery causes a weakness in the muscle wall, which sometimes allows part of the bowel to protrude through it, causing the bulge under the skin. A parastomal hernia can occur at any time following your surgery and develops around your stoma. They can be more common depending on the following risk factors:

- ▶ Age
- ▶ Weight
- ▶ Strenuous or heavy lifting

The parastomal hernia can vary in size from as small as a golf ball to as large as a football. There are numerous abdominal support garments that are helpful in concealing and supporting the hernia. It is recommended that you wear a light support garment as prevention. However, if you are partaking in strenuous activity, it is necessary to be measured for a more supportive garment. Your Stoma Nurse can arrange this for you.

In some people, the parastomal hernia will not cause any discomfort, but others may experience a dragging sensation, discomfort or pain. This will often depend on the size of the hernia and can be eased by wearing a measured support garment.

It is possible to have surgery to repair the hernia depending on the symptoms and effect on quality of life, but this will be assessed on an individual basis by your surgeon. It should be noted that there may still be a risk of another hernia developing following the repair.

### Blockages

A blockage can be caused by:

- ▶ Food excess
- ▶ Adhesions: this is scar tissue caused by surgery
- ▶ Parastomal hernia

## 1. LIVING WITH A STOMA

### Retraction

This occurs when the stoma is below skin level. There are various reasons for this:

- ▶ Difficulties with stoma formation
- ▶ Weight
- ▶ Shape of the abdomen

If you have a retracted stoma, you may need to try a range of pouches and additional products to find the most suitable for your stoma. Leakages are more likely, but the use of appropriate products will minimise this. Finding the ideal products may take some time but your Stoma Nurse will be able to offer advice on what is best for you.

### Bleeding

The bowel has a very good blood supply, which is why the stoma is pink/red in colour. Whilst cleaning your stoma, a small amount of bleeding on the cloth is to be expected. However, if you see blood inside your pouch and/or in your stool you should contact your Stoma Nurse or GP.

If you take anticoagulants such as Warfarin or Aspirin this may increase your risk of bleeding. If the bleeding is heavy, persistent or comes from the inside of the stoma you should seek advice from your Stoma Nurse or GP immediately.

### Prolapse

Sometimes the stoma can extend in length, similar to a telescope effect, and this is called a prolapsed stoma. Despite the prolapse, your ileostomy should continue to be a healthy pink/red colour. If this changes and becomes darker it is important that you seek urgent medical advice. It is important to use your template frequently and it may be necessary to use a larger pouch to accommodate the stoma, check with your Stoma Nurse.

## 1. LIVING WITH A STOMA

Lying down may reduce the size of the prolapse, and may make it easier to apply your pouch. In some cases the use of a support belt, applied whilst lying down, can be effective in managing the prolapse. Your Stoma Nurse can advise you on the use of a support garment or belt.

### **Granulomas**

Granulomas are red lumps that can appear on and around the edge of the stoma. They can be tender and may develop at any time. Sometimes rubbing from the wafer or base plate can increase the risk of granulomas occurring. Bleeding can happen and may interfere with the pouch adhesion. The template should be checked to ensure a good fit but do not cut the template larger to accommodate the granulomas as this may allow them to grow larger.

*Your Stoma Nurse may feel it is necessary to treat with a course of silver nitrate or you may be referred for surgical excision, although this is rare.*

### **Ulcers**

Ulcers can develop for a variety of reasons that may include medication, type of appliance and as a result of your original diagnosis. They can appear as broken, red, sore areas which may be painful. Ulcers are treatable and your Stoma Nurse can advise you following assessment.

## 1. LIVING WITH A STOMA

### **Stenosis**

Stenosis results in the stoma becoming very small and tight. The output from the stoma will become watery and intermittent. Following assessment, your Stoma Nurse may use a dilator to insert into the stoma and will request you continue to do this at home.

### **Necrosis**

This is extremely rare. Necrosis occurs if the blood supply to the stoma is restricted. Initially the stoma will become a darker red/purple and may even turn black, which is an indication that the blood supply is impaired. It may also feel cold and hard to touch. It is vital that you seek urgent medical attention.



SECTION 2

**OTHER HELPFUL ADVICE**

Additional help and support

## 2. 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






## 2. 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

## 2. 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

#### **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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## 2. 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.

## 2. 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.

## 2. 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.

## 2. 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.



*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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