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INTRODUCTION

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

▶ SECTION 1: INFORMATION TO READ PRIOR TO YOUR SURGERY

▶ SECTION 2: HELPFUL INFORMATION FOR YOUR RECOVERY PERIOD

▶ SECTION 3: ADJUSTING TO LIFE WITH YOUR UROSTOMY

▶ SECTION 4: OTHER HELPFUL ADVICE

▶ SECTION 5: STOMA NURSE - YOUR BEST RESOURCE

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

The booklet has been written to help explain what a **urostomy** is and what it will mean to you **once you have had your operation**.

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

There are a number of **Frequently Asked Questions**, which may not have been covered in the three sections of this booklet. These are included on page 56. 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.



YOUR STOMA AND SURGERY

Information to read prior to your surgery



AFTER YOUR SURGERY

Helpful information for your recovery period



3

LIVING WITH A STOMA

Adjusting to life with your urostomy



OTHER HELPFUL ADVICE

Additional help and support



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STOMA NURSE – YOUR BEST RESOURCE

Get to know your local Stoma Nurse



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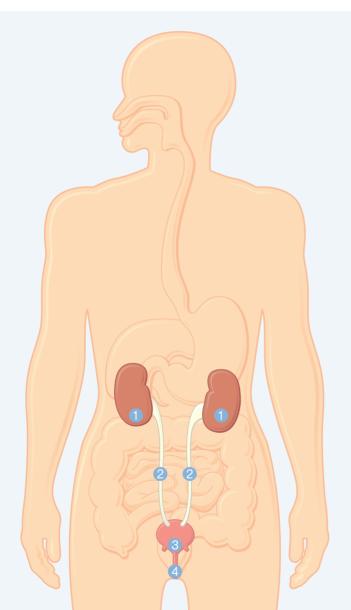
1. YOUR STOMA AND SURGERY

Your urinary system

The urinary system consists of the kidneys, ureters, bladder and urethra. Urine is formed in the kidneys, and the ureters transport the urine from the kidneys to the bladder. The bladder then stores the urine until you feel the desire to urinate, when the muscle of the bladder will contract to force urine out of the body through a tube called the urethra.

The urinary system

- Kidneys 1
- Ureters 2
- Bladder (3)
- Urethra 4



1. YOUR STOMA AND SURGERY

What is a stoma?

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

Colostomy: from the large bowel

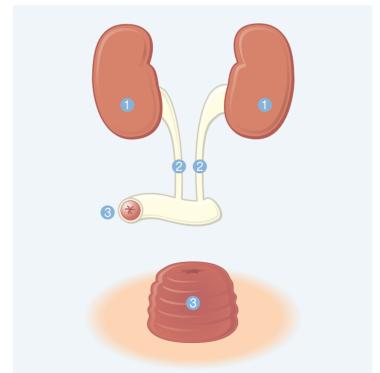
▶ **Ileostomy**: from the small bowel

▶ **Urostomy or ileal conduit**: urinary stoma (you may hear this called an 'ileal conduit')

A urostomy is usually on the right-hand side of your abdomen, but in some circumstances it may be made on the left-hand side.

What is a urostomy?

A urostomy is a type of urinary diversion which involves disconnecting the ureters from the bladder and attaching them into a short length (15–25cms) of small bowel, which has been removed and re-formed, creating a reservoir through which the urine will flow. One end of the removed piece of bowel will be closed off, while the other will be brought to the surface of your abdomen, as a urinary stoma. You may or may not have your bladder removed, depending on the reasons for your surgery. Your Stoma Nurse will be able to explain this in further detail.



Ileal conduit

- 1 Kidneys
- 2 Ureters
- Stoma

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1. YOUR STOMA AND SURGERY

Why am I having a urostomy?

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

▶ Cancer
▶ Bladder failure

▶ Trauma
▶ Congenital abnormalities

Before surgery

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



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

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

Where possible, your Stoma Nurse will involve you in marking the ideal site for your urostomy as a guide to the surgeon, taking into consideration your individual needs. However, at the time of surgery, it may not always be possible to put the stoma in the exact position your nurse has marked. A urostomy is usually on the right-hand side of your abdomen, but in some circumstances it may be made on the left-hand side. You may also see a Urology Specialist Nurse who will assist you with questions and appointments.

1. YOUR STOMA AND SURGERY

What will my urostomy look and feel like?

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



Urostomy



Urostomy with stents

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2. AFTER YOUR SURGERY

Waking up after your surgery

When you wake up after your operation, it is normal for you to be cared for in the high dependency/ intensive care unit for a short period of time. You may have drips and drain tubes attached to your body, but there is no reason to be alarmed – this is quite normal. These will all be removed when appropriate, with very little discomfort. You will be wearing a urostomy pouch, which will most likely be transparent or have a viewing window, so that your nurses can check on the colour and size of your stoma easily. A night drainage bag will be attached to collect your urine at first.

After surgery, you will have some thin tubes called stents coming out from your urostomy. The purpose of the stents is to protect the newly formed join where the ureters meet the piece of small bowel. The stents may fall out by themselves, but if they don't your Stoma Nurse will gently remove them, once the initial post-operative swelling has started to reduce. Looking after your urostomy can be a bit fiddly until this time, but management will feel easier once they are removed.

You will feel tired and it is possible that you may experience a range of emotions during this time and for some time afterwards. This will vary as we are all different.

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

After your operation, you may experience some constipation. It is normal for there to be some disruption to your bowel movements following this procedure as a result of using part of your small bowel to create your urostomy, and also because your usual pattern of eating and drinking has been disrupted. Once your bowels start to work again, you may experience diarrhoea for a short while, but this will pass and gradually things should settle.

2. AFTER YOUR SURGERY

When will my urostomy start to work?

You will notice that your urostomy will work as soon as it is formed and also that you have no control or sensation over when you pass urine. Initially, your urine may have a slight red colour to it – this is nothing to worry about and it will quickly return to normal. You may also notice some mucus in your urine or around your stoma. Mucus in urine is normal, because it is a bi-product of the inside of the bowel.

All of this is normal and is to be expected.

Your urostomy will produce a small amount of urine every few seconds, but this can vary. It is important to empty your pouch regularly, to ensure that it does not get too full. If a pouch is full, it can be more difficult to empty and may also be more noticeable under clothes. Most people will change their urostomy pouch every 1–2 days, but it is up to you.



Urostomy with stents

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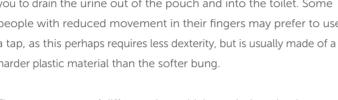
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Urostomy pouch – front and back

2. AFTER YOUR SURGERY

Wearing a stoma pouch

Your Stoma Nurse will usually help you decide which is the most suitable pouch for you. A urostomy pouch has a non-return valve discreetly placed inside the pouch which prevents the urine from flowing back and pooling around the stoma, reducing the chance of urinary infections. All pouches will also have a tap or bung to allow you to drain the urine out of the pouch and into the toilet. Some people with reduced movement in their fingers may prefer to use a tap, as this perhaps requires less dexterity, but is usually made of a harder plastic material than the softer bung.



There are a range of different sizes which are designed to be worn under your normal clothes. Pouches are waterproof, so you can choose to have a bath or shower with it on or off. It is up to you, but remember, you will have no control over when your stoma functions.

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

Using a night drainage bag

Your stoma will work throughout the day and night, so it is advisable to use a night drainage bag at night. This will allow the drainage of your urostomy pouch during the night to prevent you having to get up to drain your pouch. You will be advised by your Stoma Nurse regarding the type and use of night drainage bags.

Using a leg bag

Some people with a urostomy may choose to use a leg bag, which is attached to their urostomy pouch to provide additional capacity and prevent the need to drain as often. This option might be something you choose for long car or train journeys, if you are unwell or not very mobile.

2. AFTER YOUR SURGERY

Changing your stoma pouch

Ensure you have everything to hand before changing your pouch:

- > A clean stoma pouch
- Scissors and template (if required)
- Dry wipes or plain kitchen roll (not cotton wool, tissues or toilet paper)
- Disposal bag
- Adhesive remover (if required)
- Cup (to catch the urine before the new pouch is attached)
- ▶ Mirror



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



To change your pouch

- Draw the template of your stoma onto the adhesive of the pouch, then cut it out. Pouches are also available in pre-cut sizes.
- Ensure the tap or bung is closed on your new pouch.
- Drain your pouch.





Cutting the hole



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

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2. AFTER YOUR SURGERY

Pouch removal

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

adequate and acceptable.

- ▶ To remove the pouch, carefully release the adhesive, working from the top down whilst supporting the skin. You may choose to use an adhesive wipe or spray as you peel away the adhesive to help with removal.
- ▶ Once removed, fold the adhesive section of the used pouch in half so it seals.
- Place your pouch into a disposal sack.
- Use dry wipes (kitchen roll is an alternative) and water to clean around the stoma. Place these in the disposal sack (do not put them in the toilet as they may block it!)
- Ensure the skin around the urostomy is dry.



Peel

2. AFTER YOUR SURGERY

- Remove the backing film from the adhesive of the new pouch.
- ▶ Fold the top half of the adhesive back, then position it around the stoma, working from the bottom and smoothing upwards with your fingers. Take time to ensure there are no creases in the adhesive and use the warmth of your hands to mould the pouch to your skin, making sure it is well stuck!
- Securely close the disposal sack and put in the normal household rubbish bin. DO NOT flush a used pouch down the toilet, as it will cause a blockage.



Position



Press



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

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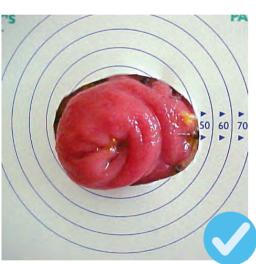
2. AFTER YOUR SURGERY

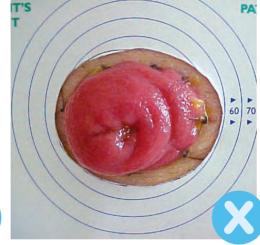
Caring for your skin

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

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

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





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

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

2. AFTER YOUR SURGERY

Aim to keep your skin in optimum condition by considering:

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



TIP: To remove the hair around your stoma you might find it helpful to use a plastic deodorant lid or empty toilet roll cardboard to place over the stoma, for protection, and shave around it. If you experience sore skin, please refer to page 45.



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3. LIVING WITH A STOMA



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 46.

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.



DO NOT LIFT DO NOT TWIST YOUR BODY

DO NOT REACH

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.

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



3. LIVING WITH A STOMA

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WARNING: It is not recommended to take a sample from your used urostomy pouch or night drainage bag.

Infection

Urinary tract infections (UTIs) are common. In people with urostomies, it affects the upper part of the urinary system: the ureters and kidneys.

Signs and symptoms of a UTI

- > Flu-like symptoms
- ▶ High temperature
- Pain in back and sides
- Shivering
- ▶ Chills
- Cloudy and/or smelly urine

Treatment of a UTI

It is important that you contact your GP or Stoma Nurse if you experience any of the above symptoms. They will need a sample of your urine and will advise you when to take a sample, as the urine should be as fresh as possible.

Ideally your Stoma Nurse will take a urine sample using a catheter which is inserted into your stoma. However, it is also acceptable to obtain a urine sample from a clean stoma without a pouch on. You can do this by obtaining a sample pot from your Stoma Nurse or GP and holding it directly underneath your stoma, allowing the urine to collect in the pot. It is important to ensure the pot does not touch your stoma or skin, and your fingers should not come into contact with the inside of the pot.

Be aware this may take some time and you will need to fill at least a quarter of the sample pot.

3. LIVING WITH A STOMA

A UTI that is causing symptoms is usually treated by a short course of antibiotics, following collection of a urine sample.

Tips to avoid a UTI

- Drink plenty of fluids
- Ensure the tube of your night drainage bag is kept clean
- Drink cranberry juice or take cranberry tablets

If you experience recurring UTIs speak to your Stoma Nurse as you may need to change your urostomy pouch and night drainage bag more frequently.



TIP: Cranberry juice and tablets are not currently considered a treatment for urine infections, and for some people they can help prevent urine infections. However, please be aware that if you are taking warfarin, you should avoid any products containing cranberries.



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3. 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.

Some foods may affect the colour and smell of your urine:

- Beetroot
- > Food dyes
- Red drinks
- Asparagus

General advice

You should aim to drink around two litres of fluid a day. This should be increased in hot weather or if you sweat a lot e.g. when exercising, or if you have a raised temperature. If your urine appears dark, this may be a sign that it is more concentrated, so you need to drink more to ensure that the urine is diluted and lighter in colour. If your urine remains dark, odorous or cloudy, this may be a sign of infection. Please seek advice from your Stoma Nurse.

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

3. LIVING WITH A STOMA

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.

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.

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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3. LIVING WITH A STOMA

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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.

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.

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.
- ➤ 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.

3. LIVING WITH A STOMA

- ▶ 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.

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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3. LIVING WITH A STOMA

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

It is a good habit to open

the capsules and sprinkle

them on your food.

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.

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.

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

3. LIVING WITH A STOMA

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.

Swimwear

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

Female

- If you are happy to wear a bikini- great!
- 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.
- ▶ If you wear bikinis, a high-legged style may cover your stoma. Alternatively, choose a tankini top (long, vest-style top) to wear with bikini bottoms.
- Wear a sarong on the beach and at the side of the pool. It can be easily removed when you fancy a dip.



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





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3. LIVING WITH A STOMA

▶ 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

3. LIVING WITH A STOMA

Coping with the emotional challenges of having a stoma

Your stoma may have been formed for a variety of reasons including cancer, trauma or incontinence. 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 times of sadness and 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.

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Warning: Intercourse via the stoma should never be attempted as this can be very dangerous.

3. LIVING 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.

This surgery will impact on your sexual function and is due to physical changes to this area of your body. Nerves, blood supply and surrounding areas will be affected. There should be time to discuss this before and after surgery with your Stoma Nurse and Urology Surgeon.

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.

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.

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Women

In some cases this type of surgery involves the removal of the womb and part of the vaginal wall. You may experience loss of sensation, pain or dryness. 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.



Mer

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, damaged or cut during surgery. 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 effective.



3. LIVING WITH A STOMA

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 should be able to arrange this for you.

"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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3. LIVING WITH A STOMA

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."

"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."

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

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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3. LIVING WITH A STOMA

Medication

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

- Antibiotics can alter the colour of your urine
- Some anti-depressants can make urine blue/green coloured
- > Warfarin can make urine orange coloured

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

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.

3. LIVING WITH A STOMA

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.

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 urine:

Any change in your urine could contribute to sore skin. Highly acidic or alkaline urine may affect the adhesion of your pouch. This could be a sign of infection and you should consult your Stoma Nurse.

> 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.

> 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.



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

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3. LIVING WITH A STOMA

Infection

Please refer to the 'Early days at home' section, page 26.

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.

Parastomal hernia

A hernia is a weakness in the muscle wall. A parastomal hernia can occur around the stoma and is 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 affect 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.

3. LIVING WITH A STOMA

Retraction

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

▶ Difficulties with stoma formation ▶ Smoking

▶ Weight
▶ Multiple abdominal and/or

Shape of the abdomen emergency surgery

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 urine 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 bowel can extend in length, similar to a telescope effect, and this is called a prolapsed stoma. Despite the prolapse, your urostomy 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.

3. 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.

Phosphate deposits

This occurs when your urine is too alkaline and forms grey crusty deposits on your skin, and can result in sore skin and leakage. These deposits must be covered by your stoma pouch and it is important not to cut the hole bigger. Treatment includes white vinegar soaks: either by dabbing the surrounding area with a cloth soaked in equal parts white vinegar and water, or spraying or covering the area with this same solution. Your Stoma Nurse will show you how to do this. You should also increase your fluid intake.

3. LIVING WITH A STOMA

Stenosis

Stenosis results in the stoma becoming very small and tight. The output from the stoma may appear delayed and then suddenly spurt out. This is due to having such a small opening to the stoma, causing a build up of urine. Following assessment, your Stoma Nurse may use a dilator to insert into the stoma and will request you continue to do this at home. You may need surgery to refashion your stoma.

Necrosis



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SECTION 4

OTHER HELPFUL ADVICE

Additional help and support

4. 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 below, so that you can refer back to them in the future.

My Stoma Nurse:	
Contact Details:	
Email:	
Stoma product codes:	

(I)

Scan your QR code to download the app for FREE









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 (see left) 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



4. OTHER HELPFUL ADVICE

National Directory of Ostomy Associations

AUSTRALIAN CAPITAL TERRITORY:

ACT & Districts Stoma Assn Inc.

- **(02)** 6205 1055
- stoma@ACTStoma.onmicrosoft.com
- www.actstoma.net.au

NORTHERN TERRITORY:

Cancer Council of the Northern Territory Inc.

- **(08)** 8944 1800
- stomy@cancernt.org.au
- http://nt.cancer.org.au/

WESTERN AUSTRALIA:

WA Ostomy Assn Inc.

- **(08)** 9272 1833
- admin@waostomy.org.au

NEW SOUTH WALES:

NSW Stoma Limited

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

Ostomy NSW Ltd:

- **(02)** 9542 1300
- orders@ostomynsw.org.au
- www.ostomynsw.org.au

QUEENSLAND:

Gold Coast Ostomy Assn Inc.

- **(07)** 5594 7633
- gcoa@bigpond.com

NTH QLD Ostomy Assn Inc.

- **(07)** 4775 2303
- admin@ngostomy.org.au

QLD Ostomy Assn Inc.

- **(07)** 3848 7178
- admin@gldostomy.org.au
- www.qldostomy.org

QLD Stoma Assn Inc.

- **(07)** 3359 7570
- admin@qldstoma.asn.au
- gldstoma.asn.au

Toowoomba & South-West Ostomy Assn Inc.

- **(07)** 4636 9701
- bob.schull@bigpond.com

Wide Bay Ostomates Assn Inc.

- **(07)** 4152 4715
- wbostomy@bigpond.com

SOUTH AUSTRALIA:

Ostomy Assn of SA

- **(08)** 8235 2727
- colosa@colostomysa.org.au
- www.colostomysa.org.au

Ileostomy Assn of SA Inc.

- **(08)** 8234 2678
- info@ileosa.org.au

TASMANIA:

Ostomy Tasmania Inc.

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

4. OTHER HELPFUL ADVICE

VICTORIA:

Bendigo & District Ostomy Assn Inc.

(03) 5441 7520

Colostomy Assn of Vic.

- **(03)** 9650 1666
- info@colovic.org.au
- www.colovic.org.au

Geelong Ostomy Inc.

- **(03)** 5243 3664
- goinc@geelongostomy.com.au
- www.geelongostomy.com.au

Ostomy Assn of Melbourne Inc.

- **(03)** 9888 8523
- enquiries@oam.org.au
- www.oam.org.au

Peninsula Ostomy Assn Inc.

- **(03)** 9783 6473
- poainc1@bigpond.com

Victorian Children's Ostomy Assn.

(03) 9345 5325

Warrnambool & District Ostomy Assn Inc.

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

Local Support Groups

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

4. 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.

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.

Why do I have to see a Stoma Nurse when there is nothing wrong with my pouch or stoma?

The experience and trained Stoma Nurse can detect very slight changes, this will assist you with your quality of life. The technology in pouches changes quickly. A Stoma Nurse can keep you up to date, leak free, skin healthy and trouble free.

4. 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".

Pouch: (External): A term used to describe a stoma appliance worn over a stoma to collect urine or stool/output.

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.

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.

Convexity:

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

Diarrhoea:

Loose, watery stool

Hvdrocolloid:

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.

Ileal Conduit:

Another word for a urostomy

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.

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4. OTHER HELPFUL ADVICE

Oncologist:

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

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.

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

Stoma Nurse:

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

Urostomy/ileal conduit:

A urinary stoma.

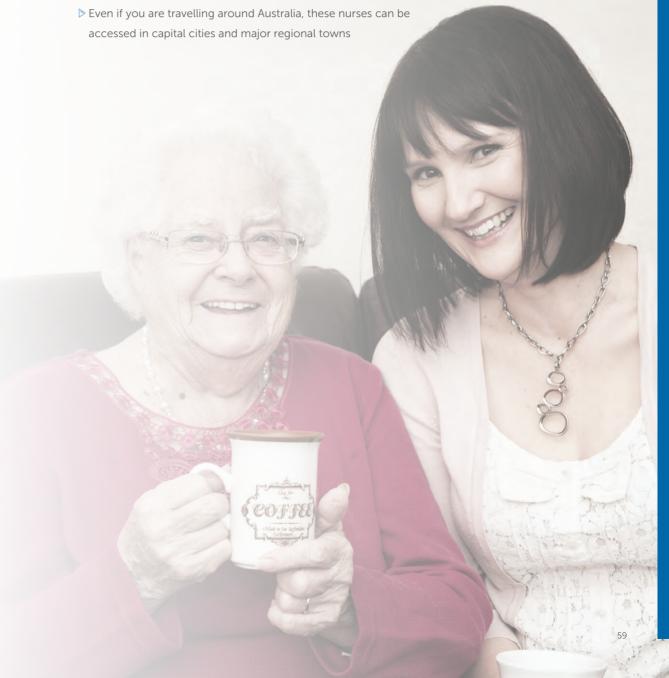
5. STOMA NURSE - YOUR BEST RESOURCE

Your friendly Stoma Nurse

Get to know your local Stoma Nurse. They are only a phone call/ email distance away.

Don't put up with red skin or leakages, they can be solved quickly

See your Stoma Nurse annually, it will only take 10 minutes to check your stoma, skin and pouch size. You wouldn't let your car go without a service for 12 months!



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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)



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