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LIVING WITH YOUR OSTOMY

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FNZOS MISSION STATEMENT
To enable member Societies to best work together with families, medical professionals and Health Authorities to ensure that, in New Zealand, all Ostomates and persons with related surgeries receive, free of charge, care and equipment that will enable them to lead normal lives of optimal quality.
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This booklet has been compiled in collaboration with colostomates, ileostomates and urostomates and is based on their own experiences. It is produced by Ostomy New Zealand for those affected by ostomy surgery or their carers and family members.

Ostomy surgery as is not uncommon and after convalescence and familiarity with appliance management, the new ostomate can confidently return to normal living in the sure knowledge that no-one will know that your “plumbing” has been modified unless you choose to tell people.

You may be reading this because you have been advised that ostomy surgery is recommended and you know little or nothing about ostomies. Be assured that information, help and confidential support are readily available from your local Ostomy Support Group as well as from various health professionals and stoma care nurses who are specially trained to ensure the speedy return to normal living.

To contact your local support group, visit our website http://www.ostomy.org.nz, ask your stoma care nurse or contact Ostomy New Zealand. Their current address can be found in “The New Zealand Ostomate” magazine, available free from most hospitals.
INTRODUCTION

What is an ostomy?

An ostomy is an opening created on the abdomen through the skin surface for the discharge of body waste. It replaces the usual system of disposal. An ostomy is created during surgery to maintain normal body function without a rectum, diseased colon or urinary bladder.

The opening is called a stoma - from the Greek word meaning mouth - and the body waste is released into a special bag, often called an appliance.

There are a number of different types of ostomy surgery, the three main types being colostomy, ileostomy and urostomy (urinary diversion). The day-to-day care and management is different for each type.

A stoma may be formed as a temporary measure, as part of other surgical procedures, and may be reversed after several weeks or months.

A person with an ostomy is often known as an ostomate. There are about 6,500 people with an ostomy in New Zealand, made up of colostomates (66%), ileostomates (21%) and urostomates (13%).

A COLOSTOMY is an artificial opening in the colon (large intestine) which is brought to the surface of the abdomen. It may be needed due to cancer of the bowel, diverticular disease, a congenital condition or because of internal injury.

Discharge from a colostomy will vary in consistency and frequency, depending on its location in the colon and the types of food consumed.

An ILEOSTOMY is created by bringing part of the ileum (small intestine) through an opening in the abdomen and is usually done when the colon (large intestine) is diseased, requiring complete removal, or to rest a part of the large bowel due to conditions such as IBD, Crohns disease or Colitis.

Discharge from an ileostomy is fairly constant and often watery, and contains digestive enzymes.

A UROSTOMY (sometimes called a urinary diversion or ileal conduit) is formed when urine must be diverted from its usual route out of the body, to the surface of the abdomen. The urinary bladder is usually bypassed or removed because of cancer, urinary incontinence, congenital conditions, spinal injury or some other condition.

Discharge from a urostomy is urine which tends to flow or spurt frequently.
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A colostomy is a surgical opening in the large bowel bringing it to the surface of the abdomen (Figure 2). The opening is usually made just below the navel to the left side and is called a stoma. It can be as small as 2.5-4cm or as large as 4mm, round or oval in shape, shiny, wet and dark pink in colour, similar to the inside lining of your mouth and occasionally bleeds a little; it will gradually shrink after surgery until it assumes a permanent size some weeks later. Although stomas are rich in blood vessels they do not transmit pain or other sensations and require little care. The stoma should be gently cleansed with plain soap and water at each appliance change. Water will not enter a stoma so it is not necessary to cover it during bathing or showering.

Problems that can arise include prolapse, stenosis or narrowing and hernia, all of which will need to be discussed with your stoma nurse.
The reason you are a colostomate is generally because of cancer of the bowel, injury or accident or some bowel malfunction. It must be remembered that as a colostomate you can no longer dictate to the bowel, the bowel will work when it wishes. Instead of perhaps previously having one bowel movement a day, you will possibly find that there are now several smaller ones, indeed some colostomates find that eating and bowel activity are closely linked. In this, as in all aspects of life with a colostomy, each individual will settle to their own unique pattern. There are no rules, as this booklet attempts to show, only guidelines and helpful hints.
FOOD AND DRINK

No special diet is required unless ordered by your physician. You may wish to avoid some foods which cause gas or odour, or are hard to digest. Alcohol can be drunk in moderation but carbonated drinks can cause gas problems. After surgery you may find your stoma noisy, but this will settle down and rarely causes embarrassment in public. Eat in moderation 3 times a day at regular times in the early stages, introducing new foods one at a time. If you find one particular food upsets you, discontinue it, but try it again at a later date. The next time there may be no reaction.

MEDICATION

Any medication you take will work just as effectively as before. Prescription drugs, vitamins aspirin, and other medications will continue to be absorbed into your body just as before your colostomy.

Some medications may change the colour, odour or consistency of your stool. Non-prescription medications, like antacids, can cause constipation or diarrhoea. Antibiotics may make your stool thinner than normal, and may even cause diarrhoea. If you have questions about any medications you are taking, ask your doctor, pharmacist or stoma nurse.

RECTAL DISCHARGE

Following rectal surgery, you may still feel the urge to open your bowels. This commonly occurs and is a normal feeling. You may pass mucus which is a normal bowel secretion. If you experience ongoing irritation, contact your stoma nurse for advice.

IRRIGATION

Some colostomates may consider irrigation as a means of management. The purpose of irrigation is to stimulate peristalsis (the wave-like movement of the bowel) thus promoting evacuation of waste material (faeces) remaining in the bowel. For those people suited to irrigation it allows them the freedom of wearing a smaller flat appliance. People who irrigate must have a descending or sigmoid colostomy (most of the large bowel remains). Discuss this with your surgeon and/or stoma nurse for advise on this.
ILEOSTOMY

An ileostomy is a surgically created opening into the small intestine - through an opening in the abdomen. The end of the small intestine (ileum) is brought through the surgically created opening in the abdominal wall and sewn, forming the stoma. The procedure usually involves the removal or disconnection of the entire large intestine (Fig 4). In some cases part of the small intestine and/or the rectum may be removed as well.

Ileostomy surgery may be proposed for a number of reasons, but the most usual is in patients with Inflammatory Bowel Disease (ulcerative colitis and Crohn’s disease). Here, many factors are taken into consideration including the severity and site of the disease, the failure of medical treatment, the presence of complications such as fistulae and the extent to which the disease interrupts daily life.

Fig 3
If your life has been ruled by IBD for several years you will probably feel vastly relieved that something is being done to return you to good health. Within a few days after the removal of the diseased part of your gut, you will be amazed at the speed with which you start to regain your appetite, weight and energy! IBD is very debilitating, so the return of health and strength will be especially precious to you.
FOOD AND DRINK

When ileostomy is very new the discharge may be quite fluid. And in order to reduce the amount of output, it can be helpful to avoid highly fibrous foods as this stimulates the small intestine. It is important to maintain a healthy well balanced diet being aware of the importance of chewing food well.

One of the main functions of the large intestine is to absorb water and salt from the waste matter stored there. Although the small intestine gradually adapts by increasing its own absorption of water, your body will probably need more fluids than it did before surgery. To avoid becoming dehydrated, you need to drink plenty of water, or other liquids each day and you should pass a minimum of 1 litre of urine each day. Electrolytes can be helpful with this. Keep an eye on your urine output as it should be straw coloured.

A major increase in the ileostomy output (due to a number of factors including an attack of gastroenteritis or a mild obstruction) must be treated seriously. And medical advice should be sought.

Foods that can help thicken stool include apple sauce, mashed potato, ripe bananas, marshmallows, noodles, yoghurt and cheese. Such episodes should be few and far between as stated earlier.

BLOCKAGE

Ostomates may experience a blockage; this can be caused by foods such as nuts, coconut and some vegetables and fruit. You may experience colicky pain, which is usually of a temporary nature. In the event of a blockage, you will notice that either the output from your stoma has stopped for longer than is usual or that your bag contains excessive amounts of watery fluid. Not all blockages are remedied and will require medical attention.
If your output changes significantly in consistency, colour or quantity and you feel unwell with stomach pains and/or nausea or vomiting, you should contact your doctor or stoma care nurse and stop taking solid food. You must continue drinking water in small quantities until the blockage clears and/or you have been seen by your stoma care nurse or doctor. If blockage occurs, your stoma may temporarily change in size or colour.

**Possible causes**

May be related to your surgery
Plug of food: for example nuts, citrus fruits, sweet corn, coconut or other high fibre foods, some people may need to chew some foods more carefully
Drugs - some pain killers may slow down the output
Blockages are usually remedied easily, but may require medical attention.

**RECTAL DISCHARGE**

Following rectal surgery you may still have the urge to open your bowels. This commonly occurs and is a normal feeling. You may pass mucus which is a normal bowel secretion. If you experience ongoing irritation, contact your stoma nurse for advice.

**MEDICATION**

With an ileostomy, some medications – including large tablets, coated pills, time release capsules and birth control pills – may pass through your system without being completely digested. Always tell your doctors, dentists, and pharmacists that you have an ileostomy. They can generally prescribe – or help you to select – alternative forms of medication.

After your surgery never take laxatives. For a person who has an ileostomy, taking laxatives can cause a severe fluid and electrolyte imbalance.

Some medications may change the colour, odour, or consistency of your stool. Non-prescription medications, like antacids, can cause constipation or diarrhoea. If you have questions about any medications you are taking, ask your doctor, pharmacist of stoma nurse.
A urostomy is simply an artificial opening in the urinary tract on the body surface (Fig.6). On occasion, it may be a direct opening from the ureters or bladder, but by far the most common urostomy is the ileal conduit. This form of urinary diversion has been popular for many years as a means of solving the problem of what to do when the bladder is lost through accident or disease or when it does not develop its normal function or control.

The ileal conduit uses a short segment of the small bowel, isolated from the rest of the bowel but with its blood supply intact, to provide a means of conveying urine from the ureters to the outside collecting appliance. To one end of this short piece of bowel the ureters are attached and the other end is brought through the abdominal wall to form a stoma.

**Fig 5**
The stoma is fashioned as a spout to allow a collecting appliance to be fitted and to prevent urine coming into contact with the seal of the appliance to the abdominal wall. Urine is produced continuously down the ureters into the bowel segment and hence to the outside. Intermittent contractions of the bowel segment, in an ordered fashion, called peristalsis, aid the passage of urine along the conduit and lead to the urine being discharged from the stoma in small spurts, at fairly regular intervals.

Whether the bladder is removed or remains is of no significance to the function of the ileal conduit. The person’s own bladder may need to be removed because of the disease process that destroyed it, or it may be left behind as a functionless organ that is now no longer in use. Because of the success of urostomy appliances in providing leak-free systems, an ileal conduit may the best way of managing an otherwise unmanageable incontinence.

Occasionally an internal pouch is formed on the inside of the abdomen using a segment of bowel and is emptied by intermittent catherization.
**THE URINE**

Urine is the complicated end product of the work of the kidneys and provides the way we maintain a very stable chemical environment in our bodies. It is normally slightly acid, with only a slight odour, varies in colour depending on its concentration and is sterile. The urine from an ileal conduit differs in two ways. Firstly it contains a variable amount of mucus. All bowel produces some mucous and the segment used for ileal conduits maintains its mucus production. Threads of clear mucous can be seen in the urine from ileal conduits and are normal.

Secondly, all bowels have a normal population of bacteria and these are added to the urine as it passes along the conduit. Bacteria acting on substances in the urine produce ammonia and other substances leading to the strong and unpleasant odour associated with urine that is no longer sterile and has been standing for some time. This need not occur, as higher fluid intake will lead to more frequent flushing of the conduit and a decrease in the number of bacteria. Substances (such as Redoxon 1000mg daily) can be taken to maintain the acidity of the urine as many bacteria find difficulty in growing in urine that is not alkaline. Antibiotics will also temporarily minimise the problem but are not without risk if taken for long periods.

**POSSIBLE COMPLICATIONS**

While not as good as a normal bladder, an ileal conduit with a well fitted, well functioning appliance is often the next best thing. It enables people to live near-normal lives with few restrictions. Complications are usually minor and can be dealt with easily when there is close cooperation between ostomate, stomal therapist and surgeon.

A defect with an ileal conduit as opposed to the normal bladder is that it can be quite seriously infected without causing any symptoms noticeable to the urostomate. If this is unrecognised then the infection can develop into a more severe one with complications. Therefore regular taking of specimens of urine or examination using a catheter inserted into the...
conduit to look for silent infections is sometimes advised. Special combined catheter/specimen containers are available to easily do this. Bag specimens of urine are useless as they are usually contaminated by the stoma and the skin.

Stone formation is usually a result of infection, inadequate fluid intake and dietary factors. Kidney damage can result from uncontrolled infection or be a reflection of the back pressure effects.

Reabsorption of some urine constituents in the ileal conduit, especially chloride and acid, can occasionally cause nausea, vomiting, lethargy, over breathing and even coma. This can be prevented by treatment from your doctor, and detected early by blood tests.

Urine appears intermittently at the stoma, being discharged in small spurts, but ejection of urine in narrow, long streams indicates obstruction at the stoma. This may require surgical attention.

Crystals may form in the urine, some being deposited on the skin immediately around the stoma. At each appliance change the crystals should be thoroughly rinsed away to prevent skin excoriation.
THE STOMA CARE NURSE (STOMAL THERAPIST)

The Stoma Care Nurse is a senior registered nurse who has undertaken a special course in the care of people with stomas. Most of the larger hospitals have a stoma care nurse; many of the smaller hospitals employ a nurse in a part-time dual position.

You can contact your stoma nurse and also get details of outpatient clinic times through the hospital or community nursing service. It may be necessary to make an appointment for a consultation, but a phone call may be all that is needed to get an answer to that query you have.

A stoma nurse is able to help with teaching you all aspects of stoma care and is there to ensure that you are using the appliance that best suits you. Stoma nurses will arrange for ongoing supplies, and are there if you have any problems with the management of your stoma. A surgeon may request the stoma care nurse to site the stoma prior to surgery; consideration is given to the selection of a flat area of the abdominal wall, identification of skin folds, creases, scars and other irregularities which will be avoided to ensure the optimal position for the stoma. Advice may be given to the patient re weight gain or loss, if this is indicated for successful appliance management.

If at some time you consider changing to a different appliance, this should always be done in consultation with your stoma nurse.

It is generally advised that ostomates are checked annually to ensure that all is well and that the most suitable appliance is being used.
THE STOMA

A stoma is a piece of bowel brought through a small incision in the wall of the abdomen onto the skin surface. It is then turned back on itself like the cuff of a sleeve and stitched. Stomas vary considerably in diameter and length according to the type of ostomy and the handiwork of the surgeon.

- Colostomates will usually have their stoma situated on their left side, slightly below the level of the navel.
- Ileostomates will have their stoma on their right side; the diameter will be roughly 35mm and the length about 30mm. No two stomas are alike.
- Urostomy stomas are usually on the right hand side of the abdomen, and are often somewhat longer in an effort to form a spout to lead the urine well away from the skin.
- A stoma is pink and moist, and contracts from time to time due to peristalsis (intermittent contractions of the alimentary canal which facilitate the passage of its contents). Its covering is much more delicate than skin and therefore bleeds easily, particularly in the early weeks or months. The stoma is like the lining of your cheek and when rubbed may bleed slightly, but should stop promptly. If bleeding continues, notify your stoma nurse or doctor immediately if you are concerned.

Your stoma nurse will probably offer to introduce you to an established ileostomate. The first surprise will be that this visitor dresses and acts just like any other visitor to the ward! No-one knows of the ileostomy unless actually told. How could anyone know - there is no bulge, no odour, no restriction on diet and activities. Go ahead and ask all those questions that have sprung to mind. Your visitor will gladly give honest answers, knowing full well what it is like to be a new ostomate.
OSTOMY APPLIANCES

The skin surrounding your stoma must be protected as far as possible from faeces (or urine), hence the need for a correctly fitted, comfortable appliance which should be leak- and odour-proof. As a new ostomate it makes sense for you to learn as much as possible about the selection and use of appliances and new developments. Most hospitals have a stoma care nurse (or stomal therapist) who specialises in ostomy care and you will find them to be an invaluable help to you. You will be shown procedures which you will quickly master. Initially the management of your appliance may seem to be a major consideration in your day but once you return home you will quickly find it becomes part of your routine. Only when the pouch needs emptying will you give it a thought and even then, to deal with that is but a minor chore.

There are a large number of ostomy appliances available manufactured by different Companies. Your stoma nurse will advise on these, and which is the best appliance for you. Later she may suggest another type or later still you may like to experiment with other products yourself when you see the types available. These are generally on display at Ostomy Society meetings and seminars, or free samples may be obtained from the Companies which advertise in the NZ Ostomate. This 4-monthly magazine is available free at the place where you collect your appliances.

Your stoma nurse will teach you how to change your appliance and will call at your home for a while after your discharge from hospital to give you further help and advice and will provide follow-up assistance after your discharge from hospital. Information on supply companies and their products is available in NZ Ostomate Magazine which is available to all ostomates or on the Ostomy New Zealand website. If you have a spouse or close friend it is sometimes a good idea to involve them in appliance changing at some stage, so they will know what to do in an emergency or sickness. However the main aim for all ostomates should be to acquire the ability as quickly as possible to change the appliance themselves. This gives a greater feeling of independence, a necessity for complete recovery.
There is a wide range of appliances available and all are light weight, odourproof and inconspicuous. Many pouches contain an integral filter which can be activated or left untouched.

The composition of the backing which adheres straight onto the skin (often referred to as the wafer, flange or base plate), provides excellent skin protection provided it is neatly fitting around the stoma.

Appliances may be “one piece” or “two piece” and drainable or non-drainable.

A “one piece” system is designed to adhere straight onto the skin and is composed of the collection bag, seal and outer adhesive ring in an all-in-one unit.

A “two piece” system is where the wafer is separate from the bag. This might be used by someone who wishes to change the wafer only twice a week, but can empty and/or change the bag as required.

A closed or non-drainable system is used when someone has a colostomy and the bowel is moving only once or twice a day.

A drainable system has Velcro closure. The bag is designed to be emptied when about one third full.

A person who is able to irrigate may use a smaller appliance which is changed after each irrigation.

A urostomy appliance may be a one or two piece system, but differs in that it has a tap at the bottom, plus a one-way valve incorporated into the pouch so that urine drains to the bottom and the stoma is not continually bathed in urine. Night drainage bags are available and can be easily attached.
EMPTYING THE APPLIANCE

Closed (or non-drainable) One Piece System - As required appliances should be removed, emptied and discarded and a new appliance applied.

Closed (or non-drainable) Two Piece System - As required the appliance is removed from the face-plate, emptied and discarded and a clean appliance fitted to the face-plate.

Drainable Appliance - (One or two piece system) simply sit on or stand at the toilet, undo the closure and allow the contents to empty in to the toilet. Wipe the opening of the appliance with toilet paper and reseal. Please dispose of all used appliances as you would a disposable nappy.

CHANGING THE APPLIANCE

A new ostomate will soon master the art of changing the appliance and taking good care of the skin. If the appliance begins to leak under the adhesive, it must be changed as faeces or urine under the appliance seal will damage the skin. Prevention is the best method of keeping the skin healthy. If the appliance begins to leak under the adhesive, it must be changed. Patching does not work, since irritating faeces or urine under the appliance seal will damage the skin. On the other hand, too frequent changes don’t help as the skin may be damaged by repeated removal of adhesives.

It is advisable to put together a pack of all the things you might need and carry this with you. Among other things this might include: several spare appliances, base plate, skin wipes, tissues, scissors, bags for disposal and a peg to hold clothes out of the way.
How Will This Impact My Life

After surgery you will be understandably tender in the abdominal area and, if the rectum has been removed, you will also experience discomfort in this area until your wound heals. Be patient with your body, it has been through major surgery. Over time, as you recover, the discomfort will diminish.

You may feel overwhelmed at the changes to your body and be anxious about how this will impact on your life. This is natural. It may be helpful to talk to someone who knows how you feel at this time. Contact your local ostomy support group who will be happy to support you with a phone call or a visit. Alternatively seek out social media chat forums where you can share your concerns. Be reassured that you are not alone, many have been where you are now and can provide reassurance and helpful tips for dealing with day to day problems.

Only those you wish to tell will ever know you are an ostomate. Your attitude towards your stoma, and that of your close friends and family, will be the most critical factor in ensuring you make a full recovery. Be assured that your life can and will return to normal.

Long term, there should be no need to alter your occupation or lifestyle. As your health and strength return, you should be able to resume your normal activities. However, anyone with a stoma has an increased risk of developing a hernia. For this reason, heavy lifting and high contact sports are not advisable unless you can protect the stoma. Good products are available for this purpose. Always ask medical advice before returning to heavy activities.

Your stoma care nurse and your local ostomy support group will work together to help you through all the physical and mental adjustments you are faced with. Your ostomy is your second chance at life and, in many cases, a much better quality of life!
CLOTHING

Once your stoma care nurse has helped you to find the most suitable and neat fitting appliance for your body, you should be able to wear the same clothes as before. No-one need know you are wearing an appliance unless you choose to tell them. Options are available to purchase undergarments specific to your needs.

FOR MEN

As a rule men have little difficulty with clothing. A very few may have to wear an elastic binder for the abdominal muscles and this is prescribed by the surgeon when necessary. Slacks and trousers that have a little pleat at the waistline have enough fullness to make the appliance unnoticeable. Most men find that it is better to wear their singlet outside their “Jockeys” for easy management of the bag. Some may find it helpful to use braces for trouser support.

FOR WOMEN

It is perfectly possible to look just as smart as you did before surgery, in fact with returning good health you will probably feel inspired to go out and about more frequently and enjoy wearing the latest fashions.

Do not be afraid to wear reasonably tight fitting garments over the hips - you will not prevent the stoma from working.

If, before your operation you were more comfortable when wearing a girdle, try your oldest, most comfortable one first. The position of any fastening can be adjusted to make the management of your ostomy easier. Others find a firm pantie and pantie hose all they need. For easy dressing foundation garments should have a hole for the stoma, with hooks and eyes above the hole in the garment, so the bag does not have to be pulled through the hole. The garment adjusted like this wraps around the appliance.

Colostomates travel the world without problems; just remember to carry an adequate number of appliances with you. Your local Ostomy Society can supply you with a medical certificate which may be useful when going through Customs and they may query the packs of plastic bags in your luggage!
TRAVEL

With very little extra organisation, an ostomate can travel in New Zealand or overseas. The following points will be useful:

- Keep your equipment in a cool place: a car boot can get very hot and cause deterioration to adhesive etc.
- Carry some spare appliances with you in your hand luggage on plane or train as other luggage can be lost for considerable periods of time.
- Plan to use the type of appliance with which you are totally familiar.
- If planning a long stay away, take all the appliances you will need for your whole trip, plus emergency supplies.
- Ask your doctor to prescribe some anti-diarrheal medication - be careful about “drinking” water in some countries. Bottled water is widely available.
- Obtain a travel certificate from the Ostomy New Zealand website or your local support group. Once completed by your doctor this will explain your circumstances.
- Take along any medications you need and ensure everything is labelled.
- Some ostomates find it advisable to provide shade for their stoma when sitting for long periods in the sun e.g. when travelling by car, bus or train.

HAVE A GREAT TRIP!
Because ostomy surgery is a body-altering procedure, many people worry about sex and intimacy and about acceptance by their spouse or loved one.

For most people sex can be as good as before, or even better if you have had years of illness. It is not unusual for sexual feelings to subside in the face of urgent health concerns - whether chronic or sudden - and this is true for both men and women. The restoration of your enjoyment of sexual activity and a warm, loving adult relationship with your partner will be one of the rewards of accepting an ostomy and is a major part of your rehabilitation.

For women, pregnancy and delivery are usually uneventful and no more hazardous than for non-ostomates. It is advisable for all ostomates to seek medical advice before embarking on pregnancy.

Some colostomates and ileostomates find that medications pass through the stoma undissolved and you should bear this in mind if taking the contraceptive pill.

Should any difficulties or doubts arise, consult your physician.
There is no difference in the actual operation for a child or an adult and all sections of this book would apply for the appropriate type of ostomy.

However, parents have to learn to cope with a very unfamiliar situation and not pass on any of their initial anxiety to their child or the rest of the family. Involve your child in caring for his or her ostomy at an early age. A child with an ostomy at a young age should be taught self care just as they are taught toilet training. Siblings should be taught the difference in each other.

Support from other mothers and fathers is available - ask your Ostomy Society or stoma nurse for contacts. It is often helpful for the child to meet another young ostomate.

School age children obviously have a few special needs and a limited number of officials will have to be informed if the child is to have ready access to a toilet when the appliance needs emptying. The requirement to drink plenty of fluids may also need accommodating, but in general the child ostomate will not expect or need to be treated as “different”. Participation in all activities, including sports, is perfectly possible and there will probably be no need for school friends to be told of the ostomy unless your child chooses to tell them.
Frequently Asked Questions

Q. What should I tell my friends?
A. This is entirely up to you. If you want to keep your ostomy a private matter, then pre-think some simple answers to the questions that may come. As much as possible though, let in close friends and family. The more you share with them the more they will be able to understand and support you.

Q. Will my stoma be sensitive or painful?
A. There are no nerve endings in the stoma itself, therefore there should be no pain or other sensations.

Q. Will I be able to play sport again?
A. All sports should be possible again once you have regained your strength. Be mindful to protect the stoma when playing high contact sports, good products are available for this. Your stoma is not a sterile site so swimming and other water sports are an excellent choice. All forms of physical activity will help you regain strength and control over your body again.

Q. Why haven’t I met any ostomates?
A. Think a minute. Maybe because an ostomy doesn’t show. It can be kept a secret, if you wish. It is possible that some of your best friends are ostomates.....you never can tell!

Q. How can I adjust to living without a normal rectum or bladder opening?
A. Remember adjusting to glasses?
   Dental braces?
   False teeth?
   Hearing aids?
   It is amazing to see what the human body can get used to.

Q. When will I be able to return to work?
A. As soon as you have regained your strength you should be able to return to your normal occupation. Ostomates work in all occupations, no-one need know what you have been through unless you choose to tell them.

Q. How often must I attend hospital after my operation?
A. You will probably have a check up in 4 to 6 weeks in the Out Patients department and then at 3 to 6 monthly intervals. Eventually, you may be seen on a yearly basis or totally discharged. At any time you can ask to see your stoma nurse or surgeon if a query arises.
Q. **My stoma looks raw and bleeds, is this normal?**
A. As per notes in book. Maybe the appliance is not fitting correctly.

Q. **How do I dispose of my appliance?**
A. Dispose of your appliances just as you would a soiled nappy. Appliances are not recyclable, nor are they compostable. Please use landfill disposal as per your local district council rules.

Q. **Will I need to remove my appliance when showering?**
A. You can shower and bathe confidently in the knowledge that your appliance is waterproof and will dry easily. Many people remove the appliance to shower but this is entirely your choice.

Q. **Can I still wear a seatbelt?**
A. Yes, definitely. Your seatbelt should fit low and snug across your hips, below your stoma.

Q. **Will I still be able to have children?**
A. Yes. Your ostomy should not be a reason for you to avoid sexual activity or pregnancy. However, female urostomates should seek medical advice prior to pregnancy.

Q. **How often do I need to empty my appliance?**
A. There is no exact answer! For colostomates it may be once or twice a day, and for ileostomates and urostomates it varies up to 7 or 8 times in 24 hours.

Q. **Can irrigation be used as a means of management?**
A. Only colostomates can use irrigation and then only after medical advice and suitable instruction. It is the strongly preferred procedure of many colostomates and allows the person to control when to have a bowel movement. Some irrigate daily, others find alternate days appropriate - you can forget you’re an ostomate for 24 or 48 hours! Some people experience a few problems; consult your stoma care nurse.
Q. Am I able to change my type of appliance?
A. From time to time you may see advertisements for new types of appliances that would suit your needs. Every ostomate has the right to have access to the most suitable appliance for their individual needs. Talk to your stoma nurse about this, but please be mindful that your stoma nurse may be restricted as to what she can access for you.

Q. Will the perineal wound take long to heal?
A. It can take just a few weeks or sometimes over a year for healing to be complete. Different techniques are used for dealing with the empty space where the rectum and anus have been removed. The wound may be left open and firmly packed with gauze; as the wound heals from the inside out, the space gets smaller and smaller and the amount of gauze is reduced. Some surgeons loosely baste the skin together, inserting soft drainage tubes to remove blood and other fluid by either gravity or suction. Whatever the technique, your sore bottom can be more of a concern to you than the stoma!

Q. How can I support my night drainage bag?
A. Place it in a bucket standing on the floor beside the bed. This will keep it in an upright position and help prevent leakage.

Q. How long can I expect to stay in hospital after my operation?
A. In general 7-10 days. Once you are able to manage your appliance, you will be allowed to go home and will continue to receive support from the stoma nurse and your Ostomy Society visitor.
For skin that gets lived in

Get more confidence and more peace of mind so you can get on with life. Caring for an ostomy can be a challenge – but it doesn’t mean you have to miss out on life. 3M™ Cavilon™ No Sting Barrier Film helps protect the tender skin around your stoma, for improved comfort and pouch adhesion.

Not all barrier films are equal. Try Cavilon™ No Sting Barrier Film today and experience the difference for yourself. For more information, please visit our website 3M.co.nz/ostomy.

Read the label and follow the instructions. Do not use on infected areas of skin.
Ostomy societies were first established in NZ in 1961 and have been undertaking a variety of services and support to ostomates since. Centre Ostomy New Zealand and its member support groups are not-for-profit, charitable organisations.

Membership of your local support group is vital in ensuring continuation of the following services.

**OSTOMY NEW ZEALAND SERVICES**

- Advocating on behalf of all ostomates in NZ to ensure a continuation of your rights.

  ✓ Access to the most suitable cost free appliance for your needs.

  ✓ Ensure that all ostomates receive a high level of medical care and access to appropriate information.

- **Biennial National Ostomy Conference** - an opportunity to network with others from across the country and hear a variety of medical and motivational speakers.

- **Coordination of Youth Activities** - linking young ostomates from across our country and coordinating a variety of appropriate activities.
OTHER OSTOMY INFORMATION AVAILABLE

SPEAK TO

A stoma care nurse - contact your local hospital or community nursing service
Another ostomate - visit our website for contact details of your nearest Society or Support Group

USEFUL LINKS

http://www.ostomyinternational.org - The International Ostomy Association is committed to the improvement of the quality of life of Ostomates and those with related surgeries, worldwide. This website also has links to both the SPOA (South Pacific Ostomy Association) and 20/40 focus, a website of particular interest to those in the 20 to 40 age group.

IOA TODAY - “A Quarterly Ostomy Related Newsletter” bringing you Ostomy related information from around the world four times a year: Winter-Spring-Summer-Fall. Subscribe by connecting to website -http://www.ostomyinternational.org/IOAToday

NEW ZEALAND WEBSITE - www.ostomy.org.nz where you can download NZ Ostomate Magazines.

APPLIANCE SUPPLY COMPANIES - All companies have useful information booklets and DVDs available & offer a FREE helpline.

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Charter of Ostomates Rights

This Charter of Ostomates Rights presents the special needs of this particular group and the care they require. They have the right to receive the information and care which will enable them to live a self-determined and independent life and to participate in all decision-making processes.

It is the declared objective of the International Ostomy Association that this charter shall be realised in all countries of the world.

The Ostomate shall:

• Receive pre-operative counselling to ensure that they are fully aware of the benefits of the operation and the essential facts about living with a stoma.

• Have a well-constructed stoma placed at an appropriate site, and with full and proper consideration to the comfort of the patient.

• Receive experienced and professional medical support, stoma nursing care and psychosocial support in the pre-operative and post-operative period both in hospital and in their community.

• Receive support and information for the benefit of the family, personal carers and friends to increase their understanding of the condition and adjustments, which are necessary for achieving a satisfactory standard of life with a stoma.

• Receive full and impartial information about all relevant supplies and products available in their country.

• Have unrestricted access to a variety of affordable ostomy products.

• Be given information about their National Ostomy Association and the services and support which can be provided.

• Be protected against all forms of discrimination.
RESPONSIBILITIES OF OSTOMATES

- To use the appliance agreed between the Ostomate and the Stomal Therapist. This need not rule out trials of new appliances supplied by an Appliance Distributor or manufacturer to either the Stomal Therapist or Ostomate.
- To use appropriate Ostomy equipment in an efficient and effective manner.
- To work in conjunction with health carers to maintain a standard of health and hygiene which is appropriate to the Ostomate situation.
- In the event of an Ostomate developing problems to consult the Stomal Therapist without undue delay.
- To return to Stomal Therapist any faulty appliances complete with packaging.
- When a dispute or difficulty occurs that normal DHB complaint procedure is followed.
- To maintain a reasonable supply of appliances stored in a cool dry place.
- Dispose of appliances in a manner that is hygienic, appropriate and considerate to others.
- When appliances are no longer required they should be returned to the Stomal Therapist.
- When a dispute or difficulty occurs that normal Crown Health Enterprises complaint procedure be followed.
- All Ostomates are encouraged to join their Local Ostomy Society.
Is the skin around your stoma normal?

Healthy skin should be the rule, not the exception.
If you experience any of these symptoms, talk to your STN. It could be a sign of a peristomal skin complication that should be addressed to prevent further discomfort, damage or problems with your pouching system.

- Redness
- Rash or irritation
- Itching, mild to severe, even when skin looks normal
- Discomfort or pain
- Excessive bleeding
- Bumps

If your skin doesn’t look or feel right talk to your Stomal Therapy Nurse. At Hollister Ostomy Care, we believe peristomal skin deserves better.

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