

New Way Forward

Ileostomy | Post-Op



*A helping hand through recovery, adjusting and easing
back into being and feeling yourself*



A Bigger Life



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Living a bigger life with your stoma

Following stoma surgery, it's natural to have a lot of questions and concerns. This book will help you adapt to living with your new stoma and help you live your bigger life.

The information is general and some of it may not apply to you but you can visit abiggerlife.com for lots more information on living with a stoma with real life stories and advice from a Clinical Advisor.

Your Stoma Care Nurse will be there to support you after surgery. You can note the name and contact details of your Stoma Nurse below.

My Stoma Care Nurse:

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Contact Details:

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Questions

Record the questions you might want to ask your Stoma Nurse here:

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After your surgery

Managing the early days of being an ostomate?

During day 1-2 after surgery you won't be expected to do a lot with your stoma pouch, the nurses on the ward will help you. Your Stoma Nurse will visit you and teach you how to manage your stoma.

Once you are confident in being able to manage your stoma you will be able to start planning to get home. It is possible that you may experience a range of emotions during this time and for some time afterwards but don't worry it is normal to feel overwhelmed during the first few weeks with your new stoma.



Getting home

It's a good idea to use this handy check list to ensure you feel comfortable with each step before being discharged from hospital. This will help you manage your recovery, both physically and emotionally.

Tick these off when you have done them.

- ☐ Confident in changing and emptying my pouch on my own
- ☐ Had a shower and washed myself on my own
- ☐ Went for a short walk down the corridor
- ☐ Eating and drinking as recommended by my Stoma Nurse
- ☐ Help has been arranged for when I get home
- ☐ Family assistance has been arranged if I need it
- ☐ Process in place for how I will order my products
- ☐ Thinking about a bag for carrying my supplies when I go out and about
- ☐ Record the contact number of my Stoma Nurse
- ☐ Set up a follow up appointment with my Stoma Nurse

First pouch change at home

Great, you are home. You're doing really well! Your first empty and pouch change at home may seem scary but don't worry our tips will help you.

We know products can be confusing, we advise you write down.....

Name and type of pouch:

Seal:

Accessories:

Emptying your pouch

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. Find a comfortable position either sitting on the toilet or standing.



Tip: Put some toilet paper in first to stop water splashing when you begin emptying your pouch. Have some more tissue paper ready to clean the outlet.

First pouch change at home

It is important to have everything ready before you start. You will need:

- A cloth to protect your clothes
- Cloth for washing and drying your skin
- Disposal bag to put all of your rubbish into
- Your new stoma pouch
- A measuring guide for measuring your stoma
- A pair of scissors for cutting out your new pouch
- Some adhesive remover spray for taking your pouch off
- Any other accessories you are using



Removing your pouch

- 1 Use your adhesive spray to peel off your pouch



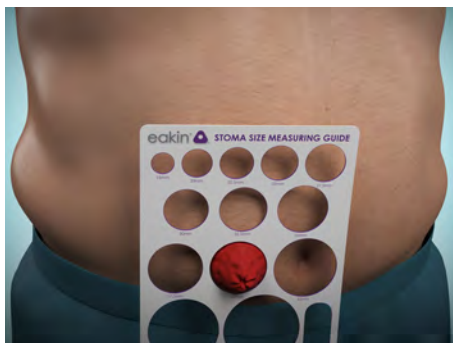
- 2 Fold the bag over itself to seal it closed and put into your disposal bag
- 3 Use a tissue to remove excess faeces from your stoma and your peristomal skin
- 4 Use a wet cloth to wash your skin



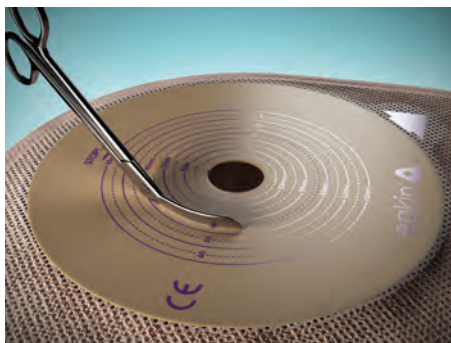
- 5 Use a dry cloth to dry your skin
- 6 Your skin and stoma are ready for applying a new pouch

Applying a new pouch

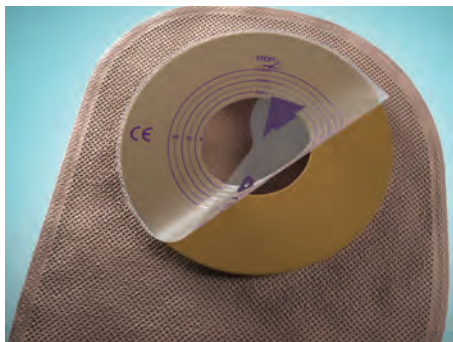
- 1 Measure your stoma



- 2 Cut out shape and size



- 3 Remove backing paper



- 4 Apply pouch as instructed



- 5 Place hand over pouch to adhere to skin



- 6 Discard used pouch in disposal bag





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I followed the steps just like the nurses taught me, since I had my supplies already out, something I strongly suggest for even experienced ostomates, I didn't get anxious about having to find things

Saleem Juma, works out a lot, plays lots and lots of video games, ostomate since 2013

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At home

How do I order my supplies?

Discuss your options with your Stoma Nurse and record the details here:

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What is normal and when to seek help

When you are experiencing physical changes with your stoma, it is important to know if they are normal for your stage of the journey or if you need to seek help. It's also important that you feel well with your new stoma and you are coping emotionally.

This handy guide should help keep you right.

My stoma – What's normal

- Output – Initially your output will be loose but this will start to thicken to a porridge like consistency when you start to eat normally.
- Stoma changing size – Within the first 6-8 weeks your stoma will shrink in size. The process to ensure your pouch fits is straight forward. Use your measuring guide once a week to measure the size of your stoma and cut your pouch to the most appropriate size.
- Very occasional leak – It's not uncommon to develop some leakages when you are starting to learn how to manage your stoma. This should not happen regularly, seek help if it continues.
- Output colour – this may vary depending on the food you have been eating.
- Output smell – this may vary depending on the food you have been eating.

My stoma – When to seek help

- Stoma stops working
- If your skin becomes red and sore
- You experience extreme pain
- If you experience frequent leakages

My emotions – What's normal in the first few weeks

- Fatigue/tiredness
- Low mood
- Feeling helpless and scared
- Feeling overwhelmed
- Reluctant to manage stoma
- Increased anxiety/awareness about stoma/pouch

My emotions – When to seek help

- Continuing low mood
- Not emptying or changing your own pouch – not able to achieve independence
- Family/friends concerned about how you are coping
- Continuing to feel overwhelmed, helpless and scared

Know that you are never alone. Join our online community, where, from the comfort of your favourite armchair, you can be amongst people who understand, where you can share and discuss experiences, challenges or any topic you choose relating to life with a stoma.

Or maybe you prefer to just listen to others to start...

Visit abiggerlife.com/community for support.
Contact your Stoma Nurse for help and advice



Food and drink

What can/can't I eat?

With your new ileostomy you may have some questions around what food you should and shouldn't eat.

Where possible it is best to eat a low fibre diet and stick to bland foods at the beginning. You can start to reintroduce your normal diet routine slowly. If you think a particular food is causing problems, try avoiding it for 2 weeks, then reintroduce it into your diet. Which foods affect you depends very much on your current diet and your own digestive system. Experiment and enjoy!

What food to avoid

You want to avoid things like nuts, mushrooms, sweetcorn and coconut, as they might result in a blockage if not properly digested.

Food blockages

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

How to know if you have a blockage

- Your stoma will stop working or you will only produce very loose liquid output.
- You might get cramps in your stomach or you may be sick.

What to do if you think you have a blockage

- Lie down, relax, stop eating but continue to drink.
- If it is a food obstruction it could pass within a number of hours.
- If after 8–12 hours you haven't had any normal bowel motion and are continuing to experience abdominal pain or sickness you should visit A&E.

Keeping hydrated

Keeping hydrated is an important aspect of living with a stoma. For many people it is just making sure you are drinking plenty of fluids throughout the day. You should try to drink 6-8 glasses of water each day along with any other drinks such as tea or coffee. Top tips to keep hydrated would be:

- In warmer weather if you are perspiring more you will need to drink more water.
- If you experience diarrhoea, try to measure your output over 24 hours and within that time try and replace as much as you are losing. If diarrhoea continues for more than 24 hours or you are not able to drink enough to replace the amount of fluid you are losing, seek advice from your Stoma Nurse or GP.
- Fizzy drinks can cause wind, so a good tip would be to open the bottle or can letting some of the fizz go out before drinking it.

Visit [abiggerlife.com](https://www.abiggerlife.com) for more information on food and drink guidance.



“ The main thing is that this is all trial and error – everyone is different and some people have higher tolerances than others. Also, you must remember to chew your food well, so that it’s broken down into smaller pieces. This helps the digestion and allows your body to absorb as much goodness as possible. ”

Andy Fletcher, Grandad and keen gardener,
ostomate since 2008

Alcohol

Even though you have a stoma there is no reason why you can’t drink alcohol.

However, things to note would be:

- Red wine can cause you to have slightly looser bowel motions.
- Some beers and lagers which are fizzy can cause you to have a lot more excess wind in your pouch.
- Drink in moderation and ensure you keep managing your stoma and pouch.
- If you are on other medication check it is compatible with alcohol.

Exercise

Great, you are starting to feel ready to do a little bit of gentle exercise. You're doing really well. Exercise is good for everyone but taking up exercise again following surgery should be a gradual process. You should discuss with your Stoma Nurse before resuming exercise. Our tips will help you start slowly.

Start slowly

If you took part in physical activity before surgery there is absolutely no reason why you can't get back to that again. You should be able to resume all the activities you loved before surgery, and possibly even can do new activities you weren't able to do before. If you have never taken part in physical exercise before it is important to start off slowly. A gentle walk or swimming are both very easy on your abdominal muscles.

Regaining strength

Regaining strength is a long process that takes patience, take one day at a time. When you feel ready, add other types of exercise that you enjoy like running, cycling, hiking, swimming, pilates, or yoga. If you attend fitness classes, it is a good idea to inform your instructor that you have recently had ostomy surgery.

Ensure that you stay hydrated by drinking plenty of water. Take your time, listen to your body and rest if you experience any pain. Enjoy getting back to exercising!



When you feel ready you can start to add other types of exercises. You can read more on abiggerlife.com but for now just take one day at a time. Why not set yourself a goal to go for a 10 minute walk every day until you feel your strength improving.

Can I wear my usual clothes?

There really shouldn't be a huge change in the clothes that you wear, unless you have lost a lot of weight following your surgery. If you feel confident and comfortable in your clothing, you don't have to change what you normally wear.

After surgery

Your tummy is going to be tender, you will want very comfortable clothes and loose trousers.

Going forward

It's important to think about what makes you comfortable.

Some people like to wear lycra vest tops or lycra underwear to hold their pouch in tightly.

Ladies

High waisted jeans sit nice and high on your abdomen and hide your pouch well.

A scarf is a good accessory if you are self-conscious as it distracts the eye.

Men

For many men, they just go back to wearing their everyday clothes with some very minor adaptations.

Some men decide to wear braces rather than a belt on their trousers.



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**There's no reason at
all an ostomy should
limit your clothing or
jeopardise your style.**

Laura Zappulla, loves to travel
and go on adventures all over
the world, ostomate since 2013

”

Let's talk about sex

If you are in a relationship it is important to be open and honest with your partner about how you are feeling following surgery. Sexual function in women is usually unchanged, but sexual potency of men may sometimes be affected for a short time. For further information you should contact your Stoma Nurse.

For physical recovery you need to give yourself 4-6 weeks for healing before trying to regain your full sex life. Within these first couple of weeks do not forget about touching, kissing and cuddling as they can help provide the intimacy that you and your partner need.

In order to be able to feel comfortable and relaxed, some tips would be:

- Empty or change your pouch before beginning sexual activity.
- It may even be possible for you to wear a smaller more discreet pouch.
- Some companies have created underwear that holds your stoma bag in place but have a velcro closure at the gusset. This allows intimacy without having to remove all of your clothes.

Contraception

After stoma surgery your contraception may need to be reconsidered if you are a female and normally use the contraceptive pill. It would be advisable to talk to your GP or family planning clinic as some medications are absorbed differently and may not be completely effective with an ileostomy.

Fertility

Having a stoma should not impact on your fertility whether male or female.



Intimacy for the LGBTQ community

The same concerns and anxieties are present in gay or lesbian relationships but the challenges for people who belong to the LGBTQ community may be slightly different to those who are heterosexual.

The relationship between a Stoma Nurse and any patient can develop into one of openness and honesty where it is an easy conversation about anything that is causing concern. Talking about sex and problems associated can be difficult to initiate for both parties. This will be even trickier if you are not open about your sexuality, the chances are your nurse or other health professional will probably assume that you are heterosexual, so it's important to be open. If you are a gay male and have had surgery which has meant your rectum and anus has been removed, you may have more questions about resuming sexual relationships.

The one crucial fact is that the stoma should never be used for penetrative sex.

Pregnancy

Having a stoma should not affect your ability to conceive and carry a child. Pregnancy is a really good sign that your body has healed from surgery and that you have returned to good health.

Does my stoma get bigger?

The answer is yes, as your abdomen grows and stretches so will your stoma. You may need to increase the size of your baseplate or flange. You should visit your Stoma Nurse for regular check-ups.

Can I deliver my baby normally?

Normal delivery is recommended in most instances, there are always exceptions, so it is best to discuss with your midwife and your doctor and explore all the options.



Bon Voyage

Air travel

Travelling on a plane can be a stressful experience for anyone, however if you are travelling with your new stoma for the first time, going on a plane can add that extra layer of anxiety.

Some tips to make the experiences less stressful would be:

- Check your supplies and order extra in advance of your departure date
- Carry your travel certificate with you in your hand luggage.
Visit abiggerlife.com to download your travel certificate.
- Be prepared and have a checklist with everything you could possibly need to bring on your holiday. You can download our handy holiday checklist on abiggerlife.com.
- Divide supplies between your hand luggage and checked luggage. Take more than you would normally use
- If you are stopped at security you can ask to be searched in private if the security guard wants to look at your supplies. You could have your medical supplies in clear see through bags.
- Some airports now have a 'hidden disability' lanyard which can be worn around your neck. This identifies you to the staff as someone who needs a little more support, time or understanding. Check with your airport for more information.
- Wear comfortable clothing especially for a long-haul flight.
- Go for it and enjoy your holiday!



Road travel

If you drive a car, once you start recovering from surgery you will be thinking about starting to drive again.

Some tips things to think about would be:

Insurance

Just check with your own insurance company when you are covered to drive.

Being prepared

Keep a kit bag in your car with a new pouch and wipes.

Building confidence

When you feel ready to start travelling, go somewhere that is familiar to you for the first time.



For more information and advice on travel visit abiggerlife.com

“You shouldn’t be controlled by your stoma on how you live your life, live it to the full with no regrets. That’s what I am trying to do and going on holiday was just the start of it.”

Aneica Duffy, camogie player and general sporting fanatic, ostomate since 2014

Common myths busted

Myth 1 – Everyone will know you have a stoma

Not at all. When you are dressed no one will be able to see that you have a stoma.

Myth 2 – It smells

People fear that everybody will be able to smell your pouch. This is not the case at all if you have a pouch that is working well. They are all fitted with filters that filter out the air through charcoal. The only time you will smell it will be when you are emptying or changing your pouch and if that's not the case you should visit your Stoma Nurse as there may be a better pouch for you.

Myth 3 – I am the only one with a stoma

That is not the case. Around the world there are many people living well with a stoma so you are not alone. You can visit your local stoma support group or visit online support groups to talk with others who have a stoma.



A good night's sleep

Sleep plays an important role in your physical and emotional health so it's important to get a good night's sleep, some tips would be:

- Before you settle down for the night you should empty or change your pouch.
- Try and eat your main meal before 7pm in the evening to allow your stoma to do all its work before you settle down for bed.
- Be careful with your food choices. Try to avoid anything fizzy or fibrous food in your last meal before bed.
- Many people do tend to develop a bit of a sixth sense when managing their stoma. You will wake up in the middle of the night and realise that your pouch needs to be changed.
- Support your body with pillows, try and put one in between your legs or under your back. This will help you get into a comfortable position to try and get a good night's sleep.



telling others

Friends and family

You don't need to tell anybody if you don't want to. However, it might be much harder to keep that secret. You don't need to tell everybody, just your close inner circle of family and friends, it will make it easier for you to relax and be yourself.

Work colleagues

Just like with family and friends, who you tell and what you tell them is entirely up to you. However, it is a good idea to tell your close work colleagues so that they can understand and support what you are going through.

New relationship

You don't have to tell a new partner or someone you have just met on your first date that you have a stoma. No one will be able to tell you have a stoma just by looking at you, it doesn't take away from who you are, it is only a small part of you.

Learning the lingo

When you are introduced to the term ostomy or stoma you may not be prepared for the vast amount of new words and phrases that you will hear associated with it.

To help your understanding, we have created a basic ostomy terminology guide, based around different pouching systems/products and common ostomy problems that you may encounter.

Making sense of stoma products

Adhesive Remover	A helpful tool to ease pouch removal and to clean the adhesive that might stick to the skin after removing the pouch. Available in spray or wipe format
Appliance/Pouch/Bag	A collection device worn over the stoma to contain body waste
Convexity (Convex stoma appliances)	Convexity is defined as the outward curving of a base plate or skin barrier. The convexity allows a retracted or flush stoma to stick out more to ensure the output is directed into the pouch to prevent leaks. (You should seek assessment from a stoma care nurse before using a convex pouch)
Filter	Lets gas escape from the pouch but not odour
Flange/Baseplate	The flange is the adhesive part of the pouching system that sticks to the skin around the stoma
Ostomy belt	Belts that wrap around the abdomen and attach to the loops found on certain pouches. Belts can also be used to help support the pouch and provide additional security
Seal/Ring	An absorbent ring that can help prevent leaks. It is placed over your stoma before applying your pouch
Skin barrier/Skin protector	Used to help protect the skin under the flange and around the stoma from irritation caused by harsh output. They also help with the adhesion of the pouch
Skin barrier paste	Paste that can be used to fill in skin folds, crevices or scars on the abdomen underneath the pouch flange, thereby creating an even surface and a better seal
Stoma measuring guide	A card used to measure the stoma from the base. This is useful in selecting the right pouch size
One-Piece pouch	This system has the pouch and adhesive base plate (also known as flange, wafer or skin protector/barrier) combined as one item
Two-Piece pouch	This system has a separate pouch and adhesive base plate which attach to each other using either a clip-on or stick-on coupling system

Understanding stoma problems

Ballooning (of stoma appliance)	Occurs when a stoma pouch/bag fills up with gas. This is most likely to occur when the filter is blocked or ineffective or where there is no filter on the pouch/bag
Excoriation	A term used to describe severe skin damage around the stoma, where the skin integrity is broken, leading to a moist, bleeding area
Hernia	A weakness in the muscle layer where internal organs may protrude. A parastomal hernia appears as a bulge around the stoma (the bulge being loops of intestine), is a common complication which may occur weeks, months or years after stoma surgery and can cause discomfort and problems with stoma appliances
Maceration	When the skin immediately around the stoma is excoriated and moist
Pancaking (of stoma appliance)	Caused when faeces stay on top of the stoma, and do not move down into the bottom of the pouch/bag
Peristomal skin	The skin immediately around the stoma
Prolapse (of stoma)	Occurs when the bowel protrudes through the stoma opening in the skin further than was anticipated
Wear time	This is the length of time a product can be worn before it needs to be replaced. This can vary depending on the product and your individual output

If you are concerned about any of these problems please contact your Stoma Nurse.



you're not alone

Stoma forming surgery is a major life event for the majority of people. You will want to seek support after your surgery to help learn how to manage your stoma and how to adapt your life to living a normal life with it.

Associations

There are many voluntary associations who are very active among different communities. They exist as a vital support network and information guide. They also have booklets of information that they will provide you with throughout the year.

Ask your Stoma Nurse for the details on the support groups in your local area and write them down here:

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Online

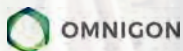
There are online communities who provide very good information and support from people in a similar situation as yourself. There are many options available such as social media channels, online forums and groups. If one doesn't work for you, try the next.

Our website abiggerlife.com provides lots of advice and allows you to learn from and connect with other ostomates.

While these groups can be a great way to connect with other people who are in the same situation as you, they aren't appropriate for receiving specific medical advice. There are no two people the same, if there is something that doesn't seem right you should always go back to your Stoma Nurse as your first point of call.



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Australia: **1800 819 274**
New Zealand: **0800 440 027**

info@omnigon.com.au
www.omnigon.com.au



Visit today **abiggerlife.com**

A warm and friendly space you can visit any time of day or night and keep coming back to. You, the person, are important. A stoma shouldn't define you, it is just a small part of a bigger life. We're here to bring together support, encouragement, information and engagement in pursuit of that bigger life.

