



OMNIGON



Starting over...

**living with
an ostomy**



WRITTEN BY **VIV PARRY**

Contents

03

Prologue

The beginning

04

Intro

05

Viv's Blog

Before the operation

06

Visit with Stomal Therapy
Nurse or Stomal Clinic

07

What to prepare before
the procedure

08

Check list for return home

09

In hospital (post op)

11

Prepare to leave hospital

12

Medications and appointments

~

Home again

13

First solo pouch change

14

Time to get dressed

15

Back to work

~

Social life

~

Exercise

16

Off to sleep

~

Ongoing

17

Stay in touch with your feelings

~

Resources

Prologue

The beginning...

Arriving home after my ostomy operation I could easily have fallen in a heap. Living alone, the task of managing my new reality seemed like a mountain I could never conquer. As the first days turned into weeks then months I slowly adapted to living with an ostomy. With each new situation eventually resolved I thought “How good would it have been to know how to sort these issues months ago”.

I decided to keep a diary recording my problem solving successes. “Maybe someone else going through the same procedure might gain some benefit”. One night I started writing my blog; it felt like I had been waiting 18 months to tell my story, the words came easily. I shared a few early pages with fellow ostomates and was grateful for their encouragement.

I soon realised the narrative needed essential information about ostomy products and professional support options as well; I wondered how I would gain access to the information and importantly how I could publish and share my work with fellow ostomates.

I received an email from an ostomy product supplier, **Omnigon** (an Australian company) announcing a new website called **Omnigon Connect**; a support and resource hub for ostomy patients. The site looked really impressive and featured a resource section as well as valuable information.

With nothing to lose and hopefully heaps to gain I approached Omnigon about my ostomy project explaining “I needed help to complete my unique ostomate handbook”. Within days the Omnigon team responded offering to provide whatever support was needed; from proof reading to product information including professional advice from the Omnigon Stomal Therapy Nurse, Jan.

My product information, professional advice and publishing all sorted!

I am so grateful to Omnigon for the opportunity to share “Starting Over”. I hope my fellow ostomates will be encouraged to write their stories too.

Omnigon Care Solutions
(product information)
www.omnigon.com.au

Omnigon Connect
(ostomate support hub)
www.omnigonconnect.com.au



Intro

Dear fellow ostomates,

Welcome to my world... **Living with an ostomy.**

In the summer of 2019, I found myself entering hospital for a bowel operation I was completely unprepared for. Now almost two years on I feel ready to share with you my lived experience in a simple handbook I wish I had with me from the start of my ostomy journey. This blog follows my procedure from pre-op, in hospital, post op, to after care.

I need you to know this story is entirely about my personal experience. My medical history and reason for my ileostomy operation will understandably be vastly different to yours. My aim in telling my story is to encourage you to explore the best possible options to suit your specific ostomy needs.

I haven't searched for answers to every question; we are all so unique in our individual situations. Instead, I have given you the questions to ask the professionals you will meet along the way; to help you feel confident about the decisions you will need to make for yourself.

This handbook also provides general information on day to day basics from "What underwear will I need after the operation?" to "How will I manage back at work, socialising, where do my supplies come from, do I have to pay?" I write about my successes and "muck ups" as a new ostomate and how I navigated my transition back into everyday life.

We are truly fortunate to have excellent support services we can easily access. It is important to know how we can find the advice we need, ongoing.

I am hopeful through sharing my personal story you will gain a sense of what lies ahead. I trust this handbook will inspire you in a positive and helpful way to find the best possible version of your new self. You can do this! Together we will succeed and every day will become easier.

Let's get started!

- Viv Parry

Before the operation

You have just heard the news! You are off to see the specialist surgeon to learn about the procedure that has been recommended to resolve your bowel problem.

It's always good to have someone with you as an extra pair of ears and to remind you of the questions you need to ask. Remember, you are the patient and should not be expected at this early stage to know everything about your proposed surgery.

Ask exactly why you need this operation and the reason why you will be required to have a stoma? Will the stoma be temporary or permanent?

If you feel the need for additional reassurance it is not uncommon to ask your GP for a referral for a second opinion. It is well worth the trouble to have an independent assessment; your Gastroenterologist specialist will fully understand and support your need to feel confident about your procedure.

Remember
you are the
expert in
your life



Visit with Stomal Therapy Nurse or Stomal Clinic

The decision to proceed has been made and you are now moving on to the next stage. You will be asked to visit a Stomal Therapy Nurse or attend a pre admission stoma information session, before your procedure.

This is a really good idea and one to make sure to attend. Like me you might have explored a few pages on the subject but it all seemed surreal and not that easy to understand.

The role of this specialist nurse is to explain in detail about life with an ostomy and to answer any questions you might have. It's hard to know what to say let alone ask questions, but the following points could be useful:

- Ask to have a look at the products you will need and an explanation of how they are used. This demonstration proved reassuring because the products are flesh coloured and contoured to fit your body.
- Ask if you will be given support and training during your stay in hospital.
- Try to gain as much information as you can from this session including sharing your fears and concerns about how you will manage when you return home, go back to work, get back into your exercise routine.

Please refer to link below for more frequently asked questions:

omnigonconnect.com.au/my-questions/

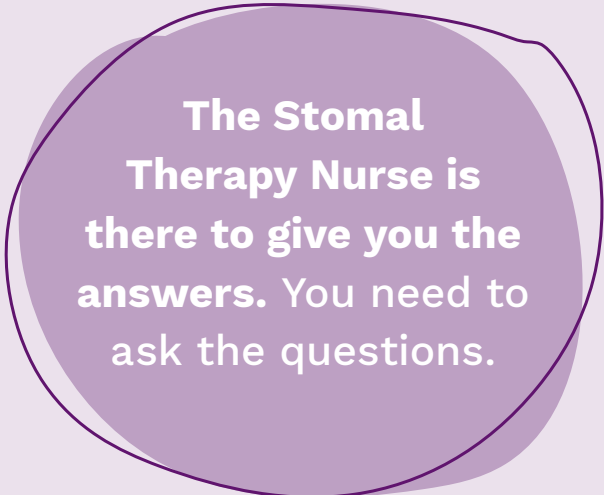
Remember there is no question that can't be asked.

During this important session you will have an opportunity to discuss with the Stomal Therapy Nurse the best possible site for your stoma. The Stomal Therapy Nurse's professional experience in this significant decision will guide you to your optimal choice.

Decision settled! A circle will then be drawn on your skin to outline the stoma position. It all starts to get real when the black marking pen appears.

Ask the Stomal Therapy Nurse to give you a sample pouch to attach to your stoma site to help you adjust to the situation. I had to admit I found this session heartening. Pouches are quite discreet and I could imagine how choosing the right clothing styles could easily keep my pouch out of sight.

Session over: take time out to congratulate yourself for advancing through this challenging stage. It's back home to work out what you will need to prepare for your hospital stay.



**The Stomal
Therapy Nurse is
there to give you the
answers. You need to
ask the questions.**

What to prepare before the procedure

What to take in: Underwear seems to be at the top of the question list. My advice would be regardless of your stoma position I would opt for briefs that are worn lower down and out of the way. Understandably the stoma area will be tender so elastic from high waisted underwear could be uncomfortable.

You will have the option to stay in a hospital gown if you don't want to bring night clothes with you. If you do bring pyjamas make sure the pants have loose drawstring waist ties. I opted to wear T-shirts under my hospital gown and had a warm top to wear if I was cold. A dressing gown is essential because you will be up

and walking quite soon. You might be given hospital bed socks with non-slip soles to walk about in, bring your own secure slippers or sandals, just in case.

It's a good idea to find a comfortable pair of track suit pants (draw string waist or loose elastic) and a loose top to wear into hospital and back home again.

Essential to have:
Paper and pen to write notes after the Dietitian, Physiotherapist, Stomal Therapy Nurse visits.



Check list for return home

We are not really getting ahead of ourselves, it is a good idea to sort a few things out to be ready and organised for your home coming.

Clothing: This is the time to check your clothing wardrobe for loose and comfortable pants and tops to wear around the house in the first few weeks of your recovery. Make sure the waistbands are adjustable and the tops are reasonably loose; it's a good idea to layer up with easy fit T-shirts and comfy tops. We will revisit clothing again later in the guide.

Ostomy supplies: You will receive your individual ostomy supplies each month. Ostomates are truly fortunate; the Australian Government covers the cost of our ostomy supplies and any necessary ostomy support products, ongoing. There is a modest annual SAS (Stoma Appliance Scheme) fee; you can collect your supplies or elect to pay postage costs. All these options will be explained to you when you join up. You will be ordering your supplies in advance each month, the quantities allowed are generous and you may well have items

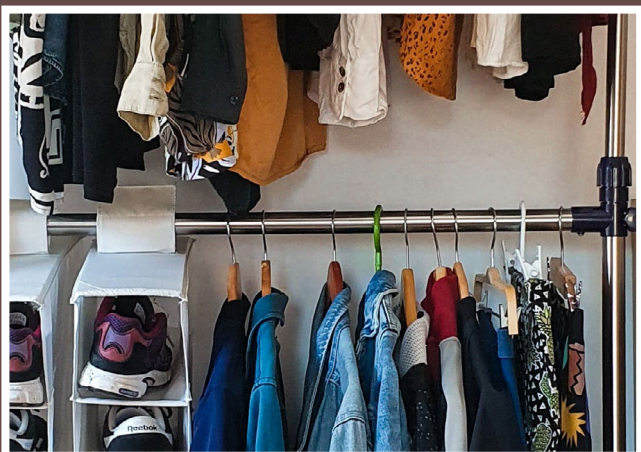
left over. It is recommended you stockpile one extra month's supply.

You will need to create a safe place for your supplies; somewhere you can easily locate what you need and check how your supplies are going. One week's supply in a zip bag stored in a dry, cool place in the bathroom works well.

Food supplies: After your procedure you may find there are some changes you will need to make to your diet. Ask the Stomal Therapy Nurse or your Surgeon to provide you with some Stoma Dietary Advice so you can stock up with the right type of foods for when you come home.

Personal: This could be the moment to have that haircut you have been thinking about. I found having at least my hair under control was a boost to my morale.

**Be prepared
and think ahead**



In hospital (post op)

It's all over and you are back in your room. In my case I felt tired but overall surprisingly fine. Where had the time gone? It seemed like a lifetime since I arrived at the hospital but it was still the same day... lots of nurses around the bed, my vital signs being monitored regularly. I felt quite comfortable thanks to the medication I was given. I noticed I had gained some tubes but no sign of my newly acquired stoma, all under wraps. I was in no rush to meet my new life's partner. Happily when my stoma did appear it was neatly contained in a pouch and we both had extra time to get used to each other.

The Stomal Therapy Nurse arrived each day to guide me through the process of changing the pouch. The first pouch change was all hers, two days later it was my turn. A basket with a selection of ostomy products was placed on the bedside table and we were good to go! I carefully laid out all the necessary items and one by one I followed her advice as she observed my below average attempt, reassuring me it would be easier each time. This process is challenging because it is so new to us. Despite feeling anxious, I could imagine myself before too long coping reasonably well.

Omnigon have kindly provided a selection of their products pictured here to give you an idea of what you will need. Omnigon have three different brands of pouches and accessories which not only provides greater choice it also allows for the provision of individualised solutions.

To view the full product range, please visit:
www.omnigon.com.au/products



Even though you will feel overwhelmed some days, it is important to practice your pouch change when you are under the daily care of the Stomal Therapy and Ward Nurses. You will reap the benefits of your in-hospital training when you get home. Once you become more confident with the changeover process, start to ask questions: "Is this going to be the best pouch system for me ongoing? Will I have a choice in selecting a different pouch system before I leave? "What if I have problems in a few months' time; can I change my ostomy products later on?"

It's really important that you feel comfortable with your pouch system. You haven't had one before but you need to talk about any issues that you feel might be improved. i.e." The pouch seems really long, is there a shorter version?"

**Practice,
practice,
practice**

In hospital (post op)

Dietitian: You will receive a visit from the Dietitian who will discuss your usual diet with you and give advice about what food items in the short term, may not be suitable. I had to make some dietary changes and have now worked out ways to still have most of the food I enjoyed without causing any problems. I asked the Dietitian to call back a second time before I left hospital. Food is such a basic but important part of our quality of life; you will be pleased you took the extra time to be really sure of your dietary needs.

Physiotherapist: Another important member of your support team is the Physiotherapist. You will receive advice

on how, from now on, you will need to get in and out of your bed correctly, how much exercise and general lifting you will be able to do and importantly, WHEN! You will be advised what activity/exercise is allowed at timed stages over the first three months. Great news about no vacuuming for a while...

Showering: Your pouch is water resistant but can feel a bit damp after a shower. A nurse clipped a sheet of plastic around my waist before my shower and it worked well keeping the pouch reasonably dry. A close friend made me a plastic apron with elastic ties, a perfect reusable solution.

Handy solution:
Plastic apron
with elastic ties
for showering



Prepare to leave hospital

Your surgeon and Stomal Therapy Nurse have decided you are going home in a day or two. While the good news sinks in you can be excused for wondering how you will manage your new stoma routine at home.

The nursing team have this all sorted. My Stomal Therapy Nurse called by to reassure me there is a support service ready to assist with any questions I might have and the contact details. You will be presented with your box of supplies (the same as you have been using) and detailed information about setting up your membership with your local Ostomy Association.

As mentioned earlier this wonderful organisation is where you will send your monthly order for the supplies you will need. Apart from being a very efficient organisation the Ostomy Association team includes a Stomal Therapy Nurse and a dedicated, friendly and really helpful group of volunteers.

You will soon get into the routine and the quarterly magazine (received with your supplies) is a really good source of information about the latest products, dietary advice, ostomate's letters and stories.

Special Diet: I decided to have a second visit with the Dietitian to make sure I had all the necessary information I needed at home. Having an ileostomy I knew I would need to be careful with my diet ongoing.

Some ostomates lose weight after the procedure; I did and the Dietitian made sure I received additional nutritional support in the form of supplement drinks. I was given the supplement product information so that I could order more for myself at home.

Fluids: Your stomal team will explain to you about the need ostomates have to be mindful of their fluid intake. Of course this is dependent on your own personal requirements. It is important to make sure you know exactly how much your daily target is and ask how best you can monitor your intake.

It's about having a successful recovery, getting your strength back and moving on with life; your stoma team want the best possible result for you.

Your writing pad and pen will come in handy to record any instructions you receive.




Medications and appointments

The Pharmacist called by to discuss the prescribed medications I needed to take home with me, making sure I knew exactly which medication to take and when.

The Stomal Therapy Nurse asked me to make a time to come back in (within one to two weeks) to check how I was managing. One month after my procedure I had

a second appointment with my Stomal Therapy Nurse as well as my Surgeon to discuss my procedure, pathology results and assess how my recovery was going. For any follow up appointments you can bring someone with you to learn about your stoma journey and understand what your needs will be in the future.



Milestone moment:
I confess I was a bit emotional.
It was a relief to have the
procedure over with;
now the discussion was all
about getting back into life,
recovery and the future.

Home again

You are back and it's so good to be home. Rest is very important after any operation and this procedure is no exception. Take your time to put your supplies away; it's a great idea to change your pouch the day you are leaving hospital (depending on your setup). You can leave that little challenge

for the next scheduled changeover when you are a bit more settled in at home.

Make sure to continue with your daily fluid quota and maintain your meal routine including the nutritional drinks suggested by the Dietitian, if still necessary.

First solo pouch change

Here are some personal tips that may be useful for you:



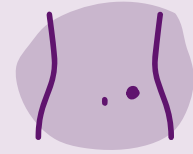
BE PREPARED

Lay out all the items you will need on the bathroom vanity bench. Count them off to make sure you are all good to go. Remember the number for next time.



YOUR ROUTINE

Try to remember your practice routine in hospital (check your notes). It is pretty obvious, but it will take a little time to relax and be confident with the routine.



BE KIND TO YOUR SKIN

Remove your pouch gently, as your skin always needs to remain in good condition. Don't rush the process. Keep replacements on hand if you muck up, and need to start the change again.



KEEP TRACK OF BAG CHANGES

A diary can help you keep track. My pouch needs changing every second day. Every month I write **K** for **Keep** and **CH** for **Change** on alternating days because I still lose track "Did I or didn't I change the pouch yesterday?". Early bag changes aren't an issue; but problems can arise if you change the pouch late and the adhesives no longer stick to your skin.



TRY OSTOMY ACCESSORIES

Another personal choice is to utilise all options as far as products are concerned. I use the seals and the extra flanges for added security. Ten seconds more time to apply could mean hours of extra secure wear time!

I could have listed all the funny and stupid mistakes I have made but it would take another booklet. Instead I will share a few tips that I have learned:

CHECK THE POSITION

Make sure to place the pouch on straight. This will take practice (check in the mirror). The slight discomfort I felt turned out to be the pouch applied on an angle.

DRY SKIN IS BEST

Make sure skin is dry at pouch changeover time. Replace the pouch before a shower not after for best results.

CAREFUL CUTTING

It was not a smart idea to trim the little plastic belt loops off the sides of the pouch because I didn't need them; my scissors poked unseen holes into the pouch... oh dear.

Time to get dressed

It is a good idea at your first post operation appointment with the Stomal Therapy Nurse to ask to be measured up for a support pull on garment or support belt. This useful item will smooth out your stoma pouch under your clothes and importantly help protect and support your stoma area.

I still like to wear casual pants or jeans with an easy fit waistband. A personal choice is to layer outfits to create length and a flattering line. Wearing a fitted top as the first layer; depending on the weather I add a shirt or light sweater then a long open jacket over the top. There are some really good websites you can explore for extra ideas. (Search: Best clothes to wear with an ostomy) Dark colours and patterns are great

to disguise any issues you might worry about. Front pleated pants for men and women look great for any time of day or night.

You have time in the first few weeks to work out some outfits you feel confident wearing. Experiment and try new combinations with old favourites; when you have set up at least three outfits put them aside in a separate section in your wardrobe ready to wear at a moment's notice. Some people care more about what they wear; I am one of those people. It took me a while to accept I couldn't wear everything the way I used to. I'm getting back to feeling good about my clothing choices again and realise the issues that worried me were not even noticed by others.

TIP: Omnigon are specialists in support garments, from briefs to support belts. You will need to keep your ostomy site well protected from possible hernia issues; the Stomal Therapy Nurse will measure you accurately to make sure you have a correct fit.



**OSTOMY
SUPPORT
GARMENTS**

To view full the **Omnigon Support Garments** range, please visit: www.omnigon.com.au/explore/support-garments/

Back to work

Going back to work means so many things: Your operation is over, your recovery is on track and your old/new life is happening. It's a real sense of achievement and rightly so. If you can arrange to start back on reduced hours for the first few weeks this could help in not being overly tired. It is really important to remember to keep up your necessary fluid intake and try to maintain a nutritious diet.

Prepare a set of your pouch supplies to have close by at work just in case you need to have a changeover. There are great shaving gear bags or make up purses that will hold your supplies well and fit easily into your desk drawer or bag. Working with an ostomy is not a problem at all and should not cause you any inconvenience. If your work requires lifting or carrying heavy items you need to speak to your Surgeon and Physiotherapist while you are in hospital to get the best advice on protecting yourself after your stoma procedure.

Social life

After an operation, moderation in most things is recommended. Accepting invitations and going out with friends and family will be fine and should be welcomed.

A few points that could be useful if you are going to be dining out: It is really wise beforehand to check the list of foods that will not cause you issues. I am still cautious and steer clear of anything on the "*Food and drinks to avoid list*." You can go online and view a copy of the restaurant menu to work out your food selection beforehand.

The Dietitian will have reminded you to chew your food well; this applies to restaurant food as well. Ostomates do need to be careful with their diet especially in the early days, but that's not a big price to pay for being well and able to enjoy a great social life.

Exercise

Discuss your exercise routines and sporting hobbies with your Surgeon and Physiotherapist to gain the information you need to get back to enjoying all your favourite pastimes.

www.omnigon.com.au/resources



Off to sleep

The Physiotherapist might have recommended the best sleeping position for your type of ostomy; you have probably worked that out for yourself by now.

Here is the interesting news... your pouch can only hold a certain amount and that means you will need to check your pouch situation during the night.

It's not unusual for people to get up during the night to visit the bathroom, it's possible you will be doing the same. It is recommended to check your pouch about four hours after you go to bed, i.e. 2 a.m. (this is not a typo). Some ostomates set an alarm; others work out their own routine. Another safety option is to use a mattress protector for added peace of mind.

Please remember to use this safe guard pouch check. Unless you are a really light sleeper, you will soon go back to sleep.



Ongoing

A few months have passed and you can feel yourself getting stronger; your new life is on track to achieving all you had hoped for. It's time to go over a few necessary topics to keep your recovery progressing well. The skin around the stoma needs to be well cared for so that it stays in peak condition and looks just like the skin on the rest of your body. If you are not sure about your situation you may want to check with your Stomal Therapy Nurse and book in for a review.

You need to make sure the pouch you are using is still the appropriate size now that things are returning to normal. You can add this to your list when you visit your Stomal Therapy Nurse. It's important to measure your stoma on a regular basis; a stoma measuring guide will be provided to you before you leave hospital. If you are cutting out the opening for your pouch or base plate, check for a measuring guide in the box.

Omnigon products are clearly shown on their website. You can request free samples online at any time. This is a great way to make sure your personal supplies are up to date with the latest developments. Seek advice from your Stomal Therapy Nurse to make sure you have chosen the right products; once ordered supplies can't be returned.



Stay in touch with your feelings

I have written about the many different stages of my ostomy journey from the first appointment with the surgeon, through to the hospital stay, going home, diet, what to wear and how to deal with the new and different aspects that having a stoma brings into our lives.

We need to talk about how we feel emotionally as well; there has been so much going on in a short space of time and not a lot of private time to ask ourselves how we are doing and how we feel after all we have experienced.

Personal reflections: It may help to acknowledge your true feelings to a caring friend, family member, your Doctor, Stomal Therapy Nurse or other Health Practitioner.

Join an Ostomy Group to share your feelings with your fellow ostomates.

Let the significant people in your life know what might be helpful and unhelpful.

Don't stop yourself from feeling emotional, don't block your fears. Accept at times this new way of life will get to you.

Find a positive reason to understand how your life will be improved for all the years to come. Acknowledge to yourself what you are grateful for.

Starting over with an ostomy is a new way of living your life - but it is only one part of the overall plan.

Ostomy products available today make the ostomy routine manageable in a discreet and surprisingly acceptable way.

You will manage. You can do this.

GOOD LUCK!

Wishing you the best possible ostomy outcome; rest assured you will have genuine care and support from everyone involved to get you there.

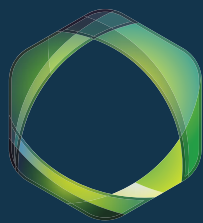
Resources

Ostomates can access websites such as **Omnigon Connect** where you will find genuinely helpful information and trustworthy advice.

The additional advantage of being able to connect with an Omnigon Stomal Therapy Nurse to book a video call or phone consult, is very reassuring.



AU **1800 573 171** NZ **0800 600 074**
info@omnigonconnect.com.au
www.omnigonconnect.com.au



OMNIGON

Care Solutions

AU 1800 819 274
NZ 0800 440 027

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