

Thriving Beyond Today

Power of choice
as you manage
your stoma through
chemotherapy



Eakin
Healthcare

make a note of it...

We've written this guide for you to keep throughout your journey.

So why not use this page to make a note of all the important details, like the name and number of your stoma nurse, your stoma type and oncology team.

Stoma Nurse

Hospital

Telephone

Stoma Type

Operation Name

Date of Surgery

Surgeon/Consultant

Oncology Nurses

Appointments

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.....

.....

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It's all about you

You've come through a lot so far. From finding out your diagnosis, to telling family and friends plus treatment beginning - it can feel like a lot all at once.

Be so proud of yourself, although there may feel like so much to learn and adapt to, **you will find your own way to manage your stoma, in your own time.**

You can use this booklet to help you prepare for changes to your routine that you may experience as chemotherapy begins, so that you can feel **more in control and prepared.**

You'll be able to read important details, with none of the jargon, with advice approved by trained stoma professionals. Along the way, we've added tips from individuals just like you who have a stoma, have undergone chemotherapy and who each have a passion for sharing their experiences to help others.

Remember this is **your journey**, take it at your own pace. While today may feel tough **you can do this.**



If you do have any more questions or concerns, simply go to our website at www.eakin.eu



Chemotherapy with a stoma

About 6 - 8 weeks after your ostomy surgery, you will typically begin cycles of chemotherapy.

While you have gone through a lot of change and learning in those first few weeks post surgery, it's important to know there are a number of side effects from chemotherapy that can impact your stoma care routine and make it a bit more unpredictable.

This booklet covers some of the main side effects that you may experience that could have an impact on your stoma care. It contains helpful advice and tips, including from individuals who have gone through chemotherapy with a stoma. The aim is to help you feel more in control should you experience some of them.

You may find you experience none of these specific side effects, one of them or all of them. Your experience will be unique to you.

Most of these side effects only occur during treatment and your routine will settle back to normal after chemotherapy ends. However, if you are still experiencing side effects post treatment, it is important to talk to your oncology team or stoma care nurse.

NOTE: If you are experiencing issues such as leaks, sore skin, or pain around your stoma do not hesitate to go back to your stoma care nurse - they would much prefer you are happy and confident in your routine rather than experiencing issues.



Output changes



Fatigue



Dexterity challenges



Skin complications



Changes to stoma and body shape

Coping with output changes



Chemotherapy drugs can irritate your digestive system which can cause you to feel nauseous or experience constipation and/or diarrhoea.

With chemotherapy, regardless of your ostomy type, you may find you have more irregular and increased amounts of fluid output (diarrhoea) which could also result in your pouch filling more quickly than usual.

While not pleasant, it is a very common side effect and can occur in phases as the chemotherapy drugs work through your system.

If you are beginning to show signs of dehydration such as feeling very thirsty, passing less urine than usual, passing dark yellow strong smelling urine,

feeling dizzy or lightheaded, feeling tired, sunken eyes, **it is vital you speak to your healthcare professional.** They will be able to advise you on the correct amount of fluid intake along with potentially introducing rehydration sachets and also anti-diarrhoeal medication.

PRACTICAL TIPS

For dealing with changes in output

Drink water - slow and steady!

Looser output can lead to dehydration so it's important to keep your fluid levels up.

Try and drink slow and steady throughout the day and consider drinks with electrolytes to help balance what your body is losing.

Balanced diet

Certain foods can sometimes make output more liquid. Ensure you have a balanced diet and don't eat too much of certain foods such as higher fibre wholemeal bread, cereals, pulses, leafy vegetables, spicy food, caffeine or alcohol. Instead opting for more starch based foods such as white bread, potatoes (without the skin), sweet potatoes, white pasta and rice which can help to thicken output.

Ask your care team if you can speak to a dietitian about a specific diet plan for during your chemotherapy.

PRACTICAL TIPS

Medication

If you are struggling with higher levels of output you can speak to your stoma care team as there are anti-diarrhoeal medications available.

Create change kits

Consider creating ready to go change kits and leaving them in the bathroom. If you have increased output and need to change more regularly this saves time and effort plus everything will be in one place. Kits could include:

- Pouches with baseplates precut
- A seal or accessories you use
- Disposable bag
- Wipes
- Odour eliminator or air freshener

Choosing the right routine to help with increased output

Think drainable

If you're using a closed pouch, why not try a drainable bag to allow you to empty rather than replace the pouch.

Try a 2-piece system

Rather than having to change your whole system, a 2-piece lets you just change the pouch more often, especially if you are using a closed pouch.

Consider a larger pouch size

With increased output bigger is better! A larger pouch can handle more output when needed. Ask your stoma care nurse upfront on the variations within your pouch range - you will get to know your cycle and may need a bigger pouch only a few days during each cycle.

Absorbent seals are important

With looser output adding a seal to your routine could help to prevent leaks from occurring.

www.eakin.eu

Try an output thickener

These are inserted into the pouch and help turn the liquid into gel giving you greater control, and ease of emptying.



For me bananas really helped to thicken the output up. I'd be very conscious about what I was eating and drinking.

I find that drinking a lot of water can personally loosen my output – in general. So, I would drink little and often so I didn't become dehydrated. Plus, I also tried to drink drinks with electrolytes in them as I was conscious about how much I was going to be losing through the more regular, looser output.

Amy



Looking after yourself through fatigue



Chronic fatigue is a second common side effect of chemotherapy. Fighting cancer can be both mentally and physically exhausting.

Aside from your body fighting cancer and dealing with multiple medications, you may be eating less so don't have as much energy - this is aside from the sheer amount of change you've been through. It is completely understandable if you are exhausted - and you have every right to be. The most important thing is you look after yourself and you listen to your body, resting where you can.



SCAN HERE
to find out how Kathy experienced fatigue during her chemotherapy journey and what she did differently



PRACTICAL TIPS

For coping with fatigue during chemotherapy

Prioritise comfort

When you're tired everything can feel much harder or overwhelming. Try wearing loose clothes that allow you to feel comfortable no matter where you are. Look for elasticated band for trousers and layers to keep warm too.

Sleep when you can

Steroids may keep you awake during the night meaning you are even more tired during the day. If you can, have naps if you are tired to help your body recover. In lounge areas, have extra blankets or pillows easily accessible to lie down and even eye-masks or ear plugs to allow you to sleep without being disturbed.

Don't feel under pressure

You may have commitments but try not to plan a lot or put too much pressure on yourself during your treatment. Ask for help, especially if you have dependants who need your time too. Try and take time to relax.

PRACTICAL TIPS

Try gentle exercise

The benefits of exercise can't be overstated, from aiding your physical health to your mental well-being.

Even a walk around the garden or to a local park may help you feel more awake and stretch tired muscles. We always recommend talking to your stoma nurse before resuming exercise and when you do, remember to take it slow and be patient.



Choosing the right routine to help during fatigue

When you are tired the last thing you want to think about is changing stoma care product so it's important to discuss up front with your stoma care nurse products that have longer wear times or higher absorption that can therefore adapt to changes in your routine.

Some things to talk to your nurse or delivery company about are:

Consider pre-cut pouches

This gives you one less job to consider in pouch preparation - win!

Think about a higher output drainable pouch.

We have heard from ostomates who struggled to find energy to change their pouch, others talked about how they would continue to sleep through, even if they could feel a leak beginning. If you're sleeping more a bigger pouch will help capture additional output meaning hopefully less changes for you, or that extra 5 minutes in bed.

The most common side effect I faced from chemotherapy was fatigue. It was never just a feeling of being tired or sleepier than usual. It was a bone deep exhaustion that made daily activities challenging between cycles of chemotherapy, while my body tried to recover.

Rest is really important. You should listen to your body and rest when needed. However, too much inactivity can exacerbate fatigue. So it's a case of finding a balance.

Exercise if you can, any activity can improve your mood and energy levels, even if it is just taking a walk or getting outdoors.

Mohammad

Consider a thicker seal.

A seal offers an extra layer of protection against leaks as when tired the last thing you want is sore skin and more washing.

Change kits

Just like with looser output, creating ready to go kits when you're feeling less tired will help in periods of exhaustion - just grab and go.

If dexterity becomes difficult



During chemotherapy you might find you have pain, numbness or tingling in your hands and feet. This could be a sign of neuropathy and although common, it is important to speak to your oncology team.

These dexterity challenges can mean you don't have the same level of hand coordination as you may usually have or you are sensitive to cold things.

PRACTICAL TIPS

For coping with dexterity challenges

Wrap up warm

Cold sensitivity can be a real challenge with neuropathy. Simple things like touching metal door handles to taking things from a fridge can cause pain. Consider buying a pair of warm gloves to protect hands, even leave extras near your fridge as a reminder.

Consider easy options

If your hands aren't coordinating the way they typically would, putting on a pair of buttoned jeans or zipping up a coat might be hard. Consider pull on trousers and pull over hoodies or other warm clothes that are easy to dress in. Small things can give you control and help prevent any frustration - comfort, ease and warmth is what's in style.

Ask for help

Don't be afraid to ask for help, especially if you are finding daily activities hard. Neuropathy usually resolves after your chemotherapy treatment ends, so asking for help while you are struggling is ok.



During the chemo treatment I had cold sensitivity with neuropathy in my hands and my feet. You know, my hands were definitely a lot more clumsy, and it's harder to do more difficult little things.

Getting your bags pre-cut for you and trying to have everything ready, so having the kit ready there in the toilet all ready. Just having things pre prepared just makes it all a little bit easier.

Kathy

Choosing an easy routine for dexterity challenges

Consider pre-cut pouches

Just like with tiredness, consider pre-cut pouches. Holding a pair of scissors may not be easy and cutting your pouch wrong could leave gaps allowing for leaks. Ask about baseplates that are already cut so you don't need to worry.

A second layer of protection

Equally think about an easy to use, mouldable seal. Any inaccuracies in pouch cutting then you have a second layer of protection around your stoma. There are seals with a cut out section available you simply need to wrap around your stoma as well if moulding is difficult.

Closed vs drainable pouches

Think about closed vs drainable pouches - you may find it easier to apply a full pouch rather than emptying or it's easier to empty. Try both and find out what works for you. Your nurse or delivery company can help you with samples.

Simplicity reigns

Keeping your routine simple can really help with dexterity challenges - choosing a small number of adaptable and easy to use items.

SCAN HERE

to find out Kathy's experience with neuropathy and what she did to help herself.



Caring for your peristomal skin



Sometimes skin around your stoma can become broken and sore if output has sat on it or from repeated removal of your pouch.

Not only is it painful and unpleasant, but when the skin is sore it can become wet which makes applying the pouch and maintaining a secure seal around the stoma more difficult.

The good news is not only is it treatable but also in many cases completely avoidable, simply by following a healthy skin routine.



During my chemotherapy I found my output increased dramatically during the first few days, which led to more bag changes.

As my stoma is a colostomy, drainable bags don't really work for my output, (unless I've an upset stomach). I mainly use closed bags and had to change my bags a lot more frequently, which led to the skin around my stoma being uncomfortable and sore.

The wipes I use are amazing for my skin, soothing it and helping with redness.

Amy

PRACTICAL TIPS

Clean and dry your skin

Clean and dry the skin around your stoma using warm water every time you change your pouch.

Find a good fit

Leaks are a major cause of sore skin, so make sure your pouch fits snugly around your stoma – neither too loose or too tight. You might also want to try a seal as a second layer of protection against leaks.

Eat healthy

Care for your skin from the inside-out by eating a healthy, balanced diet and nourishing it with vital minerals.

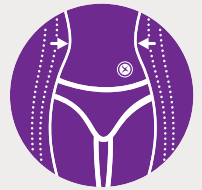
Drink water

Chemotherapy is known to dry your skin out so staying hydrated is a must! Try and keep your fluid levels up.

Think skin friendly

Consider products that don't include additives or ingredients that may cause skin reactions and definitely try and avoid alcohol based accessories! Also think about a seal to add extra protection to at risk skin around your stoma. Preventing irritation is much better than trying to manage it once it's occurred.

Consider how your body is changing



Don't feel like eating?

With so much going on in your body with chemotherapy, it is not surprising to find your appetite has reduced or you just don't feel like eating. Weight loss is really common during chemotherapy and as such your body shape will be changing.

It's therefore important to measure your stoma regularly to ensure your baseplate is being cut to the correct size. If your stoma is changing size, moulding a seal securely around your stoma could help prevent leaks if your baseplate isn't 100% accurate! Flange extenders that go around the outside of your pouch for more security may also be helpful.



During chemotherapy, everything tasted horrible to me – including drinks which was really difficult as you're so conscious of dehydration and how this affects your output.

After initially losing weight, I have put it back on, so my stoma has therefore grown with my body. It's something to be conscious of – your stoma changes as your body does so be aware of this with your bags.

Summa

PRACTICAL TIPS

Healthy diet ideas

- Full and varied - it's important to eat a balanced diet with fruit, vegetables, proteins and carbohydrates.
- Smaller portions - try eating new foods in small portions to see how your body responds.
- Avoid eating late - Try not to eat large meals late in the evening to decrease the amount of stool output overnight.
- Keep a journal - make a note of the effect certain foods have on your stoma.
- Chew well - help your digestive process by chewing your food into smaller pieces, especially foods like peanuts, or other solids that could cause a blockage.

Be good to yourself, try and get the balance of all food groups but make sure to have a treat along the way too - you more than deserve it!

Thriving beyond today.

You are going through so much in a short period of time. Take a moment to think about how strong you have been from diagnosis through to your treatment. Although you might be taking each day at a time, learning as you go, as you continue life with your stoma yes there will be adjustments but it doesn't stop you from thriving and achieve all you wanted to.



Now because I'm back to doing so much that I can do, I don't take as much time to step back and reflect on my achievements.

And when I do it almost kind of blows my own mind and think, wow!

Having a stoma has opened up so many opportunities and it's been an enabler for me to do things and to live life in a way that I wasn't living my life before.

Take some inspiration from people like myself and other people who have come through that journey. And you know, I've been from one extreme in the darkest places to now and seeing life in a completely different way and having my eyes opened and just being grateful for every single day that I have now.

Kathy



I have a love / hate relationship with my stoma - and that's ok! It's there, it saved my life, I don't hate it but I sometimes struggle to be grateful for it too.

What I want to continue to do is find others who have gone through similar to me and encourage us all to speak up and normalise it. Bowel Cancer happens (literally s*** happens!) and I want those who are going or have gone through it to know they're not alone.

Summa



Remember, every individual responds differently to chemotherapy. What you experience may vary from others.

I've always felt that I needed to control the narrative that I was managing the cancer, not the cancer dictating to me what I can or cannot do has given me a sense of meaning beyond the 9:00 to 5:00 grind and my perspective on life has changed dramatically. I could say for the better.

Mohammad



Speaking with people who understand how to use the products and also how stomas work, in my opinion makes me feel seen, heard and understood. Especially at a time when having a cancer diagnosis is a lot to get your head around, then add in receiving a stoma.

Amy

Your stoma nurse is always there to help

Your stoma nurse will be with you throughout your journey, guiding and reassuring you from pre-surgery to post-op and beyond.

That's why they should always be your first point of contact for help and advice – and why, we're proud to support them and you.

And we're here too

If you have any questions or need support on your journey you can read our online blog and view the stories of other ostomates who have gone through similar experiences to you. Check out Amy, Kathy, Mohammad and Summa's blogs on their experiences with lots of practical tips and advice.





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Working together. Improving lives.

If you would like to share experiences of chemotherapy and your own hints and tips to support others going through similar, reach out on the “Share Your Story” section of the website.

We would love to hear from you.

Email: mail@eakin.co.uk Telephone: +44(0)28 9187 1000

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