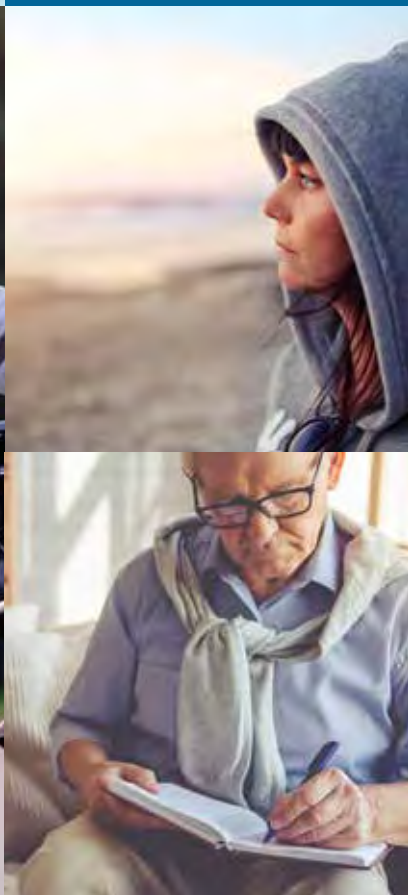


# Ostomates Journal "I'm still me"

Your personal journey to rediscovering you



**With expert advice and support from  
UK medical professionals**

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# About the authors



## Donna Butler

Donna Butler is a registered UKCP psychotherapist, and eye movement desensitisation and reprocessing (EMDR) trauma therapist, as well as being a registered nurse. She worked in the NHS for more than 30 years at Brighton and Sussex University Hospitals, first as an A&E nurse, then as a therapist. During this time she led services in supporting staff from multi-allied professions – including nurses, doctors, paramedics, police and fire service personnel – supporting them through wellbeing and mental health issues.

She is now a consultant psychotherapist and director of Donna Butler Associates, providing specialist therapy for individuals and couples, as well as for organisations where she offers debriefing and post-incident support and training. She regularly presents at national conferences.

You can contact Donna at [db@donnabutlerassociates.com](mailto:db@donnabutlerassociates.com).



## Gill Hasson

Gill Hasson has written more than 25 books on the subject of wellbeing for adults and children; books on emotional intelligence, resilience, assertiveness, happiness and overcoming anxiety. She has co-authored, together with Donna, *Mental Health and Wellbeing in the Workplace*.

Gill also delivers teaching and training for education organisations, voluntary organisations and the public sector in the UK, as well as businesses in both the UK and the US. Gill's particular interest and motivation is in helping people to realise their potential.

You can contact Gill at [gillhasson@btinternet.com](mailto:gillhasson@btinternet.com).





## Laura Coster

Laura Coster is a registered dietitian who is passionate about helping people feel confident in managing their health and find joy through what they eat. She has worked in the NHS advising people at various stages of their stoma journey and continues to help promote gut health to all.

She has collaborated with Fittleworth on various projects such as our Ostomates Kitchen and Hydration guidance resources, alongside some of our blog posts.



## Rachel Stokes

Rachel Stokes has been co-director of Zest People, along with her husband Stu Stokes, since 2004 and, more recently, marketing outreach lead for its sister company ReferAll. Her career as a health-improvement specialist spans more than 30 years working in public health and wellbeing projects for the NHS, local authorities and leisure trusts.

With an 'all things healthy' lifestyle, a diagnosis of a serious cancerous tumour in the lower bowel almost five years ago at the age of 46 came out of the blue for Rachel. With no symptoms to speak of, it was a huge shock. Two and a half years of treatment, three surgeries, a recurrence and two stomas (one a permanent colostomy) later, Rachel is totally loving life again.

# Introduction

**Ostomy surgery is often followed by grief and mourning for the loss you have experienced. As well as changes in your bodily function and appearance, you may have lost confidence in yourself and your abilities.**

*But what exactly is confidence and why do we need it? Confidence is not about what you can or can't do. It's what you think and **believe** you can or can't do.*

When you're not feeling confident, you're likely to believe that things won't turn out so well. In a variety of situations, you may tell yourself, "This is going to be so difficult." Or you might say, "It's not going to turn out well – it's going to go wrong." You may

tell yourself, "I can't do it" and because you **believe** things won't turn out well, you may feel reluctant to even try. Furthermore, if you do try and setbacks occur, if you were already lacking in confidence then you're likely to feel discouraged and give up.



On the other hand, if you're feeling confident about a particular situation or event, you probably think along the lines of "I **can** do this", "I'll give it a try" and "Things will work out fine." You might tell yourself, "I can ask for help if I need it." You have a positive attitude towards yourself and your abilities, and you believe that events and experiences are likely to turn out well. You're able to work at overcoming the difficulties, **believing** that things can get better. And that's why you need confidence – to encourage you to be positive and give you hope for the future.

Regaining confidence and positivity after surgery can take time. No doubt you've heard this quip before: 'How do you eat an elephant? One bite at a time!' The same is true for recovering from surgery and adjusting to a new way of being. Taking it one bite, one step at a time, with patience and support along the way, you can move forward with your life.

# How to use this journal

**This journal presents an opportunity to help you build confidence in yourself, your abilities and your future.**

Each of the 'reflective pages' offers prompts to help you reflect and write about how you are feeling. You can write in this journal every day, every few days or once a week – there are no rules! However often you choose to write, you are encouraged to think about how you've been feeling recently – both physically and emotionally. You may want to write one sentence, a few sentences or even just simple words such as 'awful', 'great', 'sad', 'angry', 'better', 'hurting', 'pissed off' or 'resentful'.

It's important that you don't ignore, suppress or deny any negative thoughts and feelings, or the difficulties and challenges you may be struggling with. Whatever the difficulties, you're not being silly or imagining them. Your feelings **are** real and valid.

Writing about a recent challenge or difficulty can help thoughts from going round and round in your head. Once you've got them down on paper, you then free your mind to think about possible ways forward; to think about what or who could be helpful, and what resources and support do you might need. Then, when you've come up with a possible solution, you can think about what the first step forward might be. That first step might, for example, simply be to make contact with a person or organisation that can give you some information or advice.

On the right-hand reflective pages you're encouraged to think about the positive things that have happened – no matter how small – in the past few days/weeks and to continue thinking in a positive way, as well as plan something nice you are going to do for yourself in the next few days.

Acknowledging the difficulties and challenges before moving on to more positive, hopeful ways of thinking and being are the themes of the reflective exercises that Donna and Gill have outlined on pages 10-23 in this journal.

The creative reflections are exercises that Donna uses with her psychotherapy clients and workshops, while Gill has dipped into her mindfulness books to contribute the beginner's mind and small pleasures exercises.

As well as encouraging you to reflect and look forward, pages 24-33 of this journal include some helpful information and advice. Ostomate Rachel Stokes reflects on her experience and offers her pre-op and post-op advice. Dietitian Laura Coster gives tips and advice on ways to adjust your diet after surgery. Donna Butler offers reassurance on the subject of intimacy and sexuality when you have an ostomy. The final pages of the journal feature a list of organisations that can provide further information and support, as well as some social media accounts you may find it helpful to follow.



## **Remember – how do you eat an elephant?**

One bite at a time! The same is true for recovering from surgery and adjusting to a new way of being. Taking it one bite, one step at a time, with patience and support along the way, you can move forward with your life. Once you've completed the journal, look back over your entries for the first few weeks and you'll see how true this is!

**Date:** .....

**How I've been feeling, physically and emotionally:**

.....

.....

.....

**Recent challenge or difficulty:**

.....

.....

.....

.....

**What or who could help me to manage this current difficulty?**  
**What can I do? What resources and support do I need?**

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The first step I'm going to take towards a solution is:

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Positive things that have happened in the past few days/weeks:

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Nice things I'm going to do for myself in the next few days:

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# Creative reflections

**The healing power of the imagination, nature and art have long been recognised as providing respite – even an escape – from life’s difficulties.**

**Nature, creative pursuits and art can also aid us in processing feelings and gaining a deeper understanding of ourselves.**

First World War veterans, for example, physically and psychologically traumatised by the events they experienced, found great comfort in nature and art. As well as the men on the front line, women also turned to creative pursuits to help them process their experiences. Norah Nielson-

Gray served as a volunteer nurse with the Scottish Women’s Hospital based at Royaumont Abbey, France. She painted in the daytime after completing a night shift to help her manage the stress of her job.

In another example, the 19th-century poet William Wordsworth understood the healing nature of the images that poetry can create. Wordsworth had his own experiences of sadness early on in his life; when he was 13, his mother died and his father sent him to boarding school. He then didn’t see his five siblings for more than nine years. The first few lines of his poem ‘Daffodils’ reflect his feelings of loneliness and disconnection.

---

*I wandered lonely as a cloud  
That floats on high o’er vales and hills,  
When all at once I saw a crowd,  
A host, of golden daffodils;  
Beside the lake, beneath the trees,  
Fluttering and dancing in the breeze.*

---

**Just as Wordsworth uses metaphor in his poetry, the following reflective exercises work with image and metaphor to aid positive change.**



# Exercise 1: Imagine a landscape

What you'll need:

- Coloured pencils or felt-tip pens, crayons or chalks.
- The following blank pages in this journal or separate, larger sheets of paper.
- Somewhere peaceful to sit.

## Before you start:

Please be reassured, this is not about how good you may or may not be at art, it's simply about engaging with your imagination. You may want to use several colours, or you might just use one or two. Try not to judge how you are doing – just have a go!

Read the instructions for each exercise, one at a time, then draw each image that you imagine before moving on to reading and doing the next exercise. It's important for the process of reflection that you do both parts of Exercise 1 before moving on to Exercise 2.

Rather than read through each exercise yourself, you might want to ask someone else to slowly read them to you instead.



## Exercise 1: Part 1 – The past

- Close your eyes and imagine a landscape that represents what the past has been like for you, regarding your health, your operation and your body. It might be an urban landscape that comes to mind, one filled with buildings. It may be a landscape or seascape.

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- Notice the colours, or if what you are seeing is in black and white. What about the shapes and textures: are they jagged and rugged? Smooth and rounded?

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- Be aware of how you are feeling – physically and emotionally – seeing this image. Notice which part of the image you are drawn to – it might be a rock or a building, trees or fields.

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- Imagine this image has a voice – what would it say to you about the experience you have been through with your health (just the first thing that comes to your mind)?

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- Now, draw the image into your journal.

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- Take time to notice and think about what it feels like to reflect on the past, and to know that time has gone.

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- Once you have finished drawing, you may want to write a few lines describing the thoughts and feelings you were aware of while doing this exercise.





## Exercise 1: Part 2 – The future

- Close your eyes again and imagine how you would like your future to be, represented as a landscape. Imagine something positive!
- Again, notice the colours, the scenery, any buildings, or you may just see a scene from nature. Let the details come to mind.
- Now, imagine a small path in front of you and a slight slope that is easy to walk up.
- When you reach the top look out into the distance, feel the sun on your face and notice what's on the horizon – a confident, positive scene of hope.
- Imagine if the horizon could speak to you – what positive message would it give you (the first thing that comes into your mind)?
- Be aware of any bodily sensations and emotions at seeing a positive image in front of you.
- Again, draw the scene into the journal, or on a separate piece of paper.
- Notice how it feels to draw what you have seen as positive. You have seen what is termed in therapy as 'a rehearsal of the possible'.
- Keep the drawing somewhere to remind yourself that you can be confident of the appearance of good, positive things on the horizon!



## Exercise 2: The budding tree

Similar to the music we listen to or the clothes we wear, the artwork we like (be that photos, paintings or images) is an expression of who we are – our character, our experiences, hopes and dreams – and how we experience the world. All and any of our emotions – love, frustration, anger and hope – can be expressed through art.

Rather than read through each exercise yourself, you might want to ask someone else to slowly read them to you instead.



- Close your eyes and imagine a tree in winter. The skeletal outline, bare, with dark branches.
- The tree is resting and the buds are asleep for winter.
- Now visualise the sun. Recall a time when you were last in the sunshine, your most ideal temperature, and imagine the sun on your face.
- Notice small buds popping into blossom. Each of these buds represents positive aspects of your life, things you already do, people you love to see and things you would like to do in the future. This might be spending time with loved ones, travelling, walking, exercising, gardening, working on a new project or creative activity, maybe even dancing.
- In the journal, draw the outline of a tree with many branches. Write down your personal tree of wishes for the future, represented by new buds. Label each new bud, for example, 'see friends', 'exercise daily'.
- Notice how you feel drawing these – and how it feels looking at the future with all its potential.
- When you have finished drawing the tree with its buds, sit back and imagine the tree has a voice. What positive words would it say to you (the first positive words that come into your head)?

Finally, if you were to give each of these three drawings a title what would they be?

If you like the tree image and it feels positive, take a photograph on your phone and make it your screen saver, to remind you of good times to come!



# Beginner's mind and small pleasures



In life, we mostly take changes in our stride – the changes in the seasons and the weather, the time a TV programme is scheduled or your team is playing, or a change in the menu at your favourite restaurant.

But facing a more serious change can leave you feeling disorientated and vulnerable, among other things. It's easy to lose confidence – to believe that you won't be able to cope with the change in circumstances and that things won't turn out well.





Although adjusting to the changes that occur in your life after ostomy surgery can be difficult, it doesn't mean you won't soon enjoy a full and active life. It is, however, important to acknowledge – and not ignore or deny – the challenges and difficult emotions that those changes bring.

What are the negative things that you think change can bring? Uncertainty and loss? What else?

Write down your thoughts here.

## Exercise 2: Having a beginner's mind

**Negative thoughts and feelings about change are all valid; whatever fears and concerns you have are real and true. But in order not to get stuck in a rut with your concerns and anxieties, you need to show yourself that you can adapt to change and move on with your life.**

A mindfulness approach suggests that, rather than resisting change, you should let go of past ways of thinking and doing, and instead adopt what's known as a 'beginner's mind'. A beginner's mind encourages you to start afresh and respond to things as they are right now, in the present. With a beginner's mind, you free yourself from your assumptions and expectations, and engage with yourself, experiences and activities as if for the first time. You let go of the past and begin again in the present.



You can better adjust to change by seeking change. Deliberately making changes is an effective tactic for coping with the inevitable changes that will occur in your life. Here are some ideas to help you develop a beginner's mind.

- Drive, walk or cycle a different route to somewhere you regularly go. You could even take a different route from your normal one around the supermarket.
- Visit a place that you haven't explored before. Walk around a part of your town that you've never been to, or take a country walk on footpaths you've not walked before.
- Try a new food or cook a new dish for dinner. Go to a different restaurant or pub from the ones you might usually choose.
- Watch a film or TV series, or listen to a podcast that you know nothing about already; you've not read any reviews or heard anyone talk about it.
- Listen to music differently. Choose a favourite piece of music and, as you listen, focus throughout on an instrument or element that you wouldn't usually be aware of. Maybe it's the drums or the bass. Perhaps it's the lyrics.
- Move the clock to a different place in the room. Move the teabags to a different cupboard.
- Try a new activity – a dance class, yoga or tennis. Try canoeing or paddleboarding. Learn a new language, to play a musical instrument or any other skill where you start as a beginner.
- Do something brave: go on a roller coaster, watch a horror movie, hold a spider.



What were your thoughts and feelings as you engaged with the new way of doing/being? What did you notice? How did you feel? What was easy and what was difficult?

What would make it easier to accommodate and adjust to the change? Perhaps it would be to have been better prepared and to have had some information before you made the change? Some instructions or a map perhaps? Or support from other people as you experienced and adjusted to the change? Write about it here.

## Exercise 3: Small pleasures and comforting things

*'Look out for what makes you smile and surround yourself with it as much as you can.'* Ilona Burton

Because changes in our lives can often be difficult and disorientating, we need to mitigate the difficulties with familiar comforts. Small pleasures that anchor us to the moment provide stability and bursts of happiness.

Whatever your circumstances, there's a world of small pleasures that can bring you moments of happiness every day. What are your small pleasures? A bubble bath, a hot shower, warm towels? Fresh clean sheets? A book by one of your favourite authors, listening to a familiar piece of music or watching a favourite film? Maybe, on a cold morning, it's putting on an item of clothing that's been sitting on a hot radiator? Maybe using a spoon to eat the froth on your cappuccino is a small pleasure of yours. What about a lie in? A kiss, a cuddle or holding hands? Perhaps it's an open fire, sitting in the sun or going for a walk in the rain? Dancing in the car? Tomato soup? Eating pizza for breakfast? Maybe talking to your dog or cat is one of your small pleasures.





Start writing a list of your small pleasures here. Add to the list whenever you think of something else that you enjoy and that makes you smile.



# I'm still me, just a little different



Rachel Stokes is a Fittleworth ambassador. As an ambassador, Rachel shares her experiences of Fittleworth's services and support to help empower other people when they find that, just as she did, life has taken an unexpectedly different turn. A diagnosis of a serious cancerous tumour in the lower bowel almost five years ago, at the age of 46, came out of the blue. With more than two years of treatment, three surgeries, a reoccurrence and two stomas (a reversal and now a permanent colostomy), Rachel tells us she's now totally loving life again.

Here, she reflects on her pre-op and post-op experiences, and shares her tips and advice.

## PRE-OP

### Practical tips/experiences:

- Read all the brochures and look at all the web links your healthcare professional recommends to you. Ask any questions you have – no question is too small or insignificant.
- Prepare as much as you can pre-surgery. Where feasible, plan some time for a little rest and relaxation. I worked up to the day before my surgery, until I had to rest due to bowel prep. I wish I had known I wasn't taking enough time to prepare myself and my body for surgery. I probably kept busy to stop myself from thinking about what was ahead. However, it didn't stop me thinking and I felt more tired than I needed to.

### Clothing:

- Set aside clothing you feel comfortable wearing and that makes you feel good, ready for after the operation. For example, a long-line T-shirt/dress, but not voluminous and tent-like!
- Organise several different outfit combinations – enough for a week – to emphasise that each day is a new day when you get dressed in the morning.
- Take the jeans/trousers/skirt you wear most often to your pre-stoma marking-up appointment. Where the waistband sits on your waist is very important. Once your stoma has been formed in surgery, it can't be moved so it's crucial you do this to make clothing choices easier in the future.



## PRE-OP

### Practical tips/experiences:

- I watched ostomates' helpful videos on YouTube. It really gave me knowledge and confidence to face what might be happening to my body.
- Whatever's going on in your life, surgery and recovery are now your priority. I was having surgery for the removal of a bowel cancer tumour and (probably) waking up with a stoma too. I didn't know too much ahead of surgery as it happened quite quickly, all I knew was that it would ultimately make my life better than if I didn't have the operation.
- I draw on my faith, which gives me reassurance that I am not alone in both the good and the difficult times. When life is difficult, I try to give myself a break and allow my faith to take the lead. Think about who or what you will turn to for support when you're struggling.



# I'm still me, just a little different



## POST-OP

### Practical tips/experiences:

- With the support of my Fittleworth stoma nurse, I tried an assortment of pouches to find the best fit, style and security for me. I was amazed at how much the material and style of the pouch (flat v convex) make a huge difference. My advice is don't give up – with support, you will find what works best for you.
- Get your body moving. When your doctor has given you the all clear, build up activity slowly but do keep moving. After I returned home, my goal was not to have too many days when I didn't go out. By this, I mean in the garden or a few steps down the path, or to the end of the road, with someone else to begin with. Before I knew it I was going to the park and back! This built my confidence no end.
- When my stoma 'wakes-up' it can start gurgling. It's usually when I least want it to. I find this very embarrassing when I'm not with people I know well. So I excuse myself, where possible, for a few minutes until it passes. Although I know people don't mind, my way of dealing with wind noises is to pre-empt a few moments before. If this isn't possible, I pre-warn people that I have a stoma that may make a few noises.
- I am fortunate to be able to irrigate my colostomy. Check with your doctor or nurse if this is possible for the type of procedure you've had. If it is and you'd like to give it a go, ask your stoma nurse for their support and advice. It takes about 45 minutes in the morning or evening (I do mine in the evening because it suits my lifestyle). You'll need access to a bathroom during that time and a bit of patience for good measure. Is it worth it? Absolutely! Colostomy irrigation has improved my quality of life. I'm thrilled with the confidence it's brought me.

### Emotional tips/experiences:

- My mindset – my attitude and approach – is what has enabled me to feel happier and more confident with my body shape and image. I'm me, just a little different. I still exercise and do most of the things I love doing – with a little consideration for Maggie, my stoma. How did Maggie get that name? It's a nod to the wonderful NHS nurses at Worthing Hospital who looked after me (that is a story for another time!)
- I thought everyone could see my stoma pouch under my clothes, but it was really only me who knew it was there. Now it doesn't even cross my mind.
- Rest when you feel you need it. Put your feet up, close your eyes, do a breathing exercise or have a nap. Sometimes this is hard to do, especially when you've got over the initial post-surgery phase and feel you should be doing more. When I did take time to have short rest intervals I noticed it really improved my energy levels and in turn my ability to be more positive without even trying.
- I found that first thing in the morning was my most difficult time of day. When I woke, even before I opened my eyes 'all this' hit me. So I accepted the offer of six counselling sessions. To my surprise I benefited enormously. I was advised to write down how I had slept when I woke up each morning. After a little while practising this technique, I started jotting down things that were on my mind or bothering me. A simple task that seemed to get me through to breakfast!

Now that you have read Rachel's experiences, with a coloured pen, highlight three to five of her tips you think would be most helpful for you to follow.



# Fuel mood with your food

While having a colostomy or ileostomy means your digestive system has undergone some changes, you may still be able to eat the same foods. Everyone is different and where some people with ostomies can eat and drink anything, others have found it helps to swap one type of food for another. There is so much you can eat and enjoy, so keep experimenting to find balance between what you love and keeping well.



## *Find your love for vegetables!*

It's understandable you may be unsure about eating certain vegetables after stoma surgery due to potential unpleasant gut symptoms. Perhaps you've never been a fan of their taste and texture, however the nutrients they provide are important for many aspects of our health, like our immune system.

Stable blood sugars can also help maintain our mood and the fibre in vegetables, as part of a balanced meal, helps steady the release of sugar into our blood. Certain hormones that our brain uses to maintain our mood are partly created by using vitamins found in vegetables.

### To make vegetables more appealing:

- Rather than always boiling vegetables, try steaming, grilling or roasting.
- Experiment with flavours by using herbs and spices while cooking – try paprika, oregano and spice mixes.
- Add a dressing or sauce after cooking – experiment with gravy or extra virgin olive oil mixed with lemon juice.

### For easier digestion:

- Add just one extra portion of fruit or vegetables over a few days to check how your gut reacts.
- Try peeled fruits and vegetables.
- If cooking, try them softer at first and adjust as you go.
- Try vegetables blended into dishes, such as red peppers in tomato sauce for pasta dishes. You could also try the green smoothie recipe on the Fittleworth website: [www.fittleworth.com/ostomates-kitchen](http://www.fittleworth.com/ostomates-kitchen).





## *Water doesn't have to be boring!*

If we've not drunk enough then it can reduce our physical and mental energy levels, triggering a lower mood. If you've got a stoma, you may find it a struggle to drink as much as your health professionals have advised. Here are some ideas to get creative and make water more interesting!



- Add some flavour, try fresh fruit slices, cold-infusion 'teabags', or no-added-sugar squash.
- If your gut is sensitive to caffeine, try decaffeinated options.
- If you can manage them OK, have juice or smoothies on occasion – try our black forest smoothie on the Fittleworth website: [www.fittleworth.com/ostomates-kitchen](http://www.fittleworth.com/ostomates-kitchen).
- If you lose a lot of salt from your stoma, try savoury drinks. Mix half a teaspoon of yeast extract with a mug of boiling water.
- Some foods contain water too, such as fruits, vegetables, yogurt, cottage cheese and soups.
- If you're having occasional alcohol or fizzy drinks, find the balance between enjoyment and feeling well.



## Brain-friendly fats



You may be concerned that fats in your diet could result in pouch smells and looser bowel movements. Everyone's tolerance varies, and it usually increases over the weeks and months after your surgery. Research shows that particular fats may be linked to mood improvement through actions like reducing inflammation and maintaining a healthy brain structure. Here are some ideas to add some brain-friendly fats to your meals.

- Have two portions of oily fish a week, e.g. salmon, fresh tuna, trout, mackerel. To help reduce pouch smells, have fish with milk or cream-based sauces and fresh herbs like parsley – try our fish pie or salmon goujons recipes, available on the Fittleworth website: [www.fittleworth.com/ostomates-kitchen](http://www.fittleworth.com/ostomates-kitchen).
- Sprinkle ground linseed/flaxseed on your morning cereal. Have some peanut butter or almond butter on toast.
- Try avocado with egg on toast or mash up an avocado to eat like a dip.
- Add olives (chew well) to pasta dishes and casseroles.
- If you can't manage any of these foods, you might like an omega-3 supplement (containing both EPA and DHA, 450mg in total).

# Having higher-fibre carbs



Eating less fibre can help reduce unpleasant gut symptoms in the first few weeks after your stoma surgery. After this time, including some higher-fibre carbs in your meals can help reduce mood fluctuations by balancing your blood sugar and insulin levels. It's unlikely all higher-fibre carbs will be off limits for you.

## If you are reintroducing or increasing fibre, try:

- One higher-fibre food a day, in a smaller portion, e.g. if you usually have one or two slices of white bread, swap one slice for brown bread.
- Chewing especially well – taking your time to eat means you get to enjoy your meal for longer!
- Experimenting with different higher-fibre carbs such as brown rice, quinoa, wholemeal pasta and porridge oats.





# Intimacy and sexuality when you have an ostomy

For many people, intimacy and sexual relationships can be an important and fulfilling part of life.

Whether you have had a colostomy or ileostomy formed it's natural to feel anxious about how stoma surgery might impact on new or existing relationships. Most likely, you have concerns and questions.

The extent to which surgical procedures and ostomies affect intimate relationships varies from one person to another. Certainly, there will be a period of readjustment following surgery, physically but also mentally. Having a stoma may contribute to you feeling self-conscious, shy and embarrassed about how you look, or you may feel anxious about the physical aspect of sex with a bag that is attached to your abdomen; you might worry that the bag could become dislodged.

You may be concerned that sex will be uncomfortable – painful even – and that it will affect your ability to experience orgasm, and if you are a man, your ability to keep an erection. Your partner may be worried about hurting you during sex and feel anxious themselves.

Be assured that intimacy and sexual relationships can continue after ostomy surgery. Whatever your concerns, it's important to voice them and to talk through possible solutions with patience, kindness and consideration.



Ostomy surgery may present more or different concerns for single people. You may want to consider when is the best time to tell someone about your stoma if you are considering having sex with them. As in any intimate sexual relationship, there needs to be mutual trust and respect, so do encourage each other to be open about any concerns either of you may have.

## Top tips

- Discuss sexual positions that may help to avoid dislodging the bag (or discuss your concerns about this happening).
- Empty the bag prior to sex.
- Wear an 'intimacy wrap' to hold the bag snug to your abdomen. There are a variety of styles available to buy online.
- Consider clothing – a T-shirt or camisole for example – that may be more comfortable during sex, or may help reduce any inhibitions you have about your body.
- Start slowly, but don't change what you like during sex, unless it's uncomfortable.

If, as a result of your surgery, you experience sexual difficulties, do discuss these concerns with your stoma nurse or GP. Don't be shy! Remember, they are used to having these types of conversations and are there to help. If you do experience difficulties, acknowledge to yourself that you've been through a lot; it's not an easy time, and it's OK to feel sad or frustrated, and that your body will need time to recover from surgery. Then turn your mind towards getting help and support, and know that with that support you will find a way through and things will improve over time.

There is a wealth of information regarding sex when you have a stoma, which your stoma nurse will be able to tell you about. There is also a great deal of information available from social media platforms – particularly YouTube and Instagram – where people are having open and helpful conversations about their experiences of being an ostomate and having a fulfilling sex life ... still!

Finally, do be aware that your stoma does not define who you are, it is another aspect of you, just as your sexuality is too. You're still you, just different!



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**How I've been feeling, physically and emotionally:**

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**Recent challenge or difficulty:**

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**What or who could help me to manage this current difficulty?**  
**What can I do? What resources and support do I need?**

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The first step I'm going to take towards a solution is:

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Positive things that have happened in the past few days/weeks:

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Nice things I'm going to do for myself in the next few days:

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## Further information, advice and support



### Colostomy UK

[www.colostomyuk.org](http://www.colostomyuk.org)  
Tel: 0118 939 1537  
Email: [info@colostomyuk.org](mailto:info@colostomyuk.org)  
24-hour helpline: 0800 328 4257

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### Urostomy Association

[www.urostomyassociation.org.uk](http://www.urostomyassociation.org.uk)  
Tel: 01386 430140  
Email: [info@urostomyassociation.org.uk](mailto:info@urostomyassociation.org.uk)

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### Ileostomy & Internal Pouch Association

[www.iasupport.org](http://www.iasupport.org)  
Tel: 0800 018 4724  
Email: [info@iasupport.org](mailto:info@iasupport.org)

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### Ostomy clothing

Etsy: [www.etsy.com/market/octomy\\_clothing?](http://www.etsy.com/market/octomy_clothing?)  
vblush: [www.vblush.com/productdisplay/  
ladies-white-ostomy-nhs-underwear](http://www.vblush.com/productdisplay/ladies-white-ostomy-nhs-underwear)

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### Mind

[www.mind.org.uk](http://www.mind.org.uk)  
Infoline: 0300 123 3393  
Email: [info@mind.org.uk](mailto:info@mind.org.uk)

### Samaritans

[www.samaritans.org](http://www.samaritans.org)  
You can call the Samaritans on 116 123 any time, day or night.  
Email [jo@samaritans.org](mailto:jo@samaritans.org) and get a response within 24 hours.



# Social media accounts to follow



## Twitter

**@MeetAnOstoMate** – a community for people undergoing ostomy surgery



## Instagram

**@ostomyinspo** – a community where women can find inspiration

**@lifewithastoma** – all life issues looked at in living with a stoma

**@hannahwitton** – ostomate who discusses all things stoma, relationships and sex

## YouTube

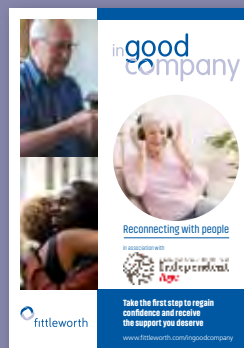
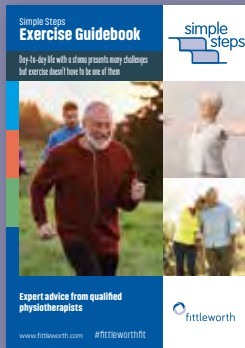
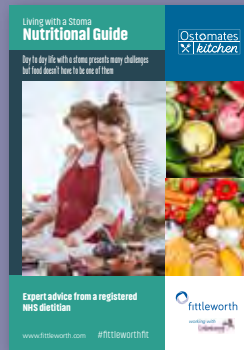
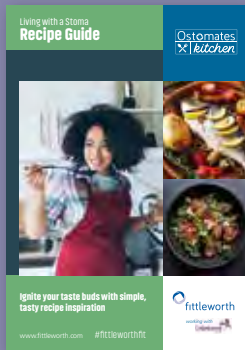
**Mr ColitisCrohns**

*Just a guy changing his stoma bag*  
[www.youtube.com/watch?v=4C02rO-QZPA](http://www.youtube.com/watch?v=4C02rO-QZPA)

**Hannah Witton**

*Sex with a stoma*  
[www.youtube.com/watch?v=SSYdKcXj3GM](http://www.youtube.com/watch?v=SSYdKcXj3GM)

# More expert guidance on living with a stoma



Visit **www.fittleworth.com**  
or call **0800 169 0024**  
to request your free copy

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Scotland:

**0800 783 7148**

Nurse line:

**0800 378 413**



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