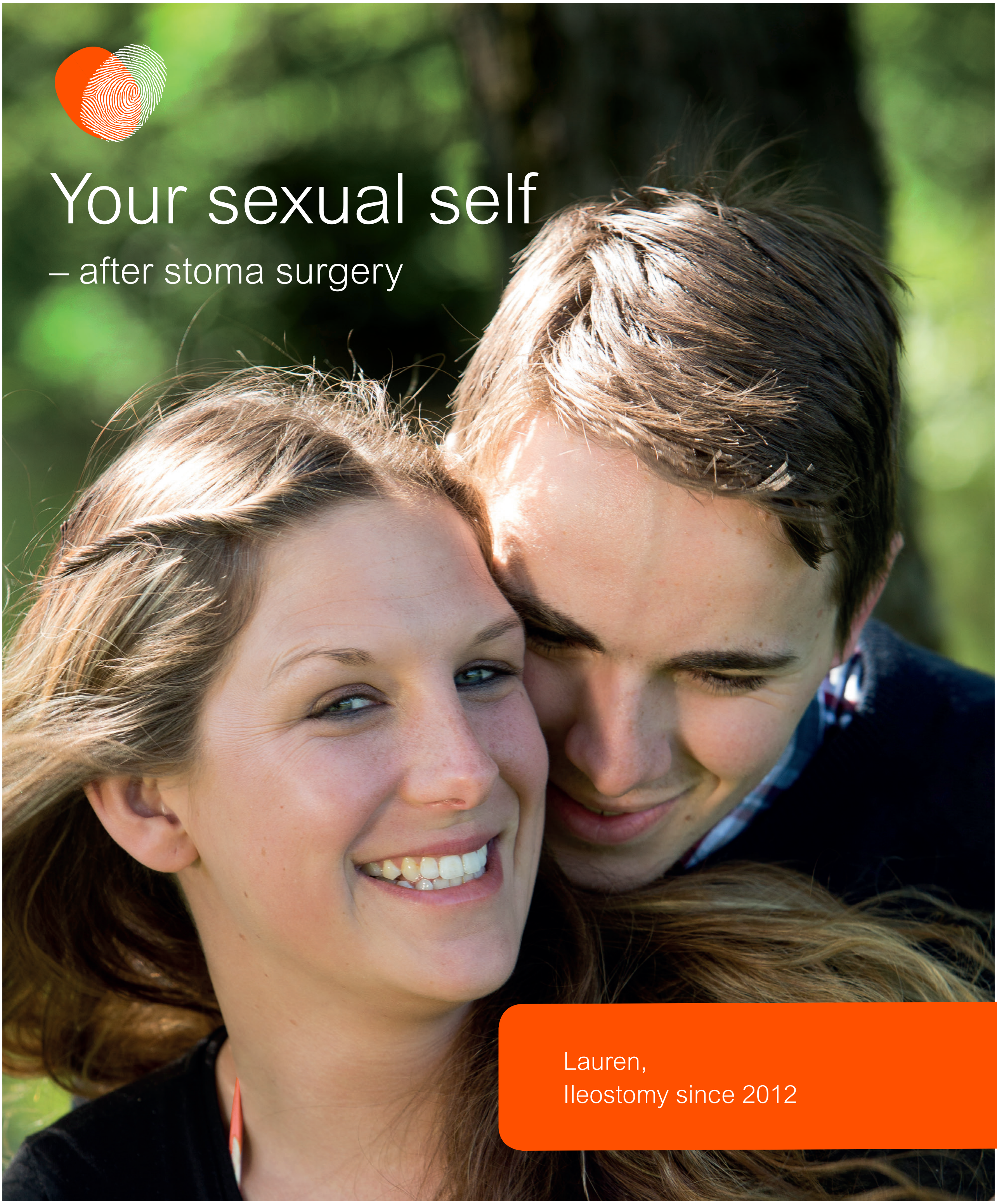
Your sexual self

– after stoma surgery



Lauren,
Ileostomy since 2012

Dedicated to Stoma Care

dansac

Joshua,
Ileostomy since 2014

Hello

Welcome to ‘Your sexual self – after stoma surgery’

This booklet sets out to discuss how sex, sexuality and sexual expression can be affected by stoma formation, using some of the common themes that patients and stoma care nurses have highlighted. It also aims to offer some hints and tips that will hopefully help if you are feeling a little lost, worried or curious with regard to your sexual recovery following stoma formation.

All people, no matter their age, relationship status, culture or orientation are sexual beings. ‘Sexuality’ means the way we experience and express ourselves as sexual beings[1] and is a fundamental part of who we are. Although lovemaking is certainly a component of sexual expression, there is an awful lot more to it than that!

The book is set out in colour coded chapters so that you can easily identify those that are most relevant to you (and avoid those that are not). We understand that some people may wish to read the whole booklet from cover to cover and others may choose not to read it at all.

Because each chapter can be read on its own, there are some basic recommendations that have to be outlined repeatedly. The most important is to talk to your partner if you have one, or a close friend or relative, and use your stoma care nurse - they are probably your best resource. If you simply cannot find the right words, there is a pull out card at the back of the book that you can hand to your preferred health care professional, to help get the conversation started.

There are many, many aspects to sexuality; we could not possibly address all of them in one handy booklet. We intend to focus on the eight topics that most commonly arise when talking to people who have had stoma surgery. There are other booklets and web resources that are specific to particular disease groups e.g. cancer[2,3], inflammatory bowel[4], spinal injury[5]) which may offer more detailed information and we would encourage you to use whatever resource you feel is going to help you the most.

Do what is best for you.

This booklet is not meant to take the place of your professional health care provider. It is provided as an extra educational resource to help guide you with supportive information.

Acknowledgements & Authors

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Content

1. Early expectations

This chapter sets out to introduce some of the topics people have raised in the early days after surgery, regarding their recovery and what to expect.

Who you are, what is important to you and what you expect from life are very personal things. You are unique – and so is your sex life. How much you express and value your sexuality, celebrate it and enjoy its place in your life is also different from the next person and for that reason, there is no ‘normal’ when it comes to sex. Different people have different needs and your ‘normal’ is what is right for you.

Going through a life-changing illness or injury creates a significant imbalance to your ‘normal’ world. It affects your body and your mind and has an impact on those you love and who love you. How you respond and how you are supported may be influenced by many factors, including the presence of or absence of a partner, the family you grew up in (and whether they are close to you now), your personality, your religion, community or social network and your earlier life experiences.

Things that positively influence how easily you adapt sexually can include having a relationship that is based on trust and open discussion, having a sex life that values intimacy, love and pleasure above ‘performance’. Additionally, ability to ‘give and take’, to ask for what you want and to ask for help[6] can be important. This may be a relationship you have now or hope for in the future.

There are a number of regular recommendations that are good for everyone and which build good foundations for general well-being as well as sexual recovery. These are having a balanced healthy diet, regular exercise and good company.

Taking responsibility for your rehabilitation, eating well and building up your fitness can help you to feel good about yourself as you grow in confidence and strength. Sharing this with someone who matters to you is a bonus.

There are a number of concerns that are frequently mentioned in the early days and weeks following stoma surgery. These may not seem directly related to sex and sexuality, but they are a good place to start as they are issues that worry people and worry generally doesn’t help you to feel confident.

Privacy versus sharing

Sharing your thoughts and feelings about what you have been through and what you are still experiencing is usually encouraged as it enables others to support you. Often other people want to help, sometimes in a practical way, sometimes by listening; it makes them feel good to help someone they care about. But it is also true that how much you want to share, who with and when, is entirely up to you. Some people tell everything to everybody, others strongly value their privacy and are naturally very reserved, while most people are carefully selective about whom they tell. There is no right or wrong.

One thing you can be certain of is that anything you discuss with the stoma care nurse will be dealt with sensitively and confidentially. If your stoma care nurse feels that someone else might be able to help, or that you would benefit from a referral to another health care professional this will always be discussed with you first.

Managing early recovery

Sometimes it seems that everyone is in a hurry to see you getting better, from the weeks before your operation, through your in-patient stay and then afterwards from the community teams as well as visitors and well-wishers.

It can start out feeling very safe, but can become rather stifling, so that privacy is hard to find. It is often a good idea to set a regular rest time in the early weeks and let everyone know when that is, so you can have some time for yourself, your partner – and for a nap.

Expect to have good days and bad days in the weeks following surgery. Both physically and emotionally you are likely to be up and down. Some people like to keep a diary of progress, so that they can look back and see how far they have come.

Whether you write a diary, blog, video yourself, or none of these, take note of how your body is recovering and take time to get to know it again. Set yourself realistic goals for the short term, medium term and long term. Discuss them with your stoma care nurse if you are unsure whether they are reasonable or not. These may be sexual goals, or may be general ‘getting better’ goals. There is no right or wrong.

If you are culturally different from your stoma care nurse, it may be useful to you both to talk through what having a stoma means to you and those who share your background or faith. Talking about it will mean that you get truly inclusive care and that you can be directed to resources and information that are useful to you. There are information sheets on so many aspects of stoma care and if there isn’t one that directly suits your needs, you’ll still be amazed at how resourceful your stoma nurse can be!

When is the right time?

This is up to you, but really, it cannot start too soon – in small and simple ways in the early days, concentrating on how you look and feel and building your strength and confidence, is all part of reconnecting with 'you'.

Go slowly, with little steps that help you to get to know your altered body, perhaps starting by standing in front of a mirror and looking at and touching your body. Recognise your thoughts. These may begin with sadness or anger or even disgust but over time things will improve as you adjust.

If you are able to share this with your partner, then ask them to stand with you at the mirror while you touch your skin. Tell them what you feel, if anything hurts or areas feel numb, so that they know and don't have to guess. Next, you might let your partner touch. Speak out loud your thoughts and feelings, describe what you mean to each other. This can be really useful later, when it comes to lovemaking.

Not everyone wants to share this intimacy of course. That's okay, but do tell your partner if anywhere hurts. Beyond that, you can consider wearing a top or tee-shirt, stoma belt or stay in your underwear – no-one says you *have* to be naked! It's advisable for you to both read chapter 7 once you are ready to move on to more active lovemaking. If you can read it together, even better!

Expectations of your partner

Partners often request to be shown how to care for the stoma 'just in case'. You need to decide how comfortable you are that your partner learns and is involved. It is often a good idea to talk to the stoma care nurse about this and have it clear in your mind and remember this is your body and your choice.

With regard to your partner's expectations of lovemaking or sexual intercourse, again this can create anxiety. There is some adjustment for you both and you both need to feel comfortable and ready to experiment in order to improve the chances of a happy outcome. If you have lost your libido (sex drive), which commonly happens in the early weeks, talk to each other… and agree to review the situation as you recover. Your partner probably wants to hear that this is common and temporary! Try to offer and to accept hugs and affection and if you have always shared a bed, try and stay in the same bed.

If you are single

Those going through stoma surgery without a partner suffer all the same sexual side effects and worries as those people with a partner and sometimes more besides. There is no-one to experiment with along the way. The worry about whether and when to tell a new potential partner about the presence of the stoma can feel very confusing. Try not to let this worry grow. If the stoma is a big issue for a potential partner – remember, it's not you, it's them! Maybe they need time to adjust, or maybe they are just not 'the one'. Be who you are, with friends you trust. Enjoy hobbies and activities that please you. Grow your confidence and 'tell' when it is right for you.

Read more in Chapter 4 'Relationships'.

Big decisions

Sometimes having a life-threatening illness or injury is a springboard for re-evaluating life and making big decisions. Perhaps there is a lost dream that it now feels extremely important to grab hold of again, a 'bucket list' that has to be emptied, a relationship that has floundered for some while and needs to be worked on, or let go.

People have been known to do all sorts of things in the aftermath of illness; sell up, buy a camper-van and 'hit the road', leave their partners, emigrate, start a university degree. Many will say that they had to do this very soon after their illness, because they felt that if they waited, they wouldn't do it at all.

If you find you are now re-evaluating your life, try not to 'jump' too soon. Taking time to recover, having people around you that you love and trust and allowing time to let life settle will not mean you lose your motivation for change. It will mean that you can enter into that change in a stronger body and more organised manner – it will let you 'look before you leap'. ■

Hints and tips

Confidence comes from getting to know your body again and accepting the changes, as well as having faith in your appliances.

If you are worried about baring your body entirely, wearing a top, tee-shirt or stoma belt, or choosing a pouch cover may help you to feel more comfortable when it comes to lovemaking.

Accept compliments, go people watching – how many people truly look at each other? No-one except those you tell knows that you have a stoma.

Do something that you are good at, enjoy your success and share it with someone who matters to you.

If you are not ready to make love, talk about it, suggest a time for reviewing the situation and start courting again – have fun with cuddling and kissing or even just holding hands.

Take your time.

Helen, Colostomy

”Initially the thought of sex when you have a stoma seems like an odd combination. However I found that once I had had my colostomy and began to irrigate, thereby necessitating the need only to wear a stoma cap, it was all very possible. I did not in any way feel different from how I had done pre-stoma and my husband frankly didn’t seem to notice!

It could promote humour whenever the stoma cap filled with air and produced its usual inelegant noises – I certainly found it funny – nothing wrong with a bit of schoolboy humour.

It is understandable that when you have a stoma, you could feel a little self-conscious about sex but I just reminded myself that the stoma is not my persona but just a bit of slightly more unusual anatomy which isn’t pinned onto my face. I don’t believe that it has changed who I am and therefore hasn’t changed the relationship I have with my husband.”

Helen,
Colostomy since 2007

2. Body Image

This chapter sets out to discuss some of the difficulties people have raised when trying to come to terms with a changed body.

'Body image' by most definitions has two elements. Firstly, there is the picture in your mind of how your body looks (its size, shape and appearance for example). Secondly there is what you believe, think and feel about your body. How you view your body has many influences including your culture, the media, fashion, age and wellbeing amongst others.

It is common for body image to change through the years, though this 'natural' change generally happens gradually and you adapt without really noticing. Stoma formation imposes big and sudden changes to body image, both physically and emotionally and therefore can have an impact sexually. The process of adjustment and acceptance often takes time, though of course is variable from person to person. Give yourself the time you need.

For some people, regardless of the reason for their stoma or whether their stoma is temporary or permanent, coming to terms with a changed body can be particularly overwhelming. There is no way to reliably predict who will struggle with body image changes and who will adjust easily. Openness and honesty about how you are feeling about the changes to your body is the key to finding a way forward.

Try to explain how you feel about your body now to your partner or supportive friend. It is possible that negative feelings that become strongly established can lead to depression or anxiety, affect your sense of identity, your participation in social activities and the way you behave towards those around you. Give them the best chance to understand and be there for you. It can be really hard for them too, watching the person they love in emotional distress.

Remember that your stoma care nurse is available to you and is well trained to support you while you adjust and recover. You can be assured that you are not the only person who ever felt this way or who needed emotional support. Stoma care nurses want to help you to heal, inside and out. If you would like your partner or a close friend to be present while you talk with your stoma care nurse, that will be fine. It is often really useful to have someone else listen in, to remind you of what was discussed and reinforce any advice you are given. It may also be useful to read Chapter 3, *Feelings and emotions*.

Some people find that seeking information from other sources is a great option. Some hospitals, support groups and associations have a 'buddy' scheme where you can be introduced to someone who has experienced the same surgery as you or who has overcome the same difficulties. Other people like to use websites, or read blogs and prefer the anonymity of this option. Again your stoma nurse can often advise on the best place to look. Please remember though that some websites do not offer research-based information (or good advice) and blogs are usually posts about someone else's opinion and may not be medically sound. Check with your health care team before taking any such 'advice'. ■

Hints and tips

Try not to avoid going to new places or seeing new people. Avoidance can reinforce the idea that you will be stared at and that you won't be able to manage. Perhaps start with a walk in the park, everyone is busy doing their own thing, they are not even looking in your direction and there are toilets there, just in case you need them. You've a high chance of a successful outing!

Rather than worry about someone being too curious, rehearse some one-line statements that you can use to deflect curiosity. Try look them in the eye, stand tall, smile and say something like 'I want to forget about that for now – let's talk about you'.

Remember what originally attracted your partner to you – it probably wasn't your tummy!

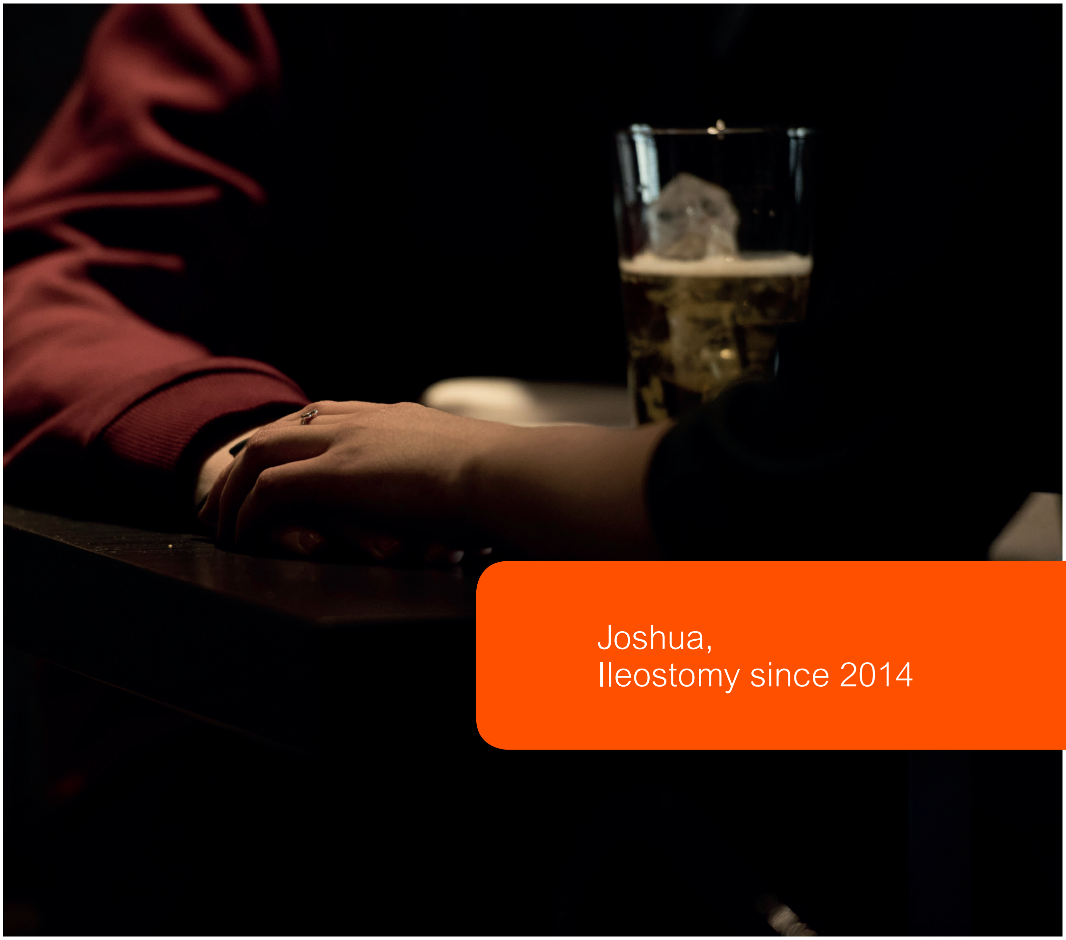
Consider what is positive about you and your appearance, say it out loud so that you hear it as well as think it.

Remember, if it is a positive feeling that you have, or a positive feeling that has slowly grown, perhaps your stoma comes to represent well-being and being rid of illness – it is good to share that too!

Elisabeth, Ileostomy

"I came home from hospital with an ileostomy. I wasn't expecting it. I had my one and only episode of Ulcervative Colitis and was haemorrhaging. I had no choice but to have the surgery. I had a 6 month old and 3 year old and had no time to think about how I looked.

I describe myself as a coper. I was given the choice of reconstructive surgery (J. Pouch) but chose to keep my ileostomy as I was well, I can do everything and feel that I have a good quality of life. My husband has never made any issue over my stoma and I have had my ileostomy for 15 years now. It has never been an issue, he was more worried about my health. I am off to New Zealand this summer and recently started running. I plan on wearing a bikini to show off my new six-pack!"



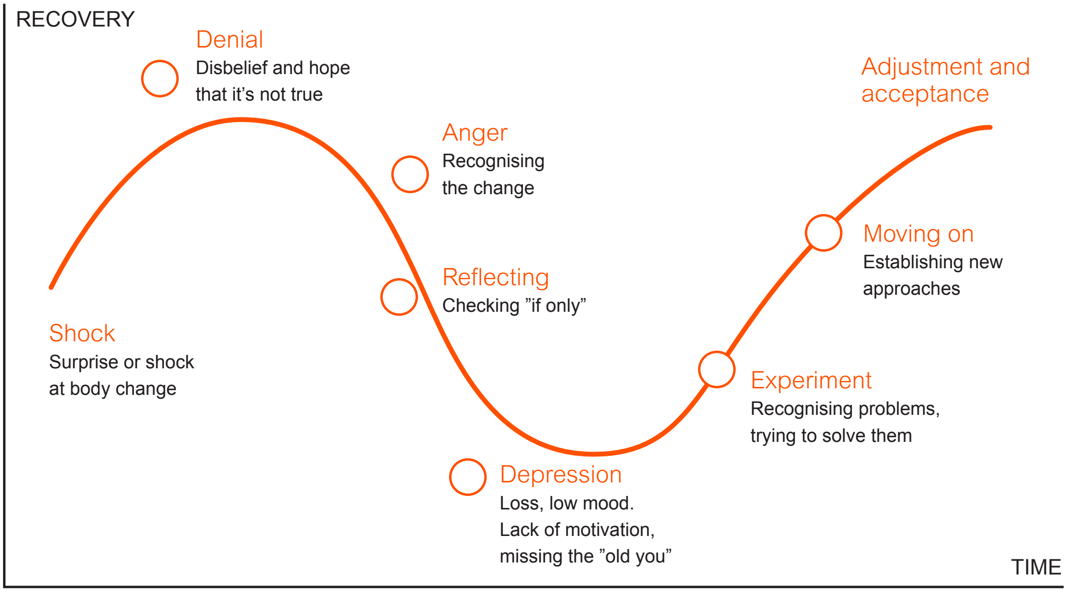
Joshua,
Ileostomy since 2014

3. Feelings and emotions

Bewilderment and loss

For many people who have stoma surgery, a long and healthy life lies ahead. Despite this, a deep sense of grief can be present after stoma surgery. This loss can be multi-faceted and associated with 'loss' not only of a bodily function – the control of bowel movements, but potentially loss of the healthy person they used to be; loss of body image; loss of social life, loss of privacy, loss of ability to do what they did before. This is part of a grief process that can be very profound for some. It can feel like 'a complete loss of the life I used to live'.[7]

There are a number of stages to the process of coming to terms with grief and loss and these can happen in any order, moving back and forth in waves, gradually moving nearer to adjustment and acceptance. Knowing about the stages of grief can help you to understand your feelings and emotions and to recognise waves of grief when you are suddenly having a bad day, after a period of doing well.



Based on seminal work by Kubler Ross 8 & 9

Like other losses you may have experienced in life, you can overcome this, one step at a time, with support along the way.

Anger

Many people suffering illness experience anger at some point. Some people are angry with the disease, asking questions like 'Why me?' It can feel unfair and undeserved for you and for family and friends who are possibly suffering alongside you. This is a natural part of the grieving process and of adjustment, it can give strength and help you to realise that something is bothering you and help you to find a solution. It can also help you to fight your illness, to be determined, or to help you to tell others what is bothering you.

Anger however can turn into a very negative emotion when it stops you thinking clearly, simmers away constantly – taking up energy that could be better used, or leads to aggression aimed at those who have no responsibility for triggering the anger[10]. This anger is no longer useful and can damage relationships. Taking steps to manage this unhelpful anger is important.

Talking through your ”anger triggers” with someone who knows you well is a great place to start. Are there lessons to be learned, is there something you need to change? Take constructive action. Find a way to diffuse this anger – through physical exercise, or deep breathing or relaxation exercises. Take a look at *www.mentalhealth.org.uk* where relaxation exercises can be downloaded. Try not to let your partner have all of your anger, just because they are ‘there’. This only adds to any sexual complications.

Worry, fear and anxiety

Worry about illness returning is a common theme reported by patients. Sadly this worry may be a very real possibility for some. Facing an uncertain future is hard. Worry about what is to come, or of the unknown, can be a big trigger for stress as loss of confidence plays its part. It can feel utterly consuming and you may find yourself withdrawing from the very people who love you the most and who can help you the best, your partner, family and friends.

As always, talk. Talk to your partner, your friend, your surgeon, your oncologist, your stoma care nurse, or your GP about your fears. Not knowing what to look out for or what to expect can lead to feelings that are very difficult to deal with and can build up to become persistent fear and anxiety.

As you leave hospital, there are so many new experiences to be faced for the first time, with your stoma as company. Feeling fearful and anxious is common when there is a sudden and major change from what has been previously ‘normal’. Fear and anxiety can have an impact not only on how you feel but on how you think, your ability to get on with day-to-day life, how your body behaves and how you relate to others.

Fear, when it is sudden, for instance in response to a threat such as an angry dog attack, releases a burst of adrenaline into the body, a chemical sometimes referred to as the ‘fight or flight’ hormone. It raises the heart rate, gives a surge of energy and helps to either run away from a dog or to fight off the dog. It is designed to keep us safe.

When this same hormonal response is released for a long time because of constant anxiety and there is no end to the feeling of ‘threat’, it can feel dreadful. The heart rate stays high, sometimes feeling like palpitations, the shakes develop, there may be light-headedness, lack of concentration and a feeling of unrest as that energy surge has nowhere to go. It can also trigger a short temper and snappiness with others close at hand.

Apply fear, anxiety and adrenaline to sexual rehabilitation and it is easy to see how you can end up feeling ‘dreadful’. It can spark arguments (fight), blocking intimacy and pleasure seeking, self-confidence and of course, sexual warmth. An additional risk is that the adrenaline surge will tempt you to withdraw from what you feel to be threatening situations and those who can help you (flight), to ‘hide’ and seek some kind of safety that way. This situation is not good for your sex life at all, especially if the ‘threat’ is sex itself.

High levels of anxiety and adrenaline in men can cause reduced libido (sex drive) and difficulty getting and maintaining an erection; women can also find it harder to have any sexual feelings of desire and vaginal lubrication may be reduced. This can lead people to believe that the surgery itself has caused ‘sexual dysfunction’, when actually it is the emotional response to the surgery which is causing the problem. Try not to assume this is a permanent situation. An unhappy outcome to lovemaking can further reduce confidence and create a downward spiral of frustration, sadness and more anxiety. If you can deal with the anxiety, you have a much greater chance of a good sexual experience.

If your anxiety is constant, or not improving over time, call your stoma care nurse or GP. Medication can help and there are often counsellors and psychologists attached to your GP surgery or your health care team who can help you to move forward. Try and keep an open mind about this. They are a great resource and can offer strategies to help you manage your emotions. This is a positive step. Please remember that. ■

Hints and tips

Share your feelings…talk if you can, or write them down. Writing down your feelings gives you something to look back on over time, so you can see how you have progressed or perhaps use them to support someone else in the future.

If you are feeling depressed every day, with fewer or no good days, seek help. If you do nothing else, call your stoma care nurse and tell her, or ask a family member to do it for you.

If you are very anxious about starting lovemaking again, share that with your partner. Together try and work out how you can make it easier, set small manageable goals and aim for achievable success.

If you have always shared a bed with your partner, try to stay in the same bed. There are some simple strategies that can help you to manage anxiety when you recognise it building up:

1. Cut back on caffeine in tea, coffee and soft drinks. Caffeine can contribute to and magnify feelings of anxiety.
2. Try relaxation exercises and practice them. Use the techniques before you expect to make love.
3. Adopt a message to yourself that you can say in your head to remind yourself that this feeling will only last a short time. ‘Relax, you’re fine’ or ‘I’m okay’ will do nicely.[10]
4. Communicate. Apologise if you have been hurtful and take steps not to let anger or anxiety lead to snappiness or aggression.
5. Take your time with lovemaking. If you know you are tense, explain to your partner and both of you make allowances. Try and keep the focus on pleasure giving and taking, rather than on ‘performance’. Hug, caress, reassure.
6 Try not to assume that a lost erection, or pain, or a lack of lubrication is a permanent state.

The mental health foundation has a number of excellent resources that might help, including podcasts. They can be found at *www.mentalhealth.org.uk*

Brenda, Ileostomy & Terence, Colostomy

”I (Brenda) had my stoma before meeting Terry, at first I worried a little that it might get ”in the way”. Terry was very understanding and probably worried about my stoma more than I did in the early days.

Since Terry had his stoma we just find it a source of amusement. It never gets in the way of a cuddle and keeps us close. We still live a full and active life and Terry has even moved in with me since his surgery.”

Brenda, Ileostomy since 2011
Terence, Colostomy since 2014

Joshua
Ileostomy since 2014

4. Relationships

This chapter sets out to explore the impact of relationship stress and some simple ideas that may help.

Relationships are complex, even in good health and everyday life, relationships are complex. Relationships are put under considerable strain when life is not straightforward or a crisis arises, when change is forced upon it, or when someone is ill. Illness can mean reduced household income, one partner absorbing the day to day chores and trying to continue with work, as well as being the emotional support for children and the 'patient'. Considerable strain for everyone can be the result.

Stress, worry, anger, anxiety and fear are not good for you, your partner relationships or sex life, as this can potentially affect your ability to relax, and impact your confidence, sexual desire (libido), and sexual function.

Dealing with stress in your relationship is important, it affects you both and like ripples in a pond, can touch others around you. Understanding the causes of your stress is necessary. You and your partner can work through this together, recognising that neither of you can fix a relationship under strain by yourself!

Try to talk through all of the things that are stressing you both. Writing them down is often advised because you can then go back and put them in order, the most stressful and pressing issue first, going down to the little niggles. You can then make a plan to tackle one or two of the big issues and perhaps one or two of the little niggles for starters (a quick 'win' is good for you). Remind each other that this exercise is not about criticism and stay focussed on improving things. Doing this together can really help not only to reduce the stress, but can bring you closer.

Acknowledging the stress you are each under and the effect it is having on your relationship, expressing gratitude for the support you each offer and making plans together are positive steps for intimacy and sexual recovery.

If you are single

Being single often means that you turn to family members or close friends to help with your long term recovery, the stresses of life, managing your household and your illness. Don't be afraid to ask and to take up offers of help – especially in the early days. There are no prizes for doing this all by yourself.

When it comes to your sexual recovery, this can be another stress all of its own. Chapter 1, ‘*Early expectations*’ talks about ‘the time to tell’ a potential new partner about your stoma – but there are ways that close friends can help you here too.

Good friends don’t exclude someone who is not able to do a particular activity – they change the activity. But they need to know what your ability is, your energy levels and your fitness – so they can choose wisely and by including you, help you grow your confidence and reconnect with ‘you’.

Adjusting to your body changes can be helped by showing your tummy to someone you trust (and is curious to see), so that when you show it to a new partner, it won’t be the first time you have ever done that.

Take your time with someone new, enjoy romance, affection, intimacy and foreplay. Communicate. There’s no rush to get naked!

There are physical changes for both men and women that may influence your sexual ability, comfort and pleasure. Being able to openly discuss those changes with a partner may reduce worry and increase understanding.

If you are concerned about your ability to get and keep your erection, or to be comfortably penetrated, then trying things out on your own first can be a good idea! Physical changes are further discussed in Chapter 7.

For everyone, whether you have a partner or not, it is often easier to talk about deeply private matters as you walk side-by-side with someone who you are close to, sharing what is on your mind. It’s also a good way to make space for hearing about their life and worries as well – it is healthy communication and support becomes mutual. Hopefully, you’ll also get some positive feedback about your progress – and if they don’t volunteer it, then ask for it! ■

Joseph, Ileostomy

”When I had my stoma I thought I’d never have sex again or even want anyone to touch me or look at me. It’s now the complete opposite I have more confidence and feel the most sexiest I have ever felt It’s changed my life and I’m never going to look back. My partner doesn’t even notice my bag while being intimate.”

5. Orientation

This chapter acknowledges some of the concerns faced by people who do not identify as heterosexual (straight).

As was discussed at the beginning of this book, we are all different from each other. Old or young, black or white, able or disabled, gay or straight, you are unique and your health care team know and understand that.

If you are transgendered, there is a fair chance that the team will know already, from your medical history and notes, but it is still recommended that you discuss your reassignment treatment and the gender of your partner, so that you can share any particular worries you may have.

What your health care team cannot know without you sharing it with them, is if you are gay or lesbian or bi-sexual or gender non-binary. They cannot know how your particular surgery is likely to worry you, or potentially change things for you sexually, without you telling them.

You are the expert on ‘you’ and health care professionals are often very glad if you can explain to them what it means to be ‘you’. If you can share, it means less assumption, less confusion and often, better experiences and outcomes.

Of course it is up to you what you share and who you share it with. Perhaps you are not ‘out’ at all, or perhaps are not ‘out’ to everyone. Perhaps you are just discovering your sexuality, or have a long term partnership or many lovers, you may identify as straight but have same sex lovers occasionally. Whatever your unique situation, your health care team just want to work with you as a partner in your own care; listen to your worries, support you and those important to you, and ensure that you have access to information relevant to your sexual identity and orientation.

Whatever your gender and whatever the gender of your partner, whether you define as gay or straight, this is important:

If receiving anal penetration has been an important part of your sex life, we would strongly encourage you to talk to your health care team about your future sexual activity, following bowel surgery. Above all, your stoma should not be penetrated nor should you ever push anything into your stoma as this can cause significant damage which may lead to further surgery. ■

Hints and tips

Try and help your health professional to help you by sharing your sexual orientation and worries with them.

Christopher, Ileostomy

”When telling people you have a stoma, I tell them that I have had bowel problems which has meant I need a stoma. You don’t need to worry about it or do anything with it. Fitness can help you to feel good about yourself as you grow in confidence and strength. Sharing this with someone who matters to you is a bonus.

Graham
Urostomy since 2014

6. Roles

This chapter is about sexual roles and how these may change following illness or injury.

Sexual roles are, like everything, influenced by many factors, but in partnership terms tend to settle into a pattern that works for this particular relationship.

Perhaps one person is always the one who reaches out to the other and starts a sexual encounter, or maybe you are both able to initiate sex. It may be that one partner is more active and one more passive during lovemaking, possibly one person suggests position changes or is more adventurous or creative than the other.

How it all happens varies from couple to couple, and sometimes from one time to the next. Initiation can happen perhaps by talking about it and agreeing, perhaps by making a ‘date’ in the diary, perhaps by routine ‘Saturday night’ sex, or maybe by giving clues, kissing and caressing and hoping for a positive response.

What happens next can be influenced by the roles taken in the general relationship, experience, personality and sometimes habit. They also often change with the length of the relationship, the age, health and physical ability of the individuals.

Roles can become fuzzy and uncertain when illness strikes and particularly when communication about sex is difficult.

If the person who does all the initiating gets ill or injured, they are not necessarily in a position to start things off. That doesn’t necessarily mean that they don’t want to be sexual.

Perhaps the person who is normally passive is simply unable to fill that now empty role – they have never practiced being the initiator and feel awkward and uncertain. That doesn’t necessarily mean that they don’t want to be sexual.

Changing roles can be really difficult. Many couples find it impossible to talk about their needs, to ask for what they want and at that point allow assumption and feelings of rejection to grow. Further to this, other changed roles such as not being able to work – to be ‘the breadwinner’ or for that matter, ‘the homemaker’ can erode sense of self and sexual identity. Equally it can be a direct journey from partner to patient, or lover to carer, or even a shift to a ‘parent and child’ type relationship – but a hard journey back to a mutually fulfilling sexual partnership.

There are people who can help. Psychosexual therapists are trained to help people to talk, to identify their needs, to learn to initiate sex – or to politely decline – to communicate and to practice. More information about psychosexual therapy can be found in the next chapter. ■

Steve, Colostomy

"My stoma was an emergency for Diverticular disease. It was a shock and following surgery my wounds broke down and needed dressings from the district nurses.

I managed my colostomy well from the beginning and found a stoma pouch that was more discrete than the one I had been discharged from hospital with. The stoma was not the issue. It was more the fact that I can only describe myself as becoming very needy. I have never been a person who needs someone and I really felt this need for care and compassion from my partner. She completely appreciates this and understands. Her support is invaluable."

Helen,
Colostomy since 2007

7. Sexual function and resuming an active sex life

This chapter discusses in **very direct language** the potential impact of stoma surgery on sexual function as well as some of the medications and resources available to both men and women.

Resuming an active sex life does not generally mean leaping into action with full penetrative intercourse the first week after your operation. In fact, this is absolutely not recommended – as gentle rehabilitation is usually required for even the most menial of tasks, such as making the bed in the first place!

Most surgeons will recommend a period of taking it easy, lasting about 6 weeks. By this time, you are likely to be moving more easily and more comfortably and at least beginning to resume your usual activities, hobbies and generally ‘finding yourself’ again.

What is clear is that there is no right time to resume intercourse! This is down to you, your relationship(s), how you feel, what sex meant to you before your surgery, your desired sex life now, all of those things we have mentioned in the other chapters. It is a very individual thing.

It is always suggested that talking with your sexual partner is very likely to help when it comes to ‘it’. Being worried about your partner and how they will react, about how your body will feel and respond, and about how your stoma/product will behave creates too much tension. Remember to talk and reduce that tension.

Talking about sex with your partner may not be something that you have ever done. If that is the case, then having to renegotiate your sex life or invent a new way of doing things can be really tricky. There is help out there if you simply cannot talk about it together. Your stoma care nurse may be able to help you, or may suggest a sex therapist referral. Psychosexual therapists are trained to help people negotiate difficulties in their sexual lives and relationships and that includes those caused by illness or injury. For some, this is just about talking it through once – with the therapist as a facilitator, while for others a programme of therapy is desirable.

There may be a psychosexual therapist in your local hospital or perhaps your stoma care nurse can advise. Alternatively, many RELATE centres have a psychosexual therapist to which you can self-refer. You can find RELATE in the Yellow pages or online at www.relate.org.uk where there is information on all the services they offer. You can find out more about psychosexual therapy at www.COSRT.org.uk which is one of the regulatory bodies of psychosexual therapists in the UK and they have a ‘find a therapist’ facility too.

Sexual confidence

‘Finding yourself’ again can start very soon after surgery, as energy levels allow. Getting back to the things that you are good at or that make you feel good is a great start. Dressing in your usual style, rather than to ‘hide’ your middle can go a long way to re-establishing your identity. Taking compliments (and even writing them down) is good too. Perhaps you have been chronically ill for a long time and having your stoma represents the end of a long road and the start of a new healthy you. Maybe you are only at the beginning of your journey and are facing other treatments, feeling depleted and constantly tired – do what you can to stay in touch with who you are, and who you will be again.

Sexual confidence is also helped by stoma confidence. There are many different stoma products on the market and some will suit you more than others. There are two piece, one piece, small and super discreet, opaque bags, covers for bags, wide belts etc. Find out, get samples and settle on the one that you are happiest with. If you are confident with the practical matters to do with your stoma, such as pouch security, capacity and bowel activity (or urine production for those with a urostomy) and take some simple steps (such as emptying or changing the bag before-hand), things are likely to be more relaxed.

It’s usually a good idea to negotiate and agree the first time you are going to ‘have sex’ or ‘make love’. You can make some practical preparations as well as set some goals and ground rules. It helps you both to be clear about what you expect to happen, what you are willing to try and what you are not going to try - and that can help reduce anxiety and boost confidence. Fatigue and loss of libido are common features in the early weeks and months. Remember that sex doesn’t have to be energetic, nor does it have to start with deep desire[11], perhaps it is possible to make some allowances. Negotiate tender, gentle, connected lovemaking.

Generally it is better to start slowly, holding each other, touching, kissing and caressing. Discover together if there are any altered sensations, numb skin patches, or if it hurts anywhere. You can ‘map’ each other’s bodies…where do you like to be touched, what do you like less – talk as you touch – it can work both ways and can be great fun! Grow your confidence and share the experience, as well as how you each feel about it. It is always better to set an easily achievable goal and be successful, than to have high expectations and suffer disappointment.

Build up slowly, keep talking to each other about what you want to achieve each time, think about positions and what is most likely to be physically comfortable and practical. When (or if) it comes to penetrative intercourse, think ahead. Stress can play a big negative role when you have intercourse for the first time. Stress alone can cause some men to struggle to get or keep their erection and women may need additional lubrication. Please remember that neither are necessarily permanent or due to changes caused by surgery. Try not to make assumptions. This is almost certainly not because your partner doesn't want to have sex with you. You can read more about stress in Chapter 4.

For women

Pain during penetrative intercourse is known as dyspareunia. This is the most commonly reported side effect for women following stoma surgery. It is thought to be caused by anatomical changes following surgery, reduced sexual desire and arousal, but is sometimes made worse by stress and reduced lubrication[12]. These problems often improve over time but meanwhile you can take some steps to help matters.

Firstly, talk to your partner about what you feel and keep them informed about your comfort levels. Try to manage your stress (read Chapter 4). Buy some lubricant and be ready to use it. There are many different lubricants – water based, silicone, or oil based and different colours, flavours and sensation. They are available in the supermarket, pharmacy and online. Some are available on prescription. (Oil based lube should not be used with latex condoms as it can reduce reliability. Silicone based lubes can cause deterioration of silicone dilators and sex toys).

For women who could experience orgasm before surgery, it is rarely damaged by surgery – though some drugs, particularly those for nerve pain or depression can stop or delay orgasm.

Some women choose to take a painkiller before intercourse, while others choose not to have penetrative sex until things are much more comfortable. If this is the case explain and find alternative pleasures with your partner.

Many women are offered vaginal dilators or vaginal 'trainers' following low bowel surgery or radiotherapy. They often come with a DVD or written instruction for use. The idea is to stop your vagina from becoming tight and scarred by treatment. Practicing with dilators can also be a good way to know how to relax and position yourself. If you are offered dilators, you do not have to accept them. Perhaps having penetrative intercourse is not one of your goals anyway – and of course there are other methods of checking out your vagina – using lubricated fingers or a sex toy, but start small!

If you have not been offered dilators, perhaps this is because your surgery comes with no risk to your vagina. It's ok to check that out with your stoma nurse – in fact, we encourage you to do so.

For men

Treatment options for erectile dysfunction.

Some men have problems with erection prior to their surgery, while others have problems caused by surgery. Either way, it may become desirable to have some treatment for erectile dysfunction.

The treatment options are many and varied and may include psychosexual therapy and / or tablets, injections, vacuum pumps, suppositories, creams and implants, depending on how motivated you are to restore your erection and which of the options is acceptable to you. The first step is to talk to your stoma care nurse, surgeon or GP.

Tablet treatment is not medically advisable for some men, but if it is safe to try, often GP's will start tablet treatment as a first step. There are erectile dysfunction clinics (sometimes known as andrology clinics) in most hospitals and this would be the likely next step if tablet treatment is not possible or doesn't have the desired outcome.

Remember that sex can be great without erection or penetration. Orgasm can usually be achieved with a soft penis as the nerve pathways for erection and orgasm are not the same. ■

Hints and tips

Fatigue and loss of libido are common after surgery. Take the time you need to recover or make allowances in your sex life.

Try body mapping. Take it in turns to allow your partner to touch your body from top to toe, front and back. Talk to each other about what feels nice – soft touch, kissing, blowing on the skin for instance, as well as what areas are less pleasant, sore or numb. Include the head and face in the exercise. Say what you like about your partner's body too. Revisit this exercise over time, to see if anything has changed.

You are usually encouraged to empty or change your bag before lovemaking. If you need to change your base plate, or if you are using a one piece bag, allow at least 30 minutes for a good seal to be achieved before commencing lovemaking. Minimise worry. Whilst it is not acceptable to everyone, trying things out on your own (masturbation) is often a good idea. When it comes to lovemaking, talk about what you want to do and what you don't want to do.

Talk to your partner about how things may be different and make a plan. Do you need to take a more passive role than usual? Do you need to consider alternative sexual positions? What else might be helpful to achieve a happy outcome?

Remember that 'lovemaking' doesn't have to mean 'intercourse'. Many people have very satisfying sex lives without penetration.

This is important;
If receiving anal penetration has been an important part of your sexual repertoire, we would strongly encourage you to talk to your health care team about your future sexual activity following bowel surgery. Above all, your stoma should not be penetrated nor should you ever push anything into your stoma as this can cause significant damage which may lead to further surgery.

Joshua, Ileostomy

”I don’t panic about being intimate anymore, with my pouch it’s like all that anxiety has disappeared!

Since having my surgery I am now in a relationship and have no problems with my pouch.”

Joshua,
Ileostomy since 2014

8. Reproduction and reproductive decisions

Reproduction and decisions about fertility preservation are discussed in this chapter.

Whatever your gender, it is really important to have a discussion with your health care team about the risks of your surgery on your sexual function and ability to have intercourse, and your fertility and ability to have children before your operation, if your family is not complete. The presence of a stoma should not, on its own, affect your fertility (ability to have a baby) but it remains strongly recommended that you have that discussion, so it is clear in your mind. If your surgery has already happened and you are not sure about your fertility status, it remains important to check, if it is a concern to you. Talk to your surgeon at your next consultation or ask your stoma care nurse for advice.

Patients having stoma formation for cancer may require additional therapies such as radiotherapy or chemotherapy as part of their whole treatment. At each stage in your care, you will be told about the side effects of each treatment and complete a consent form. You should at this time be told about any additional impact on your ability to have children, as well as about contraception whilst on treatment. Again, if you are unclear, go back and ask those questions. It may be that you've simply forgotten what you were told, it is a very chaotic time and there is only so much your brain can take in – health care professionals understand that and will be glad to go over things with you.

There will sadly be people whose families are not complete and whose fertility is likely to be at risk. For some people, illness can be managed and surgery postponed until later, when babies are born and families are complete. For others, particularly when dealing with cancer, treatment has to start very quickly.

The urgency to treat can rule out some fertility preservation options for women, as completing particular procedures can take a number of weeks, delaying cancer treatment too long. There are still some possibilities to be explored. Following discussion and agreement with your cancer care team, this is most likely to begin with an urgent referral to a specialist team at your local fertility clinic. These are sometimes known as 'assisted conception units'.

Fertility issues are not only experienced by women. Men undergoing stoma surgery, particularly those having surgery on the lower bowel, or having bladder and prostate removal with formation of urostomy will also be counselled regarding the possible impact on sexual function (ability to get and maintain an erection and to ejaculate) and fertility. Sperm storage or 'banking' can be an option and again this would usually require referral to the local fertility clinic or assisted conception unit.

More information regarding the options for both men and women can often be found on the website of your local fertility centre, or alternatively from the Human Fertilisation and Embryology Authority – along with statistics regarding successful pregnancy outcomes; www.hfea.gov.uk

Learning that you will no longer be able to have the family that you dreamed of or that there will be long term sexual consequences from your stoma surgery can be devastating. Your stoma care nurses want to help and to support you. Please talk to them so that they can help. ■

Hints and tips

Be clear about the risks to your fertility before each treatment.

If your treatment is over and you are unsure about your fertility, ask.

Allow your stoma nurses to support you. Talk to them about what this means to you.

9. What next?

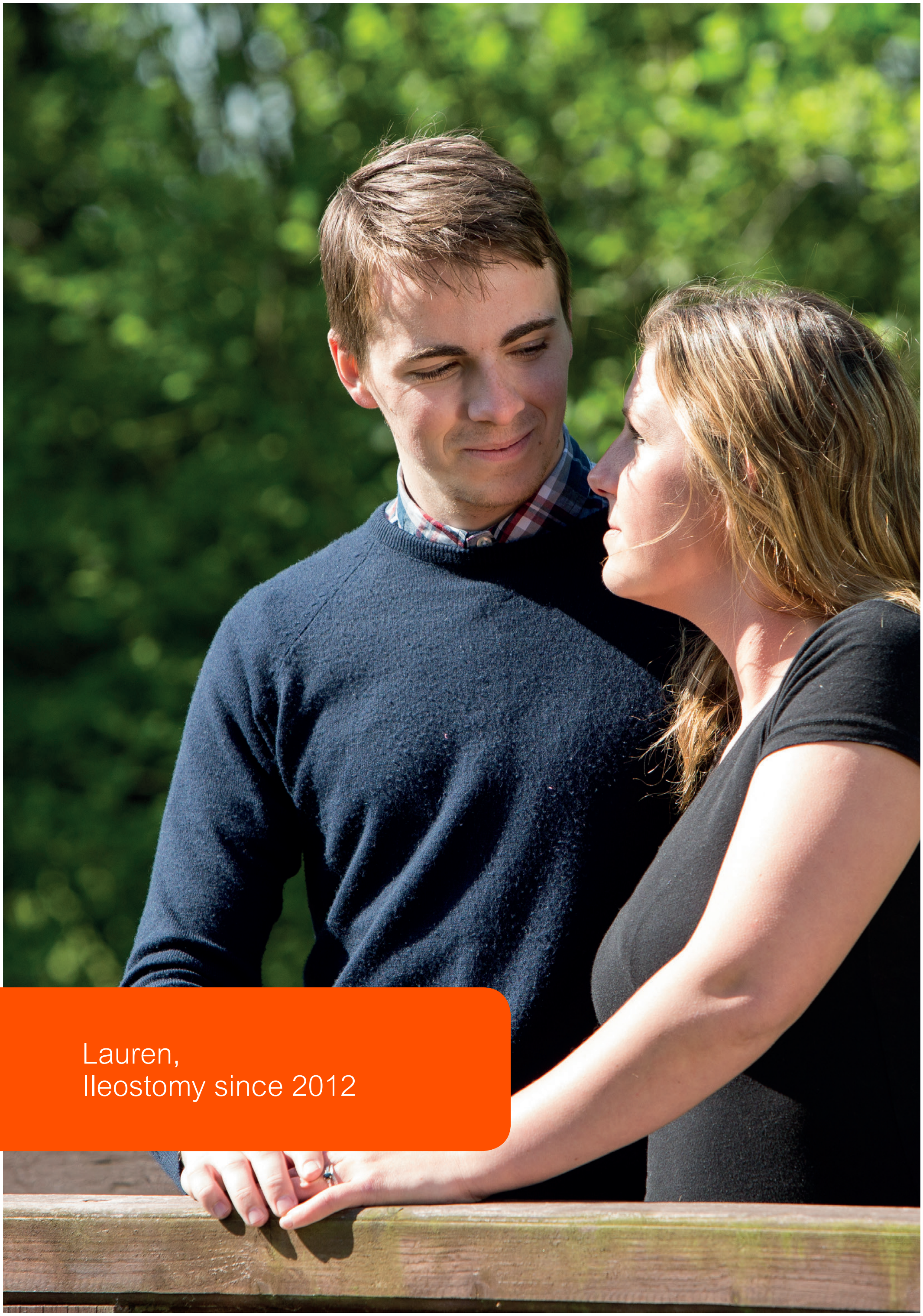
Despite everything that has been said, sexual worries are not inevitable.

Many people going through stoma formation recover sexually, in their own time, without additional support, or referral or therapy. They find their own way.

Some reinvent their sex lives, finding greater closeness, better communication, shared pleasures and more satisfaction. Others choose to let go of their sex lives and feel liberated and are glad.

If you do want to recover and are struggling to make progress in any aspect of your sexual rehabilitation, please talk to your stoma care nurse or one of your other health care team. They really do just want to help.

If you cannot find the words to start the conversation, tear off the slip at the back and hand it to the person you feel most comfortable with, and will help you best.



Lauren,
Ileostomy since 2012

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Links

DANSAC:
More patient education from your stoma care company. www.dansac.co.uk

The Lesbian & Gay Foundation – www.lgbt.foundation

Relate – www.relate.org.uk

College of Sex and Relationship Therapists – www.cosrt.org.uk

Human Fertility and Embryology Authority – www.hfea.gov.uk

The Sexual Advice Association:
Factsheets about sexual function and treatment options.
http://sexualadviceassociation.co.uk/factsheets/booklets/booklets-factsheets/

The Mental Health Foundation.
(Lots of resources for mental health and emotional well-being, + podcasts for relaxation) www.mentalhealth.org.uk

I am affected by sexual changes following my stoma surgery.

Please can we talk?

Name

Adress

Postcode City

Email

Phone

Privacy statement: Your privacy is important. Personal information (information that can identify you such as your name, address, telephone number, gender, age and personal health information) shared with your stoma care nurse may be used to help them contact you to talk. Your stoma care nurse will make every effort to keep your personal information private, confidential and secure and in accordance with all applicable privacy legislation.

Please consider using this tear section to start discussions with your Stoma Care Nurse or other chosen Health Care Professional.

Find more information:

www.dansac.com

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