



Living with a Stoma: Home & Work Life



Ostomy Care
Healthy skin. Positive outcomes.



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A glossary is included at the back of this booklet to help with terms you may not be familiar with.

Many people worry that their stoma will spoil relationships with the other people in their lives. Your loved ones, friends and colleagues are a vital part of your life. In fact, they can contribute significantly to your recovery from surgery and the return of your pre-surgery lifestyle.

We have created this booklet to help you and your family or significant other understand the changes from your surgery. Inside, you will find helpful information about the decisions you will make as you resume your personal and work life.



What to expect after surgery

One potential benefit of your surgery can be relief from uncomfortable symptoms or the feeling of weakness. Still, you will face new challenges, especially during the first weeks and months after the operation.

Plan to take it easy as you recuperate at home. It takes time to get back to feeling fit again. Don't expect to be back to normal immediately.

A certain amount of emotional stress is to be expected after surgery. When leaving the hospital, some find they are thinking and worrying about their stoma all of the time. For most people, this is a passing phase. It takes time to get used to the idea that you have a stoma. It may take months before these feelings pass. It is important to know you are in control of your pouch management.

During the first weeks and months, you will be learning about your stoma and how to manage your new pouch. You will not have to deal with this on your own. Your stoma care nurse will help you, and assistance is also available from the local support groups. Be sure to ask your healthcare professional for a list of contacts.

Getting used to managing your stoma may be a challenge. It is similar to riding a bike or driving a car — it's easy when you know how to do it, but frustrating when you are trying to learn.

The stoma

Your stoma will probably be swollen after surgery. It may take several weeks for the stoma to shrink to its permanent size. While stomas come in a variety of sizes and shapes, a healthy stoma:



- Is pink or red in colour and is slightly moist
- Is not painful
- Bleeds easily when rubbed or bumped (for example, when washing), but should resolve quickly. If the bleeding continues, contact your stoma care nurse or healthcare professional

Stoma output should empty into your pouch without leaking under the skin barrier. If the output from the stoma is bloody, you should contact your stoma care nurse.

Temporary stoma

If you have a temporary stoma, it may be loop or double barrel. A loop stoma may have a supporting device (called a rod, or bridge) usually removed after 5 days, (your Consultant Surgeon will decide). Be sure to remind your healthcare professional about this if it has not been removed by the time you leave hospital.

Healthy peristomal skin

The skin around the stoma is called the peristomal skin. Get into the habit of cleaning the peristomal skin each time you change your barrier. For most people, warm water is sufficient for cleaning.

The peristomal skin should be intact without irritation, rash, or redness.

It should look similar to the skin anywhere else on your body. A properly fitting skin barrier and the right barrier formulation helps protect the skin from being irritated by the stoma output.

If you discover red, broken, or moist skin around the stoma, seek the assistance of a stoma care nurse. Be sure to assess the peristomal skin on a regular basis to ensure the skin is healthy and to help address any issues in a timely manner.

Getting back to daily life

Soon after your surgery, you may feel the only thing that matters is that you have been ill and that you now have a stoma and pouch.

A stoma may place a few restrictions on what you can do. Once you have mastered the practical care of your stoma and the pouch — and this should not take long — it will become part of your daily routine.

Today's pouches are discreet and no one ever needs to know that you are wearing one. It is up to you to decide who you will tell and how you will go about it. If you have been very ill over a period of time, your friends, relatives, and co-workers are concerned about you. When they see you looking better, they will not only be pleased, but they may want to know what type of treatment you had. It is, of course, for you to determine what details you reveal to others.

It is natural to be concerned about what to say to other people. In general, if you feel uncomfortable, other people will too. Be open and honest with those people you think need to know and say nothing to others, unless you think it is important.



Involving people closest to you

Stoma surgery is considered to be major and is only done in cases of serious or life-threatening illness or following a serious injury. There is a good chance those close to you are aware of what you've been going through. For others, your need for an operation might be unexpected news.

The first thing you should talk about with those close to you — particularly those who live with you — is that although you are back home, you will not be back to normal right away and that recovery will take time. They will need to make allowances for this, and so will you. There is often no need for you to be limited because of your stoma. Take one step at a time, and let those closest to you know what you are aiming for.

You will need time on your own to change your pouch. At first, this may be time-consuming, so allow some extra time and space for yourself.

TIP

Remember that those around you will take cues from you. If you are comfortable, confident and straightforward about your health, people are generally accepting and unaffected.

Sharing pouch changing habits

Your stoma is part of your life. It is also part of your family's and your partner's life. Some people find it useful if their partner or a family member knows how to change and empty your pouch, in an emergency. Bringing those close to you into the details of your stoma care can be great for your relationship, and your peace of mind. Some things to review include:

- The pouch should be changed on a routine basis depending on your type of stoma and what works best for you
- Wear time is based on personal preference and stoma characteristics, your stoma care nurse will be able to provide support and guidance for this
- If your wear time becomes erratic or unpredictable, consult your stoma care nurse
- Pouch wear time may decrease during warmer seasons when you are perspiring more or during times of increased activity

- The best time to change the pouch is in the morning before you have had anything to eat or drink
- Prepare your new pouch before you remove your used pouch

TIP

If you experience leaks or skin irritation around your stoma you may need to consider trying a new skin barrier or pouch that better meets your needs. Be sure to seek the assistance of a stoma care nurse to get these issues resolved as soon as possible.



Questions from children

Young children may want to know why you had the operation and what has happened to you. This is something to think about before these questions are asked.

How much or little you decide to tell your children or grandchildren, and whether you decide to show your stoma to them, depends on the nature of your family as well as the age of the children. Honest and simple explanations are important, and they help form the basis of good relationships with younger family members.



Dealing with emotions

People with stoma surgery react with different emotions and responses. People express their feelings by talking with friends, family or others who have had similar experiences. Some find reading and learning about their situation works best for them.

Strong and intense emotions should not be kept to yourself. Get them out into the open, talk about them, and discuss them with your family. This may help you work through your feelings. If you are not making emotional progress and this is affecting your quality of life, then you should consider talking with your GP, healthcare professional or a support group. Your stoma care nurse may be the first to point out these issues and provide you the required information to start.

Telling relatives & friends

In addition to the people who live with you, other relatives, friends and neighbours may be concerned about you. There is no need to go into detail, unless you choose. But you will need to be prepared for the inevitable questions.

One way to satisfy their curiosity is to explain you had a serious illness that became a threat to your life. Because of that, you had major surgery and now wear a stoma pouch. With an explanation like that, there are very few other questions that can be asked unless you want to offer more information. If people see that you have adopted a straightforward attitude, they will very likely take their cue from you.

As the weeks and months go by, you may meet new people and make new friends who will not know and do not have to know anything about your stoma. There is one particular time when you will probably have to consider giving the full explanation about your stoma. That is, when you are contemplating a sexual relationship. Your stoma will be evident and you will want to be prepared to talk about it.



Returning to work

If you were working before your surgery, you will need to decide when you are ready to return to work. The time for this varies from person to person. The severity of the disease, the reason for your surgery, your recovery time, your age, and the type of job you do, all affect how long it will take you to get back to work. Talk to your healthcare professional about this.

There are, however, some important points to remember. If possible, don't rush back to work. Take your time. Going back before you are ready may cause more problems in the long run.

There are one or two other precautions you can take to help maintain your peace of mind. Carry a change of supplies with you in the car or in your work bag. Do not leave products in a car during heat or extreme cold. Also, keep a change of supplies in your desk drawer or locker at work.

Feeling tired can be a real problem, even months after your operation. If you are experiencing low energy, it may help to know that this can happen to almost anyone. If it is an option, you may want to return gradually, perhaps by working part-time before going back full-time.

As a general rule, you're ready to return to work if:

- You can empty your pouch without assistance**
- You are able to change your pouch without too much difficulty**
- You are confident you have enough energy to do a day's work**
- You feel comfortable about travelling to work**
- You know what to do if your pouch leaks and needs to be replaced in an emergency**



Your stoma in work situations

Some people wonder if a stoma will interfere with their work. If your job involves sitting at a desk all day, your stoma and pouch should present no problems.

For some who have had rectal surgery they may find sitting for extended periods to be problematic. The solution is to make sure you have a comfortable chair or a cushion. These problems with the perineal wound, to give its proper name, usually disappear within a few months should you be effected. If the discomfort does not improve, talk to a healthcare professional.

Bending and stretching

If you have a job that calls for a lot of bending and stretching, two useful things could help. First, wear a pouch that can be attached to a stoma belt while you are working for added security. Secondly, wear loose-fitting clothing and avoid constrictive belts and tight trousers. Seek advice from your stoma care nurse with regards to a suitable support belt.

Perspiration

If your job is fairly active, you may perspire at the area where the pouch is attached to the skin. This can be particularly frustrating because sweat and/or oily skin can reduce the effectiveness of the adhesive holding your pouch in place. You may need to change your pouch more often. An option is to use a skin barrier that copes better with perspiration. Your stoma care nurse or your supplier can provide recommendations.

With patience, perseverance, and a sense of realism, you can manage your stoma as part of a regular routine and lifestyle. It should not be an obstacle in your personal or professional life.

Resources and Organisations

Your healthcare professional and your stoma care nurse will be very important resources for you in the days ahead. You also have ongoing access to online information, or printed educational materials, at www.hollister.co.uk/en-gb/ostomycare/educationaltools such as:

- **The “Understanding Your Stoma” Booklet Series**
Provides information on lifestyle-related topics such as diet, travel, sports, and fitness
- **“Caring for Your Loved One with a Stoma” Booklet**
Provides information and support for your loved one(s), in helping you live life to the fullest after stoma surgery
- **“Routine Care of Your Stoma” Care Tip**
Provides information on how to care for a stoma
- **“Stoma Educational Theatre” Video Modules**
Provides an overview of stoma products, helping you to choose the products that are right for you and learn how to use them
- **“Living with a Stoma” Video Modules**
Provides insights from other people who have been through stoma surgery on how to lead full and productive lives

Stoma support groups are also available to individuals who have had stoma surgery. Here, you are able to interact with people who are facing many of the same challenges that you are. The ability to discuss issues with someone who understands what you are experiencing can be very beneficial.

Urostomy Association



Tel: 01386 430140

Email: info@urostomyassociation.org.uk

Web: www.urostomyassociation.org.uk

Colostomy UK



Admin line: 0118 939 1537

24 hour Helpline: 0800 328 4257

(Practical and emotional support)

Email: info@ColostomyUk.org

Web: www.colostomyuk.org

Ileostomy Association



Freephone: 0800 018 4724

Email: info@iasupport.org

Web: www.iasupport.org

Ileostomy & Internal Pouch
Association

Glossary

Colon

Another term for the large intestine or last portion of the gastrointestinal tract.

Colostomy

A stoma (surgical opening) created in the colon; part of the large intestine or colon.

Ileostomy

A stoma (surgical opening) created in the small intestine.

Perineal

The area between the anus and the genital area.

Peristomal Skin

The area around the stoma starting at the skin/stoma junction and extending outward to the area covered by the pouching system.

Pouch

The bag that collects output from the stoma.

Skin Barrier

The portion of your pouching system that fits immediately around your stoma. It protects your skin and holds the pouching system in place.

Stoma

A surgically created opening in the gastrointestinal or urinary tract. Also known as an ostomy.

Stool

Waste material from the bowel. Also known as a bowel movement.

Urostomy

A stoma (surgical opening) created to divert urine.

Wear time

The length of time a pouching system can be worn. Wear times can vary but should be fairly consistent for each person.

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