Lifestyle Series

Maintaining Personal & Professional Relationships with an Ostomy



Hollister

Attention to Detail. Attention to Life.



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Please note that this booklet is a supplement to and not a replacement for the advice from your healthcare professional.

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 resumption of your pre-surgery lifestyle.

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

A glossary at the end of this booklet briefly explains terms that you may not recognize.

After Surgery

One potential benefit of your surgery can be relief from uncomfortable symptoms or the feeling of weakness. Either way, 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 and is normal 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.

During the first weeks and months, you will be learning about your stoma and how to use your new pouch. You will not have to deal with this on your own. Your Stoma (Ostomy) Care Nurse will help you, and support is also available from the Stoma (Ostomy) Associations. Be sure to ask your nurse for a list of contacts.

Getting used to managing your stoma may be a challenge. It is something like riding a bike or driving a car – easy when you know how but frustrating when you are trying to learn.

You may have accidents and leakages early on; this happens to almost everyone with a new stoma. It is important to use the experience of an accidental leak as a learning experience for the next time. Leaks will happen less and less often as you learn to manage your stoma. If you have an ileostomy you will use an ileostomy pouch, one that is drainable. If you have a urostomy, you will use a pouch with a tap. If you have a colostomy, you will use a drainable or closed pouch depending on your needs or preference. For each type of stoma, there is a wide range of options from a number of manufacturers.

You will be given a pouch when you leave the hospital. Your Stoma Care Nurse can be a valuable resource if you would like to explore what pouches best suit your lifestyle.



Getting Back to "Normal"

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 – this will become part of your daily routine.

Today's pouches are discreet and no one ever needs to know that you are wearing one. In fact, unless you want to tell someone, they need not know that you have a stoma.

It is important 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 likely want to know what type of treatment you had. It is, of course, for you to decide what details you will 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 major and is only done for serious or life-threatening illnesses or following a serious injury. There is a good chance those close to you know or may have guessed that you had a serious problem. They most likely worried and suffered along with you through your illness and operation. For others, your need for an operation might be a real shock.

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. When you get home, you may find that a calmer time in the household will help you when you are changing your pouch. Make sure that everyone in your home knows that you could be in the bathroom for some time.

You will also want to identify the best time to change your pouch. Find a time when your stoma is not overactive. This is determined, to some extent, by when and what you have eaten and drank. Many people find that first thing in the morning is best, when the stoma is generally least active.

There is no “best” time for everyone. You will find what is right for you by trial and error.

When you change your pouch, you will need access to clean, warm water to wash the skin around your stoma. You will need a space to keep your supplies, and they should be kept in a dry, cool environment.

Your stoma is part of your life. It is also part of your family's and your partner's life too. Some people find it useful if their partner or a family member knows how to change and empty their pouch, in an emergency.

Questions from Children

Young children may ask questions. They 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. There are books and dolls available from ostomy manufacturers that are age appropriate to help with these questions.

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 bottled up. 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 seeking advice from a professional or 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

Beside from the people who live with you, other relatives, friends and neighbors also could be concerned about you. There is no need to go into detail, but you will want 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 an ostomy 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.

Actually, the need to go into even this much detail soon passes. 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 or marriage. In either case, your stoma will not remain invisible and you will want to be prepared to talk about it. There is a separate booklet in this series entitled, *Love and Sex for People with an Ostomy,* you may want to explore.



Returning to Work

If you were working before your surgery, there may come a time when you consider returning 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 doctor 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 really ready may cause you more problems in the long run. Think of the return to work as a series of steps to be taken one at a time.

1. You can empty your pouch without assistance
2. You are able to change your pouch without too much difficulty
3. You are confident you have enough energy to do a day's work
4. You feel comfortable about traveling to work
5. You know what to do if your pouch leaks and needs to be replaced in an emergency

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 handbag. 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 possible, you may want to start back at work gradually, perhaps by working part-time before going back full-time.

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.

Some of those who have had rectal surgery have rather sore or tender bottoms for some time after surgery, and sitting for extended periods may 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. If the discomfort does not improve, consult your doctor.

Lifting heavy weights is not recommended for the first 12 months or so after going back to work so you don't put undue strain on your healing body.

If you have a job that calls for a lot of bending and stretching, two useful things can 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.

If your job is fairly active, you may perspire at the area where the pouch is attached to the skin. This can be particularly annoying because sweat can reduce the effectiveness of the adhesive holding the pouch to your skin. 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 a manufacturer of stoma supplies can advise you.



Conclusion

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

Additional information: Please visit the Hollister website www.hollister.com or www.C3Life.com

Glossary

Colon – The large bowel (intestine).

Colostomy – A stoma opening into the large bowel.

Ileostomy – A stoma opening into the small bowel (intestine).

Ostomy/Stoma Association – An association or club for people with stomas.

Perineal – The area between the anus and the genital area.

Pouch – A specialized bag used to collect bodily wastes from the stoma.

Stoma – An artificial opening into the body, in this case, the digestive tract. From the Greek word meaning mouth or opening. Also known as an "ostomy."

Stoma Care Nurse – Also known as SCN, or ET (Enterostomal Therapy Nurse), STN (Stomal Therapy Nurse), WOCN/WOC (Wound Ostomy & Continence Nurse). This is a specially trained nurse with broad expertise for the care of people with stomas.

Urostomy – A urinary stoma. Also known as urinary diversion and often created as a (ileal) conduit.

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