

# Adjusting to Life with an Ostomy



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You have had major surgery. Now you have an ostomy. You will have many questions and wonder if life will ever be normal again. After people adapt to this change in their body, they go on to lead very active and productive lives. This booklet will give you information to help you understand some of your feelings and help you to become independent again.

Our health care team is here to help you through your time of change. We have a lot of experience helping people who have a new ostomy. We will teach you the things you need to know about taking care of your ostomy. We will support you while you work through your feelings about your ostomy. We will help you figure out what you need to change to get back to your normal life.

Adapting to your ostomy is a continuous process. It takes time. You will have some good days and some bad ones. This is okay. It is normal so expect to go through this. What is important to know is that adapting to your ostomy is a process and will happen eventually. With time, support and information, you will return to your normal life.

### **Awareness of Change - What happens now?**

We will help you get back to being independent. You will learn how to take care of your ostomy. We will help you learn to cope with the change in your body. You may not want to look at your ostomy. You may not like the smell. You may have many feelings and unanswered questions:

- Will people know I have an ostomy?
- Will it smell? How will I control the smell?
- How do I clean my ostomy?
- What about sex?
- Will I ever be able to leave the house again?

### **Changes: There will be changes!**

You are going through a major change in your life. Your concerns are normal. Your health care team is here to listen to your concerns. We will help you to learn the skills you need to take care of your ostomy and make it fit into your lifestyle.

When you go through this change, you will have many different feelings. If you were not prepared for the change, at first you are likely to feel shock. Shock protects us. It slows down the information that you take in about the change. You may feel numb. You may not feel connected to the things that are happening around you.



When you are in shock, you have difficulty making sense out of what is happening. We ask questions like: Why is this happening? Why me? When the shock decreases, we begin to experience other feelings that change things. Some of these are:

- Fear
- Embarrassment, shame, disgust
- Anger, rage
- Sadness

These feelings happen usually because you feel helpless and out of control. This is also a normal part of the change. When you got your ostomy, you did lose control of your:

• **Personal care**

Before your ostomy, you could have a shower, bath or wash yourself. Now you have to do these things with a pouch over your ostomy. Now, you must take care of your pouch when you do these activities.

• **Body functioning**

Before your ostomy, you did not have to think too much about passing urine or moving your bowels. Now you must give these activities your full attention until you get used to your ostomy and learn how to make it a part of your life. Sometimes you may feel anxious because of this new routine.

• **Body image**

You have your own style of dressing and presenting yourself to the world. You may enjoy physical activities. Now you need to adjust the way you dress and the way you join in physical activities to include your ostomy.

• **Loss of a part of your body**

You may have lost part of your bladder, bowel or rectum. Your body works differently now. Because your body has changed, how you see yourself and how you relate to yourself may change too.

**Your Initial Response - How will I react to my ostomy?**

You may adapt immediately, learning how to care for your ostomy and getting on with your life. However, most people take time to adjust to their new situation. For example, with an ostomy, you lose the ability to control gas. You may have started to grieve the loss of feeling normal and are unsure of the future. Here are some normal reactions:



- You may want to be alone and not with others
- You may get angry or resent others who do not have to go through this change
- You may become dependent on others to take care of you
- You may withdraw sometimes and lash out at other times
- You may deny, for a while, that your new ostomy will make a change in your life.

Being in denial is normal. At first this will protect you. But if you stay in denial for a long time, you will develop other problems. You may need the help of a counselor to work things out.

It is normal to respond like this when you are dealing with your feelings about your new ostomy. To adjust to your ostomy in the long term, you must recognize and express your feelings. Each person does this at his or her own pace. These feelings and how you deal with them are the beginning of the coping process. Coping will lead to adjusting to your ostomy.

### **Acknowledgement - Facing the Changes!**

Eventually, you will accept the changes in your body. You will feel more comfortable. When this happens, you will probably take more interest in caring for your ostomy. This will be something that is private to you and your health care professional.

Around this time, you may feel more comfortable talking about your concerns and worries about living with an ostomy.

- You may be afraid of other people being aware of your ostomy when you go out.
- You may be worried that your pouch will leak or burst.
- Perhaps intimacy with another will be difficult for you to consider now that your body has changed.
- You may wish to talk with a close friend, partner or health care professional.

As you gradually learn to accept your ostomy, it will become easier to figure out your own way of tackling problems. You will learn to cope in a way that works best for you. As you overcome obstacles, you will increase your confidence level.



## **Adaptation - Getting on with Life!**

Adapting to your new ostomy means that you have survived your losses. You have begun to adjust to the physical and social changes that happen because of your new ostomy. You move on with your life and begin to "take charge" of your ostomy. You will find that:

- You trust your skills and the equipment (e.g. emptying and changing the pouch on your own; the pouch staying on for a reasonable length of time)
- You care for your ostomy as part of your daily routine (e.g. carrying an extra pouching set with you when you are out; changing to a smaller pouch for such physical activities as swimming, sex, etc.)
- You pay attention to the new equipment instead of your internal body signs (e.g. looking and checking the pouch at times for seal and over-filling)
- You take steps towards getting back to your previous lifestyle (e.g. going back to work; going over to a friend's home; working out at a fitness club)
- You look for options and support when you have problems with your equipment
- You readily discuss your experiences with people you feel comfortable with, such as family or friends,
- You recognize that you are not alone (e.g. contacting an ostomy support group)
- You want to learn more about your ostomy and seek out information
- You accept yourself; you accept that you are still the same person with an ostomy; and you accept that you have the strength to adapt to the changes that come with having an ostomy

### **Remember:**

Adapting to your ostomy is a continuous process. You will take your own time. You will have good days and bad days. It will be okay. Learning to adapt to your ostomy is a process. With time, support and information you will return to your normal life.

**Where do I get more information or help if I need it?**

If you need more information or have other questions, talk to any one of your health care team. We are here to help you.

<b>Member of Health Care Team</b>	<b>Name</b>	<b>Phone number</b>
<b>Ostomy Therapist</b>	<b>Claudia Ganson</b>	
<b>Nurse</b>		
<b>Social Worker</b>		
<b>Dietitian</b>		

**Notes:**

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