

A BEND IN THE ROAD (Psychologically Coping with an Ostomy)

"A bend in the road is not the end of the road, if you remember to take the turn."

This phrase, and title of Joan Lunden's book of principles for dealing with change, characterises what it takes to adapt to change: a new perspective.

Having an ostomy requires not just a new lifestyle that incorporates changing an appliance or chewing food more carefully. It requires a new perspective of ourselves and the concept of wholeness.

Assumptions about Life

Our culture teaches us that we are entitled to certain things; health, wealth, beauty, fitness, comfort, pleasure and power. Some people learn early that, because of their skin colour, religious heritage, place of birth, or physical deformities or handicaps that they are not as privileged. But for many, we grow up with these assumptions that we are OK and nothing bad will happen to us.

When tragedy strikes for the first time, it brings all the trauma of a world-view shattered. Suddenly, all we grew to trust and assume is challenged. Perhaps I am vulnerable to pain, loss and discrimination. Grief is a multi-stage, multi-dimensional process that brings intense feelings and questions:

<i>Shock:</i>	<i>Numbness. Why me?</i>
<i>Denial:</i>	<i>It's not me. This is not happening.</i>
<i>Bargaining:</i>	<i>I'll try anything.</i>
<i>Anger:</i>	<i>If only the doctor was better. Blame family/job.</i>
<i>Depression:</i>	<i>I'm damaged goods. Nothing will be OK again.</i>
<i>Acceptance:</i>	<i>I'll do the best I can. Self-care.</i>

For people facing an ostomy, most have addressed these questions related to the illness that brought them to the point of surgery. Whether it was Crohn's, colitis, cancer or accident, something challenged the assumption of health and fitness. Living with illness reveals our vulnerability, facing possible death, dealing with loss of ability.

From a medical perspective, it is easy to say that an ostomy will help you to feel better and improve quality of life. For most people this is true. The pain and inconvenience of the disease will be gone. But while an ostomy can restore health and wellness to the physical body, how we cope psychologically will determine how well we recover from the trauma/illness/surgery/change.

Facing the Fears

An ostomy is a mixed blessing. It is a medical miracle that offers restored health and wellness, energy, activities. But it leaves a permanent scar and reminder of damage.

When someone (*or a loved one*) first faces ostomy surgery, there are medical fears and questions:

- "How bad will the pain be?"
- "What are the possible complications?"
- "How will I learn to use and change the appliance?"
- "How do I find a good surgeon?"

Fortunately, these questions can be easily answered by a Stomal Therapy Nurse. It is the emotionally based fears and questions that endure long after leaving the hospital.

Common Emotionally-based Fears

- Fear others not accepting the ostomy
- Being seen as damaged or defective
- Losing sexuality (*not attractive*)
- Fear of being "found out" (*odour, accident*)
- Fear of having to change (*clothing style, job, activities*)
- Fear being out of control

It is interesting to note that most of these emotional fears are really about how others will treat us.

The Key is in Your Attitude

"When we can no longer change a situation, we are challenged to change ourselves."
Victor Frankel.

How people face change and fear is somewhat determined by their personalities. It is extremely difficult, if not impossible, to go from a cantankerous, bitter, grumpy person to one who easily copes with pain and change with a positive spirit. But the more we know about ourselves and the more we are willing to be open to change, the better our resiliency and coping will be.

"The good news is that the bad news can be turned into good news when you change your attitude." Robert Schuller.

Psychologists have developed numerous theories to describe how our thoughts/emotions/actions are interrelated to one another. A change in any part of the system automatically influences change in the other areas. If one focuses on the emotionally based fears listed above, life will be a miserable experience. But, if we can think positively and take care of ourselves positively, the positive emotions of acceptance will come.

We all know that a positive attitude is a good thing. But in times of change and transition, it can be critical. Emotional and physical healing is enhanced when one thinks positively. Research on brain chemicals and cognition levels reveals that positive thoughts release endorphins (*like those released during a "runner's high"*) while negative thoughts release the chemicals seen during major depressive episodes. Positive thinking alone can't pull someone out of a major depressive episode, but for many, a daily dose of positive thinking can get us through a lot of stress.

"Every adversity, every failure, and every heartbreak carries with it the seed of an equivalent or greater benefit." Napoleon Hill.

The trick is finding the seed, the truth of potential benefit in the midst of the pain. Here are some truths to focus on:

1. An ostomy is part of you. Like having brown hair. It is part of your body. Not an illness, not a condition. It is part of your state of being. It may have resulted from illness or disease, but it is now a physical part of you.
2. You have control over what you tell and how. This process will allow you to tell others, as you feel comfortable. You must figure out how to handle people who can't accept you now.
3. No one wants to face "an infirmity" and having an ostomy is a visible, yet hidden one. Your body is no longer intact. If you think of yourself this way, others will, too. But if you see yourself as a whole person, others will see you that way.

4. You can't change others. Whether they accept your ostomy or deny that you have a problem at all, you can't change them. Learning to accept yourself is the key.

"No one can make you feel inferior without your consent". Eleanor Roosevelt.

Look Through the Eyes of Others

We have the tendency to think all eyes are on us. In reality, people don't notice that much. Surprisingly, we are usually much more tolerant of others than we think they are of us.

A little selfishness is OK. You can't take care of everyone else's emotions. You are the one doing the most adjusting. You must determine what you need, ask for it, and find ways to get your needs met.

Don't Take Blame

Others who might not understand may think you could have done something to prevent your condition. "If you had eaten right, gone to the doctor sooner, taken better care of yourself . . ."

Inspiring Words

Allowing ourselves to face the emotional/psychological aspects of coping with an ostomy is critical to a healthy adjustment. It is more than just a surgical procedure to change the plumbing. Each person experiences a range of fears, concerns, even panic about how this surgery will affect their relationships with others.

Sometimes, other people will not be able to join us in accepting the change. The reality is that some marriages have broken up, relationships become strained, friendships change after an ostomy surgery. But your ability to set a positive tone may help them to cope more positively as well.

Search for strength and inspiration wherever you can. If your friends and family can't provide it, search elsewhere. But find the positive energy that can help you heal. I hope these words may encourage you.

"Don't give up. Keep going. There is always a chance that you will stumble into something terrific. I have never heard of anyone stumbling over anything while he was sitting down." Ann Landers.

"Nothing can stop a man with the right mental attitude from achieving his goal: nothing on earth can help the man with the wrong mental attitude." Thomas Jefferson. (This goes for women as well).

"You gain strength, courage and confidence by every experience in which you really stop to look fear in the face. You must do the things you think you cannot do." Eleanor Roosevelt.

"All things are possible when you make them so." Goethe.

References:

Lunden, Joan & Cagan, Andrea (1998). A Bend in the Road is Not the End of the Road: 10 Positive Principles for Dealing with Change. William Morrow & Co. New York. NY.

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