

Riding the emotional roller coaster 2: Ongoing distress

"I feel like everyone thinks I am back to normal. They have no idea that this is so far from the truth".

While not everyone experiences ongoing distress, research shows that many women do. After the initial shock of your diagnosis, you may find that your feelings change. Earlier feelings of panic and fear may shift to a deeper or more persistent sense of depression, anxiety or loss. These emotions may occur during your treatment, or when treatment has finished. At this time you may also be struggling to come to terms with changes in your body, and in your sense of yourself.

It is important to avoid telling yourself: "I should be able to cope". Experiencing distress is not a sign of weakness, or a failure to "be positive". Everyone needs support during difficult times. If you find that you are experiencing difficulty, you may find talking to someone helpful. If your family or friends are unable to provide you with the help you need, consider seeking professional support. Talk to your treatment team. Your well-being is their concern.

Depression

It is not unusual to feel sad after your diagnosis, during your treatment, or after your treatment. Some women, however, find that their low mood becomes hard to shake off. If your mood has been low most of the time for a few weeks, you may be experiencing depression.

- Depression does **not** mean that you are weak
- Depression does **not** mean that you are lazy.
- Depression does **not** mean that you are deliberately being morbid.

One in four women, even without a cancer diagnosis, are affected by depression at some time in their lives. In the past, you may have experienced bouts of depression yourself, or have been diagnosed with cancer whilst you were already depressed. For some women, depression may occur for the first time after their diagnosis. Depression is different from sadness. Depression feels impossible to shake off, and your enjoyment of things becomes seriously diminished. It feels very hard to be

hopeful. Here are some common symptoms of depression. These symptoms can range from mild to severe.

MOOD SYMPTOMS (Feelings)

- Continuous low mood (some women say it feels like "a black cloud")
- Irritability
- Feeling a sense of hopelessness about the future
- Feeling lonely or isolated
- Feeling helpless
- Feeling worthless
- Feeling guilty
- Feeling stupid

MIND SYMPTOMS (Thinking)

- Finding it hard to concentrate or make decisions
- Forgetting things and having lapses of memory
- Gloomy thoughts or suicidal thoughts.

Note: If you are feeling suicidal, seek help straight away from your GP or call Lifeline on 131 114.

PHYSICAL SYMPTOMS

- Low energy or tiredness
- Problems getting to sleep or staying asleep
- Sleeping more than you used to
- Changes in your appetite
- Feeling sluggish

Note: Some of these symptoms may be the result of your treatment (talk to your treating team or GP).

LEADING TO

- Difficulty in carrying out everyday tasks
- Withdrawal from friends and social activities
- Difficulties at home and/or work
- Difficulty in finding pleasure in things you used to enjoy
- Finding it hard to care about anything

Factors that are thought to contribute to depression include:

- Having suffered from depression before
- Having no one to discuss things with
- Having lots of other concerns or difficulties to deal with at the same time
- Being treated with drugs that are known to be associated with depression

If you find yourself struggling with depression, remember that it is treatable. Try not to bottle things up. Talk to people who let you say how you really feel. Being depressed will not affect your cancer, but it will affect your quality of life. Seek help from your treatment team. Your GP might also be able to make recommendations. Being depressed is never a sign of weakness, and you are not being silly if you raise these issues with the professionals involved in your care.

While it is important that you find support to help you through depression, there are some things that you can do for yourself. When people become depressed, they often have no energy or motivation. As a result, they find themselves becoming less active. The less they do the worse they feel. Therefore, it is important to increase your activity level by planning simple daily activities. Discuss with your doctor what exercise would be most suitable for you. The following suggestions may also be helpful.

- Plan to do things with other people - they can help to motivate you when you do not feel like doing much.
- Accept invitations, even though you may not feel like it. Avoiding people means you have fewer people around you to show that they care.
- If you have difficulty getting out of bed in the morning, try making plans to meet someone in the morning. This helps you to get up and get moving.
- Don't forget to indulge yourself. Do at least one positive thing for yourself everyday.
- Try to do the things that were enjoyable, interesting, relaxing or satisfying before your cancer diagnosis, for example reading, watching movies, gardening, going to the beach or the park. Even if they don't give you as much pleasure now and you don't much feel like it, continuing to do them will help you.

Anxiety

Fear and anxiety are normal reactions to stressful situations. When you have been diagnosed with cancer, it is natural to worry about what will happen to you and your family. Sometimes the worry can be very intense and difficult to cope with. You may find that you can't concentrate, you are irritable and easily distracted, you sleep badly and get tired easily. These are often symptoms of anxiety. Other symptoms include:

- Sudden feelings of panic
- Feelings of dread
- Overbreathing (hyperventilation)
- Tense muscles
- Feelings of anger
- Phobias (for example fear of needles, or some other medical procedure)

Finding a balance between understandable worry, given your diagnosis of gynaecological cancer, and a level of anxiety that seriously undermines your quality of life, may need the help of a health professional. Friends and family can also help by allowing you to express your anxieties. Not talking about these tends to turn them into "monsters".

As you progress through treatment and beyond, you will probably notice certain times when your level of anxiety is high. Many women are surprised to find that they feel very anxious as treatment finishes. Even though you may have been looking forward to its end, not having the intense medical monitoring that occurs during treatment can be scary. It is also natural to feel anxious around the time of your check ups.

"I mean, you try not to, but you get an ache somewhere and you think - is it?"

A further ongoing anxiety for some women occurs when they experience odd aches and pains. It is natural to think first that the pain might indicate a return, or worsening, of the cancer. Often women find, when they think back, there is a less worrying explanation, such as over-doing the gardening, or carrying the shopping awkwardly.

"Knowing that anxiety is common in women diagnosed with gynaecological cancers did not make it less distressing for me, but it did help to reassure me that I was probably not crazy or weird."

Remember

- Anxiety does **not** mean that you are losing your mind
- Anxiety does **not** mean that you are being negative

There are various ways of dealing with anxiety. Some of the suggestions in the section on depression may be helpful. Relaxation and meditation can also be helpful. It is also important, if anxiety is an ongoing problem for you, that you mention your symptoms to your treatment team. They can work with you to develop stress-management techniques and helpful coping strategies.

Body image

"Your whole body feels foreign, everything feels different."

Body image refers to our beliefs and feelings about how we look in comparison to how we would like to look, not only to ourselves, but also to others. This image is a mental picture. It may not be drawn from what your body actually looks like, or how others see you, but rather how you think you look.

Before your cancer diagnosis you may have been very comfortable with how you looked. Often though, women wish they had a little less weight, or a little more weight, were taller, or shorter. The media, and common conceptions about what it is to be beautiful, influence how we feel about our bodies. Our moods can also play a major role in how comfortable we feel about ourselves.

Body image issues are common in all people who have been diagnosed with cancer. Often the loss of hair during chemotherapy, or scars following surgery, can make a person feel self-conscious. Hair loss can be particularly challenging as you are so used to seeing a different image of yourself in the mirror. Some women find they are shocked at how different they look, and this can take time to adjust to. You may feel awkward letting anyone see your scar, or not want to look at it yourself. You don't have to adjust to these changes in your body immediately. In time though, most

women find that once they decide not to hide these changes, they can begin the process of letting go of hurt, anger and regret.

In addition to the body image issues associated with cancer and its treatment in general, gynaecological cancer may involve the removal and alteration of some of a woman's most sensitive organs. They are associated with reproduction and sexuality, and historically have defined "woman". For many women, these parts of the body are intimately tied to their sense of being a woman. A woman's vagina, cervix, uterus, ovaries, vulva and labia are also hidden and private. They are rarely talked about, unlike breast cancer, which through tremendous advocacy on behalf of those who have the disease, is talked about quite publicly. It is not as easy to talk to others when your disease has affected the vulva or labia. The pain of actual loss, or loss of function of these body parts, can have a huge impact on how you feel about yourself.

Often, when body image becomes an issue for women with cancer, there is an underlying fear that the changes will make them less lovable or acceptable to others. If this is a fear of yours, talk to them about your fear, rather than letting the fear grow bigger and bigger. If this doesn't help, talk to a health professional. The following tips may also help:

- Make a list of 5 qualities you have that people who care about you probably like. For example your list might include: being loving, honest, funny, loyal.
 - Add to that, 5 more qualities that you like about yourself.
 - Next, list 5 physical features of yours that you like and why.
 - Then list 5 things you are grateful for.
 - Finally list 5 achievements that you are proud of.
- 1. Keep this list handy, and read it often.
- 2. Discuss with friends and family what "beauty" means to them.
- 3. Take the opportunity to define beauty in your own way.

Loss

We usually associate grief and loss with the death of someone we love. However, death is not the only event people experience as loss.

"In a sense, we lose something at each step of life's journey, the loss of people, places and objects we have come to cherish as we confront life's hard realities" (Neimeyer 1998).

A diagnosis of cancer can represent multiple losses. You probably imagined how things would be years from now, waiting for the day when the house was paid off, you had children, or your children grew up. Waiting till you could give up work or till your life was less stressful. Now you are faced with uncertainty about the future. Treatment may also have left you unable to have children. This can be devastating. Your sense of being in control of your life may be shaky right now, leaving you feeling vulnerable and sad.

The grief triggered by such losses can be made worse by well meaning friends and family. People may say, " You're alive, that's all that counts". They may trivialize your feelings, or try to cajole you into minimizing the effects of your losses. They usually think that this will help you not to dwell on your losses. Unfortunately, this can make you feel you have to keep your thoughts private, or that there is something wrong with you because at times you cannot see "how lucky you are". If we lived in a lucky world, no one would get cancer. Women who have been through what you are going through often say "I wouldn't wish this on my worst enemy". Your sense of loss is real. With support, and with time, the losses will become less painful.

Tell family and friends that it is helpful for you to talk about your sense of loss, if it is. If this is impossible, talking to others who have been through a similar experience can help. Ask your treatment team if they can put you in touch with a support group, or someone who has also been through gynaecological cancer. Seek the help of your treatment team or contact a local counsellor or psychologist if these feelings become too hard to bear.

If you have a stoma

If you now have a stoma, this can make acceptance of your changed body even harder. You may have lost, to some degree, the freedom you had before surgery. Most people find that going out takes a certain amount of organization and planning, and it not as easy to pop round to friends or go out for the day with a stoma. In time this will probably become more manageable, but it still represents a loss in your life. You also have to deal

with other people's reactions to it. This is particularly difficult and upsetting if your partner is finding it hard to accept. Like vulvas, generally, people don't talk about faecal matter. We know that everyone's body makes it from the day we are born, but is not visible from the outside.

Most women find that once they have sorted out the best appliance that suits them, and are able to manage them, life becomes more "normal". Remember that if you are hiding it from everyone, you are living in fear of discovery. Try to discuss your difficulties with those who are close to you. Seek advice from the Stomal Therapy Nurse attached to your treatment hospital, or ask for a referral from your GP.

The Australian Council of Stoma Associations publishes the national journal "Ostomy Australia" (available three times a year). <http://www.australianstoma.org.au> .

You can also contact:

Colostomy Association of NSW (Ph: (02) 9565 4315). Operating hours: Mon to Thurs 900am - 400pm, Fri 900am - 200pm

Ileostomy Association of NSW (Ph: (02) 9568 2799) Operating hours: Tue to Thurs 10 00am - 2 00pm