

Riding the emotional roller coaster 1: At diagnosis

A diagnosis of cancer can be a devastating experience. Nothing can prepare you for the moment when the doctor says "it's cancer". Common reactions to a cancer diagnosis include, shock, fear, denial, panic, anger, uncertainty and guilt. As distressing as these emotions are, they are normal reactions. Women often describe their experience as a "roller coaster of emotions". You may find there are times when you feel overwhelmed and afraid. You may also swing from feeling sad and tearful one minute, to feeling angry the next. These sudden changes of mood can make it very hard for you to predict how you are going to feel from day to day. They can also be hard for the people who care about you. It may be helpful to talk about how you feel with your family and friends, and suggest that they read this section too, so they can understand a little better.

Shock

"You go along thinking that you are immortal and thinking you know everything will go according to some sort of plan, and then you realise there isn't a plan, or there might be a plan, but you don't know it".

Shock is a natural response to an overwhelming event. Most women say they feel numb with shock when they are told they have cancer. They often say that after the "cancer" word, they didn't hear anything else the doctor said to them. It is not uncommon to find it hard to take in all the details. You may find that your mind feels blank for a while, and you have trouble remembering things. You may need to ask the same questions over and over again. Worrying about forgetting only makes it worse. Make lists and write down questions you want answered. When you go to doctors' appointments have someone go with you, if possible. Make notes, or get someone else to take notes, so you can go over the information again later.

Fear

Once you hear the word cancer spoken, and it's you they are talking about, it is natural to feel fear. Cancer is a frightening word. The first thing women often find themselves thinking is "Am I going to die?"

From there your thoughts might go to: "Will I be in pain?" "What will happen to my family?" "How will I manage?" Your mind will probably also be filled with 'what ifs?' "What if the doctors don't find all the cancer?" "What if the treatment doesn't work?" "What if I lose my hair?" "What if I have to give up work?" The more you let yourself worry about the things for which there is no answer yet, the more you will feel afraid. A wise woman once described fear as a:

F - Fantasy

E - Expectation

A - Appearing

R- Real

Remember, many patients with cancer are cured and others live for many years. And even when the cancer is not curable, things can be done to help with any pain or discomfort, or to slow the cancer down. The secret to controlling your fear is to take one step at a time. It is easy to become overwhelmed by your fears. Break your concerns into 'things to worry about today' and 'things to worry about later'. What can you do something about today? The following four questions may help you decide. Addressing the issues that you can do something about will help you regain control over your situation.

- What is urgent **and** important?
- What is urgent **but not** important?
- What is important **but not** urgent?
- What is **not** important and **not** urgent?

Denial

It's very hard to make sense of, I mean I am only 32, and I have always been fit. And how can you make sense of that? I have three small children; I'm just starting my life.

When faced with the shock of a cancer diagnosis you may cope by denying or downplaying the impact of your diagnosis. There are a number of reasons why this way of coping may work for you.

- The thought of cancer, its treatment, and its effect on you and/or your family may just be too much to cope with all at once
- You may feel it is important to "be positive" to the point of denying that you are worried and afraid.
- You may want to downplay the effect the diagnosis has had on you, or not tell some family members, to protect them from worrying about you.
- You may feel that talking about your cancer will only make things worse.

If any of these reasons fit your situation, let people know that, for the time being, you don't want to talk about your cancer. However, as understandable as denial is in the first few days, it is recommended that you talk about your feelings. Take a look at the section on talking about your cancer on this web site if you have difficulty expressing how you feel.

Panic

"I remember those early days and nights - you feel as if you are in a different dimension where you sometimes feel isolated and shaken".

Starting the cancer journey is like sailing into unknown territory. If this is your first diagnosis you probably don't know a lot about medical procedures such as surgery, chemotherapy and radiation. This can be very scary. With cancer your life may feel literally in the hands of your doctors. This loss of control, and your ability to predict what will happen, can lead to feelings of panic - a feeling that having cancer is more than you can bear. As understandable as this feeling is, it will pass. Symptoms of panic include feeling disoriented or light-headed, having heart palpitations, feeling nauseous, and feeling sweaty and clammy or cold and shivery.

To help yourself overcome your panic, make a note of what you have already overcome since the day of your diagnosis. Somehow you got through that day, and if you are undergoing treatment, somehow you are managing it. It certainly takes lots of strength, but you have already shown that you have that strength. Remember too, that you

don't have to do it alone. Let others help you, whether they are family and friends or health professionals.

Anger

"My carefully, lovingly created world around my home, my husband and family collapsed. Nothing seemed to have any significance any more. My God, I cried, why me, what have I done to deserve this? I was angry but I didn't know at what or at whom. And I was scared, so terribly scared".

It is natural to feel angry at times. Women often feel angry with their bodies for letting them down. They say they feel "betrayed" because they had no idea that their body was developing cancer. It is also quite normal to feel that "its not fair". For example, if you have been taking reasonable care of yourself, trying to eat healthily and taking some exercise, it can feel very unfair that you get cancer when others, who seem to be putting themselves at risk of disease, live to be 100. You may feel angry at the loss of control you feel over how your life will be in the future.

It is also common to feel anger with others. You may be feeling angry or frustrated with a family member or friend who you feel is not being as supportive or understanding as you would like. Trying to be super "positive" can also result in you feeling angry, as you try to put others' needs ahead of your own. There may be times when you feel angry with the health professionals involved in your treatment and care. If you don't understand something, ask again. One of the hardest things women face is that the doctors often can not give absolute assurance that once treatment is finished you will be cancer free. We still don't have a guaranteed cure for cancer. As a number of women have observed, "We can put men on the moon, why can't they cure cancer"?

If you have a religious faith you may even feel angry with God. "Why me?" is a common thought among people diagnosed with cancer, and it is important that you don't feel guilty about having these thoughts. As you progress through your treatments, you will probably meet other women, young and old, for whom it is also not fair that they have cancer.

When you are feeling angry, the support of others who have been through the same situation can be very important. Call the NSW Cancer Helpline (Ph: 131 120) for information about local groups, or speak to your healthcare team. It is also important that you tell those around you why you feel angry. If they are not being helpful, tell them what you need. If you want a cuddle, ask for one. If you don't feel like cooking, then don't. Let them know what you need to help make you feel better.

Uncertainty

"There is always uncertainty; I don't care what anybody says. At the back of your mind, no matter how positive you are, there is always a little bit of uncertainty".

Living with uncertainty about the future can be distressing and exhausting. Women find themselves going over in their minds all sorts of questions that cannot be answered at the time. Will the chemotherapy work? Will the cancer come back? Is that pain in my back related to the cancer - is it another cancer? You probably had no idea that you had cancer when it first began to develop. This can lead you to feel very vulnerable, and unable to predict what your body will do in the future. You may feel you can't trust your body anymore. Although, for many women, the uncertainty never goes away completely, you will find that, as you get further away from the actual diagnosis, these thoughts become less frequent and less distressing.

Guilt

"If I hadn't been so stressed in the last few years I wouldn't have got cancer".

When something unexpected and frightening happens, such as a cancer diagnosis, we often search for a reason. Knowing why something has happened can help us to feel less vulnerable. In this way, you may find yourself thinking that something you did or didn't do in the past was the "cause" of the cancer, no matter how unlikely that may be. It seems that a number of factors lead to the development of cancer. With gynaecological cancer, some women

feel that past sexual activities, or taking the pill, or not taking the pill, or having children, or not having children caused their cancer. In this way it is easy to blame yourself for your cancer. However, many other women did or didn't do the same things as you, and they didn't get cancer. Just as not all people who smoke get lung cancer. Having cancer does not mean that you are being punished for something. Cancer is a disease, not a judgement. Cancer does not discriminate between good people and bad people.

Many women often feel that if they had been less stressed as they juggled their lives and responsibilities they would not have developed cancer. Again, many people live incredibly stressful lives and don't get cancer. Some women blame others for their cancer. You may be angry with a partner or parent, or angry that your doctors did not find the cancer earlier. It is important to get over this period of guilt and blame as quickly as possible, so you can use your energies to work towards living well. Guilt and blame can also be symptoms of an underlying depression. If you find yourself stuck in a cycle of blame and guilt, seek support from family or friends to help you talk through these feelings. You can also talk through these feelings with the health professionals involved in your care or contact your local community health centre or Women's Health Centre to arrange local professional support, or call the NSW Cancer Helpline (Ph: 131 120) for details of local support.