

How are you feeling?

A guide to common responses to a diagnosis of cancer.

By Clare Crombie

If you are reading this, it is likely that you or someone close to you has recently been diagnosed with cancer. As you can imagine, there are as many different responses as there are people receiving the diagnosis. Any feelings you have are valid and deserve to be acknowledged, both by you and those around you.

It is not only the diagnosis that has caused you to feel the way you do. The context in which you find yourself also has a part to play in the way you have reacted to this news. We know who we are because of certain familiar beliefs, rules and norms. We learn these ways of reacting in our families of origin and in our culture and they are an important element in our sense of belonging. However, one of the challenges of difficult experiences is the way in which our normal patterns of behaviour, of thinking and managing our lives are threatened, or may not even work any more. This can lead to a kind of paralysis in our ability to think and deal with the situation. We can be afraid that we won't be able to cope. We can feel helpless and sometimes ashamed of that helplessness.

When people talk about not coping, they often mean that they have a fear of falling apart and not being able to put the pieces together again. It may be that the family took great pride in coping, in keeping going no matter what. This may indeed have been an important quality during times such as wartime, or during lean years when there wasn't enough money and yet children still had to be fed, cared for and educated. It can almost seem disloyal to the family if you feel unable to manage. You might feel that you, like them, must keep going and not feel, and certainly not admit to feeling, needy, vulnerable, lost, angry or confused. In many families, such feelings cannot be talked about or acknowledged in spite of the fact that we all feel like this from time to time, even if we don't tell anyone.

Most people find a cancer diagnosis very disturbing. Cancer is a potentially life threatening disease which carries a lot of fear in our society. Until recently the word was almost taboo. Often, doctors did not reveal the true diagnosis to the patient, while families did their best to keep up the charade in the mistaken belief that this was the best way to offer support. Now we are much more open and prepared to talk about cancer. Even so, families, friends and colleagues will be affected and you may worry about them and find that you are trying to protect them or not burden them. This can be one of the reasons for seeking counselling. People who see a counsellor often say that they feel relieved to talk to someone they don't need to worry about.

It can be a relief too to realise that your reactions are both appropriate and to be expected, very common and entirely understandable. We hope that in describing some of the ways you may respond, this fact sheet may be of use to you in coming

to terms with what is happening to you. We include some of the most common feelings, guided by our experience of listening to many people tell their stories. If you do not find your particular response, this is not because you are out of step but because we have not included it. We would be glad to hear from you if you think that something is missing.

Shock, Denial and Disbelief

Shock, denial and disbelief are natural reactions to events which threaten our normal coping mechanisms. A crisis is something which radically disturbs and upsets the everyday order of a person's life. A diagnosis of cancer does not necessarily have to result in a crisis, but if initial shock and trauma are not well enough supported, what starts as a period of stress can escalate into a crisis. When someone is emotionally and mentally overloaded the result can be likened to a computer system that crashes.

People in counselling sessions often talk about feelings and memories of previous traumatic or unfinished events that are restimulated by their cancer diagnosis. It's as if the shock forces open the door to a cupboard in which we have stuffed all the things we don't know what to do with! In response to the diagnosis, things start slipping and tumbling out. Try as we will we can't push the stuff back out of sight. Sometimes the only solution is to make the time to take everything out and sort it through, putting some things back and letting go of others.

If you were not feeling unwell at the time of your diagnosis it may be hard to believe that you have cancer. How can it be possible? However, if you have been ill or in pain for some time, and unable to find out what was wrong, there may be some relief at hearing that there is an explanation for your symptoms and a treatment plan.

If cancer is a word which you have never associated with yourself or your family, it can be difficult to believe that it can be happening to you. It may require a big adjustment in your sense of who you are. If, on the other hand, you have lived for years with a dread of cancer, the diagnosis when it came may have simply confirmed your worst fears.

This does not mean there will not still be shock. Whatever the circumstances around your illness, when the doctor tells you that you have cancer, it is very natural to feel shock or disbelief, or both, or to go into denial. The way in which you are told will also play its part in how much you are able to take in. Denial is sometimes a necessary and useful defence, in the first instance, when shock is too great and threatens our sense of safety. Given the right kind of support and encouragement, we can move out of that state in our own time and begin to take on board what is happening to us.

This is when we may need most support from those around us and is often the time that many people first seek counselling. The counselling process can give a valuable space to digest and make sense of what has happened, and to prepare for the next move.

In any case of shock, first aid is needed. People need to feel safe, (which may mean something different for each of us), they may need to take things slowly, or at least to feel in charge of the pace as far as possible, so that there's time for events to begin to sink in. Unfortunately, this need for space may coincide with a time when you are asked to make practical decisions and responses. If this is what is happening to you, especially in the medical context, allow yourself to do what is right for you, repeat questions if necessary, write things down. Have someone with you who knows what questions you want to ask and is willing to ask them for you. Make sure you understand what is being said, record consultations, in fact do anything which meets your needs. You may get ideas from people who have been through something similar, or you may want to find your own way.

We all respond to trauma and change in different ways. Some people want to talk and tell those close to them. Others want to stay quiet and let things sink in. You may want to make decisions on your own, or you may want to have input from family and friends before taking any action. You may need more medical information. There is no one right way. Gentleness and patience will help you find your way through, one step at a time.

Anger

Anger is frequently labelled a 'negative' emotion, by implication something bad. However, emotions themselves are neutral. They are like electricity. It is what we do with them that makes them seem negative or positive. Electricity can be used to kill, or it can be an essential part of life, providing heat or illuminating darkness.

Some of us feel afraid when we are angry and yet it is very understandable. Anger is a natural reaction to loss, particularly when we feel powerless, and cancer can bring with it many losses. Many people speak of loss of control. We may also lose our self image, body parts, income and career prospects, energy and sense of a future, to name but a few. As the person with cancer you will be dealing with your own losses, as they become evident. You may think "why me?" Meanwhile, relatives and friends will be reacting to your situation too. You may worry about them, or you may wish to distance yourself from their anxieties.

A positive way to look at your anger is to make use its energy to support yourself. Anger can be a powerful force for change and some people report that when they manage to harness it, it has helped them to become clearer about what they want and don't want in their lives. It can empower us to speak out assertively when we

need to make demands and requests. In the film *Analyze This*, Robert De Niro says "Anger is a blocked wish, what do you want?"

Anger seeks to be heard. As children we often learn to be ashamed or frightened of anger. It can be a liberating experience when we speak out rather than squashing down our angry feelings and eventually becoming depressed.

It takes energy to hold back strong feelings. This means that our energy is not freely available to us for other things and we can feel tired and heavy, perhaps hopeless and unmotivated. If you are holding in your feelings because you feel there is no one you can talk to or no one who wants to listen, counselling can be a useful first step towards doing something different.

Loss

Events involving loss and separation happen throughout our lives. Some happen to all of us and are a natural part of development. Often, because a change is seen as positive, we do not even recognise the loss involved. For example moving house, leaving home, getting a new job or retiring, the birth of a baby. We learn to keep quiet about the losses involved or even to hide them from ourselves.

The most obvious loss is death, the final separation, but serious illness brings losses right from the moment of diagnosis. People frequently speak in counselling about the loss of certainty, of control and autonomy, loss of trust in our bodies, of self esteem, of dreams and plans for the future, in fact the loss of ability to think of a future. These losses involve the patient and their relatives and friends in a process which is similar to bereavement, even when a full recovery takes place.

If the illness is terminal, loss and bereavement are experienced as ongoing processes, rather than something that starts only with death. This is known as anticipatory grieving and, when there is a long illness, can be part of the landscape of a family's existence for years. This puts a particular kind of strain on all family members and everyone needs support, which is not always readily available.

Fear and Uncertainty

Following a cancer diagnosis in themselves or in a friend or family member, most people feel fear. There is a school of thought which says that Western society lives in constant fear of death, whilst also working hard to keep its presence out of awareness. This causes a tension or anxiety sometimes referred to as death anxiety. Whatever we cannot see or talk about becomes more frightening and dreadful. Cancer breaks our rules and taboos by forcing us to confront the possibility of our own death, as well as making it more difficult to avoid talking about it. You may find that your fear lessens once you make the time to explore in a non judgmental way. You may discover that you are more afraid of the process of dying than of death

itself. Even though pain relief is now highly developed and effective there is still a lot of fear of pain associated with cancer. Most people acknowledge having fears of the loss of control and autonomy which come about because the treatment for cancer is often unavoidably invasive.

Those who have children may fear for them or for their partners and loved ones. As with anger, Western society tends not to approve of showing fear and as children we are taught few ways of dealing with it, apart from hiding it away. Although talking may not take the fear away, it can relieve it, bring it down to size and take the shame and dread out of it. Some parts of our fear lessen when we are given the appropriate information and can understand the forces we are up against.

Although we like to live as if we have certainty, in fact the only thing we can be certain of is uncertainty! Cancer brings this into the foreground and requires us to live it moment by moment. Finding ways to live as much as possible in the present may be the best approach, although this is of course easier said than done! Learning to meditate can be helpful as it teaches us simple ways to practise focusing on the here and now, and provides a balance to the worries and thoughts about past or future.

Blame

As humans we have a strong need to know why something has happened and perhaps to lay the blame at someone's door. We seem to feel more at ease in the world if we can separate things into right and wrong, us and them, good and bad. Randomness and inexplicable causes make us feel very anxious.

Although you may believe you can identify the cause of your illness, it is usually not that simple. Causes of cancer are many and doctors rarely know specifically what has caused yours. Even though you may feel at a loss without a clear explanation, blaming yourself is not helpful because it keeps you in the past rather than allowing you to see how you can best adapt to the present.

Resentment, Guilt and Communication

It is understandable to feel resentment at times when you have cancer, as will your family and friends. Sometimes we substitute guilt for resentment and criticise ourselves rather than telling a partner or friend what we are cross about. For instance you might be aware of feeling guilty that you have got out of touch with a friend. If you look a bit deeper you may realise how resentful you are that it is always you that seems to initiate talking about your cancer. With this awareness you might choose to tell your friend how you feel. Interestingly, you may then find out that she has been holding back because she thought that you didn't want to talk. Many misunderstandings can be cleared up when someone takes the first step.

It is nearly always helpful to bring these feelings out into the open, if you can find non-blaming, assertive ways to do so. If that feels impossible or inappropriate with the person concerned, you may find it helpful to talk it through with a counsellor or perhaps with someone who has had a similar experience to you.

Withdrawal and Isolation

Our need for closeness and contact varies. Most of us need to be alone at times, and we know when we want company or closeness. Sometimes these needs change when you are diagnosed, or during treatment. This is quite natural. It is helpful if you can recognise your changing needs. There is a lot to take in and digest. If you find yourself withdrawing a lot, you might decide to look for some new sources of support, for example from those who have shared similar experiences, perhaps a cancer support group, or in counselling.

Depression

Depression has been described as the best way to hold ourselves together when we feel as though we are falling apart. It is distinct from being unhappy, however terrible that may be. Dorothy Rowe says 'The experience of depression is that of knowing yourself to be utterly alone in a prison whose walls are as impenetrable as they are invisible. Inside that prison you have become your own worst enemy'. Many people who are depressed feel unable to maintain their usual social contacts and so end up feeling isolated and unsupported.

The word depression is used to describe a wide range of feelings from having no will to live to mild despondency. You may find yourself using it to describe times when you feel low in energy and are generally gloomy and unmotivated. If you have the chance to look at these feelings more closely, for example in counselling, you might find that you have stronger feelings than you've been prepared to admit to. Perhaps you are really very sad, or angry or even both.

We sometimes use the word depression when we know that we feel unhappy but don't know why. If you feel low or miserable, or if your doctor asks you if you are depressed, you may find it useful to think about whether there are any feelings that you have been denying or pushing down.

If you are particularly sad or low you may find the pressure to be positive or to get back to normal especially hard. People around you may imply that if you aren't positive you will jeopardise your recovery. Many people report that they hide or mask their true feelings thinking, "I must be strong for my family" or "Other people are worse off than me", or "Crying and being sad won't get me anywhere." These can be ways to stop ourselves and those close to us from knowing how much we are in pain. The energy it takes to keep the feelings down can make us feel even more

tired and weak and this only adds to our depression. The fear of what might happen if all the feelings burst out sometimes causes anxiety as well.

In order to understand what you mean by the word 'depression' it's important that you feel safe enough to begin to really look at your feelings, either on your own or perhaps in counselling.

If you feel depressed during or after chemotherapy, consult your doctor. If you are generally exhausted and low because of treatment, you will almost certainly feel emotionally low as well. In this case it can be that rest and recuperation are the main things that you need.

Finally, it is quite natural to feel depressed at some time during your cancer experience. As much as possible use your feelings to stay in touch with your needs. Feelings are pretty good indicators of what you need. Keep on finding ways to get these needs met, make sure you have support and be kind, tolerant, and friendly towards yourself whenever you can.

Attitudes to Death and Dying

Talking about death is still a taboo in many families. A surprising number of us do not make wills or think about how we would like to be cared for if we become sick. Many couples have found it too scary to discuss difficult subjects like care of children in the event of the death of one of them. We often fear that to do so would be to invite illness or death into the family, or at least would appear morbid or negative.

A diagnosis of cancer makes it much harder to avoid thinking of death and the implications of loss. If you are seriously ill you may worry that it is cruel or offensive to talk openly about dying, or about a future when you might no longer be there. And remember that your loyalty to your family 'rules' may not make it easy ever to talk about these subjects. And yet it is natural to need to discuss things openly with those close to you. The fear of seeming callous or of burdening or upsetting someone you love can lead to a situation where each person is isolated with their own fears and anxieties.

If you feel unable to share your fears and worries with the very people you would normally consult in times of trouble, remember that talking about death doesn't cause it, just as not talking will not prevent it. Many people have told us that they feel relieved when they have the courage to look at death, sometimes with a counsellor, and that a deeper strength then makes them more able to take charge of their life.

Children and Families

We frequently talk with people who are worried about how and when to talk to their children about illness, death and dying. We can send copies of useful reading material, as well as taking time to talk through this area with you, if you like.

Deciding how and what to tell your children is a very personal matter. Only the family members concerned will know what feels right. Even very young children have thoughts and feelings about illness and death. They need to feel that it's ok to bring their worries to adults, that they will be heard and will get clear and truthful responses. If they imagine that their worries and fears are too much for the adult, they may hold back and worry on their own. They will need reassurance that the illness is not their fault, that they could not have caused it and cannot make it better by changing themselves or their behaviour. Unfortunately children's feelings about loss often get buried. Adults sometimes like to believe that children are too young to understand, or that they need to be protected from feelings. Sometimes the children's feelings may be too disturbing for the adults!

Adolescents can find themselves in conflict. The illness of a parent makes it harder for them to separate and move on at the time when they are gaining independence. It's hard to find the balance between allowing space for the young person's grief and encouraging them to grasp life and move on.

We need to find appropriate ways to give children clear and coherent information, and respect their feelings as and when they arise, rather than keeping them in the dark about things that are affecting the family as a whole. Children and young adults pick up on atmospheres and changes in the family. If they are not given coherent explanations they will come up with their own, which can often be more frightening than the reality.

This doesn't mean that children have to be told everything, but they do need to have a story that makes sense. And it doesn't have to be a pain-free story. Children can deal with difficult feelings provided they are not left alone with them. Each family member needs to be listened to and valued. Family difficulties don't disappear because a major life event like cancer occurs. People don't suddenly become easy to get on with or more loveable because they are ill! We still have to negotiate all the usual complex dynamics within the family or network of friends.

Family members and friends of the person with cancer need to pay attention to getting enough support and space for themselves and getting their own needs met, otherwise there is a danger of burning out. This is one of the reasons that The Cancer Counselling Trust has always emphasised that counselling is available for anyone who has a cancer issue.

When your Treatment is Over

Most people talk of being surprised to find how difficult this time is. Hospital appointments provided a structure and purpose and suddenly that structure is no longer there. People feel very much on their own. Those around them may want them to be feeling on top of the world now the treatment is over. There can be an expectation to get back to 'normal' but most people who have been through an experience of cancer say that they feel totally changed and not at all 'normal' inside.

Sometimes there is pressure to get back to work before you really feel ready. You may feel guilty that you have had to ask for so much support from family and friends. Now that the treatment is over you thought you would be able to start giving back, and you may be surprised or disappointed if, like many people, you find this to be one of the hardest times. You may have looked forward to being able to move on from being a 'cancer patient', only to find that you feel as though the story is only just beginning. Your energy is probably still low, and feelings that have been on hold start needing attention. This is the point at which some people start making a radical revision of what they want to do with their life, questioning their work and stress levels and reviewing how they want to use their time.

It is not a sign of failure to feel that you need help when you finish treatment, in fact you will probably end up feeling stronger if you can accept your 'weakness' and allow the vulnerability that perhaps had to be kept at bay during the treatment to emerge. Taking time with a counsellor to make sense of the experience and make decisions about the future can be very useful at this stage.

The Chinese word for crisis contains characters for opportunity as well as danger. Many people have found that taking the opportunity to sort out that over full cupboard has led to life-enhancing decisions which would have been almost impossible to make without the stimulus of the crisis!