

MYTHS, MEANINGS AND RE-EVALUATIONS

EXPLORING COPING MECHANISMS IN ILLNESS

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- **Jane**

Jane is a 46 year old woman who has been admitted into hospital for a course of chemotherapy to treat lung cancer. Doctors suspect that she may have secondary deposits of cancer in her liver. While her long term prognosis is not good, they hope to halt the spread of the disease and relieve some physical pain. Jane had a radical mastectomy 4 years ago. She is divorced and has remarried, with 2 children from her first marriage aged 24 and 22, and 3 children from her second marriage aged 11, 9, and 4. She is a strong energetic woman, the family are heavily dependent upon her.

- **Robert**

Robert is an elderly gentleman who collapsed in Harborne High Street and was admitted onto a very busy medical ward. After seven days of tests, a Consultant Surgeon arrives to inform him that he has an inoperable tumour. He asks the Domestic to call for a Chaplain. He shares his story with great courage. His wife died forty years ago to leave him to bring up two young daughters. Twelve years ago one daughter died of cancer. Since then he has cared for his elderly mother who died earlier in the year aged ninety-two. He holds the Chaplain's hand and says calmly, "I'm not afraid of dying but I'm scared stiff of going home on my own - I'm absolutely alone".

- **Michael**

Michael is a divorced 34 year old who has been given a diagnosis of terminal cancer. He becomes more withdrawn and, although he is compliant with the ward routine, he refuses to engage with any offers to talk the matter through, however informally it is offered. The nursing team refer him to a Macmillan nurse. When she arrives, Michael says firmly, "I don't need you. I am getting better. Please go away".

- **Margaret**

Mrs Roberts is a 52 year old married woman with three grown-up children, aged 32, 28 and 27. She is a Deputy Headmistress at a local junior school and a leading light in the local amateur dramatics society. She had a hysterectomy two years ago and is in hospital for a course of chemotherapy to treat her cancer. Her prognosis is good. It takes the Staff Nurse two hours to take her details for the ward records because Margaret asks a whole series of questions about the symptoms of her cancer and the likelihood of her cure. She wants to know in precise detail the nature of chemotherapy and seems concerned, not with

whether the chemotherapy will be successful, but whether the cancer will come back after she has been cured. She also explores with the Staff Nurse the possibility of alternative therapy. As the Staff Nurse makes her excuses to leave Margaret asks, "Why has this happened to me?".

• Janet

Each morning Janet busies herself with setting her bedside cabinet in order and making the bed in her ward area. She then proceeds to help the Domestic with the tea and encourages each of the three patients in her area to get up and assists them in washing. She's busy, very active and always enthusiastic and optimistic. She is determined not to let the cancer get the better of her and her advice to her neighbours is, "Don't dwell on your illness - don't let it get you!".

We all assume that we are safe from threat and operate from an illusion of invulnerability. It is others who are victims of disease, crime and accidents. So when faced with a diagnosis of any sort that is catastrophic, people go through a complex process of re-evaluation and appraisal. This is described by psychologists as a person's Survival Schema. This re-evaluation is a process by which the individual selects, filters and interprets the information that they are hearing. A process of adjustment takes place as the individual takes a view of the diagnosis that is shared with them, gathers their perceptions about their own control in the light of that diagnosis and proceeds to work out what kind of life is possible in the light of the information that they are given. A patient's pattern of thought, feelings and behaviours associated with these re-evaluations represents a loose style of adjustment which they develop. This is a coping mechanism or an adjustment style.

Janet's adjustment style might be described as a fighting spirit. She sees the cancer as a challenge and attempts to exert control over all that it means to her. She seems to indicate that she is able to be optimistic in the light of all that has happened to her. For her it is a challenge to be overcome and she has gained as much possible information about the disease and aims to take an active role in recovering; but above all, attempt to live as normally as possible. Typical statements from others demonstrating this fighting spirit might be: "I don't dwell on my illness" or (as Janet says by her activity), "I'm not going to let this thing get the better of me". These people are the friends and neighbours that we have that seem never to allow themselves to be beaten by a cold or minor flu: they are often extraverts or organisers and the majority are women. It is hard not to admire the courage of someone who, faced with a life threatening diagnosis, responds with vigour and courage: "I'll beat it, I keep quite busy so I don't have to think about it". Janet's activity on the ward area caused immense frustration to the nurses but her 'therapy' was more effective to her fellow patients than any professional intervention.

The second adjustment style has been described as avoidance or denial. A typical example of this is a woman, who on introducing herself to a new staff nurse on surgical ward,

commented on her condition by saying, "they just cut off my breast as a precaution". There seems to be, here, a refusal to enter into the seriousness or the reality of the diagnosis. While this may be an appropriate response during the stage of coming to terms with illness, there are issues about patient autonomy and choice. How appropriate does the health care professional feel this particular coping mechanism to be? If a person chooses to get on with their life without thinking about the cancer, or indeed by denying it, then how should those around them respond? When is it right to challenge this kind of denial or avoidance? How good is it for one's deeper health to deny important reality?

The third coping mechanism is described as fatalism. Michael demonstrates this as he refuses any help and resigns himself to his diagnosis. It is clear to the nurse that his assertion "I am getting better" is not expressed with conviction but in the hope that it would keep the distance between the two. Michael sees (or chooses?) that he does not want to exert control over his diagnosis therefore the consequences of this lack of control are accepted at this stage of his journey. Of course this passive acceptance can take both positive and negative forms. To the Chaplain patients often say, rather negatively and passively: "it's all in the hands of God". More positively the patient might say, particularly if they are older "I've had a jolly good life, what's left is a bonus".

The fourth coping mechanism is described as helplessness and hopelessness. Both Robert and Michael reflect the sense of being overwhelmed and engulfed by the sheer enormity of cancer. Looking the facts in the face, how could it be otherwise? There is a terror about the brutality of this disease that numbs almost all normal activity. Often patients are unable to articulate their deep sense of existential pain and despair. The diagnosis is such an overwhelming threat and loss that no control can be exerted over the situation. The inevitable negative outcome is experienced as if it had already come about. It is as if some patients say: "there is nothing I can do to help myself". Some die before they die as they retreat into their despair and pain.

Margaret is a fair reflection of the fifth and final survival Schema which is described as anxious pre-occupation. Clearly the diagnosis here for Margaret is a major threat and she struggles with the considerable uncertainty about the possibility of exerting control over the situation which results in feelings of anxiety about the future. Some individuals cope by expressing a compulsive search for reassurance which takes various forms of anxiety. I once met a woman who had been re-admitted for some treatment after having had a diagnosis of cancer some ten years earlier. She said that she had worried every day for ten years that her cancer would come back and at times she had mild panic attacks as she searched for the symptoms to return. Some people may turn to complementary medicine for healing or demand of their religion and God an intervention to take the cancer away. In Margaret's case, her anxious preoccupation takes the form of an excessive desire for understanding and information. The question, "why has this happened to me?", is a common one and one often feared by many health care professionals.

Part of the task of the Pastor within her experience of the variety and diversity of people and groups coming to terms with illness, is to try and describe the world created by God as well as possible. In a sense we are answerable to him for the accuracy of our observations and the sense by which we interpret what we see and what we experience. With this in mind, it is important to continue to emphasise the complex and important interconnection between the physical and non-physical. That is to say, if health care professionals narrow the approach simply to the disease, the physical, then care will always be limited and limiting. This is where the concept of spiritual care is fundamental in the process of helping individuals and groups explore the myths, meanings and re-evaluations around their coping mechanisms in illness.

There is then an important distinction to make between spiritual needs and religious needs. There is a spiritual dimension independent of various conceptual interpretations of it. The picture that best helps me to understand this is that of 'the Well and the Cathedral'. The Well represents our shared human common stock of feelings. These are shared feelings and thoughts about life's meaning and purpose. The Well is the collective sense of humankind's striving for an understanding of who they are, where they are going and what life means. Some may never choose to address this dimension of their life; others are forced into it by crisis or illness. The Cathedral, then, is the physical expression, often of our own making, or shaping by society, that we choose to build to help us address the questions, feelings and thoughts in our 'wells'. So for some the Department Store or Shopping Centre may be the place that gives a sense of direction, meaning purpose and hope. Others may look for their community and their anaesthetic in the local public house. The escape of shared conversation over alcohol has long been an established habit within the community. Some people may find their sense of direction and purpose through sport, through a particular recreational pursuit or within the framework of marriage and the family. Others may, by choice or habit, find that some of these questions are addressed through faith, either in Christianity or a different religion. The point here is that spiritual and religious needs are connected but not necessarily the same. This area needs further work and exploration. Many of the aspects of coping mechanisms discussed here are spiritual, that is connected with the relevant human emotional responses, regardless of their being given a God or religious interpretation. Sometimes in the pastors' work they are very closely connected. It is worth further discussion if we ask what difference is made if a theological interpretation is given? Perhaps, sometimes, spiritual and religious needs are bound up together in one? It is worth reflecting on the fact that a range of reaction (for example, calm stoicism or resignation; hope in a better life; fear of divine judgement (rare now?)) are all part of the Christian tradition of interpretation of human experience.

Spiritual pain is a term that is often used to describe a specific form of disease in the dying. Some thought has been given to it within the context of the Hospice movement. All of our case studies above reflect a kind of living with the well, a spiritual pain, of people who are trying to make sense of their experience - struggling to come to terms with their fears of the unknown, anger, guilt or incomprehension. Within this context many people often ask where God is in their pain. Sometimes they want to know if it's clear that their

disease is terminal and what their dying will be like. Often there is curiosity about what exists beyond death. Some people simply feel pained at the lost opportunities in their life and want in some way to make amends build new relationships, live life as fully as possible in the present. What is clear to those involved in pastoral care is that this pain has a significant inter-connecting effect on physical pain and can take many forms: anxiety, fear, breathlessness and so on. The voices of illness in this chapter challenge us to recognise non-physical symptoms of disease: to understand the 'spiritual' as an integral pain of a human-being. For too often teams of health care professionals fail to work together for the patient. Spiritual disease is not recognised: it is often ignored or simply left for others to sort out. Carers too may well have their own spiritual questions from deep within their 'wells' to be answered and dealt with.

In the encounter with illness how should the pastor respond? How much realism is desirable and right morally, in Christian or other terms? Both prudence and Christianity may point in different directions, but the issue needs airing and attending to with care and sensitivity. The voices can be heard in different ways. The process of human communication is complex and fraught with difficulty. One key aspect of the process of coping lies in how the diagnosis is given, and in particular how information is shared. Many nurses have often had the experience of being present when the Doctor shares some difficult news with the patient, only to return later to realise that that information has been neither heard nor understood. This is understandably difficult. However, crucial to the person's recovery or the nature of their death is the way in which they understand the personal meaning of (in this case) cancer. The person who shares the information has a crucial effect upon how that construction of meaning takes place for the individual in the context of their family.

One of the feelings that undergirds voices here is a sense of loss of control. People feel helpless as they experience treatment as something 'done for you'; many patients adapt quickly to a passive role. Within this process of adaptation and coping there is often a search to make sense and to ask why. The questions and issues may be simple and a matter of understanding the treatment or knowing why they are taking particular forms of medication. If this search is undertaken unaided it may lead to confusion, misconceptions and fear. This is why knowledge is important because it gives confidence and control. The voices of illness, therefore, tell the health care professional to involve patients, wherever possible, in decision making. It asks that we think through what level of promotion of self-care is appropriate within the context of a home or hospital. Too often autonomy is taken away from the patient.

The other emotion experienced has often been described as feeling as if the person is 'riding on a roller-coaster'. Patients feel weepy, on edge, experience frustration, rage and annoyance which are all compounded by tiredness. The waiting and the delay in treatment and unexpected events can be very traumatic. The end of treatment can, therefore, be viewed with delight and fear. The journey back home can feel like a liberation and a new beginning For others the ward environment may be so secure and comforting that they

have anxiety about going home where there may be a lack of support and encouragement. These feelings within the voices of illness need reassurance and support. This can often take the practical form of good organisation, where investigations and results are co-ordinated quickly so that the patients are informed and their way forward is smoothed.

Another significant emotion underlying the voices, one that is often expressed non-verbally is that of isolation. The person feels isolated because of weakness, inability to write and the forgetfulness which reduces the ability of a patient to perform normal recreational pursuits. This isolation can always be reduced when there is an opportunity to talk, often quite

informally. Within this experience, patients best support one another within a ward or out-patient area because they understand what each is going through.

Common to all responses to chronic illness are the emotional reactions of anxiety, anger, guilt, sadness and depression. The pastor needs to know what underlies each of the emotions expressed. All of us feel anxious when we are conscious of danger or vulnerability. All physical impairment, disfigurement or invalidity are sources of threat and danger that give rise to anxiety. The danger is to offer reassurance too quickly and not to stay with the, sometimes impossible, ideal of taking this away. There is nothing that can be said that takes away a mother's preoccupation with her children, or a man's concern that his hospitalisation robs him of his nurturing role as the breadwinner for the family.

Individuals and communities will respond with anger when they suffer from a sense of unjustified attack. The personal domain of an individual is attacked by illness and therefore there may be questions about physical safety and self-esteem. This experience is an attack on the rules and values which a person holds very dear, as often there is a sense of the unjustness of a threat or of the effects of the threat on personal safety. Sometimes this finds expression by being focused on the doctor or nurse. People will want to ask: 'will the doctor be able to control the pain?' or 'will they really look after me however bad it gets?'. There is a sense here that an *agent*, either personal or impersonal, is abusing them. This anger might be expressed towards a spouse or the doctors or God. People might identify with other people's suffering or, indeed, project it out onto the organisation or institution. Angry patients are often non-compliant patients who disrupt the normal routine of the ward or GP's surgery. In part, they may be fighting to retain their dignity and autonomy as human agents.

Some research has suggested that patients who suppress anger and conform to the routine have a poor prognosis with malignant melanoma. It seems that within some cultures particular feelings are more socially acceptable than others; for example, sadness and fear may be acceptable but anger less so and more problematical. The voice of illness, therefore, might not be expressed in calm measured tones but have the energy, power and freedom of a scream of anger, all the more so for being repressed or resisted.

It is interesting to note the amount of guilt that under-girds some of the voices in illness and this has, at its base, a sense of self-blame. This is a very significant emotion both in people who have religious commitment and those who have none. Many believe that in some way, rationally or irrationally, the illness has happened as a result of some fault of their own making. In this process of apportioning blame, people more often than not blame themselves. Perhaps this is an obvious result of people wanting to understand why - to build up a sense of meaning in their illness. The question that they answer is: 'am I being punished? If they can find some way of expiating their sin, gaining control over it, then they might be able to overcome the guilt. Patients can often become fixated and it is not easy to help them move on. This takes the form: 'if only I hadn't done that I might not have become ill'. This line of thought may arise irrespective of there being elements of reasonableness behind it.

The reaction of sadness and depression is, of course, about a sense of loss or defeat. This best takes expression in the voice of Robert. There is a sense of loneliness and isolation, of separation from all that was valued as important and real. While some more extreme forms of depression can be treated, sometimes people can retreat into this loss and despair. There are people who find it impossible to articulate it and escape into sleep or silence.

There is then in the process of coming to terms with illness a re-evaluation of the myths and meaning about what their illness might mean. The pastoral and theological dimension is significant here. It can seem, from this perspective, that it is not the objective consequences of disease that are of prime importance but rather the way in which they are interpreted which determines a person's health and well-being. These reactions are often shaped by a variety of factors that lead to a number of different myths and meanings. Above all, what is clear is that a person's adjustment can be fundamentally changed by the kind of support that they are given.