

# A FAMILY'S EXPERIENCE OF COPING WITH MULTIPLE MYELOMA

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## ABSTRACT

*Multiple myeloma is a cancer of the red bone marrow that produces excess amounts of cloned plasma cells, osteolytic bone lesions, and the appearance of monoclonal proteins that may be found in the blood serum or urine. The aim of this article is to heighten awareness of this condition and provide some insight into the often aggressive nature of the disease within the context of end-of-life care. The narrative content portrays a vivid story of a dying mother, Susan, and how the family coped with the illness and impending death. The family had little time to come to terms with the diagnosis of cancer before Susan died. There is a definite need to increase understanding of the impact of this debilitating and incurable bone marrow cancer and to strengthen the evidence base for managing the disease in order to provide more supportive care. Conflict of interests: none*

## KEY WORDS

Coping strategies  
Dying  
Impact on family life  
Multiple myeloma  
Unrelenting disease

This article highlights an uncommon cancer that is relatively unknown within the context of end-of-life care. It presents a small part of an ongoing qualitative study that was commenced by the first author in October 2005 entitled 'Living with multiple myeloma: a study to explore patients' experiences and supportive care implications'. The aim of this article is to heighten awareness

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of multiple myeloma and provide some insight into the often aggressive nature of the disease. An illustrated account of multiple myeloma is followed by the background story of a mother who was diagnosed with this incurable bone marrow cancer. The names have been changed to maintain confidentiality of the patient, the informant and the family.

## Context

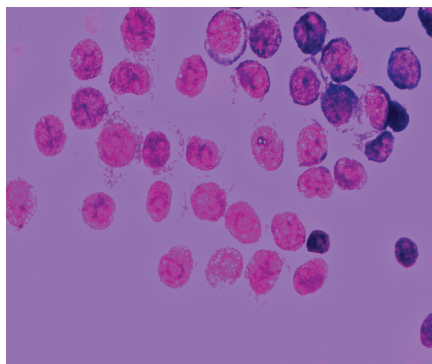
The narrative in this article describes the experiences of Marian, one of the family member respondents from the first author's ongoing qualitative study. She describes how her mother, Susan, became ill with an aggressive form of multiple myeloma and died within a few months of diagnosis. The interview was recorded and took place in a quiet room at the university 6 years after Susan's death.

The impetus for the qualitative study came from the first author's experience of working in a chemotherapy day care unit, treating patients with multiple myeloma participating in clinical trials. Ethical approval for the study was granted in August 2005 by the local research

ethics committee. The aim of the ongoing study is to explore: the meaning of living with multiple myeloma in terms of becoming ill and being diagnosed; the impact on the participant's personal or family life; the impact on other family members; the impact on the participant's professional or working life; and participants' perceptions of health care and supportive care services.

## Multiple myeloma

Multiple myeloma is a complex and diverse haematological malignancy that is poorly understood. It is cancer of the red bone marrow that produces excess amounts of cloned plasma cells (Figure 1), osteolytic bone lesions and the appearance of monoclonal proteins that may be seen in the blood or urine. Plasma cells normally produce antibodies called immunoglobulins (Igs). In multiple myeloma the cloned plasma cells (myeloma cells) produce monoclonal Igs that appear as a spike in the blood serum test called the M-band or paraprotein level. Normally there is only 1% of plasma cell content in the bone marrow. This increases to 30% and can be over 90% in multiple myeloma (Bradwell, 2003).



**Figure 1.** Bone marrow smear showing myeloma plasma cells (microscopic view). (Reproduced with permission.)

The invasion of myeloma cells (cloned plasma cells) means that the normal production of plasma cells is significantly decreased resulting in an immune system that becomes compromised leading to recurrent infections. It is unrelenting in its progression and the development of drug resistance is a major obstacle in curing the disease (Dalton, 2004).

There may be a pre-existing condition called monoclonal gammopathy of undetermined significance (MGUS), which means insignificant amounts of paraproteins are present in the absence of multiple myeloma. This can transform into multiple myeloma or other associated diseases such as lymphoma or amyloidosis in approximately 26% of patients (Singer, 1997).

Myelomas are usually described in terms of secretory and non-secretory, symptomatic and non-symptomatic or smouldering. Plasma cell leukaemia is a term used when there is peripheral blood involvement accounting for >20% of cells (International Myeloma Working Group, 2003). Myelomas are also classified according to the types of Igs and the presence of light chain or heavy chain disease (for further information refer to Hoffbrand et al, 2001). Numerous bones can be diseased with myeloma cells, hence the name multiple. The common and less common clinical features of multiple myeloma are presented in *Table 1*. The cause has not been identified but

**Table 1**

**Common and less common features of multiple myeloma**

**Common**

- Bone pain and pathological fractures
- Anaemia and bone marrow failure
- Infection as a result of immunodeficiency and neutropenia
- Renal impairment

**Less common**

- Acute hypercalcaemia
- Symptomatic hyperviscosity
- Neuropathy
- Amyloidosis
- Coagulopathy

Source: Singer (1997)

certain contributory factors may be associated with myeloma (*Table 2*).

Multiple myeloma has an unpredictable path with numerous periods of relapse and remission. The patient can die within days or weeks of being diagnosed, but may live for many years with a 'smouldering' myeloma that does not require any medical intervention. It is difficult to anticipate how aggressive the disease is going to be. A new International Staging System, developed by the International Myeloma Working Group, has recently been published (Durie, 2006), using serum B2 microglobulin and serum albumin prognostic indicators. Previously, the most common staging system used (Durie-Salmon) was criticised as being too complex and cumbersome for clinical practice (Schey and Pallister, 2004).

Despite modern treatments of combination chemotherapy and high-dose therapies such as melphalan used in conjunction with autologous stem cell rescue (autograft transplant), multiple myeloma remains incurable with a median survival of between

3 and 4 years (Bradwell, 2003). An outline of the principles of management are given in *Table 3*. The treatment is aimed at slowing down the progress of the disease, the outcome of which may be a partial, complete or no response to therapy, controlling the symptoms and improving the patient's quality of life (Morris, 2003).

The disease and treatment can cause extreme tiredness, lethargy and depression (Smith et al, 2005). The fragility of bones means that patients with multiple myeloma are susceptible to pathological fractures and movement can be particularly painful because of the presence of bone disease. Backache, back pain and collapsed vertebral

**Table 2**

**Contributory factors relating to the development of multiple myeloma**

- Genetic factors
- Weakened immune system
- Exposure to particular chemicals
- Radiation
- Viruses

Source: Morris (2003)

bones are common (Hoffbrand et al, 2001). *Figure 2* shows various collapsed vertebral bones and prior evidence of kyphoplasty, which is injected bone cement used to treat vertebral compression fractures.

*The NHS Cancer Plan* (Department of Health, 2000) has set out to improve supportive and palliative care for adults with cancer, in collaboration with the National Institute for Health and Clinical Excellence (2004). The key topic areas include the following: communication, information, coordination of care, and psychological, social and spiritual support.

**Background to the family narrative**

Marian is a senior nurse and works as a clinical nurse specialist in a large teaching

hospital. Her mother Susan died of an aggressive form of multiple myeloma, which left her family completely devastated. Her parents had been married for 40 years and they had four daughters, one of whom was fostered, and a brother. During the interview Marian indicated that she would probably get upset and she did start to cry at one point.

Susan had originally gone to her GP with a history of bad headaches. Following a number of visits the GP eventually took a blood test, which showed some abnormality. This necessitated a referral to haematology and Susan underwent a period of monitoring, which lasted 2 years. Marian was vague about the abnormality detected. However, it can be assumed that a monoclonal protein had been found in the blood serum. At this stage it could have been either a smouldering myeloma (asymptomatic) or MGUS. The family was aware that Susan's condition could evolve into something more serious such as a symptomatic myeloma but did not understand the implications if it did. Unfortunately, the onslaught of the disease was aggressive and Marian describes the illness as 'hell on earth with no quality of life in between'.

Marian appears to be a strong and articulate person. She looked upon the interview as a cathartic experience and although she became really disturbed and emotional, she insisted that she wanted to carry on. Marian seemed unhappy because she had not been able to speak to her mother about death and dying.

When her mother had asked 'am I dying?' Marian had said 'no of course not'. She says that this was because no one in the family wanted to speak about Susan's death until she was actually dying and then it was not discussed with Susan. The family had wanted to stay positive. Although Marian could see that her mother was dying and was rapidly becoming a 'dying cancer patient', her coping mechanism was to push that knowledge aside and concentrate on hoping that the treatment would be successful.

**Table 3**

**Management of multiple myeloma**

Chemotherapy
High-dose melphalan with transplant
Radiation
Maintenance therapy: support therapy: erythropoietin; bisphosphonates; antibiotics; pain relief; growth factors; emergency treatment, e.g. long bone pinning, plasmapheresis, kyphoplasty
Management of drug-resistant or refractory disease
New medication used in clinical trials: thalidomide; bortezomib, PS-341 (Velcade); Doxil (long-acting doxorubicin); arsenic trioxide (Trisenox)
Further reading: Hjorth et al (1993), Riccardi et al (2000), Hoffbrand et al (2001), Silverman (2002), Cavenagh and Croucher (2004), Weber (2004), Smith (2005), Durie (2006)

**Being monitored**

Susan had been attending a haematology clinic for approximately 2 years. Marian was on maternity leave and was able to accompany Susan to clinic visits. The family understood that there was a blood abnormality that required monitoring. The haematologist informed them that it might not develop into anything further and, as the blood count levels remained the same, the family avoided any contemplation of what might or might not have developed.

Denial is one way that people cope with situations that are difficult to accept (Copp and Field, 2002). The following narrative reflects the denial that Susan's family adopted:

*'The doctor had talked about some problems with her blood. You know I'm a nurse but I didn't really know what it was. We had this consultant who said maybe it will never ever come to anything, so we kind of lived*

*for the moment and thought OK, lets just live with it and we even used to laugh about it. I got to go with Mum to all her clinic appointments and afterwards we'd be like laughing about this consultant because it was just our way of managing it. Mum was that type of person who would manage that. She'd just forget about it and get on with life and we'd sort of think nothing of it, and it never got worse, it was always the same.'*

**Feeling unwell**

Following the 2-year period of monitoring Susan suddenly became unwell with general weakness and loss of appetite. Immediately before this period she had complained to Marian about her back feeling sore. As Susan had bilateral hip replacements this was not unusual. It was difficult to describe what the problem was:

*'I remember spraying Ralgex on her one day and you know we had such a laugh about it because this Ralgex was so cold, and she said "Ooh yes*



**Figure 2. Magnetic resonance imaging (MRI) of whole spine showing almost complete collapse of the T9 vertebral body, partial collapse of the L1 vertebral body with evidence of prior kyphoplasty. There is partial collapse of the L3 vertebral body and a large associated soft tissue mass extending into the spinal canal. (Reproduced with permission.)**

*it's really helped". Quite quickly after that mum came down with an illness and was very sick. I went to see her one day and I looked at her and I said mum you look awful go back to bed. It was a morning that we were going to go to the GP and I was going with her. I said "you can't go to the GP" because mum could hardly walk. It was all very non-specific.'*

### Diagnosis

The GP was called and knew at a glance that Susan required immediate hospitalisation. Marian states that the GP had been her mother's doctor for a long time and knew her well. Susan was admitted to hospital in early August 2000 and was informed of the diagnosis relatively quickly. Marian describes the shock of the diagnosis and how distressing it was informing the family:

*'We were in casualty and the doctor said it's your myeloma, it has flared up, that's what the problem is. Mum immediately said "I've got cancer" and she knew and you know, a diagnosis of cancer is awful for a family. I went home that day after casualty and had to tell dad, and of course he thought "that's it she's going to die" and he was very, very upset and so were all the family... that...initial shock that you've got a cancer.'*

Treatment was commenced with chemotherapy to bring the cancer under control. Susan became well again fairly quickly following initial supportive treatment for hypercalcaemia and blood transfusions for anaemia. Marian states that within approximately 48 hours her mother was feeling much better after having felt 'so dreadful'. Susan was treated with chemotherapy as an outpatient and also had several hospital admissions. Initially, Susan appeared to be progressing well and was responding to treatment. Marian's younger sister was getting married. Susan's big aim was to be well enough to be able to attend her daughter's wedding:

*'Mum's big aim at that time was Mary's wedding. My younger sister was getting married and that was at*

*the end of August, so you know how quickly this happened. So at the end of August mum made that wedding and she was really well that day, really well, like her normal self and we look back on photos and think wow! But as that day progressed, by the end of the night she was sick again.'*

### Becoming a dying cancer patient

In October, Marian went away for a week to Ireland with her husband and baby son. It was a holiday that had been planned originally with Marian's parents but Susan was not well enough to go. Marian describes the change in her mother's appearance when she returned from Ireland. The fact that her father did not recognise the change in his wife's appearance was also noted at this time:

*'Quite soon after mum had been diagnosed, it was the October and we had planned to go to Ireland all of us together with our new baby and mum and dad and of course mum's now dying, so she couldn't go and I was away for a week and came back. I went into her bedroom and just was in tears, you know. I had to leave the room in tears because there was such a drastic change, she looked so skeletal, she looked like a cancer patient, you know, quite quickly, a dying patient, and I remember being in the front room crying and dad coming in and saying "Why are you crying, she's, she's very well, she's looking"...he couldn't see any of it...'*

Within several weeks Susan deteriorated and was no longer responding to the chemotherapy. A decision was taken to change the therapy:

*'Mum started to deteriorate, so her bloods deteriorated, and they called us up one day to see them and they said we want to move on to another class of treatment because things are deteriorating and of course we agreed. We had to because there wasn't really another option. They wanted to do it, and I think from there on, no treatment was ever*

*probably going to work because mum got worse and worse and then on Christmas Day I remember coming, we'd been to Dave's parents for dinner, for Christmas Day and we came and mum had had a really bad day and we called out the emergency doctor for some pain relief and she was admitted quite soon after that.'*

Marian was informed that the new therapy (thalidomide) was not having any effect. Susan continued to deteriorate. It was suggested that the treatment was discontinued. Marian disclosed her feelings and stressed that, as a family, they did not acknowledge that Susan was dying. Furthermore, it was assumed that Susan was not aware of her impending death:

*'A new registrar came and he'd been around for a couple of weeks and I called him at home about something and he said...your mum's figures are deteriorating, I think we should stop treatment. I can't remember what else he said but I was horrified that he would actually even go there and I just said as a family we wouldn't do that, we won't stop treatment and now I, I think was that the wrong thing to do at that time because we as a family never acknowledged mum's dying, until right at the end when mum was dying and couldn't acknowledge it herself. He said to me, this registrar, that mum would be crying at night with the nurses, so maybe she did have some knowledge of what was happening.'*

The family believed and hoped for a miracle cure. They had seen an article on the internet about thalidomide and how a particular woman had been treated with success:

*'I think it was probably that we as a family were never ever going to give up. We would always have that hope and that we would always try and look for this miracle I suppose. We were reading something on the website about thalidomide. You know this woman's story that it had worked. She was taking it and then wow she had made this great*



*recovery and I suppose I'd always thought that maybe that would happen for mum.'*

Susan returned from her last hospitalisation to the family home where she had lived for more than 30 years. During that time many people came to visit. Marian recalls visitors' shock at seeing such a drastic change in her mother's appearance:

*'Mum was ill but people did start to drop in and you know it was just like the shock, people knew then that she was dying. We never told anyone. You know we were so closed about what was going on but it must have been so obvious to people. She just looked like a, you know, a corpse.'*

Marian talked about two distinct changes in her mother. One change was in her mother's external appearance relating to body degeneration because of the disease. The other was 'a very discrete difference in who mum was', implying there had been a subtle change in Susan's personality:

*'To me she just looked awful and that's how quickly the change happened and then you know, awful bruising that came on her body. You know that's horrible at the end, yeah I suppose it wasn't a very long time span but she was just bruised everywhere. She was so thin, skin and bone and, she could hardly get out to the commode and everything was such an effort. It's just awful really. I think you know as a family we knew there was something different about her, that no one else would have seen. It was a very discrete difference in who mum was and I suppose at the time I wasn't really recognising it properly. I would just think "oh you know mum's ill" but now I think back it was the whole period, very discretely she was a bit of a changed person.'*

Marian recognised that her mother had an 'underlying depression' as she had become withdrawn, distant, and tearful. Marian's thoughts were that her mother was not able to come to terms with her diagnosis. Susan was described

as having been a 'funny person' who was interested in talking with people. During her illness Susan had become 'distant'. Marian suggests that this was because Susan was afraid to talk to her family about what was happening to her. In addition, the family did not want to accept that Susan was dying:

*'I think she was frightened. Mum couldn't talk to us about it. I don't know why. Perhaps it's because we... just didn't want to accept that. You know mum had this very serious illness, that she was going to die with but we just always hoped she would recover.'*

#### End-of-life care

Susan was treated with morphine for bone pain (back pain) and lorazepam was prescribed for anxiety attacks. Marian maintains that the lorazepam was very effective. It helped calm her mother, improved her wellbeing, and she appeared to be more her normal self:

*'The one thing that mum was prescribed, that really did help her and I'm sure it was because, she did have a fear, was lorazepam. We used to laugh about it because they were like her little blue pills but when she'd had a lorazepam she, it really calmed, it calmed her in lots of ways and almost brought her back to being the mum that we knew because she would get a little bit panicky or withdrawn.'*

The whole family was 'very pleased' that Susan was at home when she died. Susan had only been discharged from hospital a few days previously. Being at home gave the family an opportunity to participate in Susan's care and to share special moments that would never be forgotten. It also gave the family an opportunity to begin to come to terms with Susan's impending death. However, Marian claims that her father could not have coped with his wife at home for much longer. Marian sums up the period of her mother becoming 'struck down' with the illness and dying:

*'Mum was diagnosed in early August and died on the 7th of February. In between, you know, it was hell on*

*earth, mum didn't have any quality of life really because she was either in hospital or if at home, was in bed. Mum wasn't able to do anymore more than that. Sometimes she could get up and be so exhausted but the one thing, I mean, she made it to our son's christening. That was in the November. Mum had quite a good day that day, but, you know, making the christening means that she got in a car got to my house and spent quite a bit of time in bed in the spare room, but she was in quite good spirits.'*

#### Discussion

Diagnosing people with multiple myeloma can be difficult (Watts, 2005). Back pain or backache is common and is often the first symptom that the patient experiences. However, people may have to attend the GP practice several times before the cause of the pain is investigated further. Patients may be attending the hospital for other conditions and abnormal protein or calcium levels are detected in the blood, which may alert the doctor towards the possibility of the presence of myeloma. Others may simply break a bone while carrying out household chores. These patients are seen in accident and emergency departments with a 'suspicious' pathological fracture.

The need repeatedly to visit the GP seeking help regarding a specific problem before a cancer diagnosis is made has been reported by Leydon et al (2003). These authors suggest that difficulties are encountered because of scarce resources, especially in deprived areas, additional pressure on GPs, 10-minute consultations and lack of experience and knowledge. With regard to this latter point, Leydon et al found that the patients with breast cancer were relatively satisfied with their GPs' ability to facilitate a diagnosis. This is not surprising as breast cancer can be detected quickly and easily because it is a solid tumour that is palpable and often visible to the naked eye. Other less conspicuous cancers, e.g. leukaemia or myeloma, may start out with non-specific symptoms such as mild anaemia or backache. In the

case of a symptomatic myeloma, the consequences of a delayed diagnosis will ultimately lead to delayed treatment and disease progression.

Susan's abnormal monoclonal protein levels were detected after having routine blood evaluations as a result of several visits to the GP, initially for severe headaches. The abnormal levels were not significant enough for treatment but necessitated monitoring and it was not conclusive that this condition would develop into cancer. It is known that a smouldering myeloma or MGUS can develop into a symptomatic myeloma (Singer, 1997). In Susan's case this was advantageous as it served as a prior warning and thus she was diagnosed quickly. The relationship between patient and GP is fundamental. Susan was well known to the GP. Her doctor was familiar with Susan's medical history and knew her as a person. One look was enough to inform the GP that something was very wrong and that immediate medical intervention was required.

The time of diagnosis is usually described in terms of 'a shock' for most people and their families (Thomas and Retsas, 1999; Maliski et al, 2002). Many are completely traumatised and in a state of bewilderment (Davis, 2002; Persson and Hallberg, 2004). Susan was told 'your myeloma has flared up'. She instantly knew she had cancer which implies a degree of awareness. It is assumed that the words 'myeloma' and 'cancer' had been used in a conversation between the doctor and patient at some stage. From the interview it is clear that this discussion did not take place between the patient and her family.

During the monitoring period both Marian and Susan knew that something sinister was potentially 'brewing' but chose not to acknowledge it as a way of coping with the situation. It appeared to be a case of — why worry about something that may or may not develop? Being forewarned, however, did not lessen the shock and distress associated with the diagnosis and the impact this had on the family. It can take a long time for family members

to come to terms with a diagnosis of cancer (Mellon, 2002). In Mellon's (2002) study, cancer survivors and family members were so shocked at receiving the diagnosis that it was a considerable length of time after the cancer treatment had ended that they finally came to accept it.

Myelomas are often referred to as being in a state of relapse or refractory which means that the disease is not responding to treatment. Finding an effective treatment is often a challenge. It might only be achieved through persistent trial and error. The disease was particularly aggressive in Susan's case. In the terminal stages of the illness no treatment will alter the course of its progression. It is unrelenting. Hope for a miracle cure has been identified in the literature (Mok et al, 2003) and this was apparently very real for Susan's family who were influenced by other people's experience of successful treatment with thalidomide. The findings from Mok et al's (2003) study are important, despite the differences in culture and beliefs, because of the implications for nursing practice. This research explored family experience caring for terminally ill patients with cancer in Hong Kong. Hoping for a miracle, despite being told that the illness was incurable, and trying alternative herbal medicine, was described as an integral component of the process of caring.

Not all families are able to talk openly about death and dying because it is too upsetting (Greisinger et al, 1997; Copp and Field, 2002). Marian describes her mother becoming subdued and distant. This was understood as a fear of talking to her family about her situation and the possibility of dying.

Marian knew her mother was dying but was unable to discuss this with her or any other family member. This suggests that family members were protecting each other and were not necessarily in denial. Marian was under no illusion that her mother was dying. However, denial of impending death is conceptualised as an individual coping mechanism (Zimmermann, 2004).

Copp and Field (2002) discuss the open awareness culture in a hospice setting and the use of denial and acceptance of dying as alternating coping strategies used by patients at different stages of the illness trajectory. Family members were seen to be protecting one another by not talking about illness and dying. While some patients were able to discuss issues relating to their situation throughout the course of their illness, others preferred to have periods when they were not constantly reminded about their imminent death. People cope by not acknowledging that a loved one is dying. They cope with 'the now' of the situation and do not concentrate on what is about to happen because it is too painful.

Lawton's (2000) work highlights strategies employed by dying patients such as focusing on the memories of their past lives and being reluctant to discuss any topic associated with the future. Lawson provides an example of this within a day care setting. Any person showing unrealistic expectations concerning future plans was immediately excluded from the inner circle of patients attending (Lawton, 2000).

The breaking of bad news is described as 'one of the most difficult responsibilities in the practice of medicine' (VandeKieft, 2001). Bad news is defined as 'news of life-threatening illness, disability or impending or actual death' (Farrell, 1999). Doctors may withhold certain information because they have concerns about its detrimental effect on patients. Furthermore, VandeKieft (2001) argues: 'Physicians do not wish to take hope away from the patient. They may be fearful of the patient's or family's reaction to the news, or uncertain how to deal with an intense emotional response.'

Marian was the recipient of bad news when the registrar told her on the telephone that her mother's condition was deteriorating and that the health care team was considering stopping the treatment. Marian was clearly upset by this comment. The doctor could have coped with the situation more sensitively by arranging

a meeting with Marion to discuss the options in person. Effective and compassionate communication is not just a matter of discussion. Health care professionals should be prepared to provide the emotional support and respond to an individual's reactions to bad news (Dias et al, 2003).

### Conclusion

The aim of this article is to describe the disease process of multiple myeloma in the context of a dying mother and the impact of the disease on the family. Susan's family had little time to come to terms with the diagnosis of cancer before Susan died. The myeloma was aggressive, unresponsive to treatment, and unrelenting. Within a short period Susan became a 'dying cancer patient'.

The narrative content provides some insight into the often unpredictable nature of the disease. The ongoing qualitative study intends to increase understanding into the impact of this debilitating bone marrow cancer; strengthen the evidence base for managing the disease and provide more supportive care, particularly at the end of life. **EOLC**

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### Key Points

- ▶▶ A diagnosis of cancer is very traumatic for both the patient and the family.
- ▶▶ The onslaught of multiple myeloma can be very aggressive. The daughter who is the subject of this article described the illness as 'hell on earth with no quality of life inbetween'.
- ▶▶ In the terminal stages of the illness no treatment will alter the course of its progression. It is unrelenting.
- ▶▶ Not all families are able to talk openly about death and dying because it is too upsetting.
- ▶▶ Some families cope with 'the now' of the situation and do not concentrate on what is about to happen because it is too painful.