

# End of life stories that give meaning to the individual's existence

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Those who care for the dying often encounter unresolved issues in patients which are displacements of emotion, evasions of questions, and secondary matters being turned into protection against approaching death. There are many ways of intervening in this process of conflict to resolve issues, give back to the patient self-respect and a measure of control, and relate him or her to the environment of care. The following examples may be generalized to many cases.

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## Introduction

Dr Viktor Frankl, the creator of the theory of logotherapy, formulated his concepts of this orientation to psychological therapeutic techniques while interned in the concentration camps during the Holocaust.

The title of his chapters in the book, *The Doctor and the Soul*, such as 'The Meaning of Life', 'The Meaning of Death', 'The Meaning of love' and 'The Meaning of Work', provide a deep analysis and explanation how we as human beings can have 'meaning' in our lives regardless of the phase of that existence or its circumstances [1].

During his internment under atrocious conditions Frankl was able to add 'meaning' to his existence. In his text *Man's Search for Meaning* he stated, 'Ultimately, man should not ask what the meaning of his life is, but rather must recognize that it is he who is asked. In a word, each man is questioned by life; and he can only answer to life by answering for his own life; to life he can only respond by being responsible' [2].

One of the memorable stories in Frankl's book is that of a young person lying in bed with a permanent paralysis who was able to find meaning through the seasonal visualization of a single branch of a tree and its flowering and death over time.

The following text is dedicated to some of those wonderful people who have journeyed through my life as a Palliative Care physician over a 12-year time frame and who chose to share with their carers rich perceptions of their lives in the known finiteness of their existence. They have given us reasons for continuing to maintain our role as carers in the hospices and homes of this world. They give great credence to the words provided by Oliver Sachs, 'it is not what disease the patient has, but what patient has the disease' [3].

## Gloria

Gloria was in many ways more unusual than other patients because she expressed feelings relating to dying that I had not seen in 11 years as a Palliative Care physician. She had an uncommon tumour that involved the lower part of her biliary tree (the bile drainage tubes from the liver). This caused her jaundice and loss of appetite and intense nausea that was greater than the pain from her liver. When I first met her she made me aware that she had known me as a colleague's secretary some 20 years previously and thus expressed a confidence in me as a physician. In my 11 years as a physician involving care of the dying, I had not had a patient in whom the person's pain could not be relieved or controlled so that their life was comfortable. My clinical assessment revealed no obvious cause for her persistent, distressing nausea and pain. Investigations of her bowel confirmed this.

Her recurring statement was 'I am afraid of dying.' Over the previous 11 years I had been unable to recall a patient saying this.

Having been given permission from Gloria to sit on her bed and talk, I learned from her the tragedy of her 69 years of 'pain'.

Her story is filled with conflict and guilt. She was a child with five other siblings. She had two brothers and three sisters. Her father was a miner who had suffered an injury at work. Gloria stated that her life at home was horrible and full of tension. Her mother and father were always in conflict. At one stage she said she loved her father but was frightened of him. She said her parents had a sexual problem. She did not know what it was. It did not trouble her, she said. Did your father abuse you? No, was the response. What was your father like? He used to get into bed with me every night and tell me he loved me and would snuggle into my back. 'What about your sisters?' I don't know she replied.

'Please don't tell my husband', she pleaded.

'No, your confidence in us is complete and sacrosanct.' What of your children, I inquired?

'I have two and they are grown up, my daughter lives not too far away and my son lives interstate.'

'Are you close to them?'

'I built my life on making them dependent upon me and when my son left to travel in Europe I was lost as I had no one and my daughter had married. Her first marriage was a disaster as she found out her husband was homosexual and her second marriage also failed.'

'I have not spoken to anyone about this before.' (At this time she now had stopped vomiting and her nausea was less.) Gloria stated she had held these emotions for 69 years and it was so hard to let go.

'So why are you afraid of dying?'

'Because, he (my father) is waiting for me. (Marked nausea and vomiting) I want to die yet I can't let go.'

As the subsequent days passed she was reunited with her children. (Her daughter was now aware via her mother of some of her childhood experiences.) Within three days of the first encounter in the hospital she went home to be at peace with her family. She died at home without pain and nausea three weeks later.

## Female – lung cancer aged 48

This lady had three children ranging from teenage years downwards. She was aware of her diagnosis and prognosis yet when visited on the ward rounds she expressed guilt related to her

causing her premature separation from her children. She believed that her smoking caused her lung cancer and this was why she was dying and leaving her children without a mother.

A review of her notes showed her cancer was a rare tumour of the lung that occurs in young women and is unrelated to smoking. No one had explained this to her. Her relief and subsequent joy was palpable and she reconciled herself with her children and husband and died peacefully.

### **Joy, the enigma**

Joy was a person whom I never really understood. She had been a very independent young woman with a rare tumour. She owned her own home, had a secure job, had not married and had travelled extensively. When she came to hospital in March she had a tumour throughout her body with large lumps protruding from her skin and scalp. We were able to control her pain, make her comfortable and had assessed her as having a poor prognosis, days or weeks. She had very few friends and during her illness had developed a relationship with a middle-aged bachelor who was very mother-dependent. He offered to manage and support her at home when she was discharged. His expectations were unrealistic. Why had she suddenly developed this male-dependent relationship in the latter stages of her life with someone of lesser independence than she had? An issue not resolved.

During the early interviews Joy showed a reluctance to change her environment to what appeared appropriate for the situation. When being interviewed she would leave the radio on and when asked if the radio could be turned off while we talked she would say, 'I suppose so if you want it that way.'

As time passed she would relate to the staff, 'Oh no, it's that time again.'

'What time?' was the reply from the nursing staff?

'He's coming.'

'Who?'

'That doctor who sits on the bed and holds my hand while he talks to me. He is strange.'

Initially, Joy did not refuse to talk to me and despite a distinct reluctance to share, we managed. She was in total control.

As months passed she began to order her meals or undertake some other activity as I began to start my ward round. The final severing of the patient-doctor relationship (non-disharmonious) came when she asked for a suppository to be given to her as I arrived in the ward.

Remarkably Joy survived another 10 months, during this period she went into deep comas, suffered fits and was considered near death several times. My last record of her (she had been under someone else's care since the suppository episode) was that she was fully awake and beginning to try and sit up in bed by herself.

### **Louise – hospitalization as a place of refuge**

Louise was remarkable as she 'knew' her illness as well as those caring for her and her 'survival' was characterized by seeking, even demanding, knowledge about all aspects of her disease. Her influence on her carers was one of the richest experienced in the hospital where individual patient experiences are rich and varied.

Louise was of Austrian-Jewish heritage and she had widespread breast cancer and chose to come to Calvary Hospital as she stated she would receive better care there than in the teaching hospital where she was resident.

In her youth she had been 'imprisoned' in a German jail during the war. She emphasized that this was not a concentration camp but a jail. She was interned with other women and felt 'safe' being in prison. Her safest time was when she developed chicken pox and had to be isolated in her own cell. Here she did not have to share and her isolation enhanced her sense of safety. She saw coming to Calvary as a recreation of the same situation. Her life was being threatened by cancer yet she had confidence in her carers to take her through her final journey. Louise had looked at her life in the final stages based on her wartime and life experiences and had studied Jungian psychology from several authors especially Clarissa Pinkola Estes who wrote, *Women who Run with Wolves* [4].

When she was given an explanation of her disease status and likely outcomes at any given stage she would listen intently, acknowledge if she understood, yet readily request a clarification if she did not comprehend what was being said. It was as if she was our educator. One of her final goals was achieved when her partially intellectually impaired daughter achieved a degree of social independence when she went to reside with her brother interstate. Ward rounds ended at her bedside. This was not by design as she occupied the last bed in the largest ward at the end of the hospital floor. All members of the team caring for her became involved in the discourse.

### **Euthanasia**

This man was a very successful Jewish businessman with no offspring, who was diagnosed with terminal cancer of the stomach. He sought a consultation with me for management of his disease. There followed an extended consultative period where he and his wife fully understood the implications of the illness. They raised two issues, one of having no desire to be admitted to the hospice and the other was whether euthanasia was an option.

I confirmed that all efforts would be made to manage him at home with his wife and this occurred in a period before home care became a major service from the hospice. I discussed with him and his wife my philosophical attitude and practice approach to euthanasia, stating it was not an option. Their request to seek another opinion was encouraged. Later his wife contacted me with to say that she understood my views, but did not fully agree with them.

My next encounter was with his family medical officer, unbeknown to me he had admitted the patient under my care to the hospice. His stay in the hospice was peaceful and pain-free and he died a gentle death. Several weeks later I received a letter from his wife expressing great admiration for the hospice and its staff and how she could now see that euthanasia was not the correct option and was grateful for the care and support she received.

### **Euthanasia revisited**

This lady was a wealthy childless woman in her 60s with a recent diagnosis of terminal malignancy. Her situation arose during the national debate on the legalization of euthanasia. Her 'acceptance' to the hospice under my care was via several other physicians who were unable to cope with the patient's demands or needs and this was exacerbated by the prevailing social disruption over the subject of euthanasia. It was also considered that I could 'sort

the problem out', even though it was well known that I had a philosophical approach that did not favour euthanasia.

I began my interview in the usual manner that involved asking the patient's history and defining the problems at hand.

Her husband sat timidly at the bedside as she put out her arm and said, 'here it is, do it.'

'Do what?', I inquired.

'Give me the injection and let's get it over with. I don't want to suffer any more.'

This lady had no pain and did not exhibit signs of her malignancy at that time.

After an extended discussion she stated that if I would not perform euthanasia for what she called 'aesthetic reasons', she would pay me \$2000 to do it. This procedure was, and remains, illegal in Australia.

As the interview was proceeding, the catering staff arrived. They asked the patient whether she would like to order her dinner. She said yes and set specific requirements that her orange juice be very cold, as that was her preference as well as ordering the remainder of her meal! The patient was totally unaware of the paradox presented in this situation.

The lady discharged herself from hospital within the hour as she felt she was very dissatisfied with our approach to her problem and why shouldn't we perform euthanasia? Her husband's only conversation during this encounter was 'I will go along with anything you want, dear.'

### **A breathing problem (the burden of guilt)**

This man was a 60-year-old accountant with terminal lung disease due to an inherited disorder (alpha 1 antitrypsin deficiency). He had recurrent admissions to hospital for his breathlessness that had created difficulties in management for his wife. His marital relationship (second) was not an easy one. But, his wife was very caring and her distress was severe with each breathless episode. At the local hospital he was now considered in the terminal phase of his illness and required hospice care.

When admitted he was on permanent oxygen therapy, was wheelchair-bound, and could not stand and go to the toilet unassisted.

Clinical assessment revealed that he could hold a normal conversation without his oxygen mask and had minimal breathlessness in completing normal conversations (this is a standard measure of the degree of breathlessness). Most breathless patients are only able to put two or three words together between gasps without oxygen. Other features of his personality showed high anxiety levels. This can occur with patients who are breathless and short of oxygen, but these patients are unable to complete full sentences in conversations.

On exploring this man's illness and excluding significant lack of oxygen in his body, we began to discuss his illness and his life with him.

One day we dedicated a special time period to this man providing him a forum in which to express his fears and anxieties about his illness. This was because we felt this man could be managed at home with his wife and without oxygen therapy on a permanent basis. It was during that time he revealed significant emotional difficulties.

Two major stress factors became evident and would appear interrelated. He felt he was a burden on his wife but needed her for security and affection. This anxiety was worsened by his unresolved business difficulties. He had been an accountant for a successful family company for many years with which they interacted socially. The patient had failed to complete their tax returns for some five years. His revelation of this to this company was

about to ruin them. He had not yet done so and he had not spoken of this to his wife. During this interview he required no oxygen therapy. He was able to acknowledge the significant role of his business stress on his life. Accepting and modifying it was an aim to be achieved.

Several days later I entered his room and said, 'I have a surprise for you.' As I uttered this statement his personality became vibrant and excited. I removed his walking frame and said 'come, walk with me'. We sat him up and began to walk him, with assistance, to the door. The visible manifestations of his breathlessness became acutely obvious, yet we managed to walk him 10 paces from the bed with small stuttering steps. He then stated he could go no further. We stopped and said 'you need to get back to bed.' He immediately turned and took normal paces back to bed, sat on its edge and took the oxygen which relieved his breathlessness before the mask was over his mouth. It was felt that each time he started to improve and became mobile he had to 'pass through the door' and confront his reality of the poor business management and its long-term social consequences.

Within a week of this episode he left the hospice to be in the care of his wife with minimal oxygen support. He had accepted the reality that he had to confront his 'burden' and resolve it before he died.

### **Losing a friend**

I had been asked to see a 40-year-old man who had unresolved pain management following a total colectomy (removal of the large bowel), for severe ulcerative colitis.

His illness had spanned some eight and a half years and at times involved passing bowel motions up to 30 times a day. During the worst phases of his illness he would need to know which railway stations had toilets that were open on the way to work so he did not soil himself before arriving at work.

At the time of his operation he was a senior accountant in the State Government Taxation Office and regularly met with the leaders of industry. One of his greatest fears was losing control of his bowel function during these business meetings. His bowel function created difficulties with other areas of his life such as watching soccer with his son and being unsure whether he would be able to make the toilets or if they were unlocked. At one stage in his illness he nearly died from a worsening of his condition when his two children were four years, and less than 12 months of age.

When I first met this man he had severe abdominal pain unrelieved by adequate doses of analgesics following his total colectomy and had not eaten for nearly seven days. In my meeting with him it was obvious that he had no organic basis for his pain and was severely depressed. He revealed he had lost 'a friend' when his bowel was removed even though it could have caused his death. By working through his responses to his disease there was an intense catharsis of emotion and within 24 hours he had no pain, required no analgesics, and was starting to eat. Within 48 hours he was eating normally and had no pain, looked much healthier and had hope for the future.

### **Patricia forking out a bit of her own medicine**

Patricia was a 69-year-old strong, soft, caring matriarchal figure with four children and many descendents her latest being born four weeks before she died. Her illness was a progressive

cancer of her pelvis that was initially treated with chemotherapy during which she experienced severe side effects of the medications. This was the initial phase of her illness and required a prolonged stay in hospital separating her from her family. Following the initial treatment she was managed in a small private hospital near her family and when the disease recurred she was managed in a hospital which made it harder for her family to see her.

With recognition that the disease was now incurable, Patricia requested to be returned to the smaller hospital, to be nearer her family. It became obvious that this request was associated with some apprehension. Further questioning revealed that Patricia had a difficult relationship with one of the nurses during her previous admission.

On returning to the hospital the first person she encountered was this same nurse who stated to her that Patricia really had no reason to complain and there was very little wrong with her. At this point Patricia picked up her fork and brandished it in front of the nurse's nose and stated: 'you have no idea what I have been through and don't trivialize what I have been through and what is happening to me.'

Over the next two weeks Patricia died peacefully and without pain from progressive renal failure.

### **Laughter—a good medicine**

He was a middle-aged Polish man with incurable bladder cancer that had spread to his abdomen and control pain was very difficult due to the tumour infiltrating the nerves and other structures in his pelvis.

From early in his illness the patient had requested he not be admitted to the hospice. He gave no explanation of why and the impression was that he saw admittance as 'the end'. This is seen as a normal concept for patients struggling with their malignant disease.

As his disease became more advanced his pain and other symptoms became more and more difficult to manage at home leading to his admission to the hospice. Once admitted his pain was controlled yet his disease status meant he would need to remain in the hospice.

The family's anxiety of this necessitated a meeting to discuss the issues at hand. The patient was unable to attend due to weakness.

The family interview began with a high level of anxiety and probing questions. During this tense interaction they all started to laugh and stated it was wonderful that the husband and their father was now in the hospice as 'he now had no control over their lives'.

Throughout their family life the patient had been an autocratic, dominating, angry man who had prevented the remaining members of the family having any significant individual autonomy. The children were all adults and some were married yet still felt under the patient's control. His 'unplanned' admission took away his controlling influence and allowed the other members of the family to become free.

### **Sometimes we miss things**

This lady was in her late 60s or early 70s and was admitted with severe bone pain diagnosed as terminal cancer.

For many years she had suffered from severe rheumatoid arthritis which had caused many complications in her body as had her treatment. During the pre-admission phase of her illness she had developed severe bone pain as one of her medications (cortisone equivalent)

was being withdrawn. Extensive investigations revealed that she had evidence of possible widespread cancer of her bones.

It was decided that no further investigations would be performed as she was now elderly and nothing could be done for her 'cancer'.

When admitted to the hospice the patient was limited to rest in bed and required a wheelchair to be moved around.

Reviewing her illness there was a suspicion that this lady's pain may be due to bone disease (collapse) caused by withdrawal of the medication. This is an uncommon but known complication of this particular medication. In her pre-admission investigations it was decided not to biopsy (take a sample) of her bone because of the convincing evidence of her 'widespread' cancer.

Subsequently, a bone biopsy was performed, revealing no evidence of cancer only the disease caused by the drug withdrawal.

The medication was restarted at her previous therapeutic levels and she became pain free and walked from the hospital.

### **The strength of youth**

She was 14 years old and was the first patient whom by treating I began my journey into hospice care. Her disease was a cardiomyopathy, a terminal disease of the heart muscle. This illness is always fatal and causes progressive breathlessness and immobility. When I first saw her she was admitted for 'another test', this time another heart biopsy, and I was asked to visit her to see if I could help in her care.

When I came and sat with her she asked, 'why are you here? I don't want another test, please.'

I stated I wanted to talk to her about herself.

As we chatted she clearly described her illness and what was wrong with her and how serious the heart problem was. She concluded her assessment by stating that, 'I know I am going to die, my heart will never recover. Please don't do any more tests, I have had enough.'

This young lady was encouraged to express these thoughts to her primary physicians, and I understood that she did so.

She died peacefully several months later without having further unnecessary tests.

### **A man of colours**

Keith was a man in his early 70s who had developed a mesothelioma (a tumour resulting from exposure to asbestos). Patients with this disease often have long medical histories complicated with severe pain and breathlessness. Fortunately Keith had no pain for the major course of his illness but was unable to walk due to the cancer affecting his spinal cord. As he lay in hospital for many months, unable to manage at home, he never complained and saw his situation as part of his life.

As time passed he related what he saw as a special gift which allowed him to see individuals as exhibiting a colour aura. These auras depended on the individual person's moods and no person had the same colour all the time. When asked why he saw people like this Keith stated that he could not fully explain it but that it had been present for as long as he could remember.

During some visits he would be reluctant to express his interpretation of an individual's colour aura.

A special attribute of Keith's stay was his closeness to people. In addition, he encouraged touching as a form of communication.

### **Looking ahead**

Rita was in her mid-70s when admitted in a very cachexic physical state. She was alert and showed no evidence of distress and was fully aware of her clinical situation. Her personality was vibrant and interactive. In her normal daily routine she wore large round glasses with spectrum coloured frames. When asked about her illness, she stated that she knew her illness was terminal and was looking forwards to dying peacefully. She then told us she had prepared herself in advance for life after death by purchasing a new set of glasses 'so she could see clearly where she was going' in the afterlife. Further inquiries led her to open up her bedside cupboard and remove an expensive embossed glasses case that contained a new set of glasses purchased less than a month before her admission. The glasses were thin gold-framed lenses with tortoiseshell ends at the earpiece ends. They were obviously expensive and had been purchased for the intention of seeing better in the future.

### **Jan – this is my home**

At the time of this writing in the 1980s, Jan was 75 years old. He was born at the end of the Hapsburg Empire. He was in the final stages of his life with disseminated cancer. He told these stories of his wanderings throughout the world and how he had never found his home. His life stories were told with softness and gentleness as he related his many journeys seeking a place to 'live in'.

The final stages of his illness lasted some six to eight weeks and he would always relate during the ward rounds that the hospital 'was his home'. He felt he had come home when he was admitted to Calvary Hospital in the southern suburbs of Sydney.

He told of his wanderings throughout the world and had the gentlest of personalities. This gentleness dissolved when he recalled with intense anger and vehemence experiences as a foot soldier for Hitler during which time he had spent three Russian winters on the Eastern Front. His appropriate anger and vocalization were often accompanied by intense tension in his facial muscles and the expulsion of spittle as he spoke of the horrors of war and his leaders.

His last journey was pain-free and peaceful.

### **Sherry and beer this afternoon**

This is the story of two elderly ladies with terminal cancer. One had disseminated breast cancer involving her lungs. She had a bubbly personality and always smiled when ward rounds were underway. The other lady was more reserved and had a terminal cancer of the oesophagus. She was fully aware of her state and had much difficulty with swallowing.

During one ward round we raised the issue of having an afternoon drink. Did they do this at home?

The breast cancer lady said she always enjoyed a medium dry sherry but had not had one in months and missed the daily ritual.

The other lady stated she enjoyed 'two cans of beer' every afternoon. So we enquired if she would like to have a cold beer every day when her bedside mate had her sherry.

She emerged from her reserved nature with a large smile and said, 'I have mine warm'.

Which beer did she like? Her reply was, 'The one with the green can' (Victoria Bitter or VB).

This ritual then continued on a daily pattern until the terminal stages of their diseases. They became great friends (initially there was reticence), using these afternoon social drinking episodes to break down the communication barriers. When the 'beer lady' was near death, it was felt the other lady wanted her to go first and she died two days after the cancer of the oesophagus patient.

### **How I helped Australia**

This delightful German lady had extensive lung cancer in her chest and was undergoing a course of radiotherapy. During her illness she had developed a hemianopia (loss of half the vision in her left eye). The brightness of her personality was revealed when she was showing how she adapted at home with her visual loss. She had unconsciously developed the habit of turning her whole body to the left rather than the usual rotation of the head with normal vision.

We enquired of her past and asked when she came to Australia. This was soon after the end of the Second World War. She was asked what her first impressions of Australia were at that time, 1955.

There was an expectation that she may have found it difficult because of her German origins.

She replied, 'It was very backward'. She was then asked what it was like in 1965. Her reply was filled with laughter when she said, 'Oh, it was much better, because I was here!'

### **Conclusion**

The final journeys here provide a wonderful summary of what faces us when we know our journey on this third rock from the sun is nearing its completion. As Frankl states, 'When we are no longer able to change a situation – just think of an incurable disease such as inoperable cancer – we are challenged to change ourselves.'

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