

Death in the Family

- an experiential account

— A Judge



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Curriculum vitae

Andrea Judge studied at UCT and obtained a Master's degree in Clinical Social work. She was employed at William Slater Hospital for 2 years as a member of a multi-disciplinary team for the treatment of alcoholics. At present she is in private practice and also works as a counsellor at UCT. Her practice involves working with individuals, couples and families - looking at the person holistically in terms of mind, body and spirit; she uses relaxation and meditation techniques for a wide range of problems, especially those relating to stress. Her special interest is in working with cancer patients and their families.

In April 1983, my son Russell, a twenty-year-old UCT student was diagnosed as having cancer. My focus is on how the family learned to deal with the crisis of a life-threatening illness.

Prior to his cancer, Russell felt like a normal young adult of 20 years - invulnerable and invincible.

Initially he experienced a series of coughs, colds and feelings of tiredness. I, like a typical mother, nagged him to go to the doctor. Eventually he did and a tumour on the lung was discovered.

Our nightmare began - overnight our reality had changed.

There was an initial period of six weeks when no one in the hospital gave us any information. We were catapulted into endless investigations - a lung biopsy and many tests but no explanations. Only a conspiracy of silence.

At this stage Russell felt totally overwhelmed by fear.

Summary

This is a personal story of a family with a teenage boy who had cancer. It describes how the family learned to deal with the crisis of a life-threatening illness; the boy's experiences in hospitals in Cape Town and abroad, his struggle not to be depersonalised and taken over completely by the hospital, but to preserve a quality of life and to cope with his dying.

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"I was so frightened I was going to die that I couldn't sleep at night," he said. "I felt if I stayed awake, at least I would live. The hospital was just taking me over. Doing things to me but not telling me."

The fear and anxiety occurred because we had no one to check out our fears and fantasies with, because we had no information, and because the doctors seemed to be denying and avoiding communication.

A pertinent example of this was when one of the surgeons actually asked *me*, a social worker, to tell my son that he had cancer.

The family was in a state of shock and turmoil. We withdrew from Russell at this stage, almost as if it was too painful for us to really be with him. There was little communication, only an all-pervading feeling of helplessness and hopelessness.

On a superficial level, life continued but, on a deeper level, it was as if our whole world had been turned upside down. We spent nights sitting together, watching mindless videos as an escape from the painful reality of the endless waiting.

Finally, after six weeks of minimal information, Russell's consultant told him he had a lymphoma. The interview lasted ten minutes and contained so

much information that we could not assimilate it. Ironically Russell later described this as:

"A most beautiful day because she treated me like a person, she gave me information and I knew I wasn't going to die just then."

We celebrated by going out to lunch.

Then the treatment began. Russell had radiotherapy for six weeks and chemotherapy for six months - one week in every month on a daily basis.

We were steamrolled into the medical process where authoritative clinicians spelt out the treatment. We were not consulted about decisions, we were not given any choices - nor were we given the time to ask questions.

In fact, I was never able to speak to Russell's consultant on my own. It was only when I learned to become more assertive that I was able to demand an interview to discuss Russell's prognosis.

At this point, we as a family began to mobilise our strengths. Our energies were not directed into the Big C but, as Russell put it:

"Surviving the Big H (meaning the hospital) and fighting the depersonalisation".

In small ways, we were able to minimise our anger and frustration, for example, through negotiation with staff, we made set times for hospital appointments so that Russell could attend lectures and could maintain contact with the real world.

It was important for Russell to remain involved with his peers. The danger being that it is all too easy for the hospital and treatment to take over one's life totally.

I remember all too clearly the utter passivity and helplessness of patients in J block (the cancer ward), sitting for hours on wooden benches, almost as if they were waiting to die.

We were not consulted about decisions; we were not given any choices, nor were we given the time to ask questions

We also had important outside support from friends overseas who sent us books, audio tapes and videos, giving information of alternative ways of coping with cancer.

For example, Russell followed the Bristol diet based on fresh fruit, vegetables, juices and vitamin supplements, which particularly helped to minimise the side effects of radiation: nausea, loss of appetite and difficulty in swallowing.

So we, as a family began to take some control over what we could do. We gradually got in touch with our resources as a family and Russell, as an



Russell Kaplan

individual, began to take responsibility for his illness.

He learned how to relax, mentally and physically, how to meditate and use visual imagery to help in the treatment.

From the beginning, the whole family was involved. My older daughter of nineteen years, along with my husband and I used to take it in turns to accompany Russell to the hospital. Not just to sit outside in the car but to be with him during treatment.

By being with Russell, we were sharing the experience to some extent. It is so easy to alienate the person. Because of the pain, one wants to block off and avoid the reality.

There is a temptation for family members to pretend nothing is amiss by continuing their normal daily routine and by isolating the person who has the cancer.

As a family we grew together. Russell emphasised this point:

"Cancer is a crisis for the whole family. Only if the family reacts as a team and changes together, can real change happen."

The family and not just the cancer patient has to change and become involved. My younger daughter of thirteen used to make his carrot juice.

We changed our way of eating to support Russell. We ate less meat and more salads. Russell began to make his own food and we shared in this by eating what he had lovingly prepared.

At this stage the family maintained hope in the face of uncertainty. We especially didn't cling to the unrealistic hope of a so-called cure. We saw the treatment as hopefully resulting in some containment of the cancer.

A crisis occurred during the middle of chemotherapy when Russell came to my husband and I one Friday and said that he was unable to go for treatment, he just felt his body had rebelled. In his words:

"I was unable to submit my body to chemotherapy. I wanted another cancer patient to talk to. It was frightening to take that step not to go."

One of his fears was rejection by his consultant, so I phoned her to explain his feelings. I felt that in this instance Russell needed the space not to go. Treatment, we realised later, is helped if the patient works with it and not against it.

Her only response was a command to bring Russell to the hospital. There was no understanding or empathy with his painful dilemma.

Russell was frustrated by the lack of communication in the hospital, especially with his own consultant, where the relationship was based on authority and power and not on trust and openness.

By being with Russell whilst receiving treatment, we were sharing the experiences to some extent

This resulted in a growing sense of isolation, so he decided to start a self support group for young adults with cancer.

He only met one person his age with cancer in the hospital. He later discovered that one of the reasons for this was a deliberate staff policy to keep those patients separated.

In fact, when he spoke to his consultant about the group, she said he should only have those cancer patients with a good prognosis. The implication of this was that he mustn't see people who might be dying. Russell felt very intensely about this. He felt that his consultant didn't understand what cancer really means - having to face an overwhelming fear of death and one's own mortality.

What motivated Russell was, in his words,

"A need for emotional support from other cancer patients."

Despite a total lack of interest from all at J Block, the self support group was established by Russell through media exposure and it functioned until we left for overseas.

Our relationship with our GP illustrates the opposite of what happened in the hospital in terms

of communication and caring. We had actually changed our GP shortly after Russell's diagnosis.

We felt we needed a person who was available, supportive, open and honest about Russell's cancer and his prognosis. We wanted a relationship based on trust and not on dependence and compliance.

We had begun to emerge from the initial stages of turmoil and chaos. We were now more able to identify and state our needs as a family.

After six months treatment, a metastases was discovered. The cancer had spread to his kidneys.

This precipitated another crisis for the whole family. Russell felt a sense of failure. He felt he had lost control over his body and he was unable to meditate.

All that the hospital could offer was another eight months of chemotherapy. Through his meditation and as part of taking responsibility for himself, Russell had learned to listen to his body and to trust what his body told him, so he decided to refuse further chemotherapy.

The family felt close to despair. As Russell summed it up:

"We reached the limit of what we could do on our own."

We needed more input of a different nature, mainly on the psychological and supportive levels.

Russell and I left for London and Bristol. We were admitted as in-patients at the Bristol Cancer Help Centre, a therapeutic milieu for cancer patients and their families. Our two weeks in Bristol, in an environment of total support and acceptance was a catalyst for fundamental change.

The Centre works alongside conventional medicine, focusing on the whole person: body, mind and spirit. Emphasis is on self responsibility, self awareness and learning to direct energies in a positive way to assist in the healing process.

Cancer is viewed as a crisis of the whole person, so to deal with it, one has to look at who you are as a person and how you deal with stress in your life.

We learned techniques of relaxation, visual imagery and meditation to cope with our stress.

For the first time, we were exposed to people talking about the quality of life and of the importance of living in the here and the now. Living each day to the full and facing death openly.

In this atmosphere of care and compassion, we were able to begin to move towards the acceptance that the cancer was not being contained. Russell said:

"For the first time it was OK to have cancer. It was such a safe environment that it was OK to let go. Bristol opened whole new doors for me. I had thought of myself as being splintered. In Bristol I learned to put the splinters together into one block of wood."

A significant development, stemming from our shared experience, was the fundamental change in our relationship.

Russell and I had always been close but at times it was a somewhat typical relationship between a teenage son and his Jewish mother. We were able, through openness and the willingness to take risks, to transcend the Mother/Son relationship. We learned to relate one-to-one.

This change in a sense, freed me to be myself. It allowed me to be vulnerable in front of Russell and to share some of my pain with him.

He experienced frustrations in the relationship with his doctor based on authority and power and not on trust and openness

Whilst in London, Russell decided to have radiotherapy, hopefully to contain the metastases in the kidneys.

What is relevant here is that our experience with the London consultant was completely different from that in Cape Town. For the first time a physician spoke of the importance of preserving the quality of life, not just extending the duration of living. Treatment was mutually negotiated and Russell agreed to more radiotherapy because he felt he was part of the treatment process and not just an object to be treated.

In spite of the radiation, we maintained our quality of life as tourists, seeing the sights of London.

A favourite and special place of interest for Russell was Regent's Park where he used to watch the swans and the Mallard ducks. Initially he pictured himself as a duck, paddling furiously and searching frantically.

Gradually he began to identify with the swans; flowing with the river, symbols of integration, balance and unity. As he expressed it:

"I was able to let go of the struggle, to yield, to learn resilience."

We returned to South Africa, having been away for three months. A priority for us was to re-establish communication as a whole family. It had been difficult for my husband and my two daughters without us. Despite frequent telephone calls, they had felt cut off and isolated from our experience.

We spent time together as a family, talking of the changes that had occurred in all dimensions: emotional, mental, physical and spiritual.

Russell and I gently helped the family to work towards the acceptance of the painful reality that

his body was deteriorating. We learned to live each day with a special awareness and intensity, knowing the time with Russell was limited.

Russell returned to the hospital on his terms, only for the purpose of monitoring his physical condition. He refused a further offer of eight months chemotherapy, saying:

"They couldn't cope with my dying. They offered me treatment for them but not for me."

The staff were unaccustomed to a patient making decisions about his treatment, especially one of Russell's age, and we met with a cool response.

Russell's consultant never made contact with him again.

Our life as a family revolved around Russell. He spent his last three months preparing for his death. Despite his physical limitations, he lived each day to the full by going to the sea in a wheel chair, attending Thursday evening concerts at the City Hall and indulging as often as he could in his favourite foods - oysters and smoked salmon.

He spent a great deal of time and energy talking to friends, helping them deal with their grief at his dying. He said goodbye to close friends, giving them each a special present.

We were completely open about his dying in the family. There were never any secrets between us. Through his unconditional love, he gave us the strength to let go of him. He was able to express his total acceptance of death:

"In saying I'm dying, I'm able to live ... I am living my dying ... the dying is easy, it's the living that's hard."

He chose to die at home, surrounded by family and close friends.

Russell had no fears about death, he didn't need anyone to tell him when he was going to die; through listening to his body, he knew.

Cancer is a crisis of the whole person; treatment should involve the whole person

He had assurances from our GP that he would not be in any unnecessary pain. He spent a great deal of time discussing and planning his funeral and who would speak at it, selecting the music and writing a special poem to be read at the service. He knew that when he was ready to let go, he would do so.

On the 20th of August, 1984, one by one, the family let go of him and he of us.

Nothing was left unfinished.

A Poem by Russell Kaplan

Written by Russell Kaplan in July, 1984 and spoken at his funeral service, August 22, 1984.

There is Now

*To which I have appended a beginning,
of sorts, and an ending, of sorts,
But mainly there is this moment*

Timeless:

*Together, you in your garden, me in my garden
We share it.*

*It links us together in a continuous present,
flowing as a river through all
the gardens of
our experience; through birth, through death,
through life, linking us in this timeless moment.*

*Yet in this motion, there is stillness
We feel it here today, rising out of pain and joy,
We try and grasp its entirety and silence
(of which I have become a part)
as it reaches out to touch us all today
to make us aware of our gentle breathing
of the rhythm of life flowing through us and
all around us:
in its beauty, its pain, its continuity
we become aware at last of our fragility.*

*As we close our eyes for a moment,
all around us we can feel love,
for it is love which gives sustenance
it is love which has given me life.*

*It is love which gives me faith and knowledge
now,
in this moment as we separate,
that life continues for all of us,
even though the depths and intensities of our
existence may vary*

*Through space and time the continuity flows,
through all the entrances and exits, all the
gardens of experience
share life's gentle rain.*

*So as in this moment I part from you all
I say hello
knowing we are all awash in the river
which always returns full circle to the sea
So as I make my exit, of sorts
and say goodbye
so too do I await you all on the further shore
I await your entrances into my garden.*

*We are linked in a continuous
present by the Now of our common experience
So Goodbye and Hullo.*

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