INQUIRY INTO GYNAECOLOGICAL HEALTH IN AUSTRALIA

Concetta Nikolovski

COMMUNITY AFFAIRS

REFERENCES COMMITTEE

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13 6 2006

Mr. Elton Humphery
Committee Secretary

Thank you for the opportunity to submit a response to the “Inquiry into gynaecological cancer in Australia”.

I am pleased to submit the following submission relating to Issues (b) (c) (d) and (e) that will assist the Community Affairs References Committee in its inquiry.
I also refer the Committee to supporting documents as separate attachment:

1] “What cancer means to some of my family and friends”.

Please do not hesitate to contact me if you require further details.

Yours sincerely,

(By email) Concetta Nikolovski

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SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

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This submission is relevant to the following inquiry issues:

(b) Extent, adequacy and funding for screening programs, treatment services, and for wider health support programs for women with gynaecological cancer;

(c) Capability of existing health and medical services to meet the needs of Indigenous populations and other cultural backgrounds, and those living in remote regions;

(d) Extent to which the medical community needs to be educated on the risk factors, symptoms and treatment of gynaecological cancers;

(e) Extent to which women and the broader community require education of the risk factors, symptoms and treatment of gynaecological cancers; and

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Cancer is frightening and too many people die as a result of cancer. As time goes by, science and technological advances provide us with better cures and treatments. Similar to any achievements, hard work and effort, endurance a strong support system and money are the key contributors to success. Generally, it is the select few that soldier on hole-heartedly striving to make it all happen. In this case, the common goal is to increase the survival rate of Cancer.

December 1993, at the age of 39, I too was diagnosed with Stage 3 Ovarian Cancer.
I immediately thought of death. I didn't ask the question "Why Me" as most people do. It did enter my mind; however I consoled myself by thinking of my mother's experience. My thoughts were "Why not me, as my mother had it and so many others have had it, now it's my turn". I was in a daze and felt alone. What amazed me initially was that the doctor who delivered me the sad news was very upset and I actually felt sorry for him.

The first I heard of cancer as a child, were the mere whispers among the adult folk. It was forbidden to say the word "Cancer". They called it "The Evil Illness". Death was imminent. It was frowned upon as if it was an infectious/contagious disease similar to Leprosy or AIDS. Fear set in, no-one was game to discuss the mysterious sickness.

I had later learnt that my grandfather had died from cancer. Being so far away, many years had gone by since my father had seen his father and to do the right thing, he left his family and flew Italy to be watching his father die. Many years after my father was diagnosed with anxiety and as

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I relate to my experiences I can understand the impact it has on one's wellbeing, whether it be the cancer victim and their family.

I had just had my daughter, Sonja November 1977 and March 1978, my mother then at the age of 42 was diagnosed with Ovarian Cancer. Fortunately, Mr. Robert Rome Senior and the nursing staff gave some hope to this was our family's first real awareness and introduction to Cancer. Treatment was available that gave hope. There were endless hospital visits and blood tests, chemotherapy, radiotherapy and then remission. Remission was like a breathe of fresh air. I was continuously there by her side.

It was only a year or so that my father had died, so the whole family pitched in helping in every-way possible. Everyone shared different duties while I cared for my mother. each contributing best where they could.

There was no funding available and nurse visits were not affordable. During the 3 months that my mother became bed-ridden, on death road, Mr. Rome Snr allowed my mother to be nursed in hospital.

So much was learnt during the 3 year battle that finally took my mother's life. I wasn’t concerned about questioning the hospital system, the medication and the doctors. It was a natural attitude to trust the medical professionals with what they were doing and there was little choice but to accept what was available. We have been conditioned to respect those people with a medical profession. They are the ones who have sacrificed their lives to committing in serving society.

My mother followed the expert advice given by the doctors and nurses and focused on trying to live her life as normal as possible. Her eldest son was planning to get married. Her illness was not going to interfere in those plans, the younger children were at school, they were not going to be distracted and pulled away from their future. As a devout Roman Catholic, she was guided by God. Her religion gave her peace while preparing for death and wondering how her children would cope without her guidance.

She made plans to ensure there were enough money for food, education and general living expenses. She was resourceful and had learnt to do without the luxury items or pleasures such as going out to a restaurant. She soldiered on with pride and dignity.

There was never any blame placed on another person there was reason for whatever happened in life.

Fortunate to have so much to focus on, it was left to the medical staff to do the rest. That gave her some comfort, but this did not cure her of the Cancer. The cancer had spread too far, it was too late, there was some hope initially, but the 3 year battle came to an end. She was loved and respected by all her family and friends who labelled her "The Saint". A Saint because even prior to her having Cancer, she was compassionate, understanding, forgiving and patient and raised 6 wonderful children. All who do her proud.

My experience has really taught me to “understand " not just "to be understanding". I have struggled in accepting cancer and trying to understand what cancer does to people.

I am fortunate to have survived as I am able to share positive energies of hope to my loved ones, family members, acquaintances alike.

Being touched by cancer and living cancer has added a new dimension into my life, a certain paranoia and living on the edge. I strive continuously to keep my well-being in shape. It has had an impact on my whole family as I struggle with coming to terms with what will happen to my daughter, will she suffer the same as I. Her journey has started at a young age. Fortunately, she has is being monitored and with careful medical attention she will be saved from the trauma that I have endured. Then, there is my younger sister who has commenced her journey by having her Ovaries removed as a preventative measure. She sacrificed having children as opposed to risking cancer. Living with cancer is an everlasting journey.

My submission is a mere snapshot that depicts how multicultural women see cancer as a death sentence and therefore a need for ongoing improvement with attention to communication/information brochures.