CANCER INQUIRY

TERMS OF REFERENCE 4 (a) (ii) and (iii)

The following are comments of my experience with bowel cancer which fall into the above.

ANGER

I wasn't angry due to the "why me?" thinking. I was angry because bowel cancer is preventable. Why didn't anyone tell me?

I felt as if I had done everything else right:

Pap-smears
Mammograms
Don't smoke
"Slip, slop, slap" & "Wear a hat"
Aids prevention
Plenty of exercise for prevention of osteoporosis and general health
Watched my diet
Cut down on tea and coffee
Drank plenty of water
Bridge and crosswords to exercise the brain and keep Alzheimer's at bay

I knew about the above from my GP, newspaper advertisements, television commercials, etc, but when I saw the blood on the toilet paper I just thought of haemorrhoids. Bowel cancer didn't even enter my head because NO-ONE TOLD ME.

It appears to me that some health problems are made "attractive" or "appealing" to the public for donations and/or publicity, eg:

Olivia Newton-John
Delta Goodrem
Children with Leukaemia
Bobby Goldsmith Foundation

But bowel cancer is so "unattractive" and the only "public face" that I have heard of who had bowel cancer declined to be involved. So perhaps unknown but willing people like me should be used to publicise it.

COST of PREVENTION

As usual funding is raised as an issue. Sure, a colonoscopy costs more than a mammogram or a pap smear, but it also saves many times its cost:

Colonoscopy - 100's of dollars
Bowel cancer treatment – 10,000's of dollars (not to mention the 1,000's that the patient is out of pocket)

TREATMENT

For patients like me who are advised they will need a colostomy, a second opinion should be sought, if only for peace of mind. I did this, and the second surgeon gave me a 50% chance of being able to have a reversal.

SUPPORT

This is very hap-hazard.

The “Look Good Feel Better” program is excellent.

The CanSupport at RNS is very good.

The psychologist at RNS was very comforting.

My initial contact with the Cancer Council of NSW was when I had been told I would need a colostomy and it was excellent. I received information booklets in the mail and was put in touch with someone in their volunteer group.

My second contact was not so good – there are no volunteers with an ileostomy.

During my third contact I was told that there were no volunteers who had had the reversal operation but in fact there was one lady who I was put into contact with from another source (connected with the Cancer Council).

The Ileostomy Association was helpful when I need to talk to someone with an ileostomy.

It appears that there is only one Bowel Cancer Support Group in Sydney – and that is in the Penrith area.

I wasn’t initially told about taking Metamucil to assist with my incontinence.

I had no idea there was an Incontinence Help Line.

I didn’t know that my Stomal Therapy Nurses could also have advised me about incontinence.

There are other things that it would be useful to know beforehand rather than finding out afterwards by chance, luck or trail and error, eg: underwear, pads, cream, special swimming togs.

I would encourage surgeons to ask their administration staff to put together a folder with all the information a patient might have need for – some of this may just be phone numbers of various support groups and supply companies.