Senate Community Affairs References Committee
Cancer Inquiry

1. We write in reference to the above Inquiry referred to the Committee by Senator Peter Cook (WA). We wish to make a number of points in relation to the terms of reference, preceded by an explanation of our experience with cancer and a general comment.

Background

2. Bill Parker was diagnosed with lung cancer in February 2004 following a chest XRay ordered by his GP. The subsequent tests, ordered by the thoracic specialist to whom he was referred, confirmed the lung cancer, nodal involvement between the lungs and metastases in the brain and spine. Radiation to the brain, followed by chemotherapy was the recommended treatment, to be determined through consultation with the oncologists at The Canberra Hospital (TCH).

3. Following the radiation treatment at TCH, chemotherapy treatment took place at the Calvary hospital as it was more convenient to Fran's place of work and to our home 50 kilometres north of Canberra.

4. Over the next seven months, our experiences with the 'system' were characterised by:

    a. lack of communication between the relevant specialists despite assurances that they would discuss our case (with the exception that the medical file was usually available);
    b. a frequent need in the early stages to repeat to various medical personnel the history of diagnosis, and at times even the results;
    c. generally speaking, a willingness to provide explanations of the rationale for the treatment and detail about it, however this was offered in a highly statistical form requiring interrogation by us to make sense;
    d. by all but our GP, a complete unwillingness to discuss any potential action other than the medical treatment being provided by the specialists;
    e. other than by our GP a view that Bill's 'case' was incurable, and that the only point in having the treatment was symptom management (even though there had been no symptoms);
    f. a failure to provide any advice that alternative sources of information existed - beyond the very limited, and medically oriented handouts from the hospital – and that this information might not only enhance the treatment, but make it more palatable;
    g. the need for us to educate ourselves and to be prepared to be assertive both in questioning the medical personnel and in handling the 'system' at various points.

5. The diagnosis of cancer is devastating for the person concerned and their family and friends. In this context the impersonal, even negative, and

uncoordinated approach to the management of cancer by the specialists and the hospitals can be very dehumanising.

6. The nursing teams in both the hospital and in the community made an effort to ensure that we had access to fairly basic medical information and to information on cancer support groups, however there was an overwhelming feeling that we (even with the co-operative and broad minded approach of our GP) were the only ones who would 'case manage' the situation.

7. By October 2004 Bill's lung cancer had halved in size, the number of brain tumours reduced from 4 to 3 (and the largest from 10mm to 2mm), and the spine 'metastases' were no longer able to be located.

8. Our 'management' of Bill's case included:

    8.1 acquisition of a wealth of information: this had a therapeutic effect in itself, however was especially invaluable for the options it opened up;

    8.2 high intensity irradiation of the brain and spine on five successive days interrupted by a weekend between days three and four and six cycles of two treatments each of chemotherapy (with carboplatin and gemcidabine);

    8.3 minimisation of intake of toxins – primarily conversion to organic food and complete removal from the diet of a range of food products with proven carcinogenic effect;

    8.4 a range of actions to maximise the health of the immune system, including:

    - <u>special attention to the diet</u> e.g daily fresh juice made from vegetables rich in antioxidants such as beetroot, carrots, garlic. Special attention to diet to ensure saliva became and remained at an alkaline pH.
    - <u>supplements</u> e.g 2.5gms spirulina daily, a known immune booster; 1.0gm daily of Vitamin C with bioflavonoids; one coenzyme Q10 tablet daily, one bioAce EXCELL with selenium, and one Korean ginseng (Blackmores)

    8.5 Elevation of the alkalinity of the body: walking about 2.5km at least once a day at a brisk pace to ensure good oxygenation of the blood. Cancer is known to prefer anaerobic conditions, a point which was <u>never</u> mentioned to us by any of our doctors;

    8.6 a range of actions to understand and capitalise on the knowledge of mind/body relationships derived from other cultures, and research in the field of mind/body medicine. None of the medical practitioners we dealt with were aware of books such as "New Frontiers in medicine' by Dr Craig Hassed(senior lecturer in General Practice at Monash University in Victoria) published under the auspicesof the RACGP, or "Molecules of Emotion' by Candace Pert.

8.7 attendance at the July 10 day residential program for cancer sufferers and their carers at the Gawler Foundation in Victoria;

8.8 one and half hours of meditation each day from mid-July after training at the Gawler Foundation

8.9 delegation of management of our vineyard to a manager to enable Bill to undergo the medical treatments and to concentrate on improving and maintaining a high level of immune system health

9. ***Of our nine pronged approach, only one has been at the instigation and/or direction of the medical profession. The rest has been planned and totally managed by ourselves, with the support of our GP.***

10. Since the treatment concluded in September 2004, the size of Bill's primary cancer has remained essentially the same (i.e. half the original size). This is an excellent result. The residual ill effects of the medical treatments (such as the loss of muscle condition) are slowly repairing, and he still has no symptoms. This is despite a totally pessimistic prognosis a year ago.

11. There are a number of factors which have enabled us to achieve this outcome. These are not necessarily available to many in the population and for those people the options available when confronted with a diagnosis of cancer must be very limited.

- We have <u>the financial resources:</u>
  - to have attended the Gawler Foundation;
  - to have been able to relieve Bill of the need to work fulltime;
  - to have acquired the information (much of which was on the internet but much is in books); and
  - to be able to afford to eat primarily organically grown food and purchase the supplements.

- We are both <u>well educated</u>, Bill a scientist and Fran an educator turned senior public servant who worked for a decade in the health industry. This:
  - enabled us to locate and interpret the information and to translate it into action in our daily lives.
  - meant we had some understanding of the medical system and its motivations which was helpful but also gave us a surety, along with good information, about being assertive when required.

- We have a <u>family and social network</u> the members of which have been willing and able to offer us considerable practical and psycho-social support as well as to appreciate what we have been doing. It is hard for us to imagine doing what we have in the past year without that informed support.

General Comment

12. The attitude and management by most of the specialists is, perhaps by the very nature of the requirement on their skills, limited to the very narrow confines of their speciality. They were knowledgeable about the evidence bases (population based trials) of their treatment, but there was complete ignorance of the evidence of research in various areas of science and other disciples pertinent to the healthy optimal functioning of the human body, and the causes of illness, including cancer. This ignorance precludes any intelligent assessment between doctor and patient of potentially productive action that an individual might consider to build those elements of a healthy body which would maximise the fight against the cancer.

13. The fundamental flaw in the current approach is that it is dominated by the particular perspectives of the medical specialities. In this context 'multidisciplinary' refers only to small teams of closely related medical personnel, and 'evidence based' is limited to population based "Cochrane style' trials.

14. While population trials are important for the purpose they serve, the reliance on them as the only evidentiary basis for 'management' of a particular cancer patient effectively makes epidemiology research and the rest of science mutually exclusive.

15. There are bodies of science representing our biological, physical and social existence (including the human body) where equally rigorous research has produced evidence of a different, but very relevant, nature. The usual scientific method of hypothesis, experiment, analysis, results, peer review, publication, replication of results, produces the 'evidence' on which most technological and human advancement is based.

16. However, medical specialists dealing with cancer not only do not use the body of biological and medical evidence relevant to cancer causation and treatment, they don't even seem to be aware of it.

17. Because cancer management approaches are population /epidemiologically oriented, patients become simply statistics. They are, in fact, individuals, each with their own body and environmental history. Patients are NOT a population cohort. While the specific medical treatments may need to be based on epidemiological evidence, and the specialist may be better for their participation in controlled medical trials, their management of the individual 'case' needs to draw on all the other sciences. In particular it needs to derive value from the science of human biology, and of the emerging field of psychoneuroimmunology.

18. If a truly systematic approach were taken the management of the case would draw upon all relevant knowledge. This includes, but is not limited to scientifically based evidence. Extrapolating from the evidence emerging about the connections between mind and body would suggest that it is, in fact,

dangerous to continue current practices. The negativity of the specialists, their denial of the power of knowledge to patients may, in itself, be inhibiting better outcomes. One was actually made to feel a little stupid when one said to the various specialists that cancer results partly from a failure of our immune system!

19. Governments, both the Australian and State and Territory, have a responsibility to ensure that support is available to every individual and that not only those who can afford to do the research and then take the actions benefit.

Term of Reference

For inquiry and report by 23 June 2005:

a) the delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

(i) <u>the efficacy of a multi-disciplinary approach to cancer treatment</u>,

The multidisciplinary team, as understood by the medical profession, is a small group of medical personnel each with his/her own specialty. This has proven to be a highly successful way of diagnosing and treating some cancers (such as manifest in BreastSreen Australia where the multlidisciplinary assessment teams were established based on research that demonstrated effectiveness).

It is an extremely limited view of' multidisciplinary'. Cancer, like many illness, is a disease the causes of which are influenced in large part by lifestyle and environmental factors (such as carcinogens in food products). Many of the solutions or cures are therefore in lifestyle change.

We are unaware of any research which has been funded to test a fully multidisciplinary,' whole of life' response to the treatment of cancer. Funded research into the multidisciplinary approach of organisations such as the Gawler Foundation in Victoria could well be supplemented by specific case controlled studies where the management of individual cancer patients is properly multidisciplinary.

(ii) the role and desirability of a case manager/case coordinator to assist patients and/or their primary care givers,

Given the requirements on individual specialists to maintain their clinical knowledge, it is probably impractical to expect them to do any more than change their attitude. This in itself is a major stumbling block to the opening up of medicine to complementary (not even radically so) views.

In our experience, the nursing staff, while having a more humane approach to patients, were equally limited in their willingness to embrace anything more than traditional medical practice.

The problems for the medical personnel is that they wish to practice 'evidence based' medicine (as they understand it) and they fear litigation. They do not have the broader knowledge or the time, and they are afraid of being misinterpreted, therefore they are not able to provide a patient with access to all the real options for both management and treatment.

Ideally General practitioners would be resourced and trained to be able to manage a truly multidisciplinary approach, however this is a long way away and they too are confined by the constraints and demands of their practices and their fear of litigation.

Therefore the state needs to take responsibility to:

- *research the efficacy of case management which brings together the medical, scientific, psycho-social and traditional disciplines, and*
- *trial case management via specifically trained case managers who bring together <u>all</u> the disciplines and knowledge and supplement the current medical practices.*

This would be resource intensive, however less so than training medical personnel to doit, and likely to be more effective. It might make people live longer and they may then access further treatments and be a cost to the medical budget. On the other hand, many cancers, if diagnosed early enough, could potentially be cured if managed properly.

The training for case managers in cancer would also have wider applicability as the 'treatments' for cancer (other than the medical ones) are essentially the same for a range of other 'lifestyle' illnesses.

(iii) differing models and best practice for addressing psycho/social factors in patient care,

There is a wealth of information available to the Committee to investigate these matters. However in our experience, the Gawler Foundation in Victoria has extensive experience in this area and runs extremely effective residential programs for cancer sufferers and their partners/carers. Ian Gawler now has over 25 years experience in integrating psycho-social elements into the management by cancer patients of their situations.

Additionally the work of Professor Avni Sali at Swinburne in Melbourne and others in the profession interested in intergrative medicine, have much to offer in this area.

(iv) differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians, and

(v) current barriers to the implementation of best practice in the above fields: and

One of the problems is that the definition of 'best practice' is limited to a medically defined practice dominated by the research from controlled trials. If there are to be real improvements in the prevention of cancer, and in its management, it will take an approach much broader than that recommended by the traditional medical perspective.

b) how less conventional and complementary treatments are researched and judged, with particular reference to:

(i) the extent to which conventional and complementary treatments are researched, or are supported by research,

In developing the many-faceted approach we have taken to the management of Bill's cancer, it was obvious to us that there is little funding for research other than for clinical trial for various drug based treatments. A very small proportion of the many millions devoted to that research might provide better outcomes for cancer sufferers and the society.

(ii) the efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies, and

There is a need for basic recognition by the medical profession that treatment should start with recommendations of lifestyle changes which will boost the competence of the patient's immune system.

(iii) the legitimate role of government in the field of less conventional cancer treatment.

Government is the only body which could enable more imaginative research, and is the only body which could risk trialling a truly multidisciplinary approach to cancer management.

Charles William (Bill) and Frances Parker

20 March 2005