Submission to the

Inquiry into services and treatment options for persons with cancer

by the
Community Affairs Committee,
The Senate, Parliament of Australia

March 2005

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founder (in 2000) and ‘facilitator’ of the
Australian Internet Brain Tumour Support Group
http://health.groups.yahoo.com/group/OzBrainTumour/

OzBrainTumour is not an organisation with a view on anything
but an open group where people
(over 200 hundred subscribed at any time these days)
share information and provide mutual support, strength and empowerment.
This is not a submission on behalf of any group,
but an individual submission informed by what I have learned, with others, along this road.

In memory of Margaret Gray 1949-2001

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RECOMMENDATIONS

1 That it be recognised that case management based on support for the whole person is essential.

2 That, in particular, the opening discussions with patients with cancer diagnosis focus on that whole perspective, not just the perspective of the first line professional.

3 That case management be focused on supporting the strengths of the person with the diagnosis and granting control and support for patients and carers who wish to have degrees of responsibility.

4 That choices of such paths of degrees of responsibility not be immutable, but subject to review and change.

5 That the management plan include assurance that all aspects of support for family are considered and developed.

6 That the committee assess or call for broad studied assessment of the value of computer-based systems for case management, with special regard for the prospective time to implement, prospective effectiveness, prospective consumption of limited resources.

7 That the committee endorse the proposition that we would improve the effectiveness of the health system enormously if 'caring' became a natural part of education, as part of a general acceptance of personal responsibility for health.

8 That the committee call for study of the pastoral needs and care for oncologists, not to identify impaired practitioners but to support their “resilience, aspirations, talents, uniqueness.”

9 That a study also be made of the education and guidance given to junior medical officers dealing with oncology patients in public hospital systems, to ensure compassion, understanding of treatment options and good guidance from their seniors and management (link with recommendation 2).

9 That empowerment through responsible case management be seen as the core need for meeting socio-psychological needs.

10 That the broad context of the state of community in Australia is absolutely relevant and ‘solutions’ within the framework just of health administration are not going to work — solutions have to be framed in new social policy.

11 That self-development programs like Gawler and King need to be brought into the ambit of reasonable care options despite the difficulties fitting them in evidence based medicine frameworks.

12 That we have to look hard at the doctor-patient relationship if health care is going to advance.

13 That a properly funded system to support GPs in managing whole cancer cases, with a network of advice, and the development of allied heath teams, be considered.

14 That the use of the internet by support groups should be encouraged, with sensible guidelines emphasising community values.

15 That we try to address problems associated with understanding the dying process, to remove some of the associated stress and allow more sensible planning for it with quality of life and best use of time. Specialness and sanctity need not mean secrecy.

16 That partners and carer parents or carer children – and whole families – be helped to a better understanding of palliative care options so they don’t destroy themselves along this difficult path.

RECOMMENDATIONS (continued)

17 That the oncology profession address the problem of different knowledge levels in regional areas by an enlightened approach to recognising that not all professionals can be all knowing, and developing improved systems for consultation and information sharing.

18 That doctors generally be encouraged to recognise that patients may get ahead of them in knowledge even of conventional treatments, and respond to suggestions from patients with a concern to nurture informed patients.

19 That arrangements for financial support for remote patients be enhanced and linked to improved case management.

20 That the committee resist recommendations for substantial new layers on the existing public health system or for massive flexibilities at this point in the PBS or Medicare.

21 That the committee make recommendations urging some measures of summitry on the issues of dysfunction in the health systems, not about the money first and as far as possible not from the trenches of organisations... or states

22 That the terms of reference for any such summit embrace:

- the need for individual responsibility for health;
- the need for community building to sustain individual health;
- the nature of the doctor-patient relationship;
- the nature of workplace relations between health and allied professionals;
- the relationship between community health and consumption of medical goods and services
- as a clearly defined second phase, perhaps with different people, appropriate balances in government expenditure and ways of containing the costs of delivering goods and services.

23 That the inquiry focus in the first instance on whether the cause of cancer – the mechanism of tumorigenesis at cell level – is understood.

24 From answers to that question, more flow:

- is research addressing that core problem?
- how best is that problem addressed?
- what proportion of cancer research is not doing that, so what then is it doing?

25 That where remedies are in widespread use and attract significant belief in their efficacy, epidemiological studies be encouraged to establish truths; results of such studies should feed into acceptable practices of advice to cancer patients, as matters quite separate from any consideration of HIC subsidy.

26 That the committee itself resist encouragement to endorse particular treatments.

27 That there be a study of community benefit and long term budgetary advantage in significant government financing of fundamental scientific research of the possible causes of tumorigenesis — away from the ‘conventional’ treatment environments where research is dominated by patent holders.

28 That consumers continue to be protected against exploitation with wonder cures.

29 That the murky situation where much is happening ‘illegally’ in the accessing of alternative treatments be resolved sensibly and compassionately to community benefit.

Thank you for this inquiry.

I wrote the following on the night after my wife Margaret Gray (at one time on Senate staff, with the Parliamentary Relations Office) was killed by a brain tumour in September 2001, 500 days after diagnosis:

> *It is evident to anyone dealing with cancer of any kind that medical science knows very little about the causes and the management of such disease, probably because the basics of cell biology are not well understood. Unprecedented amounts are spent daily on research into disease. Some of this yields commercial profit and may prolong life for some, but this should not be confused with real understanding. Gene research is popularly held to offer so many hopes, but there are other areas of cell behaviour which go neglected and may be more important. Hopefully the broadening of community discussion, on the basis of more common knowledge of the inadequacies of understanding of how organisms like us run, will lead to a future where medicine, as practised now, will be regarded with the kind of amusement that we at present show for medical 'science' of 100 years ago.*
>
> *We live in Australia which has a wonderful public health system, reflecting fairness for all. We must record our indebtedness to that system for providing Margaret with access to a great public teaching hospital offering a world standard of excellence as a brain tumour treatment centre, doctors and nurses who became 'family' to us. We must also express the concern we developed over the same period that public policy* ***and*** *public attitudes, on present trends, could seriously deprive Australia of the intellectual as well as democratic asset that exists in the public health system. There is very little in the private hospital system to compare, or that seeks to compare, with the dedication to intellectual specialist excellence in both nursing and doctoring that the public health system provides.*
>
> *This web site* [http://aplaceof.info/margaret/index.htm] *also records my own great love for Margaret. My job as a carer has been the greatest job and the finest privilege I have experienced.*
>
> *We need to recognise more clearly that in dealing with health, the carer has a crucial role. Doctors and nurses are in no way as well placed to understand a patient wholly and we must never expect that of them. We would improve the effectiveness of the health system enormously if 'caring' became a natural part of education, as part of a general acceptance of personal responsibility for health.*
>
> *To the extent that there is such anxious dependence on doctors and such popular demand for infallibility of the medical profession, we blind ourselves and doctors to the inadequacy of present knowledge and treatment and we reduce the prospects of necessary change and improvement.*

This submission is based largely on those propositions, which still seem valid.
I have sought to make recommendations under the headings of the inquiry's terms of reference, but there are some recommendations that apply to several headings. I beg forbearance.

Issue (a) The delivery of services and options for treatment for persons diagnosed with cancer

I think that before proceeding to matters of detail, we need some perspective[1] .

The sad thing is that medical science still does not know what causes cancer, why cells turn tumorous. There are several distinguishing features of tumour cells, but exactly why and in what order cells change to be like this is not settled. Some key factors are:
[1] In tumorigenesis, cells alter the way in which they make energy, they alter their *respiration*. In healthy organisms, including people, mitochondria in every cell make an abundance of energy and also carbon dioxide from sugar and oxygen (mitochondrial respiration). Tumour cells abandon this and make energy from sugar alone (glycolysis) in the manner of bacteria, also the manner of all cells before the appearance of mitochondria a billion and a half years ago, so there is something retrograde happening in the cell. Otto Warburg won the Nobel Prize for Medicine for discovering this in 1931[2] , but it seems mainly forgotten — even though it is in this area, the general respiratory health and happiness of the cell, that notions of linkage between happiness and stress and wellness and sickness are probably best understood at the level of cellular biology.
[2] cells undergo *mutation*, and this mutating process can increase in pace and be very diverse. This is the quality which is most evident as tumours grow and spread. Particularly because of the attention in biology to the human genome, this genetic mutation aspect tends to be the focus of research, though whether the mutation precedes the altered respiration seems not settled, and thus whether gene research will resolve the cancer problem is in my view moot. Guenter Albrecht-Buehler's web site discussion of 'cell intelligence' elegantly illustrates the very basic level of uncertainty behind genetic theories.[3]
[3] cells *dedifferentiate* and lose their ability to *differentiate*. Loss of this ability to differentiate in a developed organism produces cells which are not helpful, which are cancer cells; this process is not well understood[4] . *Dedifferentiation-redifferentiation* is a process which is also present in wound repair also not entirely understood.[5]
[4] tumour cells can - in malignant and aggressive forms - *reproduce* very rapidly. In medicine various things are graded from I to IV (1 to 4) in order of severity. Malignant brain tumours are graded I to IV according to degree of malignancy and aggressiveness ('benign' growths are not graded). The pathology of tumours is not simple and even the best institutions do not always agree on the identity and grading of tumour samples.

People generally have some cells making mistakes, pursuing aberrant growth and reproduction patterns, all the time — in the late 1960s, a study of bodies of healthy car accident victims in the United States found 'cancer' in every person over fifty. There are natural regulatory systems which normally allow us to avoid progressive disease by eliminating such problem cells. The mitochondria in healthy cells appear to keep watch and cause a deranged cell to commit a kind of euthanasia, known as *apoptosis*. Some theories of cancer think in terms of one rogue, mutated

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[1] Text following is derived from a document I wrote in 2002 on *Dealing with Brain Tumour* which can be found here: http://aplaceof.info/braintumours/index.html
[2] http://almaz.com/nobel/medicine/1931a.html
[3] http://www.basic.northwestern.edu/g-buehler/cellint0.htm
[4] see for example
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11108657&dopt=Abstract
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7541145&dopt=Abstract
[5] see for example http://www.bdc.brain.riken.go.jp/~rpaine/SpinalCord/ScienceAbstracts.html

cell leading on to millions. On the other hand, given that the mechanism of *tumorigenesis* (a healthy cell becoming a cancer/tumour cell) is not understood, doctors also recognise that there can be an ongoing process of tumorigenesis - no matter how many tumour cells you kill with treatments, somehow more cells may also be turning tumorous.
[5] There is another important piece of information. Tumour cells, as they proliferate, need a lot of blood supply to feed them. They thus develop new blood vessel systems which are messy and very different from normal healthy blood vessel systems. This creation of new blood vessels is called *angiogenesis* and opens the door to some treatments which try to stop angiogenesis - *anti-angiogenesis*.

I set out these general propositions to provide a basis for examination of the treatment options.

Surgical removal of tumour material (debulking) may seek to remove all tumour cells and thus all the cancer. Success depends on whether the tumour is discrete or diffuse; whether it is readily accessible for surgery; whether infiltrating or seeding by nature, whether *metastasising* (appearing elsewhere in new forms). The outcome may be simple success, or may only buy time.

> In the most commonly diagnosed brain tumour, *Glioblastoma multiforme grade IV* [GBMIV] the cell duplication period can be as short as 15 hours (tumour can double in size that quickly) and it can be the case that a 'successful' debulking operation of say a peach sized mass can be followed by comparable mass reoccurring in a matter of weeks. Recall the speed with which popular ABC journalist Andrew Olle was killed by a GBM in 1995.

Radiation and chemotherapy focus also on the rapid reproduction of cells, attacking cells when vulnerable during cell division (mitosis)... inasmuch as tumour cells are dividing frequently, they are thus vulnerable – along with healthy rapid reproducers like bone marrow (white blood cells and platelets), hair and the sensitive moist surfaces of bodily passages of the digestive and urogenital tracts. Hence the side-effects of these treatments, especially chemotherapy, by way of insult to self-image (hair loss, etc), the great hurts and pains in damp places and the risks of immune system failure and haemorrhage.

> Standard treatment for GBM has for a long time been debulking followed swiftly by radiotherapy. Chemotherapy standard in the US but not until 2000 generally favoured in Australia because of negligible benefits and hurtful impact on *quality of life*. The PBS in late 2000 altered this situation, covering the cost of a new drug Temodal [temozolomide, TMZ, Temodar in the US] (hitherto about $3700 a month). Temodal's manner of action makes for good impact on the tumour (for those for whom it works - <40%) without great impact on quality of life; many good results in terms of survival of individuals. The best results, 'miraculous' recent survival times seem mostly associated with Temodal + other treatments, but there is no funding for trials of such combinations as they are not related to commercial profit. While serious neruo-oncologists had clamoured for and secured change to the PBS in 2000, in regional centres there was reluctance to use Temodal for quite a while *and in some places this seems to continue.*

Anti-angiogenic[6] treatments focus on [5] above. It is a great irony that the most powerful of these treatments is the drug sauramide, trade name Thalidomide. Thalidomide works against cancers for exactly the same anti-angiogenic reason that it worked to prevent the growth of limbs in foetuses, back when it was accepted in the UK, Canada and Australia (but not the US) as an anti-nausea agent in pregnancy. This sad history[7] means that today Thalidomide remains a prohibited substance, though of recognised value against tumours. Thalidomide is out of patent, and so no drug company will spend the money to conduct clinical trials.

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[6] http://www.pbs.org/wgbh/nova/cancer/faq.html
[7] http://cerhr.niehs.nih.gov/genpub/topics/thalidomide2-ccae.html

> The Sydney (Royal North Shore Hospital) Thalidomide clinical trial for GBM[8] was not supported by any drug company; funding to confirm observed great value of Temodal in combination with Thalidomide seems not obtainable.

This little problem for Thalidomide, of being away from profit centres, is just the edge, however, of the broad problem of balanced study of cancer.

The money trail is closely tied to the fierce poisons of radiation and chemotherapy.

While the focus of treatment is evidence-based medicine, and while the accumulated research evidence is tied in this corner, real understanding of tumorigenesis is not in prospect. This is a great issue about the meaning of life at cellular level.[9]

It is also a guarantee that the health budget will continue to be dragged by the nose deeper and deeper into huge expenditure on often inadequate ways of treating problems partially. A suitable analogy is spending vast amounts on hazard signs and ambulance services for country roads, rather than fixing the roads and educating the drivers.

To reach a future sensible understanding of cancer requires of medical science an exploration of issues of life and death at cellular level and better understanding what is actually happening in the lives of those diagnosed with cancer. There are issues arising from the above which will be taken up below and flow to particular recommendations.

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[8] http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=11763420

[9] see Albrecht-Buhler's cell intelligence page:
http://www.basic.northwestern.edu/g-buehler/cellint0.htm
and for example this:
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list uids=9739355&dopt=Abstract

Issue (a) The delivery of services and options for treatment for persons diagnosed with cancer:

(i) the efficacy of a multi-disciplinary approach to cancer treatment

As a preamble, let me quote again this that I wrote in 2001:

> To the extent that there is such anxious dependence on doctors and such popular demand for infallibility of the medical profession, we blind ourselves and doctors to the inadequacy of present knowledge and treatment and we reduce the prospects of necessary change and improvement.[10]

and also quote former Health Minister, former Senator, former Professor of Community Medicine Peter Baume:

> If we look back 150 years, to the [medical] paradigms and practices of that time, we are likely to smile indulgently. Many of us can see clearly that the belief systems then operating were inadequate to explain events, and have been overtaken. But too many of us lack a capacity to learn from that observation about our current paradigms. If we go forward 150 years in our imagination and then look back it seems likely that practitioners of that day will smile again at our belief systems. There is nothing wrong with this - we are using the best paradigms we have. They are not perfect and they will be overtaken. We need to be relaxed and ready - and not be prisoners of the paradigms of today.[11]

I quote such to underscore that however good the team, in present circumstances it is working with limited resources and knowledge.

In 2000, when my wife Margaret's brain tumour was diagnosed, there was no interdisciplinary team in Canberra. There was also a problem with the radiotherapy queue – Peter Baume remarked to me later that at the time of his inquiry into radiotherapy service the Canberra radiotherapy queue wait was equal to the prognosis for GBM (Margaret's tumour). Poverty of information and service in Canberra led me to internet research and to finding our way to SNOG - the Sydney Neuro-oncology Group, based around Royal North Shore Hospital.

That was an effective multi-disciplinary group: a group, members of which are friends with mutual professional respect (a huge advantage) who work as a team and case manage at the medical-surgical management level. In terms of compassion, skills and matching clinical attack strategy to the attitude of the patient to fighting the problem, these people are at world standard.

There were significant contrasts between that SNOG team and professional attitudes in Canberra. And it's not just Canberra.

It is clear from discussion in OzBrainTumour, over years since, that there remains a major divide between what is available at the several serious brain tumour treatment centres in Australia and other treatment available for brain tumour patients in Australia. What becomes deeply offensive to people in these 'outlying' areas (including some largest biggest city hospitals) is that the further you go from the centre of excellence the greater the tendency for professional arrogance, complacency, disregard of life and the individual **plus** ignorance of latest treatments approved under the PBS.

Given the relatively small number of malignant brain tumours in Australia, I don't think that

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[10] http://aplaceof.info/margaret/index.htm

[11] Peter Baume *The Tasks of Medicine An Ideology of Care* Sydney 1998

there will or should be large numbers of specialists in these things. I do believe, however, that it is wrong and offensive for doctors away from such brain tumour centres to conduct themselves as many do, asserting authoritative command when their knowledge is not good and should be boosted by consultation with experts.

There are some recommendations arising from this later.

Issue (a) The delivery of services and options for treatment for persons diagnosed with cancer: (ii) the role and desirability of a case manager/case co-ordinator to assist patients and/or their primary care givers...

In 2000 I became Margaret's case manager, no one else was there to do the job, there was no notion anywhere that there should be such a person.

Our experience then I now know to be 'normal'.

Granted that there was, when we got to SNOG in Sydney (see previous section), evident collaboration between specialists on the medical front, there was no notion of whole case management. There was a social worker in neurosurgery who performed some functions related to whole of life, but within the compartmentalised life of a hospital the social worker's view was limited. (Though it was something, more than nothing, and precious at the time.)

The notion of case manager begs the question: "what is the case?" Is it the disease or the person facing threat of death? Or more - is the family the case? The burdens upon a family thrust into a cancer diagnosis, care and case management situation are enormous. The impacts are financial, emotional, job-impacting, often destructive to either or both the physical and mental health of others than the person with the diagnosis. So while there is, in the best places, a measure of case management between doctors and while there is some measure of support from social workers, the person with the diagnosis and that person's family are confronted by an enormous number of unknowns at all levels. After over four years helping others learn about side-effects and symptoms, about drugs, about how to deal with doctors to get information or get scripts, how to deal with seizures, when to call an ambulance, how to "give great history" as one triage nurse told me, back then. I know I would be a better case manager now than then — and I do not understand the general disregard or lack of concern for such that prevails so widely. Of course, there are limitations to resources, but I do not see this among the priorities for re-ordering patient care.

Deborah Lock, the 'People Power' candidate for the Werriwa by-election has written to me:

> In health, our system is a mess. Canberra thinks dishing out more and more subsidies to doctors will improve things. No-one at the moment has any incentive to keep families healthy. I'd like to see a family health broker for each family, with incentives to keep families well, and to broker the best care for them when they're unwell.[12]

That seems to me a fearful notion of abdicated personal responsibility for personal health (among other nightmare qualities related to cost and management). Somewhere there has to be a sane balance between the current lack of recognition of the need for case management and provision of varied levels of support for case management, including support for the notion that a patient or carer can indeed be a good case manager.

If you go to a presentation by any health service in Australia about the basis of its performance, you will hear the mantra 'evidence based medicine.'[13]

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[12] private email 28 February 2005

[13] There is a good discussion of evidence based medicine here: http://www.mja.com.au/public/issues/174_05_050301/craig/craig.html

Anyone taking any medical problem to a doctor will know that there is much more going on than observable practices validated using the scientific method, as evidence based medicine is deemed to be. There is a complex interplay of patient expectations AND practitioner's expectations, not only about the health or disease issue but also in a whole lot of intuitive areas.

A new Australian text book on mental health nursing contains a very powerful counter-argument to relying solely on evidence based medicine. It may require stretches of tolerance to embrace in this discussion [a] mental health and [b] nursing perspectives, but the observations seem quite germane to this discussion. I commend to you the relevant chapter[14] and these extracts in particular:

- It is not the (measurable) techniques that the professional uses, but factors to do with the nature of the relationship between professional and person, that are critical.
- In their relationships with people, professionals do use their intuition and unspoken knowledge base (tacit knowledge).
- What appears to be the key factor in determining a good outcome is the ability to use our humanness in a way that is healing.
- The above cannot be measured using the quantitative scientific method required for evidence-based practice...[p.17]

Lest anyone think such talk is not relevant to physical medicine, may I quote this from an email received (as I write, on 12 March 2005) from a member of the OzBrainTumour discussion group, the author a gentleman who himself has a GBMIV brain tumour (the worst kind), diagnosed in July 2004. This message written by a 45 year old (who has undergone brain surgery, radiotherapy, and much much more) with four teenage children, a bold sense of humour and a great zest for life, who introduced himself recently to our group thus — *a ham fisted construction worker of 20 odd years i'm not familiar with the whole computer/keyboard thing so it's a bit of a struggle at the best of times, but on top of the GBM and the drugs etc, still you all know the difficulties or you wouldn't be reading this message would you?* His latest message, as I draft this submission, says:

> Hi Dennis and thanx yr comments re the above. In answer to your question of motivating factors from the physician's point of view I beleive he was a bit reluctant to become involved with a drug that carried such a notorious label from the past [Thalidomide] and was induldging in a considerable 'fudge' in the hope that I would simply tire of asking.But once he could see that I was in contact with people that not only were taking it, but could comment on the process of it's procurement I think he felt he could "fudge" no more.That point having been reached I think he decided "let's get this over with" and a couple of hours later I popped back to his rooms to sign the papers and pick up the prescription.In short Dennis I think it shows the benefit of being an informed patient, and the value of belonging to groups like this.It's entirely possible that I might have seen info regarding thalidomide on the internet, but without the confidence engendered by members of the group, I could easily have found myself talked down by my oncologist for no better reason than he was out of his comfort zone of standard therapy.Way to go,guys I'll pay everyone back for all their help by running the "City to Surf" later this year if I get people to sponsor me 50c a wheeze I should raise a fortune. [reproduced here with consent of the author]

Stanton and Tooth argue for a balance rather than tension between evidence-based practice and the intuitive and human considerations (listed in quote above). With focus on the disease and its treatment – a deficits-based approach –

> ...the problem is to protect the person from experiencing further failure... A person's right to have the dignity of risk is taken from them. We all have the basic human right to attempt what we choose, to succeed or fail and to learn from the experience—this is how we develop and grow... In contrast, focusing on strengths values a person's resilience, aspirations, talents, uniqueness,

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[14] Vicki Stanton and Barbara Tooth, "The Context of Practice" in Ruth Elder, Katie Evans, Debra Nizette, *Psychiatric and Mental Health Nursing*, Elsevier, Sydney 2005, pp 12-27.

> what the person can do and how those strengths can be mobilised and built upon to overcome current difficulties.
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> Focusing on strengths does not mean that problems and the illness are ignored, but rather that problems will be taken care of in the process of healing. [p.18]

To those who may shake heads at such a perspective – "that problems will be taken care of in the process of healing" – applying to terminal illness, I note that life is itself a terminal process, though we like to forget that and waste days. I make these points:

- In all illness, the person with the illness (I avoid the word patient with its dependent status connotations) suffers loss of control over life. For whatever period of life, control is essential to both dignity and healing.
- All sorts of healing, on all sorts of levels, can occur in the course of a 'terminal illness.' Some bring increased longevity, some bring improved quality of life, some is 'life altering' for the sufferer *and* those around the sufferer.
- A sense of control and achievement of healing require a process of consultative case management. A system of case management denying control can scarcely be as effective.
- I think that a health system 'fix' simply cannot solve this problem, though there are things that can be done. I go back to my words of 11 September 2001, quoted earlier: "We need to recognise more clearly that in dealing with health, the carer has a crucial role. Doctors and nurses are in no way as well placed to understand a patient wholly and we must never expect that of them. We would improve the effectiveness of the health system enormously if 'caring' became a natural part of education, as part of a general acceptance of personal responsibility for health." [15]

It will be argued in reply that not everyone wants to take the responsibility of case management. I agree. This is a multicultural society with diverse views of life, death and cancer. Professor Bruce Barraclough, Director of Cancer Services at Northern Sydney Health, (now Chair, Australian Council for Safety and Quality in Health Care) remarked in discussion of their proposed interactive cancer support web site that in decades of work with cancer patients he had met no two patients who had reacted the same way to diagnosis. It would be foolish to imagine that every patient and carer should be sent away from the diagnosis consultation with a handbook of case management. But it is important that people walk away from the diagnosis with a sense of right to exist, respect for them as whole persons, assurance that there is a whole system, not just a dark tunnel with unknown stations ahead. *The fact that this will be hard to do does not alter its rightness.*

There is some work being done on development of computer systems to assist with case management and support in crisis. In Northern Sydney (where I was involved with a community consultative committees in 2002-4), there have been plans for a privacy protected database to enable enrolling of a person from the moment of diagnosis, to ensure that person's carriage all the way through every treatment and support option, and to enable up-to-date treatment and medication information is accessible to doctors in the area in the case of after hours emergencies. This is to be alongside a public, interactive web site, which should be nearing release, where a person could obtain directly relevant advice related to particular diagnosis. I have my doubts about the concept of completing forms and getting personally relevant information. The design task is huge and online things like this depression test:
http://www2.netdoctor.co.uk/testyourself/goldberg.asp
put everyone in a disease camp if they want. And they put the focus onto disease more than person if not structured properly.

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[15] http://aplaceof.info/margaret/index.htm

These Northern Sydney projects are planned to begin with the big name items such as breast cancer... how far they will extend into advice for other particular forms of cancer is problematic: issues of funding, attention span, professional commitment.

My uncertainty about the computer based systems is as to their capacity to cover the whole field sensibly soon and at sensible cost and without severe distraction of very limited professional time — time best spent with people. *How much time on work that counts, how much time counting the work?* It would be useful to obtain an appraisal of progress with such projects — or call for studies which don't assume digital wizardry is king. There are other areas such as this http://www.health.nsw.gov.au/policy/cmh/mhoat/
where workers, hard pressed by crises, have developed strong negative views of the loss of commitment to time-with-people because of time-needed-to-process-data. There is considerable doubt about benefits to the community from all the data work.

Also at Northern Sydney (and Senior Clinical Advisor to the National Health and Medical Research Council National Breast Cancer Centre from 1997 to 2003) Dr Fran Boyle has developed excellent analogies from Rugby for the way in which case management teams need to work, analogies which also allow comparisons of the qualities – in different cancer types and medical specialist fields – of the front row forwards (first line medical specialists) and their relative capacities to get the ball (the patient) back safely and positively to others on the team. Talk to her!

Doctors outside oncology have remarked to me that some oncologists develop negative views of life themselves. The intuitive reality of the process of medical consultation argued above[16] must make it all a two way process. There is probably a need for better care and support for oncologists, working as they do so often close to death, in a milieu where the basic causes of disease are uncertain, in a situation where patients commonly are shocked and fearful and may be deeply dependent in their expectations — and where failure of therapy is often a foregone conclusion, at least in the mind of the professional. A study of the health of oncologists should not be a hunt for 'impaired practitioners' but be positive, with emphasis on strengths, though also attempting to define disability from a perspective of capacity to provide care, not just keep up with the journals. In a forthcoming journal article Alan Rosen[17] writes on the matter of impaired practitioners in psychiatry, discussing stereotypes, stigma and some principles for response, care and support. That may be relevant.

It appears that sometimes very negative 'support' comes from registrars and other junior medical staff in hospitals, dealing with patients in the ward or at outpatients. Some of the burden on such staff is not very fair, as when a registrar is obliged to explain a dooming diagnosis to a patient, in a ward with multiple beds, in a matter of minutes, without support. I suspect there is some inadequacy in general training or particular narrow guidance from from senior medical staff or closure of treatment options by hospital policy. People are being hurt and life shortened and made more miserable. There is abundant case information available. The problem is not just with young doctors. On one occasion when Margaret was admitted with unstoppable seizures to

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[16] "It is not the (measurable) techniques that the professional uses, but factors to do with the nature of the relationship between professional and person, that are critical." — see footnote 14

[17] Director Clinical Services Royal North Shore Hospital and Community Mental Health Services; Associate Professor Department of Psychological Medicine, University of Sydney, Associate Professor School of Public Health, University of Wollongong

Canberra Hospital, I provided extensive written and oral advice (positive discussion) to the oncology registrar, middle aged, retreating from general practice. I also provided Margaret's Thalidomide capsules, prescribed by Sydney neuro-oncologist Dr Helen Wheeler, to be taken 300mg every night. I knew Thalidomide was not used for Canberra Hospital patients. Some days later, after an unrelated mishap led me to review the medication chart, I found Margaret had been given no Thalidomide. The nursing staff did not have it. The registrar said yes he had the bottle of capsules, he hadn't passed it on to the staff, it was a 'nasty drug'.

"Yes," drily remarked a doctor friend to whom I recounted this, "it's especially nasty if you are a tumour."

I recommend:

1 **That it be recognised that case management based on support for the whole person is essential.**

2 **That, in particular, the opening discussions with patients with cancer diagnosis focus on that whole perspective, not just the perspective of the first line professional.**

3 **That case management be focused on supporting the strengths of the person with the diagnosis and granting control and support for patients and carers who wish to have degrees of responsibility.**

4 **That choices of such paths of degrees of responsibility not be immutable, but subject to review and change.**

5 **That the management plan include assurance that all aspects of support for family are considered and developed.**

6 **That the committee assess or call for broad studied assessment of the value of computer-based systems for case management, with special regard for the prospective time to implement, prospective effectiveness, prospective consumption of limited resources.**

I further recommend:

7 **That the committee endorse the proposition that we would improve the effectiveness of the health system enormously if 'caring' became a natural part of education, as part of a general acceptance of personal responsibility for health.**

8 **That the committee call for study of the pastoral needs and care for oncologists, not to identify impaired practitioners but to support their "resilience, aspirations, talents, uniqueness."**

9 **That a study also be made of the education and guidance given to junior medical officers dealing with oncology patients in public hospital systems, to ensure compassion, understanding of treatment options and good guidance from their seniors and management (link with recommendation 2).**

see also recommendations in the next section.

Issue (a) The delivery of services and options for treatment for persons diagnosed with cancer:
(iii) differing models and best practice for addressing psycho/social factors in patient care

Please see recommendations in the previous section. I believe the key issue is empowerment and respect for the whole person.

It may be that in breast cancer and some other areas there are developed models for support of patients and families, but certainly not in the area of brain tumour. I have dealt with social workers, but they are very busy and are limited severely, within the work demarcation of hospitals, as to what they can do. Nurses of the committed professional kind have a professional commitment to whole person care but little time to put it into practice; the 'casualisation' of nursing employment is seriously damaging to the sustenance of nurse commitment to care of the whole person. I have noted the existence of neuropsychologists but have not observed any inclination to engage with patients. The physiotherapists, occupational therapists and (though less encountered) speech therapists provide nice models of whole person support and focus on strengths. Some doctors are wonderful, others are disrespectful of the person — but for the best, time is their biggest enemy.

We have to ask into what broader social context psycho-social support needs to fit. Here is some personal perspective on the fundamentals.

The pervasive effect of market driven free economic forces, along with the grip on our minds of old Darwinian notions of struggle and competition as the base for survival, are things central to the issues of care and support in Australia.[18]

The is a lack of general teaching of what has been accepted now for several decades by evolutionary biologists: that not competition, but *great cooperative circumstances are the basis of evolutionary progress*.[19] Worth recalling too the comment of Albert Szent-Gyorgi[20] that 1+1>2. Or, at more length:

> One particle, plus one particle, put together at random, are two particles, 1+1=2; the system is additive. But if two particles are put together in a meaningful way then something new is born which is more than their sum: 1+1>2. This is the most basic equation of biology. It can also be called *organisation*.[21]

Such concepts of cooperation and of the accumulative benefits of community are at a huge distance from the philosophical drift of economic and social policy in Australia in the last couple of decades. In the name of efficiency we may have been doing things that make good maths but poor science and poor prospect of sustained success.

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[18] I note in passing that on 5 March 2005, the *Sydney Morning Herald* front page major story indicated that the Premier was determined to get to the bottom of the social issues in Macquarie Fields, where riotous events had followed an incident involving car theft, car speed, car accident. Whereas the Motoring Section of the same paper, same day, led with a *'good buy'* recommendation for a car – whose finish reportedly left something to be desired, which was said to be a bit difficult to drive at a lawful speed and which had (my opinion) pretty appalling fuel consumption – priced at a bit more than $350,000. Don't know that Mr Carr reads the Motoring Section.

[19] Read the work of Lynn Margulis; start with Lynn Margulis and Dorion Sagan, *What is Life*, New York, 1995

[20] Nobel Prize for discovery of vitamin C, 1937: http://helios.physics.uoguelph.ca/summer/scor/articles/scor141.htm

[21] Albert Szent-Gyorgi, *Bioelectronics: A Study in Cellular Regulations, Defense, and Cancer*, Academic Press New York, 1968, p 4.

There seems a lack of evidence that all the funding adjustments, subsidies and reform of the health sector have actually led to a healthier community.

To get the models of social and psychological care right for a whole raft of people dealing with cancer, we need to support concerns such as these expressed by Hugh Mackay:

> In amongst that catalogue of complaint about the gap between our values and the way we're actually leading our lives constantly re-emerges this word community. We feel as if we should live in a community, yet we don't know our neighbours. We yearn to live in a safe neighbourhood where people are at least on nodding acquaintance with each other, where you recognize the people across the road and round the corner and at the park but we haven't quite got there yet

and Mackay's praise of young people:

> This is a generation who are connected; who are more tribal and whose message to the rest of us is: if you want to live with some sense of comfort, some sense of identity, some sense of security in such a turbulent, ever-changing world and living with changes that will tend to fragment us and keep us apart, you'll have to work at getting back together, you'll have to work at making these connections[22] .

This also seems a message that can directly be related to how to care for people dealing with cancer. I don't think the answers are in another great layer of organisation within the health system. It needs to begin in education, with teaching about community and mutual care. And extend into empowerment of individuals dealing with life crises.

Many people benefit enormously from following programs such as those of the Gawler Foundation outside Melbourne and Petrea King's Quest for Life Foundation outside Sydney. Such programs do not fit easily with evidence based medicine as there is no way to point 'scientifically' to single cause–single effect. Being unsubsidised, these options are beyond the reach of many. Being outside evidence based medicine, they are not recommended by many doctors.

The status of doctors and the meaning for people of illness and health is also at issue in all this. Despite all our modernity, we all have certain degrees of *shamanic expectation* of doctors. Going to the doctor generally means for most people something psychologically more significant than ducking down the corner for a bit of 'evidence based'. Here is a conundrum — how do you empower people, encourage people to be independent, if for many of us a state of dependence and *belief* in the doctor (something more than trust) is integral to expectations of recovery. A pressure arises from this kind of relationship for doctors to appear and act *all-knowing* when in fact that can only be so within a small area of professional expertise, surrounded by a great deal of scientific uncertainty. If we recognised this situation – the primitive shamanic quality of many doctor-patient relationships and expectations – we might be able to deal with the consequences.

The pressure for the doctor to be right ties also to issues of liability, legality and the administrative frameworks of everyday life. The heavier the demand from those quarters, the more doctors must protect themselves by narrower and narrower definitions of what they can do, endorse, approve, suggest, offer — not just for cancer patients but from birth to death. One day, we will find that much medical practice today is *wrong* even if it is as smart as paint now. The more we enshrine current practice in godly legality and rectitude, the harder it becomes for medicine to advance. It is in this dead end of rectitude that large problems of comprehensive care arise — in the limits on health professionals as to what they can say or do without legal

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[22] http://www.ourcommunity.com.au/control/control_article.jsp?articleId=1071

risk, in the nightmare aspects of medical practice which becomes less attractive to young doctors and under huge time pressures.

I have one practical suggestion. Some general practitioners are being paid of late especially to manage mental health cases. The same might apply in cancer cases. They do it a bit, but they are often out of depth or simply bounce the referrals in the direction of the cancer specialists. A system of support for GPs who are able to and prepared to enter into agreement to manage a number of cancer cases could see those GPs building allied health support systems and making use of a clinical information and guidance network to support them. It would have to be a system of substance, not a pressure device for compliance with some arrangement.

Support Groups: I have experienced these personally in relation to my health and in relation to cancer, brain tumour in particular. At their worst, people build a life around support groups, secure identity from them, and in other ways form attachment to their illness which may not be conducive to recovery. Or the business of organisation becomes a business of self-importance. Big arguments can ensue, over small beer. At their best, on the other hand, support groups can be immensely valuable, as people discover that they are not alone, and review each other's strategies for survival and recovery. *Individual empowerment meets community strength!*

In watching the developing the Australian internet brain tumour discussion group OzBrainTumour[23] , I have been concerned that it be as far as possible without rules and as far as possible self-sustaining. The nature of this kind of internet discussion group or *list* is that a person may subscribe and then will receive a copy of every email a member sends to the *listserver* - in our case a free service from Yahoo. If you reply to any message, or write on a matter of your own choosing, then your message in turn is sent to all. As at 15 March, a total of 8957 messages since November 2000, 76 messages in the last seven days, five new members in the last seven days, 243 members altogether. Some messages are light and cheerful banter, some pursue and discuss serious treatment issues, some are with anguish about life issues. In some, people weep and get support and comfort. Some report death and some extend condolences. When we began, no one among us had died and the notion of death was largely out of sight. That situation has changed, the group has changed with it. In the last few years a number of people have, with combinations of treatments, been surviving for hitherto miraculous periods. Still, though, death comes often to the group: yesterday, a report on the funeral of a man who died surrounded by loving family, today news of a man who last wrote to the group three weeks ago, who was in good humoured phone contact with several until recently, but who died alone, no carer, not found for some time... On occasion in the past I have asked if discussion of death is unnerving for newcomers, people arriving full of hope. The overwhelming response has been that newcomers do not want such discussion avoided.

For about a year and a half the group required my constant active contribution to sustain conversation; since then it has had a life largely of its own. There have been only three modest altercations in over four years and these quickly resolved. I received messages of appreciation when I said this, to settle a little dust recently:

> Every one of us is going to make judgements good or bad about what is sensible to say to someone else in trouble - naturally this reflects our own perceptions of the world. And none of us gets it

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[23] http://health.groups.yahoo.com/group/OzBrainTumour/
Note that I have set the system up so that *every* message circulated to the group contains this statement as a 'footer': "Opinion expressed in messages to the group is not a substitute for medical advice."

> right all the time.
>
> I tend to go for the forthright, as do some others; some other people go for the soothing approach. So a person getting thoughts here is going to get an array of ideas tossed in their direction. We are all, I like to think, here of our own volition and with mature judgement and we participate to get ideas and learn from others. The accepting and rejecting of advice is for the reader. Arguing the issues to the contrary is OK; arguing moral or spiritual superiority has no place here.
>
> I believe that everyone here writes sincerely. Please consider and reflect.
>
> Each of us says what we think is [a] right and [b] appropriate. We each need to respect that in others. As in caring for a sick person we cannot do the job well if we do not seek to understand the person we care for so in discussion we cannot grow if we do not listen and try to understand the other person's perspective.

I have a huge, happy and active new life these days – www.aplaceof.info reflects just a bit of that. I am not stuck in the past with this issue. But it remains an extraordinarily humbling and important thing to stay part of this community (having at least twice resolved to leave it). It has given me faith in the ability of people to be a community if they are confronted by circumstances that mean they put aside the trivial and focus on the important in life. I have confidence that the internet can be an enormous force for good, especially in the way discussion develops with messages written over time, often written in the still of the night, very openly and confidingly — no one, no one, in four years, has suffered hurt from sharing of personal confidence, of that I am sure. This mechanism of exchanging considered messages over time is quite different from internet 'chat' where things happen in real time and conversation is abrupt, stilted and often inane. Different also from the experience of being in a meeting room with a support group, worrying about shopping or the kids at home, or whether my spouse next to me is going to last this thing out; put off by that person's jigging and that person's sniffle and that other one's pompous gittery; watching the clock, can't catch the chairman's eye, oh damn, what's the point, this chair is killing me, won't speak, let's get it over....

By contrast our group discussion has a magic on the internet. Here is another part of that note I wrote just after Margaret's death in 2001:

> Much is said that is foolish about the internet. The internet just links people who have the usual degrees of human inadequacy, and thus it depends on people whether the internet leads to greatness. Such is life; people opposed to change abolished street lighting and public sanitation in some parts of Europe after the defeat of the reformer Napoleon - we can't be amused by that and speak foul of the internet at the same time. It is very clear from our experience that the internet is a basis for the exchange of information and ideas and affection and care which is altering the way the world will in future deal [with] many things, including health. The extent that this change is for good or for worse depends on those who use it. We have sought to use it for good; Margaret clearly has inspired many and the promulgation in this place of what we have learned along the way has helped many others.[24]

So I think *this kind of internet support group can have enormous social and psychological value*.

For all of us as members of OzBrainTumour it is an exacting responsibility to be aware when you address information to one person there are many many other people reading, including some who never may write, but who, I know from having met some elsewhere, cherish their connection to the group. Over time, we have had (I am advised of new members and of those

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[24] http://aplaceof.info/margaret/index.htm

who leave) the membership of a number of doctors, a number of cancer society officers, etc. One social worker is an excellent participant, others do not contribute. There has not to my knowledge been any lift in the poor quality of material on brain tumour from the Cancer Society, there has been the vaguest of nods of recognition from professions. I have written to various bodies and asked if they would include us in their web page 'links'. People like the Federal Department's Health 'Insite' team simply don't answer. This adds to the fun, really, the independence, the autonomy. So long as people find us...

I am aware that in Northern Sydney Health's (now Northern Sydney and Central Coast Area Health) development of their 'interactive' cancer web site the notion of discussion groups has been a worrying issue for health professionals. I have, contrary to some other community voices, a firm view that doctors should NOT participate in such groups. Inevitably discussion involving a participant doctor would turn to particular case history and the doctor would be unlikely sensibly to express a second opinion on the basis of what is said in an email. We mortals, on the other hand, with immense experience of the ins and outs of treatments and side effects and scans and blood tests and disabilities and symptoms are very well placed to tell people when to call an ambulance, when to scoot to the doctor, when to try a different doctor, when they should think about the direction life seems to be going. All within an ambience of care and support. We have an enormous freedom and my judgement is that there is a great core of wisdom and sense to our discussion. It is time that professionals trusted ordinary people to be wise in these matters. That they do not share our freedom does not make us fools.

It would, however, in any framework of encouragement, be good to have sensible suggested guidelines for such internet activity. I was pleased to see that the sorts of principles of openness OzBrainTumour has adopted (rather than structure and rules) were recommended recently as keys to prospering for country towns in Queensland. I list these below[25] because it seems to me that the same sorts of issues as arise in local community (the power plays; the zero-sum arguments; the issue possession by individuals; the preoccupation with order before progress; the neglect of new voices except for faction recruitment) are the same kinds of issues that plague many support groups. At present, big noises, squeaky wheels get heard. I have heard it said in Health: "I can't seek community involvement. That would have x after me again." Much depends on the way groups are formed and recognised.

Worthwhile guidelines can only emerge if health authorities see it possible to empower community, not spoon feed people.

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[25] http://www.dpi.qld.gov.au/business/14778.html - recommendations for towns to prosper:
1. Encourage the development of a vision for the town and the planning and activity to get there.
2. Encourage diversity in every dimension.
3. Encourage the public celebration of creativity and achievement.
4. Encourage continuing education, formal and informal, for all residents.
5. Encourage the development of home-grown talent.
6. Encourage the development of a town community resource centre.
7. Encourage holders of all civic positions that those positions be held for a short and fixed period and that leadership be rotated as often as possible.
8. Encourage any mechanism that helps build a broad base of civic skills and experience.
9. Encourage the concept of 'leadership' and discourage the concept of 'leaders'.
10. Encourage travel away from the town in order to bring ideas back.
11. Encourage any mechanism that fosters the exchange of ideas.
12. Encourage any mechanism that helps newcomers feel needed and welcome.
13. Encourage every form of investment, financial, commercial, social and civic, back into the town.
14. Foster the development of opportunities for shared relaxation and play.
15. Encourage self-help and discourage dependence upon outside agents or funders.

Death: This is another matter of considerable psycho-social importance. We have great difficulty dealing with the question of dying, though it is our most remarkable experience in life. Margaret read a web site called *Crossing the Creek* [26] – about the business of dying – quite early in her illness, when she was very determined not to die. Her response was to recommend it for all to read. Many people (with and without cancer) wrote to thank her for the recommendation, saying that such practical understanding of death removed a great deal of their (as also my own) bleak apprehension and uncertainty. The preoccupation of major religions with immortality[27] does not simplify discussion of death, but we would clear away a lot of shadows if sensible discussion were possible.

This is a major problem for doctors and other health professionals — they can't lurch into "hey let me tell you about dying" in the middle of therapy. Also, doctors generally will fight very hard to keep the thought of failure of therapy (death) out of their own horizons. The palliative care specialist is unusual.

Shame, horror, guilt, sense of duty all conspire to make it hard for partners and families and friends to deal with the turn from therapy to palliative care and to the dying process. Families can destroy themselves; partners, parents (especially the parents of children with cancer) and children can themselves suffer exhaustion and illness. There is self-neglect and self-hurt from struggling where support and open thinking could make things so much better and easier and make the days available better. *Too many carers and former carers doubt their right to live.*

Recommendations:

9 That empowerment through responsible case management be seen as the core need for meeting socio-psychological needs.

10 That the broad context of the state of community in Australia is absolutely relevant and 'solutions' within the framework just of health administration are not going to work — solutions have to be framed in new social policy.

11 That self-development programs like Gawler and King need to be brought into the ambit of reasonable care options despite the difficulties fitting them in evidence based medicine frameworks.

12 That we have to look hard at the doctor-patient relationship if health care is going to advance.

13 That a properly funded system to support GPs in managing whole cancer cases, with a network of advice, and the development of allied heath teams, be considered.

14 That the use of the internet by support groups should be encouraged, with sensible guidelines emphasising community values.

15 That we try to address problems associated with understanding the dying process, to remove some of the associated stress and allow more sensible planning for it with quality of life and best use of time. Specialness and sanctity need not mean secrecy.

16 That partners and carer parents or carer children – and whole families – be helped to a better understanding of palliative care options so they don't destroy themselves along this difficult path.

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[26] http://www.crossingthecreek.com/

[27] Interesting recent discussion on the ABC: http://www.abc.net.au/rn/talks/perspective/stories/s1316395.htm

Issue (a) The delivery of services and options for treatment for persons diagnosed with cancer:
(iv) differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians

Regional Australia:

In the case of brain tumour, there is a very small number of places which can be regarded as places of expert knowledge. Among these, the number with medical case management teams and skills is smaller too.

Beyond that small community of expertise, the rest of the country (including some major hospitals in big cities) might be thought of as regional. In the sense of being disadvantaged.

It was noted earlier that some medical specialists in the regions claim to be experts where wisely they should recognise that they are not.

It will be increasingly the case that patients in the regions learn about effective (including ‘conventional’) treatments from support groups rather from their doctors. Granted that doctors consider that they receive a mixed quality of information from patients, there needs to be a recognition that an informed patient (or carer) is an asset, and ought to be assisted with the business of understanding information, rather than be dismissed.

The oncology profession needs to review some of these issues, from a basis of duty of care, do no harm and support the whole patient.

There is some financial assistance with transport and accommodation for people in the regions needing city attention. Administration of this varies in quality. It could be linked most constructively to case management by GP.

Recommendation

17 That the oncology profession address the problem of different knowledge levels in regional areas by an enlightened approach to recognising that not all professionals can be all knowing, and developing improved systems for consultation and information sharing.

18 That doctors generally be encouraged to recognise that patients may get ahead of them in knowledge even of conventional treatments, and respond to suggestions from patients with a concern to nurture informed patients.

19 That arrangements for financial support for remote patients be enhanced and linked to improved case management.

Indigenous Australians

It appears that the incidence of cancer among indigenous Australians is similar to that among non-indigenous Australians; however, detection is likely to be later in indigenous people both because of paucity of detection opportunities and the generally poorer levels of living conditions and general health. Any comment is for indigenous communities to make.

Issue (a) The delivery of services and options for treatment for persons diagnosed with cancer:

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

The single greatest obstacle is management and absence of organisational reform in the public health system. Having myself observed and participated in public sector reforms from the 1970s onwards, it was an interesting experience to spend a lot of time in public hospitals in 2000-2001 and see how they worked. If the second tier agreements of the late 1980s (the breaking down of demarcation barriers, the multiskilling) had found their way into some of the old hard case areas like mining, what had happened in health services? Who is in charge? How is it possible that in certain areas where people are daily doing identical (wonderful) work, they are paid entirely differently because they completed different undergraduate programs 30 years ago and have different bits of paper to prove it. How can it be that doctors, who are notionally in charge of the issues in hospitals are (not all, but many and proudly) so anarchically irresponsible in terms of management? What models of management, mutual support and caring are being offered to young doctors, nurses and others. And it pervades to every level.

> Early Sunday morning, major public hospital, best possible in the country. I approach the two ladies behind the inquiry desk, eventually interrupt their fretful conversation:
> "Excuse me, I think you should know that in the men's toilet the urinal is blocked and in the cubicles, three of four are obviously not flushing."
> "I'm sorry, that's a maintenance matter and it's Sunday, you'll have to speak to..."
> "Well, I was thinking that you should put up a sign and direct people to the toilets at the other end of the building for now."
> "Well no, I'm not allowed to put up a sign. I'll have to wait and speak to someone later about who is allowed to put up a sign."

Yes, obviously in hospitals there have to be rules on how to move patients, who may inject, who may prescribe, who may dispense and provide medication... and so on. But system can become obsessively rule driven; you don't have front counter problems like that if things are right at the top. It seems to me that *in the hospitals any skill broadening and demarcation elimination has varied in its impact — with the hardest impact on 'junior' and traditionally female roles and the least impact on the most self-important and traditionally male-dominated jobs*.

All of these problems are made maddeningly more difficult with limits to funds. And more difficult by the demand pressure of professionals wanting more of the latest — *AND consumers* who, in a society increasingly consumptive (to misappropriate a word to good use), lack resourceful sense of self-reliance and who are driven to believe that health is derived from consumption of medical things.[28]

The overlays of organisation and systematisation, the restructuring of regions and integrations of services, the 'enhancement' of data systems and controls are not solving the underlying dysfunctions. There has to be an analogy here somewhere from the cancer industry: "sewing up without fixing", "the cyst is inoperable", "we have to work around it". There is on the ground less joy for the practitioners, less joy for their clients. *Less health*.

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[28] I remain impressed by the specialist who, examining me for jaw pain in 1979, prescribed one photocopy of an article in the *New England Journal of Medicine* which reported that recovery from tempero-mandibular joint affliction varied inversely with both level of consumer expectation and cost of intervention by the doctor. I thank him.

The doctors of good intent (and there is some good intent in nearly all doctors) have every reason to be mad as hell at the system for a myriad reasons. Not least the increased obstacles to actual doctoring. But their drift to angry free-market postures (though still drawing on public resources) will not solve the problems other than for their personal cocooning.

The drift to the private system, supported by subsidy of insurance, supports doctors in departing the aggravations of the public system.

But that private system itself (despite some of the 'extras' of insurance schemes) enhances the consumerist expectation that health arises from consumption of delivered medical goods and services. The rising tide of pharmaceutical and technological options for such consumption is not making us a less sick society. It is more likely to bankrupt government and/or cripple public health.

Recommendations: [numbers now wrong]

20 That the committee resist recommendations for substantial new layers on the existing public health system or for massive flexibilities at this point in the PBS or Medicare.

21 That the committee make recommendations urging some measures of summitry on the issues of dysfunction in the health systems, not about the money first and as far as possible not from the trenches of organisations... or states

22 That the terms of reference for any such summit embrace:

- **the need for individual responsibility for health;**
- **the need for community building to sustain individual health;**
- **the nature of the doctor-patient relationship;**
- **the nature of workplace relations between health and allied professionals;**
- **the relationship between community health and consumption of medical goods and services**
- **as a clearly defined second phase, perhaps with different people, appropriate balances in government expenditure and ways of containing the costs of delivering goods and services.**

(b) How less conventional and complementary cancer treatments can be assessed and judged, with particular reference to: (i) the extent to which less conventional and complementary treatments are researched, or are supported by research, (ii) the efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies

Under Issue (a) I addressed an array of ideas about the nature and causes of cancer. I think it important that the committee address and query at an early point my assertion that:

medical science still does not know what causes cancer

From answers to that question, more flow:

- is research addressing that core problem?
- how best is that problem addressed?
- what proportion of cancer research is not doing that; so what then is it doing?

I personally would not accept such an answer as "I'm finding the gene that does x" until convinced that genes were responsible generally, or necessarily the best and first place to look — though it may currently be the best place to look for research funding.

There is a problem in science that while at its best outreaches it is full of hypothesis and the best minds know that, at its teaching level there is an inward towards concreteness: hypothesis gets somehow taught as fact, fact becomes dogma. Dogma becomes new research foundation. New research is increasingly particularistic and too often based on questionable assumptions.

Richard Lewontin in his Canadian Broadcasting Corporation Massey Lectures 1991[29] criticised [chapter 3] the ideological prejudice in modern biology particularly as relates to causes, or rather the tendency to seek THE cause of an effect. This he said is "nowhere more evident than in our theories of health and disease". In discussing pursuit of the 'cause' of cancer he ran through the history of cancer research: pursuing a viral cause, an environmental cause and more recently in the human genome project, of which he is sharply critical. He asks (or, in 1991 asked, but the question remains valid):

> Why, then, do so many powerful, famous, successful, and extremely intelligent scientists want to sequence the human genome? The answer is in part, that they are so completely devoted to the ideology of simple unitary causes that they believe in the efficacy of the research and do not ask themselves more complicated questions. But in part, the answer is a rather crass one. The participation in and the control of a multibillion dollar, 30- or 50-year research project that will involve the everyday work of thousands of technicians and lower-level scientists is an extraordinarily appealing prospect for an ambitious biologist...[30]

In the course of discussion in an internet support group, one thing that happens, as elsewhere in life, is that people say what they are doing because they believe they are doing the right thing. When death is lurking, we become particularly concerned to be doing the right thing and to have endorsement for that. A lot of people with cancer have a pretty good idea when the conventional doctor hasn't a lot to offer. In some of the OzBrainTumour mail, I read assertions that person x is doing very well on a combination of particular treatments for which the writer sometimes may encourage a following. How is one to respond?

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[29] R.C. Lewontin, *The Doctrine of DNA*, Penguin Books 1993

[30] Lewontin, page 51.

Not easy for me, for others in the group, or for a doctor. I certainly have no plan to dismiss or coldly dissect belief in curative process, especially in such circumstance of individual success... even though I may know of others who have taken a similar approach and have died swiftly.

I know also that particularly with a diagnosis of Glioblastoma *multiforme* the 'multiforme' is a very serious thing – these tumours vary enormously from case to case and over time. I also know that a top neuro-oncologist said this in 2001:

> Analysis can differ markedly in interpretation of material from a tumour. Experts disagree in 20-30% of cases. In the United States, in a study several years ago, material was sent to the highly respected tumour centres at the Mayo Clinic, M.D. Anderson at the University of Texas, Sloan Kettering and UCLA. There was 70% agreement between them in their interpretations.[31]

There is also the consideration that cancer is something that evidently manifests itself long after the insult that may trigger it. And that triggering impact has different effects on different people for genetic reasons and for lifetime (from uterine onwards) and lifestyle reasons.

So it becomes difficult to respond to the assertion "this works" because of the number of variables. I think, though, that serious epidemiological studies may support many proposed treatments which cannot be shown to work by reductionist (single cause-single effect) research.

Also, on a broader and more fundamental issue, I quote from my discussion of issue (a) above:

> In tumorigenesis, cells alter the way in which they make energy, they alter their *respiration*. In healthy organisms, including people, mitochondria in every cell make an abundance of energy and also carbon dioxide from sugar and oxygen (mitochondrial respiration). Tumour cells abandon this and make energy from sugar alone (glycolysis) in the manner of bacteria, also the manner of all cells before the appearance of mitochondria a billion and a half years ago, so there is something retrograde happening in the cell. Otto Warburg won the Nobel Prize for Medicine for discovering this in 1931[32] , but it seems mainly forgotten — even though it is in this area, the general respiratory health and happiness of the cell, that notions of linkage between happiness and stress and wellness and sickness are probably best understood at the level of cellular biology.

Those readers familiar with industrial relations matters will know that old sores can stick around for a long time. Lynn Margulis (see issue a(iii) and footnote 19) noted in the 1970s (and her arguments are generally accepted wisdom in evolutionary biology now) that mitochondria first appeared in cells at the time of the great climate change 1.5 billion years ago, as the bacterial waste-product oxygen made the atmosphere inflammable and outdoor glycolysis thus dangerous. There are bacteria known to invade other bacteria and consume them and Margulis argued that mitochondria were in fact 'captured' invading archaeobacteria with whom a symbiotic relationship developed. The mitochondria took over respiration and developed a new form of it, using oxygen as well sugar, producing far more energy and capacity for protein production (in ATP) and lots of the oxygen-protective (antioxidant) carbon dioxide. The mitochondria seem to have devised the first big databases — storages of DNA in newly invented nuclei. It would be diverting here to review all mitochondrial functions, but I focus on the discovery in the 1990s that it is mitochondria that control *apoptosis*. Apoptosis, or 'planned cell death' means decisions made to euthanase the cell when it goes defective, the ironic cell-level euthanasia process that moment by moment keeps us all from succumbing to cancer.

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[31] Notes taken by Dennis Argall from a presentation 'An Overview of Treatments of Brain Tumour' by Dr Helen Wheeler, Medical Oncologist, Royal North Shore Hospital (RNSH) and North Shore Private Hospital, to the first meeting of the Sydney Neuro-Oncology Group (SNOG) Brain Tumour Support Group, on 14 February 2001. Text at http://aplaceof.info/margaret/medical_Wheeler_14022001.htm

[32] http://almaz.com/nobel/medicine/1931a.html

The industrial relations analogy is this, Senator Cook.

Imagine a difficult workplace relationship between the mitochondria doing most of the work and believing after a long time that they own the show and a small business grown large — occupied by these mitochondria for 1.5 billion years. Imagine a measure of worker (mitochondria) control where the whole factory can actually be immediately shut down, labour withdrawn, apoptosis – *life ends* – if the business design is fiddled with.

Imagine next a moment of inattention on the part of the apoptosis-threatening mitochondria, inattentive because attending, say, to a difficult branch meeting, or constrained to behave well during a federal election campaign[33], then turning around to find that there was no work for mitochondria, that the boss has closed their production lines, taking the whole show back to the stone age and and beyond. Well, that's my analogy for tumorigenesis. You can shift the analogy to the cell host being fed up with the occupation and domination by the mitochondria, who have brought on all this higher organism and stress life, but you still finish with life in a tumour cell comparable to the life of an ancient bacterium. What tumour cells have done, in abandoning mitochondrial respiration and adopting aerobic glycolysis, is something very primitive (and understandable), in terms of *life* as distinct from the mathematical simplifications of life in gene study.

Recommendations:

23 That the inquiry focus in the first instance on whether the cause of cancer – the mechanism of tumorigenesis at cell level – is understood.

24 From answers to that question, more flow:
- **is research addressing that core problem?**
- **how best is that problem addressed?**
- **what proportion of cancer research is not doing that, so what then is it doing?**

25 That where remedies are in widespread use and attract significant belief in their efficacy, epidemiological studies be encouraged to establish truths; results of such studies should feed into acceptable practices of advice to cancer patients, as matters quite separate from any consideration of HIC subsidy.

26 That the committee itself resist encouragement to endorse particular treatments.

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[33] On the day Malcolm Fraser called his last election in 1983, I was guest of mine management somewhere in the Pilbara. “We've got ’em, we've got ’em, the bastards. We can screw them every day to election day!” crowed the industrial relations officer of the mine, a little too quick to the beer. His colleagues urged restraint...

My point is that cells, not just people and brains, experience stress of all kinds, and it is under stress that wrong directions threatening life can happen. Tobacco, so pervasive in use, is an easy explanation of ill-health; radiation, also pervasive and dramatic in effect, is another. But to run the gamut of every possible item of cause – mobile phones, bacon, job loss, etc., seems to me to seek the unnecessary particular. We know that in allergy, the allergens impact cumulatively. So also then in cell stress, camel's back straws on rotten days may impact in various ways on that day, as drops of rain falling on a mountain may find different streams down which to flow. Do I get cancer, do I get arthritis, do I get diabetes? Yes, predisposing factors, but also a need to come to terms with the sense of life, not just numbers and DNA instructions, in the cell.

(b) How less conventional and complementary cancer treatments can be assessed and judged, with particular reference to:

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

To the extent that conventional treatment is isolated in a corner where research is funded almost exclusively by drug companies and holders of technology patents, who else but government can finance substantial research in other fundamental areas? The entrapment of research and thus product endorsement in the drug and technology corner costs government an enormous amount of money. ‘Risk money’ committed to fundamental science away from that corner should be regarded as money well spent.

While some patients subordinate themselves to the treatment program as recommended by their doctors, others are prepared to try anything. Carers, families, are at times prepared to prejudice much of their lives and property to save someone.

There have been some unscrupulous people who propose treatments for significant profit and with insignificant or dubious health benefit. Governments have legislated to make it illegal to treat cancer unless one is a doctor. Protection against the unscrupulous is appropriate; whether existing state laws are necessary for such protection, or are overtaken by more recent competition and consumer protection law is for consideration.

There is a huge business in treatments outside what is strictly legal. Some of those treatments may be very valuable to patients. Many people believe the ‘illegal’ treatments they have chosen have been critical to success in defeating cancer.

The law allows in extreme illness for a doctor to endorse the use of treatments not otherwise legal.

In all this, there is some legal murkiness which ought to be resolved.

Resolution of murkiness must not impose obligations on doctors to disclose other ‘options’. There is a problem (discussion and recommendations earlier) of doctors who are remote from brain tumour centres of excellent adopting inappropriate know-it-all attitudes (often associated with pessimism and inclination to minimal palliative care) even in ‘conventional’ medical areas. Such attitudes cannot be changed by legislation or regulation.

A number of earlier recommendations can bear on these issues at practical level.

- Implementation of recommendation 3, for case managing the whole person ought to bring into focus a number of ideas out there about wholeness and health. Recommendation 11 is linked to that.

- A system for supporting GPs as case managers would need to establish guidelines in these areas.

- It would seem undesirable for the kind of health summit proposed in recommendations 21 and 22 to be diverted into discussion simply of alternative medicine.

- Recommendation 25 for epidemiological studies would assist in assessing roguery in claims.

Recommendations:

27 That there be a study of community benefit and long term budgetary advantage in significant government financing of fundamental scientific research of the possible causes of tumorigenesis — away from the 'conventional' treatment environments where research is dominated by patent holders.

28 That consumers continue to be protected against exploitation with wonder cures.

29 That the murky situation where much is happening 'illegally' in the accessing of alternative treatments be resolved sensibly and compassionately to community benefit.

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