SCGH BROWNES CANCER SUPPORT CENTRE

Ground Floor E Block

Department of Health

SUBMISSION TO THE

SENATE ENQUIRY INTO SERVICES AND TREATMENT OPTIONS FOR PERSONS WITH CANCER

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Please Note: Should the Committee be interested I am happy to provide further detail on these issues in writing or in person.

EXECUTIVE SUMMARY

1) The model of supportive cancer care successfully developed by SCGH Brownes Cancer Support Centre since 2001 is a way forward for integrating touch based complementary therapies and counselling in a mainstream hospital environment and should be considered an essential component of any multi-disciplinary approach

2) Such Centres would provide an ideal base for a Clinical Nurse Specialist to coordinate patient care, possibly in a case manager role, liasing with GP's.

3) Our model has been successfully adapted into three regional hospitals in W.A.

4) Lack of funding, education and understanding are sometimes barriers to integrating less conventional therapies.

5) Quality research undertaken by our centre (see attached) is breaking down many barriers to the touch and counselling based complementary therapies.

6) There is already a place for less conventional therapies to be used as complementary therapies in the mainstream medical system. In our model these therapies are complementary and not seen as primary treatments.

7) Government has a role to play to facilitate development, integration and regulation of less convention cancer treatments through properly funded research programs in respected major research hospitals.

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INTRODUCTION

This submission is made by David Oliver, coordinator of the Brownes Cancer Support Centre (BCSC), who has worked in the complementary health field for 25 years. I am currently also advising the W.A. Cancer Council Complementary Therapies Advisory Group on developing and implementing their complementary therapy (CT) policy and am also an adviser to Reiki Australia who are making submissions to the Health Training Package Review of the CSHISC.

This submission is made on behalf of the Brownes Cancer Support Centre to bring to your attention the groundbreaking efforts of Dr David Joske, Head of Haematology at Sir Charles Gairdner Hospital (SCGH). We have developed a successful working model for a Cancer Support Centre using the benefits that massage, touch, and counselling based complementary therapies can make to patients and even staff in mainstream medical hospitals. We have also assisted three other complementary centres to open in regional W.A. with great success. These are in Albany, Bunbury and Narrogin hospitals. Each has adapted our model to their own needs and each project was initiated by local staff who had an interest in having complementary therapies working alongside their mainstream treatments. We were able to supply a framework on which they could model their own centres to meet quality standards. We believe our model could easily be adapted to other hospitals throughout Australia to provide treatment and staff recruitment guidelines, quality benchmarks, research recruitment and design guidelines.
Our full research document, brochure and weekly program are attached for your interest but our research is summarised in the abstract on P. 7.

ADDRESSING THE TERMS OF REFERENCE

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

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

The BCSC is part of a multi-disciplinary approach to cancer care at SCGH. Our experience and research shows that there can be significant cooperation between mainstream and complementary therapy disciplines of health care with significant benefits for patients and also, from our observation, for staff. Refer to our research abstract P. 7.

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Many people will argue there is no or very little evidence of the benefit of complementary medical therapies (CT's), yet this is not borne out by an ever increasing amount of small research projects, that show significant improvements in quality of life for patients who receive complementary therapies.

Our data strongly suggest that combining massage, touch and counselling based therapies with mainstream medical treatments in a multi-disciplinary approach will give significant benefits for patients, staff and the system. For instance we often have staff bringing distressed patients to the Centre for support.

(ii) The role and desirability of a case manager/coordinator to assist patients.

A Western Australian Review for the then State Cancer Services Coordinating Committee recommended a role for the GP as "helmsman". We also have some experience of a cancer shared care model developed by Dr Joske and presently the subject of an NHMRC Project Grant. In that model a "Shared Care Coordinator" (in the pilot study the position was filled by a chemo-therapy-trained nurse) took on a coordinating role. Our experience suggests that nurses are ideally placed to act in this way. As they are more readily contacted by GPs, are available to see the patients more easily than medical staff, and can act as a triage for clinical problems.

It may be that in the future, cancer support centres in teaching hospitals and major cancer treatment centres would be staffed by nurses with mainstream training, who also have familiarity with and knowledge of CT's. They could act as both coordinators/ case managers and provide support with triage of patients to appropriate health practitioners when and if required. We are certainly working towards this model, but funding remains problematic.

The nature of cancer and serious illness is changing. People are now living with the disease, often for years, due to the advances of medical science. The existing support services have been battling for years to keep up with the demand from patients for information and emotional support while they are undergoing treatment and increasingly after they have finished treatment.

Interestingly, we find that once patients have finished their mainstream treatment they often don't come back into the hospital environment for support, unless they have a medical appointment.

Our anecdotal experience is that the existence of our Support Centre, with ready

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access to supervised internet, CT's, and informal support, sends a strongly empowering message to cancer patients that the hospital supports their attempts to learn more and take steps that are suitable for them to control their disease and its ramifications.

(iii) *Differing models and best practice for addressing psycho-social factors*

The National Cancer Strategy Group in its report 'Priorities for Action in Cancer Control 2001 – 2003 (publication number 2979) identified and verified that support services for cancer patients could be provided by suitably trained and qualified health professionals and not just psychologists. Our research, see attached document, shows significant improvement of quality of life for cancer patients and their carers who have CT treatments our Support Centre. There is an increasing amount of research in the scientific community supporting our findings that the strength of touch based and counselling CT's lies in the psychosocial benefit they give to patients. However, more research is needed but is difficult to perform especially at the level of randomised clinical trial evidence.

As far as we know, our Support Centre is the only one in existence in a mainstream teaching hospital in Australia. We believe our model could be used as a basis for best practice. It has been working successfully for over three years and because of its flexibility can be adapted to almost any situation. In particular our model affords an experience with dealing with the issues of medico-legal risk; and with measuring the impact of CT's upon quality of life.

(iv) Treatment options for regional Australia and Indigenous Australians

We have already assisted three other Support Centres to open in regional WA in Albany, Bunbury and Narrogin.

Our model can be adapted to any situation and so is very suitable for small regional centres.

Indigenous Australians have a long history of natural healing. While not advocating we should adopt their way of healing , there may be common ground that could be explored and developed using complementary therapies of an indigenous background.

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

Major barriers are:

- Educational. Lack of which results in entrenched cultural attitudes.
- Lack of funding for quality research programs.
- Lack of national standards/models for psychosocial/supportive care
- Diverse credentialling systems for complementary therapists
- Lack of recognition of the efficacy of complementary therapies.

- Entrenched cultural attitudes from both mainstream and alternative therapists is a barrier to effective integration of complementary therapies. Lack of understanding and sometimes mis-information lead to unwillingness to see the others viewpoint. Balanced educational programs that exchange ideas and information will assist these barriers to come down, especially if based upon quality research.

- As Professor Don Iverson recently stated at the Cancer Nursing Research Conference in W.A. "Lack of funding has meant little quality research has occurred for complementary therapies. This is often cited as a reason for not adopting CT's."

- No national model means that individual hospitals and institutions are left to devise their own systems. Access to CT's remains ad hoc, with no attempts at integration with mainstream care.

- Credentialling of complementary therapists is varied because many are not recognised by mainstream institutions or don't want to be involved. The need for national guidelines is important to allow therapies that 'do no harm' to operate in and alongside the mainstream medical system.

- Lack of recognition is related to the lack of research. A good starting is to adopt a policy of 'as long as they do not conflict with mainstream medicine' eg touch based therapies and counselling.

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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.

It is widely accepted that little research has been conducted on complementary therapies. This picture is slowly changing and that when quality research is done, it turns up interesting results.

Our Cancer Support centre in SCGH is well placed to do quality research and has already completed an initial research trial measuring Quality of Life Outcomes and Symptom Control for 564 cancer patients. The abstract delivered by Dr Joske to the ARCHI conference 2004 is appended below:

THE SIR CHARLES GAIRDNER HOSPITAL (SCGH)/ BROWNES DAIRY CANCER SUPPORT CENTRE. D Joske, Director; & Head, Haematology Department, SCGH; L Kristjanson, D McDermid, E Lobb, A Popescu, Edith Cowan University (ECU); K Wallis, D Oliver, SCGH.

INTRODUCTION: In 2001, in a teaching Hospital at Perth, our Centre opened with goals of providing information and support, and access to safe, supervised Complementary/ Alternative Medicine (CAM). The Centre receives ~150 visitors weekly, many for complementary therapy sessions, mostly counselling- or massage-based, such as Meditation, Reiki, Chi Breathing, Pranic Healing, Aromatherapy, Beauty Therapy, etc. The impact of CAM upon psychosocial and physical well-being is assessed using a symptom distress score and quality of life questionnaire. Our database collected information on 564 participants receiving 1,151 treatments between August 2002 and January 2004.

OUTCOMES: 559 participants attended 1 treatment, 428 attended 3 treatments, and 164 attended 6 treatments. 84.9% were female. The mean age (n=518) was 55 years. 70.5% were in- or out-patients with cancer, 22.7% were carers, 6.2% staff/ others. For cancer patients, of 420 listing their cancer type, 231 (55%) had breast cancer. Reiki was the most used CAM (292), then Aromatherapy/ Massage (202) and Pranic Healing (140). In cancer patients, Mean Symptom Distress Scores, an average of responses ranging from good (score =0) to bad (=10) for 7 symptom items, were assessed before treatment 1 (n=416), before & after 3 treatments (n=325 & 293) and before & after 6 treatments (n=153 & 113).

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These scores improved (17.13, 17.71, 5.09, 15.29 and 4.42 respectively). Large short-term effects were seen; scores for pain and fatigue showed marked improvement (data not shown). The Quality of Life (QoL) Scale comprised 7 items and the Mean QoL improved (scores of 26.80, 18.94, & 16.07 before treatments 1, 3 and 6). On both scales a Friedman test was performed and significance of the results confirmed. Reliability was confirmed using the Crohnbach alpha coefficients. An Empowerment Measurement Instrument is also being developed.

CONCLUSIONS: **Our data confirm a beneficial reduction in symptom distress and improved quality of life for cancer patients accessing supervised CAM treatments in a teaching hospital setting.**

(ii) The efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies.

The overwhelmingly positive response to the Support Centre from patients and staff at SCGH and from other mainstream support organisations such as the Leukaemia Foundation W.A. and the Cancer Council W.A. highlights the need to bring some less conventional therapies into the mainstream system. We believe the touch and massage based complementary therapies are the appropriate starting point. These do no harm and hence avoid the immediately controversial issues surrounding vitamins and herbs.

In the minds of many mainstream healthcare practitioners all less conventional therapies are tarred with the same brush of being alternative. However, for our Support Centre it is not about the alternative debate but more about how less conventional therapies can work alongside mainstream medical treatments in a cooperative and mutually supportive way.

Over 60% of Australians are using complementary and alternative (CAM) treatments and it is a multi billion dollar industry.

Complementary therapies by their very nature do not see themselves as being mutually exclusive with mainstream medicine. Rather they can be used alongside to enhance the outcomes for patients especially in the field of supportive care and some symptom control. Our research shows that complementary therapies are very effective in both short term and long term applications. We would be the first to say that more research is needed, especially before being considered for primary treatments.

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

Government could play a more significant role in this sector through;

- Education of medical students, doctors and health administrators.
- Fostering dialogue between the worlds of CAM and mainstream medicine (the recent development of a position statement by the AMA is welcomed in this regard)
- Promoting and funding research so more up to date information can be provided.
- Subsiding the initial trialing of cancer support centres based on our model or similar, in major public hospitals and in regional centres.

CONCLUSIONS AND SUMMARY

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2) Such Centres would provide an ideal base for a Clinical Nurse Specialist to coordinate patient care, possibly in a case manager role, liasing with GP's.

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