HEALTH CONSUMERS' COUNCIL
Tele: 08 9221 3455 Fax: 08 9221 5435
email: info@hconc.org.au website: www.hcc-wa.global.net.au

SUBMISSION TO THE

SENATE INQUIRY INTO SERVICES AND TREATMENT OPTIONS FOR PEOPLE WITH CANCER

HEALTH CONSUMERS' COUNCIL CONTACT DETAILS

Michele Kosky:
Executive Director

Consumer Representative
National Health and Medical Research Council

Submission to Community Affairs References Committee on Cancer: March 2005

Background

The Health Consumers' Council is an independent community based organisation, representing the consumers' 'voice' in health policy, planning, research and service delivery. The Council advocates on behalf of consumers to government, doctors, other health professionals, hospitals and the wider health system. To find out more you can check our website www.hcc-wa.global.net.au.

The Council assists and supports patients trying to navigate the WA health system, public/private, hospital and community based.

Terms of Reference

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

(1) The efficacy of multidisciplinary approach to cancer treatment.

Consumers report strong support for multidisciplinary cancer treatment. The benefits to consumers of multidisciplinary care include:

i. early and accurate diagnosis;
ii. treatment that meets the needs of the patient and the requirements of the disease;
iii. assessment and provision of appropriate support, particularly psycho social support;
iv. recognition and treatment of psychological disorders.

But the importance of communication and collaboration between team members, the patient and the family is seen as critical for effective multi disciplinary cancer treatment. People with cancer report that co-ordination of their care and continuity of their care are important factors in their journey with cancer. People with cancer would like to select the co-ordinator of the care and not have it imposed upon them.

The Health Consumers' Council strongly supports an identified co-ordinator of care, participating in a multi disciplinary team.

We note the barriers to such teams being a lack of interest by many medical specialists, professional turf disputes and lack of resources.

(2) Models of care for psycho-social factors.

Consumers report a complete lack of psycho-social support in hospital settings in Western Australia. The lack of a comprehensive Cancer Centre in Western Australia and the lack of enthusiasm to adopt and implement a State Wide Cancer Plan particularly affects people with cancer in rural and remote Western Australia, as well as metropolitan consumers. There is strong evidence that demonstrates that appropriate information provision, psychological interventions and emotional and social support will result in improved health outcomes including reduction of emotional distress and despair and greater participation in care arrangements.

The National Health and Medical Research Council have approved Clinical Practice Guidelines for the Psychosocial care of Adults with Cancer. What is lacking is the adoption and delivery of guideline-based care for people with cancer.

(3) Treatment options for regional Australia and Indigenous Australians.

For rural and remote patients, transport is a health issue and is inadequately addressed by all state and territory governments. For people with cancer in remote and regional Western Australia, their choice of provider and treatment is limited by the Patient Assisted Travel Scheme which subsidises transport and accommodation to the nearest specialist centre. Travel arrangements are complex, uncoordinated and expensive, though it is hoped the appointment by WA Country Health Services of local travel co-ordinators will improve the current arrangements.

For aboriginal people with cancer, an integrated service that links cancer specialists with Community Controlled Health Services has been identified as a useful way forward. The recruiting, training and rewarding of Aboriginal Health Workers is identified by Aboriginal people with cancer as an important issue that needs consideration and action to improve treatment and care.

(4) Barriers to the implementation of best practice in the above fields

Consumers' report that the lack of knowledge about the experience and characteristics of particular cancer specialists is a barrier to best treatment. In addition in oncology particularly, in public hospitals, patients report that their treatment is not explained, communication is not valued and a modality of treatment is pursued without consideration for the patient and their quality of life. Cancer patients report a lack of engagement by medical practitioners in the public system which appears to be a lack of time, resources, but most of all a lack of kindness.

B. Less conventional and complementary therapies

People with cancer report that the use of complementary therapies give a sense of control over one's destiny and allow participation in a treatment regime in a way denied by conventional health care.

Reiki massage, relaxation and meditation are all valued by people with cancer. However, patients report that should they disclose that they are considering complementary therapies or have begun complementary therapies the reaction of oncologists is nearly always contemptuous and dismissive.

Clearly, evidence based interventions would be valuable in the area of complementary medicine. Considerations should be given to investing in rigorous research into less conventional therapies.

In addition the current training of oncologists would benefit by the participation of people with cancer in a range of curriculum areas, including less conventional treatments.

Conclusion

The Health Consumers' Council is of the view that the involvement of people with cancer in the design and delivery of Cancer Services is critical to their relevance and success. This should happen at both micro and macro level.

> 'Active involvement of consumers at all levels of development, implementation and evaluation of health services is integral to their success.'

The Evidence support consumer participation in health. Consumer Focus Collaboration 2001.