

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. Funded by the Department of Health WA, the Council provides a state wide service. To find out more you can check our website www.hcc-wa.global.net.au.

The Health Consumers' Council was established in 1994. In 1996 we supported the establishment of GAIN, Gynaecological Awareness Information Network. One of Health Consumer Council's longest serving members, Ms Kath Mazzella was a pioneer in consumer knowledge and consumer empowerment for women with gynaecological cancer. It was Ms Mazzella who established GAIN. In 1996, the Health Consumers Council made representation to the task force on Safety and Quality in Healthcare. Chaired by Professor Bruce Armstrong, the issue of Gynaecological Cancer was raised in the public domain for the first time.

Some time later in 1997 Kath Mazzella wrote a small piece in the Womens' Day, seeking feedback from women who had endured gynaecological cancer. The number of responses was in excess of 80 and the stories profoundly moving, characterised by isolation, failed marital relationships, delayed diagnosis, lack of treatment options, lack of the treatment, lack of understanding and failure by medical practitioners to communicate effectively with their patients.

In 2006, consumers with gynaecological cancer report many of the same issues about their care. For women with gynaecological cancer living in rural and remote Western Australia, access to health services is limited, fragmented and highly reliant on the state-funded Patients Assistance Travel Scheme. Many consumers with gynaecological cancer report a strong sense of frustration that knowledge about the travel and accommodation subsidy is provided too late to be helpful or not provided at all.

This makes treatment for many women from rural areas prohibitively expensive. Improved outcomes have been shown for women who receive timely referral and treatment by a gynaecological oncologist supported by a full multidisciplinary team

Health Consumers Council WA

Recommendations

1. Investment in the training of existing medical and nursing services in regional and remote Australia in the screening, treatment and care of women with gynaecological cancer. This should be backed by specialist support in capital / regional cities, using available current technology to provided integrated and supportive shared care to women with gynaecological cancer.

2. A National Review of the Barriers to effective and timely treatment and care caused by the Patient Assistance Travel Scheme and Isolated Patients Travel and Accommodation Assistance Scheme.
3. The development and implementation of a comprehensive education scheme for medical practitioners and nurse in gynaecological cancer risk factors, symptoms and treatment.
4. Given the isolation and emotional turmoil of women diagnosed with gynaecological cancer, a broad community education campaign should be developed in consultation with consumers, clinicians and community groups.
5. In addition some consideration should be given to the support needs of male partners of women diagnosed with gynaecological cancer.

Conclusion

Many of the lessons learnt and initiatives taken in breast cancer eg, screening, treatment, care, palliation and support could be adapted to suit the needs of women with gynaecological cancer. The issue of gynaecological cancer neglected for so long, needs urgent attention

Michele Kosky
ED, Executive Director