

cancer voices sa

RAISING A VOICE FOR THOSE AFFECTED BY CANCER

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Executive



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“RAISING A VOICE” Consumer Forum Summary



About us

- Cancer Voices SA is an independent consumer **advocacy** group representing South Australians affected by cancer
- our supporters include
 - The Cancer Council South Australia
 - Health Consumers Alliance
- We contribute to a national network of Cancer Voices

Membership is **free** and open to cancer patients, their family, friends and carers



Key objectives

- **encourage** those with experience of cancer to contribute to all levels of decision making about the disease
- **ensure** cancer patients, carers and supporters receive the best possible information and world's best practice treatment, care and support
- **ensure** cancer patients, their carers and supporters are well represented to health professionals, government and the public
- **ensure** those affected by cancer are treated equally regardless of
 - geographical location
 - social or economic status
 - age
 - ethnicity
 - sexuality
 - gender
 - stage or type of cancer



Our voices are already heard on:

- Cancer Voices Australia Executive Committee
- Cancer Australia Reference & Advisory Groups
- EdCaN and CanNet National Programs
- Statewide Cancer Clinical Network
- Safety & Quality in Health Care Advisory Committee and Improvement Programs
- Health Connect SA
- Cancer Council SA
- Cancer Support and Regional Groups
- Health Care Forums & Conferences



“RAISING A VOICE” Consumer Forum

Theme 1 - Complementary and Alternative Cancer Medicine

- Prof Barrie Casselith, Memorial Sloan-Kettering Cancer Centre, NY USA

Theme 2 - New Cancer Drugs and Therapies

- Prof John Zalcberg OAM, Peter MacCallum Cancer Centre, Melbourne Australia

Theme 3 - Accessing Quality Cancer Information

- Prof Archie Bleyer, St Charles Medical Centre, Oregon USA
(*included commentary on Young Adults with Cancer)

Theme 4 - Cancer Carers Needs and Support

- Carers Panel - Fiona Redfern, John Newsom, Patrick & Mariann McNamara



OFFICIAL LAUNCH OF CANCER VOICES SA

- The Hon John Hill, Minister for Health
 - 13th November 2007



Theme 1: Complementary and Alternative Cancer Medicine

Prof Barrie Casselith, Memorial Sloan-Kettering Cancer Centre, NY USA



Theme 1: Complementary and Alternative Cancer Medicine

Forum Discussion

- Acupuncture - many benefits and ok if neutropenic
- Massage - a myth that it spreads cancer
- Writing as therapy - can have positive or negative effects
- Laughter Therapy - especially useful for children
- Coordinate an Integrated Treatment Program from the outset
- Positive cost savings achieved but may not be immediate
- Reiki - but the light touch technique
- Indigenous Healers - a good complement but not a replacement for treatment
- Do mineral deficiencies in modern food cause cancer - No
- Physical symptoms are alleviated by complementary therapy
- Convincing medical practitioners to advise on complementary therapies may be the challenge



Theme 1: Complementary and Alternative Cancer Medicine

Forum Discussion

Proven benefits for:

- Massage
- Mind-body - such as meditation/ relaxation techniques, yoga/ tai chi, music therapy
- Acupuncture
- Fitness (such as 20mins brisk walk/day) is significant benefit
- Nutrition and balanced diet - no benefit from supplements
- Herbal treatments not recommended
- Almost all reduce stress
- Helpful for carers and family too - not just the patient



Theme 1: Complementary and Alternative Cancer Medicine

Key Points

- High consumer interest - but we need more Information on what is beneficial
- Change terminology to Complementary Therapy or 'Integrative' Medicine or Oncology and not 'Alternative' Therapy - so "CAM" Term must go!
- Complementary Therapies are rational, evidenced based treatments that sit alongside mainstream treatment (not 'the' cancer treatment)
- Must use or provide qualified professionals trained for cancer patients
- The Memorial Sloan Kettering Cancer Centre can offer support for this system to be 'integrated' in Australian practice (see: www.mskcc.org)



Theme 2: New Cancer Drugs and Therapies

Prof John Zalcberg OAM, Peter MacCallum Cancer Centre,
Melbourne Australia



Theme 2: New Cancer Drugs and Therapies

Key Points

A scenario (Glivec - GI Stromal Tumour drug) demonstrated the progress through stages from clinical trial, TGA and PBAC to cabinet approval

- Many drugs will not be reimbursed (PBS listed) despite clinical effectiveness as fail on PBAC 'cost effectiveness' estimates
- Current system increasingly supports people rich enough to pay (social and economic inequity in cancer care is widening)
- Drug approval process needs to be transparent
- Consumer groups such as Cancer Voices will need to become the 'independent' key player in cancer drug advocacy
 - Take advice from many quarters and draw from learned experience of other bodies
 - Patient survival must be at the centre of all arguments



Theme 3: Accessing Quality Cancer Information*

Prof Archie Bleyer, St Charles Medical Centre, Oregon USA

*included commentary on Young Adults with Cancer



Theme 3: Accessing Quality Cancer Information

Forum Discussion

- All groups and nationalities get cancer and in similar proportions - cancer has no boundaries
- Consumers must advocate to have young patients treated in appropriate age facilities
- Clinicians do not see Information provision as their role
- Information is becoming more readily available on survivorship, keeping well and more advanced cancer information
- Internet chat sites are good provided they are moderated
- The Internet is an excellent source of information but it must be checked
- Cancer Voices SA formally evaluates websites before placing on their site



Theme 3: Accessing Quality Cancer Information

Key Points

- The web and media are the most common sources of cancer information - especially for Adolescents and Young Adults
- Sites must be checked for validity in terms of professional links and recommendation by field experts
- Clinicians should be engaged and trained on how to provide knowledge on Information Access to consumers
- List of 'quality' web sites provided by Prof Bleyer – these will be available on the 'new' CVSA website at **www.cancervoicessa.org.au**



Theme 4: Cancer Carers Needs and Support

Carers Panel - Fiona Redfern, John Newsom,
Patrick & Mariann McNamara



Theme 4: Cancer Carers Needs and Support

Panel/Forum Discussion

- Carers wear many 'hats' - care coordinator, researcher, advocate
- Carers need to be aware of their role, the impact on their life and be prepared for the next levels of difficulty
- Patient and their carers must have equity in decision making for treatment and care
- Need good professional advice to deal with financial and legal issues (ie power of attorney, will, etc)
- Need help navigating the complex, fragmented health system
- Carers and the patient need information on what treatments, including complementary therapies are available locally and internationally
- Carers experience physical and mental exhaustion and isolation



Theme 4: Cancer Carers Needs and Support

Key Points

- Caring includes understanding the illness and related factors
- Carers must know what support services are available - such as counseling and respite
- Carers must be offered support 'after' the carer role is complete
- Other family members (ie siblings) must not be forgotten
- The cost of cancer to patients and carers can be 'unbelievably' high - see "Cost Of Cancer in NSW Report" to calculate a \$ figure
- Medical professionals must understand the role of carers, what they experience and the impact on patient care



A Final Message

Thank You All.... for listening to our Voices



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www.cancervoicessa.org.au



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