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Update of CVSA activity

RAH radiotherapy bungle

- **834 cancer patients given wrong dose.**

If you (or someone you know) had radiotherapy at the Royal Adelaide Hospital (RAH) during the period from July 2004 to July 2006, you probably took note of the recent news reports (around 26 July 2008) revealing that one of the hospital's four radiotherapy machines delivered a dose 5% lower than prescribed to approximately 720 cancer patients.

The Department of Health media release (25/7/08) can be found at <http://www.health.sa.gov.au/Default.aspx?tabid=52&mid=449&ctl=ViewDetails&ItemID=1781&PageIndex=0>

An independent inquiry is being conducted by Associate Professor Geoff Delaney, a radiation oncologist from NSW, and will include a radiation therapist and medical physicist, also from interstate. It will look at whether the under dosing had an impact on the effectiveness of the treatment and whether any systems and processes put in place by the hospital to prevent recurrence need to be reviewed.

The SA Dept of Health was to notify patient who may have been affected, and invite them to return for medical follow-up. The HotLine set up to answer patient's questions

was unfortunately not very helpful for CVSA members who called in.

Ashleigh Moore, Chair of Cancer Voices SA had radiotherapy at the RAH in 2005, so he voiced his personal fear of less than optimal treatment, as well as drawing attention to a 'flaw in systems'. Cancer Voices SA provided statements and interviews to the local newspapers, ABC TV and Radio National, and continued pursuing this matter further. <http://www.abc.net.au/news/stories/2008/07/27/2315540.htm>

CVSA Executive met with the SA Health Chief Executive Dr Tony Sherbon to raise concerns over this serious lack of quality control and safety procedures that has put cancer patients at risk and caused additional stress. We have demand that **systems are established across the state, in public and private radiotherapy facilities, to ensure errors cannot go unnoticed or uncorrected for up to 2 years.**

Then, **two weeks later** (11 Aug 2008) when everyone thought the dust had started to settle on this issue, **another 114 patients were notified that they too had been treated on 'that' machine.**

CVSA understand the anxiety this incident has caused many cancer patients and their families. We requested an opportunity to

speak with Prof Delaney and present the consumer perspective. This was agreed to by Dr Sherbon, and members of CVSA Executive Team held a teleconference with Prof Delaney on 14 August 2008.

The ABC Stateline program presented the 'Cancer Bungle' story on 15 August 2008, featuring interviews with Ashleigh Moore and Dr Tony Sherbon.

<http://www.abc.net.au/stateline/sa/default.htm>

Further action is under way through CVSA consumer representation within the Cancer Clinical Network to ensure radiotherapy quality and safety measures are incorporated into routinely reported key performance measures.

The Safety and Quality in Health Care Consumer Advisory Committee are also addressing the issue with Ashleigh Moore already a member of this group.

A meeting has also been held with the Shadow Minister for Health, Vicky Chapman.

We now await the report of the independent review conducted by Prof Delaney.

Cancer Clinical Network

The Statewide Cancer Control Plan 2006 - 2009 provides the basis for the work of the Cancer Clinical Network. The six key main areas of activity are Cancer Prevention and Early Detection, Optimising Cancer Care, Infrastructure Planning, Workforce Planning, Cancer Research and Cancer Information.

Cancer Voices SA members on the Cancer Clinical Network Steering Committee are Ashleigh Moore and Juli Ferguson.

A new sub-committee, the Complementary Therapies Working Party commenced in August and will be chaired by Ashleigh Moore.

Progress has been made towards establishing Key Performance Indicators (and

this will be revisited to incorporate radiotherapy quality assurance).

A workshop on "Improving the availability, access and quality of Cancer Information for Clinicians and Consumer" was held in July with 10 consumer reps attending.

Find more information about the Cancer Clinical Network (and June 2008 newsletter) at the SA Dept of Health website:

<http://www.health.sa.gov.au/Default.aspx?tabid=213>

Information

Notices about meetings, workshops etc are frequently circulated to CVSA members. Recently we forwarded the invitation to attend a talk by Prof Chris O'Brien, former cancer surgeon and Head of the Sydney Cancer Centre. Prof O'Brien is now fighting a glioblastoma brain tumour. We provide some highlights from his inspiring presentation "Battling cancer: taking responsibility and creating change".

Battling cancer: taking responsibility and creating change

Just 6 weeks after his fourth brain tumour surgery, and now back on chemotherapy, Professor Chris O'Brien shared his story of battling cancer with an audience of about 200 people in Adelaide. He described the **things that help him in his day-to-day battle with cancer:**

- A positive attitude with the love and caring of family and friends
- Complementary and Alternative treatments
- Special diet. The role of nutrition in treatment of cancer is largely overlooked by conventional medicine
- Making time for Meditation, and enjoying reading great literature

Taking responsibility. Prof O'Brien felt that **every patient needs to own their disease, ask questions, be prepared to seek more advice.**

He also challenged us with the question **"Why are we so complacent** about these statistics: **100,000 people diagnosed and 40,000 deaths/year** from cancer in Australia? If these were road accident statistics, would we be so accepting of this terrible toll?"

What needs to change? Prof O'Brien suggested the problem is the way the Australian health system is set up to treat cancer. **The comprehensive cancer centre model in the USA is the example to follow.** We are reliant on the USA for medical breakthroughs. Australia is at least one generation behind in terms of quality of cancer care and integrating conventional and complementary treatments, support (such as information, education, psychological and social support), research, innovation (such as testing new patterns of practice), and patient's participation in trials.

If you are interested in hearing more about Prof O'Brien, an interview is recorded at <http://sixtyminutes.ninemsn.com.au/article.aspx?id=269920>

Cancer Voices Australia - National update

Cancer Voices SA is a member of a national network of Cancer Voices, headed by Cancer Voices Australia. The latest newsletter from Cancer Voices (June 2008) can be obtained at www.cancervoicesaustralia.org.au/ detailing activities at the national level along with updates from each state. All members of Cancer Voices SA are included on the mailing list to receive this newsletter.

Representation

Is Cancer Voices SA working for you?

Cancer Voices SA is **'Raising a Voice for those affected by Cancer'** through

**Advocacy,
Involvement,
Awareness,
Information.**

Advocacy is speaking up (often from personal experience) to draw a community's attention to an important issue, and directing decision-makers toward a solution.

We welcome your involvement and feedback to help, guide and advise us. Help us 'make a difference' towards achieving the best possible cancer treatment, care and support for South Australians.

To contact us

We welcome feedback on any of the items and issues raised in this newsletter.

Contact us by email to info@cancervoicesa.org.au or phone 08 8291 4343.

Visit our website at www.cancervoicesa.org.au/

*Ashleigh Moore,
Executive Chair, Cancer Voices SA.*