cancer voices sa

RAISING A VOICE FOR THOSE AFFECTED BY CANCER

Dear Prof Delaney

Cancer Voices SA (CVSA) would appreciate the opportunity to raise consumers concerns with you, and hope they can be reflected in your report.
We are aware that the 'Terms of Reference (TOR)' of the inquiry relate to the radiotherapy machine calibration and overall effectiveness of the treatment of cancer patients who received 5% reductions in their radiotherapy fractions. However, subsequent to the TOR being set on 25 July 2008, additional concerns have arisen relating to completeness and accuracy of administrative records which led to a further 114 patients being notified on 11th August 2008, and some poor handling of patient's inquiries.

CVSA wish to raise the following issues/questions with you:

- Will findings of your report will be made public, and accountability measures put in place to ensure your recommendations are acted upon. Can you ensure there are clear accountability instructions for the Radiotherapy Working Committee to implement?
- Are you reviewing the Royal Adelaide Hospital protocols for handling such issues? Clearly this was mishandled so what should they do differently if it were discovered today?
- Can you please explain in your report any cummulative impact of +/- 5% tolerance, and the mis-calibration. Has this moved the mean dosage down from 100% to 95%, or was the situation 95+/-5%, so the min dosage could have been 90% not 95%. We request this to be explicitly explained and reported on.
- The psychological impact on cancer patients who had radiotherapy during the period July 2004-July 2006 must be acknowledged. Cancer survivors have an ever lurking fear of relapse, so any report that suggests less than optimal care was delivered will cause alarm. A HotLine was established but was not informative or reassuring to callers.
- The accuracy and completeness of administrative records is another concern, and we wonder if all patients have really been identified. At least one consumer has contacted CVSA and is confident they were treated in TS3 but have not been contacted in either round of notifications. Can data keeping maintenance recommendations be included in your report?
- Will your report be recommending the follow-up procedures, and information from patients that should be monitored to ensure any longer term impacts of this incident are analysed; and how long should this monitoring continue?
- Who does (or should) monitor Radiotherapy Quality Assurance? Are there mandatory regular national Dosimetry procedures to ensure all public and private radiotherapy facilities are performing optimally?
- Will your report highlight any lessons that should come from this in terms of 'changes in culture', staff morale, and whistleblower bullying along with implementation of quality and safety assurance measures so mistakes are prevented or reported and dealt with quickly in an open and transparent manner?

Thank you for your time and consideration of our concerns.

Cancer Voices SA Executive,
14 Aug 2008