

9 November 2012

Professor Robyn Ward
Chair, Medical Services Advisory Committee
Department of Health and Ageing
MDP 851
GPO Box 9848
CANBERRA ACT 2601

Dear Professor Ward

Application No: 1194: Single dose stereotactic radiosurgery for benign and malignant intracranial tumours (Gamma Knife)

Breast Cancer Network Australia (BCNA) works to ensure that women diagnosed with breast cancer, and their families, receive the very best information, treatment, care and support possible.

BCNA is the peak national organisation for Australians affected by breast cancer, and consists of a network of more than 73,000 individual members and 325 Member Groups. More than 90 per cent of our members have had a diagnosis of breast cancer, and the remaining members have had a personal experience with breast cancer through a family member or friend.

Breast Cancer Network Australia welcomes the opportunity to comment on the Medical Services Advisory Committee's (the committee) 'Consultation Decision Analytic Protocol to guide the assessment of single dose stereotactic radiosurgery for benign and malignant intracranial tumours'.

BCNA supports the proposed application to review the current MBS item for stereotactic radiosurgery. Single dose stereotactic radiosurgery has significant advantages for women with secondary breast cancer in the brain, and we are keen to see a Medicare rebate available to assist women with the considerable costs of the procedure.

Any treatment which reduces the amount of time a woman must lie on a radiation couch is a major step forward. Whole of brain radiation involving 25 fractions administered over 25 week days is a deeply confronting treatment. – Susanne

Many women would have to forgo this treatment because of the cost alone. In addition to the disadvantage they suffer in not being able to have the treatment, research possibilities are lost because fewer women can demonstrate the efficacy of the treatment for future cohorts. – Joy

We often hear from women who have been given whole brain radiotherapy as part of their treatment. Although the treatment is undoubtedly useful for treating women with secondary breast cancer, the side effects can be significant, particularly for those who have had high doses or repeated

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courses of treatment. Memory, concentration and balance can be affected. This has a significant impact on women's quality of life.

The first line of treatment I was given was whole brain radiation. This, combined with the large dose of steroid required to manage the side effects, left me devastated. I lost my ability to move my body... and I was exhausted, very foggy headed and had the strange sensation of being pushed backwards at all times. This lasted for months. I ended up in palliative care in order to get my blood levels under control and also to cope with the fact that I was unable to negotiate getting myself into the toilet. – Susanne

This same woman was later able to access gamma knife surgery at the Macquarie Hospital. Her experience with this treatment greatly contrasts with that from her earlier course of whole brain radiation.

I went home the same day and the only side effect I experienced was a bit of fatigue and a joyful experience of returning to my own personality and cognitive ability. Additionally, their superior scanning equipment identified an additional four small tumours which were then included in the treatment field. – Susanne

BCNA appreciates that a rebate is currently available for targeted, stereotactic brain radiotherapy. However we are concerned that the rebate does little to help cover the cost of single-dose stereotactic radiosurgery such as gamma knife. At a cost to women of around \$30,000, this is not a treatment that many are in a position to afford. Those women fortunate to access gamma knife have told us that the treatment had significant benefits.

I am now able to walk without a walker, get myself out of a chair or off a toilet (this is transformative) and participate in my children's lives. This is most important to me as, with the threat of not being here in the future, I want to be present for the time we do have. ...

Now part of this benefit is likely due to going off the steroids but I no longer have headaches. Friends and family have noticed that I am more myself – my sense of humour, thinking process and emotional responses are more typical - and this I ascribe to the Gamma Knife. – Susanne

Gamma knife surgery (and other single dose stereotactic radiosurgery techniques) enables women to go home the same day, unlike other forms of radiotherapy that require women to attend hospital every day for at least a week. Women tell us that this additional travel, which can be across great distances for many rural women, only contributes to the side effects and symptoms they experience such as fatigue, headache and cognitive difficulties. For women with secondary breast cancer in the brain, time away from their home and families can be particularly distressing.

As a result of spending a long time in bed I developed blood clots and of course, had to give the care of my six year old twins to my parents (thankfully they were able to come from Canada to help me). – Susanne

Given the significant impact this treatment has on women living with secondary breast cancer, BCNA urges the committee to recommend that



single dose stereotactic radiosurgery be specifically included in the MBS, with appropriate rebates available for women that will genuinely assist them to access this treatment.

I have never spent \$30,000 on myself except when buying our home! I was unable to afford to pay for it so my gorgeous parents redrew on their mortgage and loaned me the money. I am eternally grateful for them for this! – Susanne

All Australian women with secondary breast cancer to the brain should be able to access this treatment with an appropriate subsidy provided by the Australian Government. BCNA welcomes the release of an initial Consultations Decision Analytic Protocol to guide the committee with its review, and will watch the progress of this application with interest.

My experience with Gamma Knife was transformative and I feel an enormous sadness that it is not available to the general population. My doctors are amazed by my improvement and I wish that everyone with brain tumours had access to this experience. I am sure that it would be a cost effective move compared to the amount of time I spent in palliative care. – Susanne

For further information please contact Nicca Grant, Senior Policy Officer, on 03 9805 2585 or at ngrant@bcna.org.au.

Yours sincerely

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