

**NATIONAL RURAL HEALTH ALLIANCE INC**

**PUBLIC SEMINAR**

**‘KEY ISSUES IN RURAL AND REMOTE HEALTH’**

**CANBERRA**

**FRIDAY, 20 OCTOBER 2006**

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***CASE STUDIES IN PATIENTS’ TRAVEL:***

***Pauline Venn, Breast Cancer Survivor, Rural Victoria***

**PAULINE VENN:** Thank you, John. I guess I’ll begin with just telling you how I got to here today. I spent two hours driving along a mountainous dirt road dodging big double log trucks, followed by a further hour’s drive on a sealed drive, only to be sat on a plane for half an hour to connect me to Canberra. Such is the plight of a rural and remote consumer. I will also take this moment to express my gratitude to the National Rural Health Alliance for allowing me to speak with you today and to also extend my gratitude to my BCNA Canberra colleague, Anna Wellings-Booth, for asking me to tell my story.

I’ll proceed to address some of the issues facing rural and remote consumers with the hope that policy rural and remote makers can bring about change that better serves the people who chose to live in rural and remote areas. My talk today is focused on consumers diagnosed with breast cancer, as I have lived and breathed the disease firsthand. However, recommendations I make further on can be applied to other illnesses and disabilities affecting rural and remote consumers.

It is a known fact that 11,000 women and 100 men Australia-wide are diagnosed with breast cancer every year. I’m unable to produce for you the stats that reveal the percentage of urban consumers to those that reside in rural and remote areas. One would be right in guessing that the minority are rural based, but nonetheless receive the same quality of treatment and support as the urban consumers. Or do they? My own personal journey with breast cancer last year presented me with many challenges, because of where I lived and because I am the mother and sole carer of a child with a disability. After my diagnosis two weeks prior to Christmas, my treatment options were to:

- (1) Have my treatment spread over a mosaic of centres. For example I could have had surgery in Traralgon, which is an eight-hour return trip from home, then followed by chemo in Bairnsdale that involved navigating a twisting winding road for the trip home after an effusion of drugs that Keith Richards hasn't even heard of, and finally radiotherapy that would have to be Melbourne-based as the new Gippsland Cancer Treatment Centre was under construction. The Melbourne radiotherapy trip was going to be a 12 hour daily return every day for five weeks; or
- (2) I could leave my mountain chateau and move near a major cancer treatment centre and have all cancer services provided in the one place.

In consideration of the travelling of the first option, I elected to go down this second path. However, things became complicated as my son's needs had to be taken into account with my plans. Many doors were closed as I sought accommodation for the both of us and in my chosen cancer treatment centre. The hospital referred me to a couple of places but I couldn't take my son with me. This highlighted for me a critical shortage in family style temporary accommodation for those already burdened with distance so far from home. I resolved my accommodation crisis by drifting between family and friends and house-sitting whilst recovering from surgery and enduring the effects of chemo, all the time creating and maintaining an environment that caused minimal disruption that was so necessary for my son's existence.

In my final cancer treatment process, I was able to secure continuous accommodation for us both. The accommodation was the result of a referral from the radio oncology social worker and was in the form of a semi-detached granny flat at rear of a retired couple's home. It was located near the treatment centre and was approved for the purpose of claiming on the VPTAS scheme.

My story validates the necessity for family type accommodation because I was the sole carer for a child with a disability, but I could also have been a story about a daughter charged with the responsibility of caring for an ageing parent that's not ready for a retirement home, a young mother with a baby, or perhaps even an indigenous person that required the support of a relative. The possible scenario is just endless on this one.

I believe there needs to be more collaboration between major treatment centres, Lions, Rotary Clubs and a registry established where these family accommodation units are located and the stay duration if they have limits. This kind of system would enable the consumers to make informed decisions about their treatment places and take the pressure off what is already an extremely stressful time. A public drive could be instigated calling for unoccupied semi-detached dwellings to become temporary homes for rural and remote consumers and their family members while they receive appropriate treatment. Some homeowners could be

given assistance to register their dwellings to satisfy the PATS schemes in the various states. BCNA are currently reviewing this issue on their policy agenda.

Whilst on the subject of PATS requirements, I would like to chew the fat with you on what I consider a very inconvenient and unnecessary requirement on the PATS claim form. In all states, as is my understanding, a person is required to validate their illness every 12 months by having a GP sign off the form to enable continuance of PATS claims. In my opinion, it serves no purpose but to inconvenience the consumer. Certain conditions require a lifetime of follow ups. It was suggested to me that 12 month referral between visits to your GP is a reasonable amount of time, so as you can give the GP an update on your condition. But I argue with that, because for me the fact that your ongoing medical relationship is with your specialist for reasons your GP referred you to him or her in the first instance, I have to really question for whom this PATS requirement really is for. Is it to satisfy a Medicare definition or some other government requirement? It does little to assist the consumer.

Take for example the woman with breast cancer diagnosis who lives on Drysdale Station in the Kimberley region. Her cancer treatment centre is in Perth. Her GP is based in Kununurra. How ridiculous is it for her to drive six hours to the GP just for him to take five seconds to put a signature on a form and then for her to come back home again. She can't claim on PATS for the trip to the GP just to get this insignificant thing done.

My suggestion to correcting the PATS requirement is to introduce exemption forms for certain types of illness and disabilities for remote and rural people. We could adopt something similar to that used by Veterans' Affairs with their colour coded health card system. A card exemption form could be validated for a set period of time greater than 12 months, dependent on what the diagnosis was. The exemption card would eliminate fraudulent claims as the treating specialist for the specified condition would still need to sign off on the claim on the day of treatment.

If we considered this process it could be specified exemption is granted on the basis that treatment can only be for the declared condition. The GP can be kept in the loop on the patient progress by receiving reports from the specialist. I don't see a reason why we can't eliminate this really unnecessary thing from the form, when the sole purpose of visiting the GP is just to sign off to say, "Yes, you still have cancer", or whatever, "You can still go and see the specialist".

In closing, I would like to present another issue that was raised on a recent BCNA Rural and Remote Working Party teleconference. The issue is breast screening and the non-eligibility for rural and remote people to claim PATS for such a service. In Victoria you can get around this by obtaining a GP's referral to a screening unit and, providing the imaging is performed or reviewed by a specialist as defined by the Medicare specialty codes, you can then meet the PATS criteria for a claim.

Breast screening is paramount in the early detection of breast cancer and for some the nearest screening unit, whether that be travelling to a mobile unit location or making the journey to a defined screening clinic, could involve travelling considerable distances to and from home. I strongly urge the NRHA and other bodies to review this point with the positive outcome of including breast screening as a PATS claimable service.

I am one of two Victorian Rural and Remote working Party members advocating for BCNA. BCNA currently have a growing list of 18,000 members and will continue to empower, inform, represent and, most importantly, link together all people diagnosed with breast cancer. Thank you.

**JOHN WAKERMAN:** Thanks, Pauline. Thanks for sharing that story with us.

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