

**Submission  
No 373**

**INQUIRY INTO HEALTH OUTCOMES AND ACCESS TO  
HEALTH AND HOSPITAL SERVICES IN RURAL,  
REGIONAL AND REMOTE NEW SOUTH WALES**

**Name:** Mr David Young  
**Date Received:** 23 December 2020

---

I am a lymphoma patient of 9 years and a cancer advocate of about 8 years. I have set up 3 general cancer support groups in the Northern Rivers, have facilitated two of them and now run one in Byron Bay. I also work with Cancer Council, Cancer Institute NSW, Leukaemia Foundation, Lymphoma Australia, Cancer Voices and others. I am currently the team leader for WMozzies the national patient organization for people with Waldenstroms Macroglobulinaemia (the rare Lymphoma that I have).

One of the frustrations we experience in the Northern Rivers is the lack of coordination in support services for cancer patients. As a support group facilitator, one does not have the time, facilities or financial support to actually promote the groups and 'get the message out' to the people that may need them. The Cancer Council does its best to support us, but it is not in their remit to help us financially or practically although they do a great job where they can. Interestingly the one organization that I thought would be the obvious choice to promote and list all the local regional support groups ( I and the Cancer Council have the list and details of all of them) was the Primary Health Care Network. This primarily because it's a direct link to information for all medical practitioners with a comprehensive web site and newsletter. However they refused to put the list of regional support groups for cancer in either their newsletter or as a menu item on their website, the reason given was that they didn't want to have to manage the list with updates etc. Basically what this highlights is that there is a basic lack of coordination with Doctors, Specialists, Nurses etc and support services and the general public and their advocates.

Another issue up here is that we could really do with some 'cancer coordinators', much like the breast cancer nurse we have in Ballina who not only gives medical advice but is the go to person (if you have breast cancer) for all advice for information about support services across the board and many associated issues, she will even advocate for certain people. All those advocates representing other cancers can only dream of such a person available for all other cancer types. And of course this brings up the issue of Equity, especially for those with rarer cancers !

Several advocates and persons from cancer organizations have approached social workers at public hospitals around this region only to be told that they are too busy, too stretched or stressed to add any more to their work load. There is also a perceived stigma with the words 'social worker' for health issues as it insinuates low class status or similar or that someone has 'social' issues.

On the issue of communication too, the Cancer Council produces some great hardcopy information brochures, however these are not available in many doctors surgeries because its up to the practice manager to order the brochures and Cancer Council does not have the resources to distribute and follow up on them.

The government needs to talk to Cancer Advocates and Cancer Council reps in this region in order to understand the problems more clearly.