

1. In addition to what is contained in your submission and evidence provided at the public hearing, do you have any further comments regarding the current provision of palliative medicine, nursing and care in Ballina and the region?

My response to The Chair's invitation to comment regarding the provision of palliative care services at the enquiry was "*What I do know is that Ballina has a palliative care unit that works well for it. It is something that has improved in the last bit but there is always a gap. I have heard some good reports. I think it is a changing space.*"

My response was without any research.

With research, regrettably, Ballina CAN [Cancer Advocacy Network] realised that palliative care was not working as well as presumed and that inequity of palliative care services appears to exist.

Ballina Hospital Background:

- Since early 2000, Ballina Hospital has had Palliative Care wards of sorts, in the original Birthing Suites.
- The drive behind these wards presence has been individual nurses taking a personal & professional interest in Palliative Care. Indeed some updated their knowledge on their own time at St Vincents and another actually painted the wards' walls with donated paint, on their time
- The consequence has been nursing staff moves affected the presence of the Palliative Care wards and the quality of care.
- As well, Ballina community organisations funded the furnishings of both wards

In responding to this question, a BCAN member, a retired nurse who trained in palliative care reported their experiences in the past 12 months at 3 different locations. The great concern was the nurse to patient ratio and what appeared to be a lack of ongoing nurse education in End of Life palliative care, in this region.

This member shared their recent experiences:

**KEY OBSERVATIONS WERE:**

1. **June 2021** at Ballina Hospital's Palliative Care, this person sat regularly for the last two weeks with a friend who had no family.
  - General Nurses attending did not appear to have specific End of Life training.
  - There were long periods of up to 2 hrs, without nurse care.
  - This person attributed these long periods without nurse care to inadequate patient-nurse ratio.

- These long periods without nurse care would make addressing breakthrough pain relief for a patient, difficult or just neglected.

- 2 **February 2021, St Vincents, Lismore**, this person was a patient at Lismore and determined similar patterns, whereby General Nurses working in palliative care seemed not to have current End of Life training.
- 3 **Early 2020 Concorde Hospital**, The experience at Concord hospital was a stark contrast to their experiences in the Ballina Lismore region.

Concorde Hospital: there is a palliative care cottage that is well resourced. The member could not find fault in the care given as they spent 2 weeks sleeping in the same room as their relative and observed first hand the most caring and beautiful attentive manner of all the staff.

The BCAN member's observations about End of Life education deficits are supported by another retired nurse who has a very active role in local consumer health. This person is of the opinion that region's Palliative Care Nurse Consultant is not undertaking education of nurses.

**ISSUE:** In the lead-up to the 2015 State Election, Cancer Council NSW campaigned for chemotherapy payments and increased palliative care services throughout NSW and was successful.

In the case of palliative care, \$100+million was promised.

Where did the \$100+million 2015 election promise for palliative care go?

Has it been shared fairly among the region when compared to city hospitals?

Because these stark contrasts of experiences between Concorde & Ballina Hospitals indicate regional palliative care services are left wanting and there is an inequity of service, nurse-patient ratios and nurse End of Life training.

2. In addition to what is contained in your submission and evidence provided at the public hearing, do you have any further comments regarding ways to improve both the access and availability of palliative medicine, nursing and care in Ballina and the region?

When it not possible for patients to die at home and they are admitted to hospital, most patients and their support would assume that there would be a consistent standard of palliative care whichever hospital they went to in this District. This consistency would be due to consistent district wide patient-nursing ratios and General Nurses regularly educated in End of Life care.

However, in the case of the Ballina Hospital – this standard appears reliant on individual nurse motivation to provide a level of palliative service that is taken for granted elsewhere.

Therefore patients & their support cannot assume that crucial care such as managing patient's breakthrough pain with pain flow charts will occur at a level that would occur in another hospital.

**Specific improvements required:**

1. General Nurses to be supported with regular End of life education.
2. Patient to nurse ratios need to be significantly improved.
3. Equity needs to occur.