Senate Inquiry into Palliative Care in Australia

Submission by Dr Yvonne McMaster FRACGP

I write as a retired palliative care specialist who has forty years experience of working with dying people in New South Wales. Since retirement, as a volunteer, I have continued to run a weekly support group for patients with advanced cancer. This information and my recommendations are the result of my experience in palliative care and from input from a large number of stakeholders throughout New South Wales.

22 March 2012

Dr Yvonne McMaster

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(a) Factors influencing access to & choice of appropriate palliative care that meets the need of the population

(i) PEOPLE LIVING IN RURAL & REGIONAL AREAS

Background

- At present, in NSW, rural palliative care depends almost entirely on an under-funded and under-staffed network of palliative care nurses. Some receive some support through contracts with metropolitan palliative care services through the Medical Specialist Outreach Assistance Program (MSOAP) so that palliative care doctors visit some regional centres on a fly-in fly-out basis. Increased workload and reduced funding of metropolitan services has limited the frequency of access in recent years.

Staffing

- There are great difficulties maintaining rural services on very limited budgets. Due to very small services, and a lack of adequately trained staff to backfill, Specialist Palliative Care Nurses are very seldom relieved. Few resources are available to actively and thoroughly engage in succession planning. Consequently when a specialist palliative care nurse takes leave a specialist palliative care nurse or Clinical Nurse Consultant (CNC) from a neighbouring service will often provide telephone coverage over a very large geographic area. This can lead to unnecessary hospital presentations which would usually be avoided if a palliative care nurse were readily accessible. Hospital presentations are often associated with lengthy waiting times in Emergency Departments which are distressing for terminally ill palliative care patients and their families. Rural GPs, as medical coordinators of the patient's care, require a good working relationship with specialist palliative care nurses and generalist community nurses. This is not always there.

- In many rural regions there are insufficient numbers of community nurses to provide adequate palliative care for even non-complex patients. Some of these community nurses do not have current knowledge and have multiple 'hats' delivering care for a range of conditions making their difficulty in keeping up to date significant. Some do not feel comfortable caring for palliative care patients. This can lead to inappropriate presentations to Emergency Departments, premature admissions and delayed discharges.

- Most specialist palliative care services are understaffed. As a result patients and families are not able to receive a comprehensive level (that is medical, nursing, psycho-social and functional care) of service and support. There is no funding identified to support succession planning and, with low staffing numbers, little time to train new staff. Community based nurses often have to be supported in the provision of palliative care by phone due to staffing constraints within the specialist palliative care services.

- Support from allied health professionals, volunteers and carers' support must be included in the model. Utilising volunteers requires coordination to be effective and in under-resourced areas this would be an additional strain on the caring team and nurses do not always have the coordination skills required. A dedicated volunteer coordinator could address this concern. There are duplicated and fragmented volunteer services provided across the community which dilutes funding and hampers the delivery of an effective service. Volunteers are only appropriate for bereavement support where a trained volunteer coordinator or other trained supervisor is available to provide guidance and professional supervision.
- Carer respite and HACC type support on a day basis or longer, needs to be available. Rural areas have little or no access to appropriate respite beds, and most have no designated palliative care beds.
- Given the limited education about palliative care which undergraduate nurses receive, Specialist Palliative Care CNCs and Clinical Nurse Specialists (CNSs) spend significant amounts of time teaching hospital and community based nurses a palliative approach to care including symptom management.
- Rural Palliative Care services need administrative support. It has been reported that one very committed rural palliative specialist in NSW was finally forced to give up her job allegedly because of lack of administrative support. There is a significant role for good managers who should have some training in palliative care systems.

Recommendations re staffing

1. Rural areas urgently require more palliative care CNCs. Then they will require a designated work area and cars(s) etc. 'Hot desking' is very difficult for senior staff (CNCs) who have educative and service development roles.
2. Community nurse numbers and palliative care nurse numbers must be increased to provide an acceptable level of palliative care to the rural community. At present "burnout" is an issue that impedes recruitment. In addition, palliative care training needs to be included in the undergraduate curriculum for nurses.
3. That regional centres be funded to provide a specialist palliative care doctor, based on population at the suggested rate of one PC specialist per 100,000 population. Centres which could benefit are Tamworth, Lismore, Grafton, Port Macquarie, Dubbo, Orange, Broken Hill, Albury, Wagga Wagga, Queenbeyan and Coffs Harbour. If Specialist Palliative Care Physicians are based in rural regions then they must be adequately supported within a specialist medical team to maintain their professional network. Although there is a now palliative care specialist in Coffs Harbour, a part time specialist in Lismore and a full time experienced palliative care CMO in Tamworth, enhancement for the population numbers is required. The role of Nurse Practitioners as a workforce strategy also needs to be considered noting the shortage of palliative care specialists.
4. Until medical palliative specialists can be found for these regional centres they should receive enhancement funding to provide an office with a manager who is given some understanding of palliative care and sufficient CNCs to be able to outreach to the surrounding area and to stream clinical support, education, and regular de-briefing for the palliative care nurses and GPs based more remotely in

their sector. No areas of NSW should lack access to palliative care services by palliative care trained nurses and GPs who have had some education in palliative care.

5. Increase access and utilisation of Telehealth services throughout NSW for Palliative Care Services including the use of Skype for consultations.
6. Specialist Palliative Care Services need palliative-care-trained allied health workers. Shared access to Allied health with already stretched oncology and aged care services will not meet the community's palliative care needs.
7. Specialist Palliative Care Nurses must be able to be relieved for leave. Long driving times must be factored into their workloads.
8. Rural Specialist Palliative Care services to be funded adequately (and recurrently) to provide palliative care services to rural patients in an equitable way. There must be funding of palliative care beds / respite beds in rural areas to assist services meet the criteria for specialist palliative care services under the palliative care framework.
9. Trained volunteer coordinators for all volunteer services.
10. Nurses need time and funding to attend regular training opportunities. This will assist patient care and reduce burnout.

Issues relating to GPs

- There can be difficulties in engaging with GPs to provide their patients with appropriate levels of palliative care, including home visits. Palliative Care competes with many other disciplines and geographical distances often present difficulties for GPs to attend education opportunities that are available. Very few GPs provide after-hours services or home visiting services, which also impacts on anticipated home death processes (discussed below).
- Some suggest that this is an issue that could be addressed by the Commonwealth and that if the Commonwealth were to introduce special Medicare Benefits Schedule item numbers that are relevant for Palliative Care then that may lead to GPs being more willing to do home visits, provide after-hours cover and give time for psychosocial support. Some suggest that Medicare Locals could introduce Key Performance Indicators for General Practice emphasising the importance of palliative care. Others draw attention to the failure of similar attempts to improve GP visits to Residential Aged Care Facilities (RACF) patients such as the Aged Care Access Initiative and Aged Care Panels initiative – both regarded by doctors and consumers in NSW as dismal failures. They believe that a properly funded and staffed specialist regional and rural palliative care workforce led by specialist palliative care doctors or nurses advising GPs and with access to specialist palliative care doctors through fly-in fly-out and telehealth is more likely to provide first class palliative care. I am of the latter view.
- The need for specialist palliative care services in rural homes, hostels, nursing homes and hospitals is obvious. Skilled GPs will always be critical to the provision of specialist palliative care services but palliative care specialists and staff are required as well.

- Some GPs and specialists can be slow to refer to palliative care services. Psychosocial and symptom control needs are frequently overlooked or ignored.
- A major issue is that many GPs in remote areas are from different cultural backgrounds from the residents of rural areas and there can be language barriers. They are brought here through the Targeted Inland Recruitment Scheme (TIRS) which has attempted to address rural medical workforce shortages. This is sometimes a mixed blessing for dying people because some of the overseas-trained GPs are not receptive to advice from female palliative care staff. It has also been reported that the attitudes to dying can be significantly different. It is reported that one doctor said:

  "You people make too much of a fuss about dying. You should expect to suffer".

- It is understood that this is not an isolated incident. Some level of competence in Palliative Medicine should be expected from any doctor in rural areas and some effort must be made to educate them in the prevailing culture.
- Education and support of rural and remote GPs is critical but requires better funding and staffing of all specialist palliative care services both rural and metropolitan as the latter provide training in the more specialised areas.
- There is not a good level of awareness of the Therapeutic Guidelines Palliative Care or British Gold Standards Framework model of support for GPs.

Recommendations relating to GPs' role in palliative care

1. All GPs working in rural areas must have up-to-date education about palliative care, both about symptom control and in managing the inevitable and universal psychosocial issues involved in death, dying and loss and grief. This may be through expansion of the PEPA system or through their accreditation requirements, but preferably through both. Some efforts must be made to educate overseas-trained doctors about the prevailing culture they will meet in rural NSW and in the complex needs of dying people and their families. See Appendices 1 & 2.
2. All specialist palliative care services must be adequately funded and resourced to have time to teach GPs and community nurses.
3. The expectation that GPs can shoulder the burden of much of palliative and end-of-life care with all it entails should be abandoned and properly staffed specialist palliative care services used wherever possible. They will teach, consult and cooperate with GPs to the great benefit of patients.
4. Adapt the British Gold Standards Framework for Australian rural and remote conditions.

Access to Palliative Care Services

- There are people in NSW who have <u>NO ACCESS</u> whatsoever to Specialist Palliative Care. In the one area there are 87,000 people without any PC access. Some areas are covered by community nurses who have to beg recalcitrant GPs to help patients appropriately or beg busy, distant palliative care specialists to make long journeys to visit patients.

- Rural Specialist Palliative Care services for the indigenous population require special consideration as do those for children (see below).
- Most rural services are only funded to provide a service from 0830 – 1700, Monday to Friday with very limited or no access to after-hours specialist palliative care nursing support after 5pm, over the weekend and particularly during the Christmas / New Year period. In many areas there is also inadequate general community nursing support which compounds the problem.
- Access to Allied Health is poor with very few positions designated as palliative care but there are allied health in oncology, rehabilitation and aged care teams. A population-based approach to palliative care Allied Health positions is needed across the state and these positions need to provide resources and support to up-skill generalist allied health staff. It may be that rural centres develop multi-disciplinary positions with, for example, oncology-palliative care or aged care-palliative care responsibilities.
- Community assistance packages: Access by palliative patients to Home and Community Care (HACC) type support is grossly inadequate. Like the previous points this leads to inappropriate presentations to Emergency Departments, premature admission and delayed discharge. Personal care & respite needs are usually required only for short periods towards end of life but more hours may be needed than the current 3 days per week for 1.5 hours. The NSW Department of Disability and Ageing is slowly introducing a system where more rapid assessment and prioritisation of needs can be processed with a 1300 telephone number which currently operates in the Lower Hunter region and will be introduced in the Central Coast this year. Encouragement to speed the process has met with disappointingly discouraging replies.

Recommendations re access to palliative care services

1. A 24/7 phone support for patients and families is a basic minimum throughout NSW with establishment of a comprehensive electronic clinical record so that advice can be informed and a 24-hour 1800 number. Nurses who answer out-of-hours calls must be paid for this and be relieved when needed.
2. HACC and any other community assistance packages must be made available as a priority for palliative patients. It is not good enough for these services to become available months after the patient dies! In order to assist patients to stay at home in the final stages of life the support may have to be for more hours a day than for other situations. The introduction of a 1300 number for priority access for palliative care patients throughout NSW must be expedited.
3. Rural Specialist Palliative Care services to be funded adequately (and recurrently) to provide palliative care services to rural patients in an equitable way. There must be funding of palliative care beds / respite beds in rural areas to assist services meet the criteria for specialist palliative care services under the palliative care framework. Specialist Palliative Care Nurses must be able to be relieved for leave. Long driving times must be factored into their workloads.

Equipment

It is understood that EnableNSW, which is a program to enable access to equipment and oxygen supplies (concentrators and cylinders), is addressing the policy for the provision of home oxygen for palliative care patients. In the past acquiring home oxygen was a difficult and a slow process requiring arterial blood gas results to be available before patients could receive the supplies. This often led to delays in patients being discharged from hospital. Palliative care patients who are breathless may not necessarily have significantly low oxygen levels. Breathlessness that is not well managed frequently leads to inappropriate presentations at Emergency Departments.

Equipment access is an issue generally as it requires good coordination of the storage, servicing and maintenance of such equipment as well as the tracking of items on loan. A lot of these tasks often fall to nurses.

Recommendations re equipment

In some areas Base Hospitals could store and maintain equipment and deliver it to homes at the request of the palliative care team or GP. Some metropolitan hospitals have used the hospital's maintenance men to do this job, freeing up nurses and allied health staff to do their own jobs,

Coordination of services

There are problems of coordination of services and care for patients in declining health in rural areas as there are in the city. Specialist Palliative Care services are best placed to be the lead services which can direct and coordinate a collaborative team approach to care. However, there is a constant danger of fragmentation of services leading to unnecessary and misguided treatments, almost always at great expense to the state.

Recommendation re coordination

Palliative care services must be funded to allow them to coordinate care properly and appropriately. This will save patients from a great deal of futile treatment and investigation and save the state a great deal of money.

Medications

- In most rural locations, the availability of adequate and appropriate medications in the home for palliative care patients is reliant on nursing staff proactively liaising with GPs and suggesting a plan of care. This relies on nursing staff (both community-based and palliative care) anticipating symptoms which patients may experience based on their disease. There are varying levels of support from GPs to provide prescriptions in advance of symptoms. Local community pharmacies do not all stock the usual medications required in the palliative setting and time delays (often days) can be experienced in the supply of medications to a patient’s home.

- Local hospital pharmacists (most rural hospitals do not have one) are not usually trained in palliative care and some do not even stock the range of basic medications used in managing the symptoms palliative care patients experience. This can lead to the need to use substitute medications which is not best practice in Palliative Care.

- A number of medications used in palliative care are not on the PBS and some patients can't afford the cost of a private prescription for medications such as Gabapentin (used in pain control), Buscopan ampoules and midazolam.

Recommendations re medications

1. Rural hospitals must have adequate provisions of drugs required to supply the needs of dying patients. There must be a minimum "stock" of medications depending on the size of the hospital. Where there are hospital pharmacists they must have some input into assisting palliative care teams with supply of medications to remote locations.
2. Expensive, non-PBS medications should be made available at minimal or no cost in cases of hardship.

Residential Aged Care Facilities (RACFs)

Many rural Residential Aged Care Facilities are not staffed adequately, particularly with regard to registered Nurses (RNs) to be able to provide adequate care for palliative care patients. Addressing the RN-to-patient ratio would be a good starting point. It must be a requirement of the accreditation of RACFs that they provide a palliative approach to care of their residents. RNs must be able to provide the full range of symptom and end-of life support including symptom assessment, the ordering and administration of medications, particularly schedule 8's and to be able to provide p.r.n. medication administration. On many occasions staffing shortages lead to unrelieved pain and admission into an acute care facility, often through Emergency Departments with unnecessary trauma for both the patient and family. Rural RACFs can only manage patients with complex palliative care needs if they are able to access support, consultation and medications from specialist palliative care teams. This requires more staffing of specialist palliative care teams.

Recommendations re RACFs

1. RACFs must be required to have sufficient trained staff to ensure the availability of schedule 8 medications around the clock.
2. Specialist palliative care services must have sufficient staff to visit RACFs where there are dying patients to prepare end-of-life pathways and to ensure patient comfort.

Bereavement services

If they exist at all bereavement services are not usually of adequate size to be able to provide a service to all families. Minimum levels of service must be established for families of palliative care patients. Generalist services, where they exist, do not have the capacity to meet this need. In fact one Palliative Care Nurse reports that the generalist services used to try to refer bereaved relatives to her because she was used to dealing with death and loss.

A review is required of bereavement support, bereavement counselling and the role of the GP, bereavement services, counselling services, psychology and psychiatric services. Medicare Plus allows a GP to refer a patient to a psychologist or social worker for bereavement counselling (services which are then covered by Medicare). However, it is

understood that palliative care specialists cannot refer patients for private psychological services.

As mentioned above, if volunteers are used for bereavement support and follow-up they must be professionally supported and coordinated.

Recommendations re bereavement services

1. Minimum levels of service must be established for families of palliative care patients.
2. Generalist services, where they exist, do not have the capacity to meet this need. If volunteers are used for bereavement follow-up and support they must have professional coordination and supervision.
3. Families of dying people should be routinely assessed for their preparatory grieving needs during the patient's illness and afterward for bereavement needs. Most will manage with compassionate acknowledgement of their feelings, others will require more structured help with trained volunteers, social workers and psychologists taking the lead where they are available.
4. Medicare provisions must allow palliative care specialists to be able to refer patients to private social workers and psychologists.

Service Delivery Agreements and Models of Care

Twining of Metropolitan with Rural Services: While some rural districts/health services have existing service agreements with metropolitan palliative care services for the provision of visiting palliative specialists for patient consultations and education and training through MSOAP, in reality, the significant increases in metropolitan palliative care demands and therefore workload have meant that these service level agreements with the rural districts cannot always be met. This leads to a difficulty in providing reliable, consistent access to support. GPs and specialist PC nurses are not confident that complex symptom control problems will be able to be addressed successfully.

- Some rural services geographically distant from metro services, but with patient pathways that go interstate, need to be provided with formal support either from NSW metro services (not occurring at present) or be provided with resources to purchase services from interstate.
- A Hub and Spoke system where a palliative care doctor works in each of the regional centres - Tamworth, Lismore, Grafton, Port Macquarie, Coffs Harbour, Dubbo, Orange, Broken Hill, Albury, and Wagga Wagga is the ideal pipe dream, however if these towns were properly staffed with Palliative Care CNCs and CNSs they could then operate a hub and spoke system which streams help, support and education to their region. In regional and rural NSW there is now only a palliative care specialist in Coffs Harbour and a part-time palliative specialist in Lismore and a full time CMO in palliative care in Tamworth.
- Doctors have been asking to have palliative care specialists in each of the regional centres for years. It would help if during their training, palliative care registrars were expected to do regular rural visits to some of the regional hubs. It is understood that Sacred Heart Hospice, Darlinghurst already provides this

opportunity. This would be a great experience for the registrars & might convince some to end up settling in rural areas.

- Telemedicine to provide specialist medical and nursing support: Telehealth services are underutilised. Resources are required to promote its use, train users and research its effectiveness in the provision of palliative care services. Enticements may be required to encourage overstretched GPs and nurses to participate. It is important to note that an increase in Telehealth is not a substitute for adequate numbers of multidisciplinary palliative care staff in rural areas.

Recommendations

1. That each metropolitan Specialist Palliative Care Service be twinned with one sector of Rural NSW to assist with the delivery of palliative care services in regional and rural NSW. To achieve this and to maintain the autonomy of the Local Health Districts, "quarantined" palliative care funding could be allocated to the relevant Rural Local Health District to enable the district to "purchase" services from the metropolitan LHD Specialist Palliative Care Service through a Service-level Agreement. The services purchased could include, but not be limited to, education, coordination, clinical and administration support. A suggested grouping of sources is included at Appendix 3 (attached to this email).

2. That the existing service agreements (in some regions) between metropolitan and rural specialist palliative care services be at least met, strengthened and gaps filled and that new linkages be opened up where none currently exist (such as to the far north coast).

3. That regional centres be funded to provide a specialist palliative care doctor, based on population at the suggested rate of one PC specialist per 100,000 population. Centres which could benefit are Tamworth, Lismore, Grafton, Port Macquarie, Dubbo, Orange, Broken Hill, Albury, Wagga Wagga, Queenbeyan and Coffs Harbour. If Specialist Palliative Care Physicians are based in rural regions then they must be adequately supported within a specialist medical team to maintain their professional network. Although there is now a palliative care specialist in Coffs Harbour, a part time specialist in Lismore and a full time experienced palliative care CMO in Tamworth, enhancement for the population numbers is required.

   Until palliative care specialists can be found for these regional centres, the centres, or hubs should receive enhancement funding to provide an office with a manager who is given some understanding of palliative care and sufficient CNCs to be able to outreach to the surrounding area and to stream clinical support, education, and regular de-briefing for the palliative care nurses and GPs based more remotely in their sector. No areas of NSW should lack access to palliative care services by palliative care trained nurses and GPs who have had some education in palliative care.

4. The role of Nurse Practitioners as a workforce strategy needs to be considered given the current shortage of palliative care specialists.

Other PC service delivery models

In 2002, the Federal Government initiated an ambitious project for rural palliative care throughout Australia. It set up pilot studies in each State and Territory. In NSW this was in Griffith. This study lasted three years and was assessed by Wollongong University in 2005 as having improved palliative care in the Griffith area. (GAPS - Griffith Area Palliative Care Scheme). It is understood that the Griffith service model (GAPS) lapsed for a number of years but was re-born at the beginning of 2011 and continues implementation. However, further comments I have received during this consultation inferred that the Griffith Area Palliative Care Service (GAPS) model is not ideal and should not be copied or replicated. In their view the model suffered from five major problems:

(i) It was based on the Division of General Practice instead of on the Community nursing service and therefore was not sustainable because there was no support for the one isolated palliative care nurse.

(ii) GPs needed to share information about their patients (electronic and meetings), so that patients can be looked after especially after hours by another GP.

(iii) There was no system for patients to be referred for specialist advice if needed. The program would have benefited from some links to palliative care specialists.

(iv) It only covered a very small area around Griffith with nearby Leeton having no PC service at all. Some called it the "Balmain Service"

(v) Advice received suggested that the funding would have been better utilised if it had been directed towards the Area CNC and that the palliative care nurse position/resource needed to be based with the Community Health service to enable efficiencies to be achieved and to provide opportunities for effective liaison with other team members.

Recommendations

1. That the GAPS scheme only be copied to the extent that every palliative care service in NSW has an 1800 number for 24/7 access to care and that cooperation with GPs be encouraged with GPs taking more interest in palliative care and improving their knowledge and skills.

2. That the twinning model of care mentioned above be introduced, or where it already operates, strengthened, with close ties with metropolitan Level 3 specialist units and each regional centre have a strong, well resourced palliative care hub or hubs with a manager and adequate numbers of palliative care nurses.

New and proposed Rural Cancer Centres

There are now Cancer Centres (either existing or planned) in Illawarra, Lismore, Tamworth, Central Coast, Orange, Shoalhaven and Albury-Wodonga. It is critically important to ensure that the needs of palliative are patients will be addressed throughout the planning and establishment process. However the established new Cancer Centre in Orange has no palliative care funding, yet its existence generates more palliative care work for the already stretched-to-the-limit Palliative Care Service. Now with other cancer

centres not yet complete there is an opportunity to encourage greater development of palliative care services in each area in question.

Recommendation

Every new Cancer Centre to have its palliative care needs urgently assessed in conjunction with the local palliative care service and to be adequately funded and staffed to meet the needs of the patients attending the cancer service.

(ii) INDIGENOUS POPULATION

Rural Specialist Palliative Care services for the indigenous population require special consideration. This is a major question of equity. This population has a very different approach to death, terminal illness and the use of morphine and other medications. Cultural differences require a very special approach and sensitivity on the part of palliative care workers. Some aboriginal patients prefer to die in their own country. Frequently this isolates them from the best palliative care which is currently available. Poor health and poverty are problems for many. Particularly concerning is that some of the newer pain medications used commonly in metropolitan practice such as gabapentin, are not on the PBS and are too expensive for many of these patients.
Aboriginal liaison officers are a major priority. The use of a palliative care enrolled nurse or assistant in nursing (AIN) to support the palliative care team manage symptom control may be needed. Aboriginal liaison officers become an essential part of the palliative care team.

Recommendations

1. Ensure remote palliative care services have aboriginal liaison officers. They are a major priority.
2. Special funding may be needed to ensure that this population gets the best possible care despite access difficulties and cultural differences. Funding for a palliative care enrolled nurse or assistant in nursing (AIN) to support the palliative care team manage symptom control.
3. Special arrangements are needed to ensure that all palliative care patients can access modern medications.

(v) CHILDREN and ADOLESCENTS

Background

The following extract is from the NSW Paediatric Palliative Care Planning Framework 2011-2014:

> *"Palliative care for children is the active total care of the child's body, mind and spirit, and also involves support for the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychosocial, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources. It can be successfully implemented even if resources are limited."*

It can be provided in health care facilities, in community health settings and in children's homes.

Specialist Paediatric Palliative Care Services are provided by Sydney Children's Hospital Network (SCHN), at both Randwick and Westmead campuses, and John Hunter Children's Hospital (JHCH).

These services are consultative services provided to children and their families in hospital, hospice or in the child's home. The services are provided by multidisciplinary teams, following referral from primary teams. Services are provided irrespective of diagnostic group, as long as the child is diagnosed as having an illness from which the child is expected to die before adulthood.

The role of the specialist paediatric palliative care service is:

- To provide symptom management and psychosocial support directly to the child and family
- To provide care co-ordination where appropriate and to ensure good communication between all service providers
- To make appropriate referrals for the child and family to other health and community services
- To support community based primary care services by providing education, resources, and 24-hour telephone advice
- To provide support for clinicians to conduct end-of-life care discussions with families, or to conduct them directly with the family
- To provide access to ongoing support in bereavement
- To ensure that care provided is culturally appropriate
- To lead service development and research in paediatric palliative care.

Referrals to paediatric palliative care are spread across the diagnostic groups, with approximately 1/3 of referrals from neurology, 1/3 from oncology, and the last third spread across a number of diagnostic groups including respiratory, cardiovascular, genetics, and metabolic.

SCHN manages the only children's hospice in NSW – Bear Cottage. Bear Cottage provides routine respite care, crisis care, step down from acute care, and end-of-life care to children receiving palliative care. Bear Cottage receives referrals for children from anywhere in NSW. However, while at Bear Cottage, the children become patients of SCHN."

Please note: Bear Cottage is mainly funded by community donations.

My Comments

1. Bear Cottage is wonderful. However situated as it is in Manly, on the coast in Sydney, Bear Cottage is not near the main population centres in western Sydney, meaning that many families find it too difficult to use it and travel for many hours each way to visit a sick or dying child, while possibly having a large family at home on the other side of Sydney or even in western NSW.
2. As with adults, in-home respite provided by non-government organisations, is variable, both in availability and quantity.
3. Respite care options must be more flexible to meet the needs of families. This includes access to a variety of respite care, including home based care and day care programs.
4. A bereavement support service is urgently needed. It should be the first priority as should counselling services for parents and families.
5. The biggest issue of all is the sustainability of the current service which is based on the goodwill of the very stretched and overworked limited personnel and almost no funding. This is unsustainable.

Recommendation

I commend you to the Final NSW Paediatric Palliative Care Planning Framework. It is an excellent document. See its pages 23 to 27 **for expert recommendations** and also **consult** Dr John Collins AM Head of Department | Pain Medicine and Palliative Care (02) 9845 0000 john.collins@health.nsw.gov.au | **w:** www.chw.edu.au

(b) Funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent

Distribution of COAG Funding

COAG Funding for sub-acute care is currently given to the area health services to be distributed. In 2009 the Northern Sydney & Central Coast Area Health Service received $24 million in COAG funding for subacute care. Of this palliative care only received $4.4 million. Yet this vast geographic area has the largest proportion of people over 85 in NSW. The palliative care services depend on this COAG funding for everything beyond the very basics of care. They particularly need it to fund registrar training positions which are of vital importance as new doctors are the life-blood of palliative medicine in a time of great shortage. The COAG funding is spasmodic and doled out at the whim of the Area Health Service. Training positions have to be dropped when the funding isn't recurrent. All this has left the workforce demoralised, making it harder to attract new graduates to the specialty.

I am told that both Victoria and New Zealand have a better system than NSW where the funding follows the registrar, not the other way around.

Recommendations

1. The Commonwealth should ensure that the moneys they would like to see spent on end-of-life care actually reach the palliative care units who are tasked with caring for the patients and families.

2 There must be transparency of decision making regarding allocation of funding by Local Health Districts (LHDs). Palliative Care Services need to know that when a programme is successful the funding will continue.

3. The Commonwealth must look at models where registrar funding money is held by a training provider such as the Sydney Institute of Palliative Medicine or the Royal Australian College of Physicians (not the Local Health Services).

(d) The effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities

The effectiveness of palliative care arrangements depends on the demand for services and the supply of palliative care services to meet that demand.

Any assessment of the effectiveness of palliative care arrangements must flow from the WHO definition of palliative care (see appendix 1), as must the design of better services.

Exponential increase in demand

True palliative care, as defined by the WHO (see Appendix 1), now exists only in very few areas in NSW and is threatened in all. There has been a shocking erosion of funding and services available to dying people in the last 15 years. At the same time there have been enormously increased demands because of increasing population and the following changes:

(i) Enormous explosion in demand for palliative care

Medicine has been so successful in recent decades that we now have a situation where a high proportion of the population is living into old age and dying of chronic neurological illnesses, organ failures and dementia requiring good palliation and often not getting it. Palliative care is expected to step up to the plate but staffing is not there to allow this. Chronic disease now represents 70% of the total disease burden. I am told that caring for these people already represents at least 40% of all palliative care workloads and some say 60% – 70%. Yet palliative care funding and staffing is still based on ancient cancer numbers. In NSW there is no funding allocated to care for these people.

> *I heard a harrowing story about a poor lady in an acute hospital in Sydney: She is frail-aged but has terrible peripheral vascular disease with ischaemia and ulcers. She has a great deal of uncontrolled pain and poor coordination of her care between different specialists. She has been told she may require bilateral amputations. She has no proper symptom control. A visit from a palliative care physician, or nurse could make her life bearable. There is none available.*

(ii) Medical and Nursing Palliative specialists are needed to teach palliation

Palliative care services must be staffed adequately to provide teaching in many areas. They are needed to teach staff in acute hospitals and nursing homes, GPs, community nurses, other specialists and rural doctors and nurses.

Some rural services have formal, organised linkages between rural palliative care services and metropolitan PC services. However staffing and workloads in metropolitan services have mitigated against some of these linkages being sustained and useful.

Many patients die in nursing homes. It is essential that palliative care services have a much bigger role in nursing homes and visit regularly. This cannot happen with current palliative care funding and staffing levels. Training of nursing home staff is needed in symptom control and in the use of syringe drivers. The GPs who currently

service patients in nursing homes have little or no training in palliative medicine. Sadly, many think the solution to all problems of dying patients is an increasing dose of morphine. This is sometimes catastrophic because morphine in the absence of pain is often not helpful. It can lead to hallucinations and delirium and can cause more trouble than it corrects. Patients and their families can suffer more rather than less as a result.

> *One man, transferred home from a Sydney hospice to what was thought to be a first class nursing home was, within a few days, given excess morphine, then even more when he became distressed. His son's last memory of his father is of a crazy and aggressive man violently pushing him away.*

(iii) In-reach into Acute Hospitals

At least half of the deaths in NSW occur in acute hospitals and much palliation is needed in these settings. More funding is needed for palliative specialists and nurses to advise on management and to assist transfer to often more suitable places, such as own homes or hospices. At the start of every term lectures should be given to the new resident medical officers/interns to ensure they are aware of symptom control and other aspects of palliative care. There is still too much suffering in acute hospitals.

(iv) Symptom control in cancer

This has become more complex and support needs are more prolonged because of improved oncology. Lives have been prolonged as has the dying process with more difficult symptom control problems occurring all along the road. The resulting symptoms are more complex and require specialist handling. Often palliative intervention can forestall the use of futile therapies.

> *A 60-year old woman with advanced ovarian cancer developed obstruction of both ureters. This was relieved by stents. Then she developed an intestinal obstruction. A laparotomy was performed to relieve this, leaving her with an ileostomy. Palliative chemotherapy was continued with intermittent blood transfusions and after six weeks she feels much more energetic and has started to enjoy life again. Specialist palliative advice was needed during this period to relieve symptoms. At one time she would have been allowed to die six months ago.*

Decline in Generalist and Specialist Palliative Care workforce

(i) Reduction in GP participation

GP's participation in care of the terminally ill is currently limited. Yet the NSW Palliative Care Strategic Framework (2010-13) and the Palliative Care Role Delineation Framework mandate that the role of the specialist palliative care service "supports and compliments the care provided by primary care services". It suggests that "specialist care may be episodic and ongoing partnerships with primary care providers are necessary to ensure the development of a single system of care with seamless referral and case management of patients" and goes on to say that when the complex needs of palliative care patients have been met by the

specialist team the patient is handed back to their GP. However at this time **most GPs are not able to provide true palliative care.**

Funding currently assumes that a large proportion of PC is delivered by primary health care providers – GPs and community nursing services. But GPs can't, don't and won't for the following reasons:

- GPs are poorly paid and generally overworked. They have to maximise their incomes by doing short consultations in their surgeries. This does not allow for complex psychosocial consultations or complex symptom control. They are often too busy to organise authority prescriptions to give patients sufficient supplies to avoid frequent trips to the GP and pharmacy leading to poor symptom control and much more stress.
- GPs have little or no training in palliative medicine and PC services are not funded to train them.

  PEPA (Program of Experience in the Palliative Approach): This federally funded scheme offers GPs two or three days training in palliative medicine with a specialist team. In return they are paid approximately $1,000 per day. GPs report great satisfaction and greater interest following such an input. However very few GPs take this up and specialist services are not funded for the extra work involved or for promotion of the scheme to GPs. The main problem is with the current nature of general practice. There are numerous calls on GP's study time. They are unlikely to have more than two or three dying patients a year. They are more motivated to take up clinics in subjects they will use more frequently.
- GP home visits have become a rarity. There is a tendency to use the ambulance service to triage patients. Some practices won't even visit to certify that death has occurred. Therefore they really can't look after dying patients in the community. When patients are "handed back" to their GP they are in effect dumped. Palliative care must keep these patients and can't expect the GPs to take them over.

Recommendation re GP involvement in palliative care

That GPs not be expected to do palliative care beyond the most basic support and specialist palliative care services be funded and palliative care workforces be strengthened to be able to pick up the slack left by changes in General Practice.

(ii) Community nursing services are also running on a shoestring. There have been funding cuts across the board. This means that many dying patients are not able to be cared for at home and suffer and die in inexperienced acute hospitals instead.

Recommendation re community nursing services

The proper funding of community nursing services is a low-cost win-win situation which will help to keep patients at home where most prefer to be.

(iii) Specialist Palliative Care Workforce decline:

Palliative medicine has become the Cinderella of medicine. Declining funding and poor treatment by some area health services has made the medical specialty of palliative medicine less attractive to new graduates. Federal strategies to reverse this trend such as Advanced Primary Care items for palliative care would help make the specialty more attractive.

Recommendations re palliative care workforce

1. That the Commonwealth study what Advanced Primary Care Items would help make palliative care a more attractive option for medical graduates.
2. That Medical students spend a day each year in a palliative care unit.
3. That training arrangements be examined to see how palliative medicine can be more attractive as a career.
4. That the PEPA scheme be made mandatory for all GPs and given more accreditation points.
5. That funding should possibly follow the palliative care registrar, not the other way around.

Hospital Palliative Care in Acute Hospitals

- Most large metropolitan teaching hospitals in NSW have palliative care teams. Some however, such as the John Hunter Hospital in Newcastle, are palliative-care-free-zones. Yet people suffer and die there!
- District hospitals such as Gosford Hospital, Mona Vale Hospital and Hornsby and Ku-ring-gai Hospital depend on visits from the palliative care services in their district. In the last 15 years, with declining funding for palliative care services, these visits have tended to be restricted to palliative care nurse visits instead of clinical visits by palliative care specialists where they can consult about problems, recommend treatments and teach. The latter ranks very high but comes last when pain and other very distressing symptoms need urgent attention.
- Base Hospitals in regional towns: There is also room to improve specialist palliative care support within base hospitals. Dying patients are often admitted under doctors who don't have adequate palliative care experience. With an enhanced access to PC physicians (who one hopes would be resident in the town, see proposals above) or from metropolitan level 3 specialist palliative care services, clinical advice and teaching will see this situation improve.

Recommendations re palliative care in acute hospitals:

1. That every teaching hospital has its palliative care team assessed and enhanced.
2. That every district hospital have dedicated regular (at least twice a week) visits by palliative care specialists to consult clinically and teach and that specialist palliative care services be funded and staffed to make this possible.

3. All these problems will be solved with increasing the funding to all specialist palliative care services allowing recruitment of staff – both specialist PC doctors and nurses.

4. That John Hunter Hospital, Newcastle have its palliative care needs urgently assessed in consultation with Hunter New England Palliative Care Service and an inpatient palliative care service started as a matter of the greatest urgency.

Hospices (Palliative Care Units)

Hospice death is frequently preferred by patients when asked near the end of their illness. By then people have an appreciation of the greater comfort that is possible with frequent expert monitoring of the situation and the greater sense of security which is possible for the relatives.

Bed reductions in hospices in recent years have led to the situation where patients who really require the kind of specialist care only a hospice can offer are transferred to either nursing homes or home. When these arrangements fall apart due to the lack of adequately funded palliative care community services it is frequently through Emergency Departments that patients are transferred into the expensive acute system.

Recommendation re hospices:

There must be a moratorium on hospice bed closures. Instead, hospices must be built up as areas of excellence and training, not only for palliative care specialists and nurses but also for GPs and other interested medical specialists.

Community Palliative Care Services

Community palliative care services are essential everywhere. Palliative care patients are best cared for at home or in hospices. It is not easy to face death of oneself or of a loved one. This is why we need a team of people to help. Patients need support of many trained specialists. Sometimes trained volunteers can help too.

Currently, throughout NSW, community palliative care teams are under-resourced and under-staffed.

Recommendations re palliative care community services

1. Funding of palliative care community services to ensure that every citizen who wishes to die at home can do so.

2. Night Nurses for all Community Services:
   Patients cared for in the community who get into difficulties after hours are frequently transferred by ambulance to acute hospitals when telephone support fails to allay anxieties. A 24/7 visiting palliative care nurse who can go to the home to advise and support could provide the extra support and expertise needed to keep the patient at home and comfortable and give the family a sense of mastery and satisfaction with the last stages of the person's life. There are major cost-savings possible here by preventing admissions to acute hospitals.

3. Securing major reductions in acute hospital admissions by delivering care at home or in the community when it is appropriate should be a major priority for the health

service; it is both cost-efficient and care-effective and places the patient and their needs at the centre of what we do.

Aged Care Facilities and Palliative Care in Nursing Homes

There is a terrible situation in NSW at the moment where patients with high-care needs in hospices are transferred to nursing homes after they have been in the hospice for a prescribed number of days. They may be too unwell to go home but their permitted hospital time has run out though their lives still hang on. It causes great distress to patients and families. The care in nursing homes is hopelessly inadequate for these patients. At present there is very little teaching of staff in nursing homes about how to manage symptoms in dying patients. Patients are under the care of GPs who are also often inadequately trained and skilled in palliative care. Appropriate medications to control distress and pain are often not available or inappropriate medications or doses are given, as mentioned previously. Frequently dying patients are just transferred by ambulance to an Emergency Department and then to an acute bed in hospital.

People are transferred from hospices to nursing homes for three reasons:

- Insufficient beds in hospices.
- Insufficient support in the community for patients to be discharged safely.
- The 35-day rule. After 35 days the doctor has to sign a form (3B) to say that the patient requires "acute care". Draconian penalties apply.

> *Picture a dying patient, no longer able to manage at home, is admitted to a hospice to die, symptoms are controlled and they feel safe. Then after a few weeks they don't die and are transferred to a nursing home instead. They feel shattered and often die quite soon, and often not at all well. It is terribly demoralising for all concerned. It is utterly immoral to push people around at this most vulnerable stage of their lives.*

HammondCare, a not-for-profit, aged-care provider of good reputation entered the palliative care service provision field in 2009. Becoming aware of the problem mentioned above and aware of the suffering it causes to patients and carers they opened a palliative care suite ('Bond House') within their own RACF at Hammondville (a suburb of Sydney). This is at HammondCare's own expense and is currently not receiving any extra external funding. Palliative care specialists from Braeside Hospital visit weekly, meet with nursing staff and GPs and prepare care plans. Early reports are most favourable with very satisfied feedback from families. An independent evaluation is underway.

This has been made possible because HammondCare have responsibilities for both aged care and palliative care in the area and through HammondCare's generosity.

How 'Bond House' palliative care suite differs from the usual aged care situation:

1. Assessment by Specialist Palliative Care Team prior to referral, whether this assessment occurs at home/residential care or in hospital.
2. Support from the specialist palliative care team; including specialist consultation in the palliative care suite, 24 hour telephone advisory service, GP support, pharmacy

access, multidisciplinary input and weekly meetings, bereavement support for families and education for nursing staff.

3. GPs with a special interest in palliative care are provided with a specific mentorship and capacity-building programme to support them.
4. In-house pharmacy licence which provides access to emergency palliative medications.
5. Designated Palliative Care Suite nursing staff.
6. All residents and their families will work with staff to plan for future care, in accordance with wishes (regularly reviewed and updated as circumstances change).
7. Tailor made palliative care education plan including the Program of Experience in the Palliative Approach (PEPA), buddy shifts and mentoring. PEPA is available to all disciplines including GPs.
8. Comprehensive education program for all staff.
9. Close links with the in-patient unit.
10. Access to HammondCare's specialist palliative care medical, nursing, allied health, pastoral care and project manager consultative services across Sydney.
11. Refurbished private rooms with ensuites.

Similar units connected with palliative care services in every area would help alleviate the current very unsatisfactory situation but would require cooperation between State and Commonwealth in the same way that there is cooperation in the Multipurpose Services units in rural areas. Only quite modest injections of extra funding could achieve a much better result throughout Australia.

The Dutch Model of having a Medical Specialty of Care of the Elderly

Fewer and fewer GPs are interested in visiting nursing homes. This leads to uncontrolled symptoms, transfers to Emergency Departments, low staff morale. One geriatric service in Sydney (Hornsby & Ku-ring-gai) used to run a course for GPs in geriatrics. This generated a group of GPs who were interested in aged care. Sadly it has stopped and the interested GPs, who have kept the system working for years, are ageing themselves and some have already retired.

The Dutch have a specialty of Care of the Elderly. The course includes a palliative care element. Morale among these doctors is much higher than the morale noted in the doctors who attend nursing homes in Australia.

Recommendation re nursing homes

1. As existing methods of delivery of care are inadequate, not only in terms of palliative care but, also, the general health care of residents of aged care facilities, and it is to be expected that there will be an increasing need because of the aging population, steps should be taken forthwith to study alternative models and, if appropriate, to design study and training courses.

2. That the evaluation of the HammondCare development be examined carefully and that a Commonwealth initiative should drive projects to have palliative care suites in nursing homes in every area where a palliative care service operates. The palliative care service would have to be funded to provide extra medical, nursing and social work support.
3. That the Dutch model of medical care in nursing homes be examined with a view to establishing it in Australia.

(e) The composition of the palliative care workforce and the adequacy of workforce education and training arrangements

(ii) ADEQUACY OF WORKFORCE EDUCATION & TRAINING ARRANGEMENTS

Recommendations

1. That a Palliative Care training coordinator be appointed in NSW to coordinate training and placement of palliative care registrars.
2. That any idea of GPs being able to do the majority of the work of palliative care be abandoned.
3. However that every effort be made by specialist palliative care services to cooperate with GPs, to keep them informed and to assist them when they are willing to be involved closely with patients' end-of-life care.

Appendices

Appendix 1: WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Appendix 2:

Palliative care requirements suggested by the International Association for Hospice and Palliative Care (IAHPC)

Table 5 – IAHPC List of Essential Practices in Palliative Care©

Identify, evaluate, diagnose, treat and apply treatment and solution measures for:
Physical care needs:
Pain (all types)
Respiratory problems (dyspnea, cough)
Gastro intestinal problems (constipation, nausea, vomiting, dry mouth, mucositis, diarrhoea)
Delirium
Wounds, ulcers, skin rash and skin lesions
Insomnia
Psychological / Emotional / Spiritual care needs:
Psychological distress
Suffering of the relative and/or caregiver
Anxiety
Identify and evaluate - provide support and when possible, refer for diagnosis, treatment and solution measures for:
Physical care needs:
Fatigue
Anorexia
Anaemia
Drowsiness or sedation
Sweating
Psychological / Emotional / Spiritual care needs:
Spiritual needs and existential distress
Depression
Family / caregivers grief and bereavement issues
Other:
Care Planning and Coordination issues:
Identify the resources and support available and develop and implement a plan of care based on the patient's needs.
Provide care in the last days/weeks of life
Identify, evaluate and implement solutions to facilitate the availability and access to medications (with emphasis on opioids)
Identify the psychosocial / spiritual needs of self and other professionals involved in the care
Communication issues:
Communicate with patient, family and caregivers about diagnosis, prognosis*, condition, treatment, symptoms and their management, and last days/weeks care issues.
Identify and set priorities with patient and caregivers.
Provide information and guidance to patients and caregivers according to available resources. Sensitize other health care professionals and workers about palliative care.

**Note:* The determination of prognosis and safe delivery of this information requires appropriate training and knowledge.

DO WE REALLY EXPECT GPs TO DO ALL THIS?

Appendix 3: Suggested NSW Palliative Care Rural Networks

Central & Western NSW Network

Metropolitan Sydney
RPAH, Concord, Westmead, Nepean, St Joseph's, Mt Druitt

Regional
Lithgow, Bathurst, Orange, Dubbo, Broken Hill

Rural / Remote
Parkes, Bourke, Mudgee

Northern NSW Network

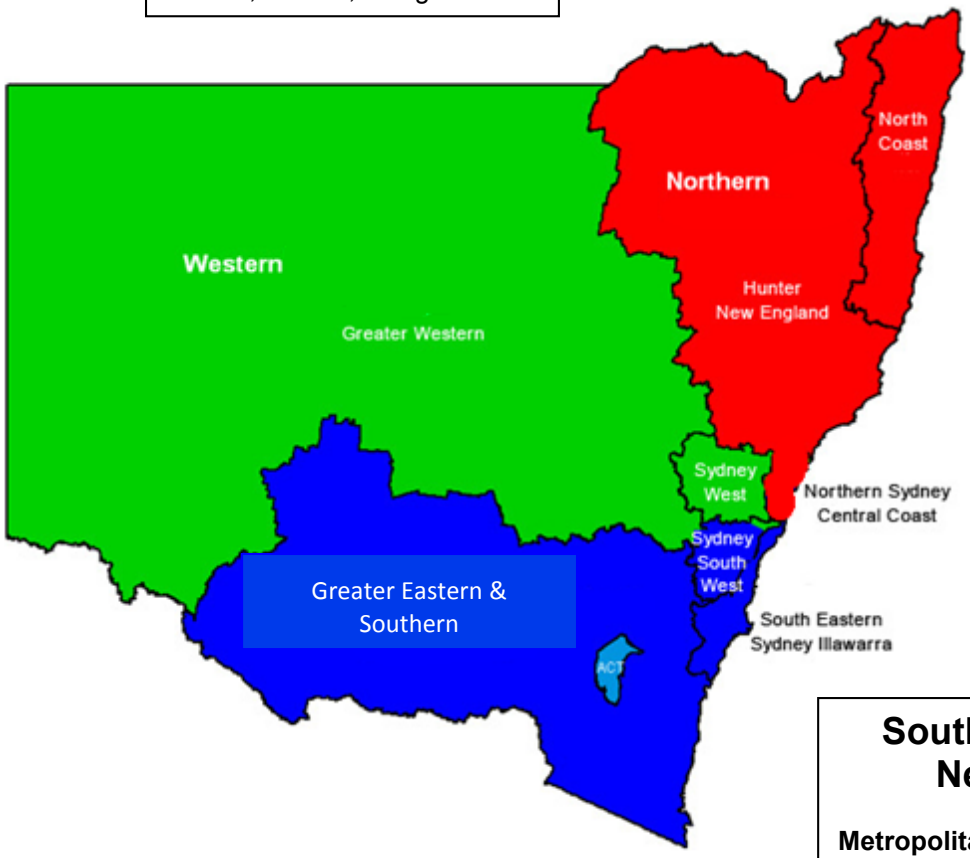
Metropolitan
Calvary Mater, Newcastle (Hunter New England LHD)

Regional:
Tamworth, Taree, Port Stevens, Cessnock, Lake Macquarie, and Upper Hunter

Rural / Remote
Armidale, Glen Innes, Tenterfield, Narrabri and

Metropolitan Sydney
Greenwich, Neringah, RNSH,

Regional:
Port Macquarie, Lismore, Grafton, Coffs Harbour



South-Eastern Network

Metropolitan Sydney
StVH, Sacred Heart, POW, StGH, Calvary, Liverpool, Braeside, Camden, Campbelltown, Wollongong

Regional
Goulburn, Queanbeyan, Cooma, Wagga Wagga, Albury, Nowra, Moruya, Bega

Rural / Remote
Deniliquin, Griffith, Leeton, Bombala, Delegate, Yass.