Submission
No 167

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

Organisation: Manning Valley Push for Palliative

Date Received: 7 December 2020

MANNING VALLEY *PUSH 4 PALLIATIVE*

Submission to NSW Legislative Council Inquiry into health and hospital services in rural, regional and remote NSW

Submission-Due Date: 13 Dec 2020

Relevance of this submission to your Terms of Reference

This submission focusses on the availability of palliative care in the MidCoast Council Local Government Area (LGA) and addresses ***item j.*** *the access and availability of palliative care and palliative care services in rural, regional and remote NSW.* In that context, it also speaks to items g. c. and a. – namely:

g. an examination of the staffing challenges and allocations that exist in rural, regional and remote NSW hospitals and the current strategies and initiatives that NSW Health is undertaking to address them;

c. access to health and hospital services in rural, regional and remote NSW including service availability, barriers to access and quality of services;

a. health outcomes for people living in rural, regional, and remote NSW.

This submission also re-presents (below) an earlier MVP4P submission, dated 18 December 2018, which we presented to the Hunter New England Health (HNEH) Local Health District (LHD) CEO and Executive group regarding resourcing the growing need for palliative care in our LGA.

Earlier State Government Work on Palliative Care Services and Needs in Rural, Regional and Remote NSW

We expect that you have access to the considerable data and 'lived-experience' provided by practitioners and community representatives during and after consultations at the NSW Heath Palliative Care Roundtables conducted in 2017 in each NSW Health LHD. There has been some qualitative change since that time in some R, R & R LHDs and rolling *promises* to increase funding and resourcing, but not full delivery, in our local experience and in anecdotal accounts regarding other parts of our own LHD – eg Tamworth – and other Regional areas.

However, we do not have the data and capacity needed to illustrate this.

Who We Are: Objectives, Achievements, Charter

Manning Valley Push for Palliative (MVP4P) is a community charity – an incorporated, registered health-promotion charity with DGR status. It was founded by its current Chairperson, Judy Hollingworth, in 2015 following requests from hospital and community-health palliative-care team leaders to help solve urgent, chronic and serious local shortages of adequate palliative care services and specialised equipment.

Our Charter is:

- We promote awareness in the Manning Valley community (MidCoast Council LGA) of the purpose, importance and value of palliative care, to encourage higher utilization and supply of services.
- We advocate for
  - proper resourcing of palliative care services so that the incurably ill receive faster and better care and other practical quality-of-life support.
  - provision of a mix of culturally diverse palliative-care practitioners (clinical and allied health} to provide a full range of palliative-support services in our area
- We assist Manning Valley patients, carers and practitioners to access important ancillary palliative care by fundraising and thus 'gap-funding', meaning providing essential and urgent home-care services and equipment which they otherwise cannot access or afford.

Our results are: $200,000 has been raised to date to purchase specialist equipment and help fund at-home, end-of-life palliative care services. Following our formal request to appoint a palliative-care specialist in the area, a specialist commenced work at Manning Hospital from July, and a permanent half-time position has been advertised, with an appointment soon to be made. MVP4P has also committed $35,000 to co-fund for six months a Palliative Care Clinical Nurse Consultant position in the hospital (with the objective of demonstrating the savings and benefits to hospital and community).

In relation to 'gap-funding' care at home for palliative patients and their personal supporters, we have funded various in-home services, for periods of days, weeks or months, for:

- 2017-18 = 27 patients
- 2018-19 = 20 patients
- 2019-20 = 21 patients
- 2020-21 = 7 patients to date

We have also purchased and donated specialised equipment to the hospital and to the HNEH LHD *Taree Equipment Service (TES)*, as well as items such as pre-pared meals, pharmacy costs, equipment-hire and providing safe access to patient properties.

This procurement and supply by us of essential equipment into the hospital as permanently items and into the TES loan-pool for the community is the most striking part of the chronic mismatch between need and resourcing: *in order to have an adequate and accessible supply of essential items, the community has to source and buy its own, which is then made available by the state government service.* 'Adequate and immediately- accessible': this is what aids quality of life and death, as so often, too often people haven't been able to get what they needed, in time.

The need remains in this area for greater palliative-care funding, focus and resources, to the detriment of the health of patients in hospital, at home and in residential-care facilities, as well as their personal supporters and carers, doctors, nurses and allied health practitioners. This electorate is among the poorest, most socioeconomically disadvantaged and most aged in the State, on a number of measures.

Why we are making this submission.

The present submission, prepared by Manning Valley Push For Palliative (MVP4P) profiled above, provides a detailed case for Government reassessing and increasing funding, staffing and other resources for palliative care. This relates particularly to our area, the MidCoast Council LGA. While such challenges also occur for other regional, rural and remote areas, this area has particularly severe socioeconomic, employment, education and ageing needs, being among the lowest districts in NSW (SEIFA indicator of economic disadvantage).

Therefore, we have included here, in full, our submission presented in December 2018 to our Local Health District, Hunter New England Health. Although the data was assembled at that date, the underlying issues, demographics and health trends continue, and if anything can be expected to worsen, for example in ageing and employment.

We believe that a permanent appointment of an 0.5 FTE palliative-care specialist to the area will be made in the coming weeks. This is of course very welcome. However, in a population of nearly 95,000 considerably more is needed. Palliative Care Australia recommends 1.5 FTE per 100,00 population. What is more, sufficient specialised nursing staff plus allied health personnel are also lacking – one reason MVP4P has offered to co-fund a six-month appointment of a Palliative Care Clinical Nurse Consultant position in the hospital, which we believe will prove the position’s capacity to pay for itself. Other positions are needed, among them certainly a palliative-care social worker.

This organisation was founded to supplement the efforts of our local community health care and hospital palliative-care practitioners to meet the increasing demand for palliative care in both hospital and community settings, and to supply otherwise unfunded specialised equipment, support and services.

It is as much our intention to make life easier for our palliative care practitioners as it is, with their guidance, to make life easier for patients and their personal supporters.

In the MidCoast Council population, there is a lack of awareness and understanding of palliative care, part of a broader lack of health literacy meaning that people don’t seek, trust or accept health care, seek help too late, report late, or are not taking medication and treatments as prescribed. There is also cultural wariness and fears: 6.2% of the population is Aboriginal or Torres Strait Islanders, compared to 3.5% of the NSW population, as a whole. There are other cultural groups in the community also, whose needs the health system does not easily meet.

Effectively then, this socially and economically disadvantaged community co-funds its own palliative care as it has not been able to get adequate government recognition, funding and support. It is our belief that this is unwise, as it exacerbates poor community health outcomes, and is uneconomic, creating other and possibly larger costs for the community and state services. Studies indicate that rates of hospital admissions and re-admissions, eg to Emergency Departments and Intensive Care Units are greater when there is reduced access to palliative-care treatment and supervision.

The Activity-based funding and Subacute Admissions Approach

The Federal Government has taken steps to address the funding models for palliative care (or subacute) admissions through the remuneration of activity-based funding (ABF). However, this funding model is predicated on appropriate levels of administration staff and data collection. In regional areas this data collection, recording and reporting is a job left to an already under-resourced palliative care specialist nurse. In effect, regional staffing issues and resource constraints may prevent the accuracy of recording palliative care activity in a service and therefore reduce remuneration to that region.

Palliative Care Needs at the Community-Health (ex-hospital) level

Where palliative care is being attempted in the community, we are not fully and effective resourced. Some features of how community-based care works in our LGA are:

General-Practitioner involvement:

GPs case-manage Palliative Care patients, and many do not have a good understanding of palliative care and its ameliorating potential. They do not initiate discussions with patients about availability and flexibility of palliative care, or referrals, and if asked, may say' you don't need that yet', speaking from a belief that palliative care is really only for the last weeks-and-days of end-of-life when 'nothing else (clinically) can be done'.

Similarly, patients are not informed by their clinical practitioners, or by other general knowledge and do not understand the potential of palliative care to improve their quality of life, and death, and so do not ask for it. In our community of low-literacy overall and especially in health matters, patients and carers would often not think to or are too shy to question their practitioner.

Many local GPs are afraid to inform and involve themselves in palliative care. Some of this relates to federal issues, such as how they are remunerated, inadequate Medicare rebates for long consultations and travel times; concerns about pain management alternatives and professional risk, and very little content on palliative care in their undergraduate and post-graduate training.

Palliative Care nursing services

We have access to very dedicated, effective, and much-loved Palliative Care nursing services. That team gets limited support *via telehealth* from Palliative Care specialists from Calvary Mater. While the hospital now has access to 0.5 FTE Palliative Care specialist on Consult basis, the specialist is not yet available for community and at only 0.5 FTE would have difficulty supporting community and hospital cases.

The Potential Benefit of dedicated Allied health services

We have no Occupational Therapist in Palliative Care, the availability of which would prevent some falls and hospital admissions

We have no Social Workers who are trained in and available to palliative care, which adds to distress and anxiety for our patients who - for example - are suddenly unable to work, or their carers who have to give up work to become full-time carers, or have take on an intensive care-role while still working.

Financial Assistance

Our patients do not have access to Palliative Care Packages through *Silver Chain* or *Hammond Care* as is or has been available in other areas. Therefore, the only access they get to personal care and domestic assistance is through key community organisations such as MVP4P, who are able to fund it on behalf of patients and their carers.

Also, patients with a poor prognosis do not live long enough to access services through Aged Care *and* people under 65 years of age often cannot qualify for neither servicesn or financial assistance.

We now re-present our earlier submission dated 18 December 2018 which we made on the resourcing of growing need and demand for palliative care in our LGA, to the Hunter New England Health (HNEH) Local Health District (LHD) executive – *as follows*:

MVP4P Submission to Hunter New England Local Health District 15 December 2018

requesting appointment of a Palliative Care Specialist
to the MidCoast Local Government Area

Prepared by:

Manning Valley Push for Palliative
Chair Judy Hollingworth

and

Great Lakes Palliative Support
Chair Deidre Stokes

1. Executive summary

This submission requests that the Hunter New England Local Health District approve and fund the appointment of a permanent full-time resident palliative-care specialist to the Manning-Great Lakes (MidCoast Council) region.

We put forward this submission on behalf of the community of the MidCoast Council Local Government Area. We have strong backing expressed by doctors, hospital staff including hospital nurses, community health nurses and allied health providers, as well as residential aged-care facilities. The MidCoast Council has also indicated its support for our submission.

Our reasons for this request are:

1) The demographics, socioeconomic and health data of the MidCoast community of more than 92,000 people show clearly that there is **a major current and growing need** for a palliative-care specialist in this LGA. This is a large and diverse area, with no palliative-care medical expertise available locally. *(The Australian and New Zealand Society of Palliative Medicine (ANZSPM) recommends 1.0 FTE palliative physicians per 100,000 population, while Palliative Care Australia recommends 1.5 FTE per 100,000.)*

2) A specialist's presence and expertise would significantly **lift the quality of care** delivered to, and the quality of life experienced by, patients at the end of life. This improvement in care would be achieved both directly and via better informed, better supported medical practitioners, both specialists in related disciplines and GPs, hospital and community nurses and allied health providers.

3) The specialist's leadership would help transition to more effective community palliative care, and in particular **increase the proportion of patients able to be treated and to die**

at home. At present while up to 70 per cent of people are said to state their wish to die at home, in Australia only 14 per cent have that wish met.

4) Significant evidence indicates that the cost of the greater investment into palliative care required to appoint a specialist **may potentially be offset, or at least reduced,** by enhanced efficiency and reduced patient costs. Due to the age profile and health status in the MidCoast region, cost reductions here could be particularly substantial.

5) The strongest reason to appoint a palliative-care specialist is that the MidCoast area already demonstrates **an unusual level of 'community readiness'** to support better palliative care. Indeed, through our two community charities, Great Lakes Hospice Inc and Manning Valley Push for Palliative, we are already co-funding our own palliative-care needs: *the extent of this funding is shown below*. The strong involvement of these two bodies means a palliative-care specialist would be welcomed and supported from all sides – by doctors and nursing and other health staff and also by family carers, volunteers and community fund-raisers.

Supporting data

This submission is supported by the following information and data, drawn from the research sources indicated:

1. The high level of need for palliative care in this area

The MidCoast LGA has one of the fastest ageing populations in the country, accompanied by a reported high incidence of conditions conducive to the need for palliative care, such as heart disease, diabetes and dementia. It also has a markedly low SEIFA, or socioeconomic index, pointing to the disadvantage level of its population.

Ageing

Data for MidCoast Council drawn from the 2016 census shows that fully 30% of the population was aged over 65. This compares with only 20.4% for regional NSW. Moreover, the ageing trend is increasing: the 65-plus aged group here five years earlier, at the 2011 census, was 4% less at 26% (compared with a regional figure of 18.1%). Anticipated population growth and increasingly aged profile mean the need will be further intensified in the next five to ten years.

Disadvantage

The SEIFA indicator of economic disadvantage, based on census data, shows for the MidCoast an index of 911. This is in the lowest fourth or fifth quintile of the 130 districts in NSW, well below the median point of 1000. SEIFA reflects key factors such as educational attainment, income levels, unemployment and unskilled occupations. ABS employment data reinforces this, showing nearly 50% of the area not in the labour force (compared with 37.9% in regional NSW). A high proportion of employed people in the area are engaged with provision of care of various kinds to those who are not employed.

Palliative admissions accelerating

The number of palliative care patients in the area is also accelerating. Palliative patients at the Manning Hospital have more than doubled in the ten years since 2008. Six-monthly figures at Manning Hospital over that time, supplied by PCOC (Palliative Care Outcomes Collaboration) were as follows:

Dec 08	*Jun 09*	*Dec 09*	*Jun 10*	*Dec 10*	–	*Dec 14*	*Jun 15*	*Dec 15*	*Jun 16*	*Dec 16*	*Jun 17*
45	37	23	50	83	–	43	69	77	97	104	103

The PCOC figures cover hospital admissions only, and do not include the many palliative patients cared for at home, in residential aged-care facilities and by the Community Palliative Care nursing team. The PCOC figures also are not able to illustrate admissions made for other reasons, but that would be better directed to palliative care – eg admissions that end up in intensive care, receiving high-input, high-cost but futile treatment.

2. Lifting the quality of care

Other specialists and GPs in this area agree that appointment of a palliative-care specialist could be the strongest contributing factor to improving the quality of care once it is clear that life-limiting illness is present and much of its progress to end of life can be predicted. The palliative-care specialist would provide not only direct consultation to patients, but also shape standards, offering advice and leadership through the many levels of clinicians and health professionals, family carers and community volunteers who are part of palliative care. It would have these kinds of ‘multiplier effect’:

- Both GPs and other specialist doctors would get input from and/or provide referrals to the palliative-care specialist.
- Nurses and allied health workers would benefit from the collaboration and advice, as well as having input to specialised palliative-care training that would build credentials, reputation and skills levels. This would also attract personnel to the area who have those skills and interests.
- Families of patients and the community at large would benefit (since virtually every individual, sooner or later, encounters the palliative care situation in their families).
- Residential aged-care facilities in the area are increasingly providing palliative care and end-of-life support in place, reducing the tendency and need to transfer patients to hospitals to die. New national Aged Care Standards, which will take effect from 1 July 2019, require aged-care facilities receiving Federal funds to provide palliative care-in-place. Palliative care in RACFs would be considerably enabled and enhanced by having a palliative-care specialist resident in the area.
- Volunteers (of whom there are many in the Manning Valley and Great Lakes: they are the largest trained-cohort of volunteers in NSW) provide support in home-care situations, taking their cue particularly from the Community Care palliative nurse team. Volunteers would gain greater understanding, more effectiveness and contribute even more from being educated by a resident palliative-care specialist as well as by other in-area palliative trained personnel, informed by that specialist.
- All the above would combine to lift the level of public understanding and awareness, increasing for example the practices of preparing advance care plans and discussing patient’s final wishes.

3. Increasing both level of care provided and the choice to die at home

Half of deaths in this country are in hospital. The Australian Institute of Health and Welfare reports that in 2014-15, approximately 50 per cent of our deaths occurred in hospitals, more than 90 per cent of them in public hospitals.
https://www.aihw.gov.au/reports/hospitals/deaths-in-australian-hospitals-2014-15/contents/summary/how-many-deaths-occur-in-hospital

Australia has an almost shockingly low proportion of deaths at home, rather than in aged care facilities and in hospitals. It is one of the lowest proportions in the developed world – only about 14 per cent, according to the Grattan report (p 5), even though between 60 and 70 per cent of Australians say they would prefer to die at home. The report places Australia second last among 20 locations around the world. The report comments: “While 70 per cent of people [in Australia] say they want to die at home, only about 14 per cent do so... A reasonable goal would be to reach the levels of home deaths achieved in comparable countries. Australia would have to double to reach 30 per cent of all deaths… comparable to Korea, Singapore, Ireland, France, Austria, Croatia, USA, Cyprus and New Zealand.” (Grattan Institute report ‘Dying Well’ 2014, page 26)

4. Offsetting costs

The cost to appoint a resident palliative-care specialist might be estimated at around $400,000 per annum. (This could be lessened if shared with private consulting, both provided directly to patients and through the two private hospitals, Forster Private Hospital and the Mayo Private Hospital in Taree, both of which are committed to providing palliative care.) In addition, the available costing studies generally indicate that increasing the capacity to support people dying at home may substantially offset the cost of palliative care – or even result in significant savings. Savings from increased palliative care include reducing admissions to acute-care hospital beds – with greater savings when the reduced admissions avoid the highest-cost areas of emergency departments or intensive-care units. *Avoiding ED and ICU admissions is also increasingly seen as desirable in order to reduce futile or inappropriate end-of-life treatments – which in effect actually enhances genuinely patient-centred care.*

- See ‘Palliative Care in NSW Business Case’, a submission to the NSW Government by Dr Yvonne McMaster FRACGP & Dr Anthony Ireland FRACP Dip PH FAChPM, 15 February 2015. They estimate potential savings in NSW from enhanced palliative care and increased home and community-based care of **$138 million** (in 2010 dollars).
- See also cost estimates in Grattan Institute report, ‘Dying Well’, cited above, and the more recent palliative-care cost study by its co-author, Stephen Duckett *(BMC Palliative Care (2018) 17:42 https://doi.org/10.1186/s12904-018-0294-4)*.
- On a global basis, a review of ‘Evidence on the cost and cost-effectiveness of palliative care’ (*Palliat Med.* 2014 Feb;28(2):130-50) concludes: “Palliative care is most frequently found to be less costly relative to comparator groups, and in most cases the difference in cost is statistically significant.” (This “comprehensive review of international evidence” of costs in all settings examined 46 papers published over the period 2002-11.)

5. Community readiness

The MidCoast LGA community has for many years responded to the need for a greater level of palliative care in the region – a response most clearly expressed by the two registered charities that fund, supplement, resource and advocate for palliative care.

Great Lakes Palliative Care Support

By far the longest established is the group, based in Forster-Tuncurry, widely known as the **Great Lakes Hospice Inc,** though its official name recently changed to **Great Lakes Palliative Care Support** (GLPCS) **.** Founded in 1989, GLH in 1995 purchased a property in Forster that became the Great Lakes Cottage Hospice. Despite considerable effort, wide community involvement and direction by a dedicated nurse, after five years it became evident that the Cottage Hospice could not be made into a sustainable facility, and it closed in 2000. However, since then Great Lakes Palliative Care Support has continued to run multiple fund-raising events and to contribute major palliative-care support to patients with life-limiting illness, plus supporting carers and families with relief from the financial and personal stress they face. Support includes personal care, housework assistance, oxygen therapy, portable oxygen concentrators, costs of medication, provision of social worker services, chaplaincy, physiotherapy, respite care and massage therapy, as well as funding respite care in nursing homes for patients whose carers need a break. GLH/GLPCS receives no government funding, relying entirely on community goodwill through donations and fund-raising. Over the past three years, income and expenditure have been:

- 2015-16: income $202,715.07, expenditure on palliative care assistance $180,751.12
- 2016-17: income $49,482.84, expenditure $57.520.95
- 2017-18 income $58,783.58, expenditure $66,912.28
- 2018-19 (to date): income $33,241.90, expenditure $26,217.75

Manning Valley Push for Palliative

A more recent addition to community support is **Manning Valley Push for Palliative (MVP4P**), founded in Taree in August 2015. The strength of community response was clear from its founding meeting: held on a Tuesday night, it was attended by more than 100 people. The initiative was a response to specific requests made by the medical community (especially hospital and community health nursing teams) to Judy Hollingworth, who became MVP4P chair. MVP4P has dedicated its funding – inspired by the work of GLH but also following recommendations from the medical community – to provide a range of equipment for hospital and community use and support services, including a monthly 'gap funding' budget for patients who cannot otherwise fund key needs. The MVP4P charter defines four key objectives:

- We promote awareness of the importance and availability of palliative care.
- We advocate for better resourcing of palliative care services so that people who are incurably ill receive better care and support.
- We advocate for provision of a mix of health practitioners to provide a full range of palliative support services to our area.
- We assist patients and carers to access important ancillary resources and services.

MVP4P has been an incorporated registered health promotion charity with DGR status since inception, and now has more than 50 members. Income and expenditure for the past three years have been:

- 2015-16: income $34,282.00, expenditure for palliative support $6,450.00
- 2016-17: income $14,584.00, expenditure for palliative support $9,879.00
- 2017-18: income $58,897.00, expenditure for palliative support $28,775.00

As at 30 June 2018, MVP4P had surplus funds of $54,186 for use on projects, and has allocated since (to 31 October) $21,162 to palliative support, plus a further $18,000 for its regular gap-funding program for the 12 months to October 2019.

6. Conclusion

In a briefing paper titled 'More Specialist Palliative Care', dated November 2016, the Cancer Council of NSW notes:

> In NSW, the number of palliative physicians is less than we need. The most recent workforce figures show that, in 2014, NSW had 0.9 full time equivalent (FTE) palliative physicians per 100,000 population.[20] This is less than that recommended by the Australian and New Zealand Society of Palliative Medicine (ANZSPM) which is 1.0 FTE palliative physicians per 100,000 population as a minimum for an adequate specialist palliative care service.[21] Palliative Care Australia recommends a higher rate of 1.5 FTE per 100,000 population to ensure the ongoing development of the specialty.[22]

The gap is felt particularly strongly in the MidCoast LGA, home to more than 92,000 people. This comment from the influential peak body representing cancer patients (said to account for some one-third of palliative patients) underlines the need felt in this region, in that we are completely without a palliative physician. The nearest available specialist is some three hours away in Newcastle.

This submission requesting a palliative-care specialist relies most of all on two facts:

1. The MidCoast Council LGA is an area of particularly high need, due to its demographic, socioeconomic and health statistics.
2. The remarkable degree to which its communities have worked hard, for a long time, to support and resource, with particularly active fund-raising, has been providing what is missing on the ground in palliative care.

Essentially, this community has co-funded its own palliative care. While this is quite an achievement in light of the SEIFA characteristics of the LGA, the ageing-population trends and forecasts suggest that the gap that these charities fill will widen, also because the volunteers they rely on are facing the same health challenges as the rest of the population (eg increasingly involved in care of others) and are themselves ageing.

Deidre Stokes, chair of the long-standing Great Lakes Palliative Care Support group, comments that the appointment of a locally based oncologist (followed recently by a second) “has made such a difference in care provision, not only to patients, carers and families but to the staff that work alongside them providing the care. We see the same need, in our ageing demographic, for a palliative-care specialist.”

Judy Hollingworth, chair of Manning Valley Push for Palliative, says palliative care in the region has to a large extent been “self-funded by the community. This is not an effective or viable approach, particularly when we need to respond to an increasing demand, as well as to keep improving the quality and awareness of palliative care.”

In discussions with the medical community, a major benefit from a full-time resident palliative-care specialist is seen as its capacity to raise all-round standards of care. Thus the impact of such an appointment would fulfil the saying *“A rising tide lifts all boats.”*

END OF SUBMISSION