

10/11/2021

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SUPPLEMENTARY QUESTIONS AND ANSWERS –

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

Supplementary Question – ONE

In addition to what is contained in your submission and evidence provided at the public hearing, do you have any further comments regarding the current provision of palliative medicine, nursing, and care in rural, regional, and remote New South Wales?

We identify THREE broad problems with regards to the provision of palliative care in country NSW. The severity of these problems, and their consequences are magnified with distance from metropolitan and regional areas. Our insight speaks predominantly to the experience of those who choose to die at home – which, in a rural setting is typically very expensive and, in many cases, simply not possible.

1. Lack of specialized palliative care staff

Under resourcing of specialised palliative care staff is apparent across each of the 7 Local Health Districts, where Can Assist operates in rural, regional, and remote NSW. The Western NSW LHD for example, covers 250,000 square kilometers, is home to 280,000 people and yet they have a total of only 21 full time equivalent positions in palliative care. This includes the one palliative care doctor in the entire LHD, who, himself isn't technically trained/accredited as a palliative care doctor, but rather as an emergency doctor.

Staff shortages mean that the lion share of service provision falls to the primary health workforce - GPs, community nurses and a handful of palliative nurses. Health professionals untrained in palliative care exhibit bias toward restorative medicine, at times unnecessarily prolonging life. This is especially complicated in rural settings where tight country communities mean that the treating health professionals often know the patient and their family. Good palliative care requires a different philosophical mindset.

Non palliative care physicians and fly in fly out doctors can be overly cautious when writing or changing end of life pain medication scrips. One-two years back, doctors who issued proportionately more end of life (EOL) pain scrips were singled out and sent letters by the TGA warning them of the consequences of overuse. With so few palliative doctor specialists, country doctors were naturally subscribing these scrips in greater proportions than their metro counterparts. TGA warnings has left many doctors in fear, which means patients are

at times not prescribed the right level of pain medication. There is also great inertia at changing scrips.

Fly in – fly out doctors tend to have only short-term immediate health issues on their mind and are simply not going to provide the same care and focus of a long-term physician.

Many palliating patients will have their drugs administered through a syringe driver – this needs to be changed daily by a nurse. Whilst this is needed often close to death (1-2 weeks), it can be much longer (8 weeks). I do not know of a Can Assist branch town where such service is funded after 5 pm on a weekday or on the weekends. This makes it difficult to die at home. In practice, many nurses work overtime (to various levels across the State). Nurses providing palliative care in the home almost never have back up – if they are sick, or on leave or on holiday, patients have no choice but to book into hospital, where beds (especially those for dying patients) are in short supply. In many towns there will be no alternative on a weekend. Distance complicates the issue even further, the sole palliative care nurse in Glenn Innes for example covers a large area, living at the edge of the shire it can take her 1.5 hours just to get to one client. Nurses are managing caseloads across the State of between 25 – 35 patients with no back up. 24-hour palliative help phone services whilst helpful, cannot fill the gap.

Community nurses who are not palliative specialists fill some gaps, however, there is no consistency around the service they provide. Community nurses in Bathurst for example, will travel and leave the direct area, where community nurses from Orange will not. The mental stress and pressure on nurses can be overwhelming.

We recently assisted a palliating woman from the small town of Merriwa who chose to die at home. She had no plan, and the local hospitals offered no in home service or care. Can Assist arranged and paid for a nursing service from Newcastle to make multiple trips to her home. Five separate visits lasting 30 minutes each was billed at \$1,373.66. The travel costs equated to 75% of the hourly nursing fee.

Social workers offer a distinctly different service to nurses – consideration and direction with regards to legal matters as death approaches, providing advice on government assistance and offering psychosocial care. They are also in short supply across the State. There is not only a lack of funded positions, but also in some cases vacancies are unfilled. Tumut hospital for example has a social worker position which has now been unfilled for some 6 years now. Positions often take 12 months or more to fill.

Bigger / inner – regional centres often have active community/charity groups who either raise significant sums of money to fund palliative care themselves or raise enough community support to successfully petition an increase in government funding for their town (at least temporarily).

Our Can Assist Southern Highlands branch for example entered a partnership arrangement with a local community hospice charity that had fundraised over \$2 million. Under this arrangement, Can Assist pays the first \$3,000 of at home palliative care nursing services for cancer patients and the charity hospice pays the bills thereafter Without this agreement

most residents of Southern Highland would simply not be able to afford to die at home. The partnership also has an agreement with a local private hospital, which offers an “overflow” service from the public hospital for palliative patients. Without this service, residents of the area would be forced into hospitals further afield and outside of their area when the public hospital reaches capacity.

Orange is an example of an active community that has come together to place pressure on government to step up with provision of a hospice facility. Some 10,000 signatures secured funding of a hospice facility for near two years, now they have a dedicated palliative section at Orange Base Hospital.

Smaller, more remote towns do not have the numbers to apply the political pressure nor the large charity funds to establish permanent and open ended fixed or mobile palliative facilities.

2. End Of Life Care packages – Roll out and staffing issues

There are a variety of packages offered by the state government aimed at giving patients the everyday care support that is required to die at home— end of life packages, hospital in the home packages, aged care, NDIS ...

Whilst these packages are designed to be reactive for palliating patients, they are at times slow to get. We know of instances whereby the patient has died prior to receiving the package.

If the package is received it is not always possible to find the care staff, even in the larger towns. We were recently told of a client in Armidale who was unable to source home care help, despite having the financial means to pay for it. In other cases, where the staff are found, they are in limited supply. At best, services will be reached for 1 hour a day Monday through to Friday, but it will typically be closer to 3 days a week. For the smaller towns, the distances are vast meaning that carers spend more of their paid hours travelling than they do providing care.

Carers are very rarely skilled in palliative care –workers lack the skills and confidence, (often with family members looking on).

3. End of Life Medications

(a) Cost – Non-PBS Listed

Can Assist branches commonly fund proportionately larger amounts of medication costs as clients enter the palliative stage. We are paying palliative bills up to \$1500 a month and this does not necessarily cover 100% of medication bills.

The most common end of life drug not PBS listed is Midazolam. Most palliating patients with a syringe driver will require this drug daily; anywhere from 1 to 10 ampules a day. This will be one of a cocktail of drugs, yet alone, it will cost up to \$50 (or more depending on the remoteness of your pharmacy) a day. There are several other key non-PBS listed drugs, for example: Dexamethasone, Ranitidine, Xylocaine Viscous.

Most of these drugs are older drugs and no longer patented, meaning that drug companies have little incentive to pitch the PBAC for PBS listing.

(b) Availability

For small town pharmacies, these EOL drugs are relatively uncommon, so inventories are not held. It will typically take 2-3 days to deliver, and patients literally die in this time. Drugs like medicinal cannabis are typically only dispensed in larger regional towns and even then, only in one or two pharmacies

Supplementary Question – TWO

In addition to what is contained in your submission and evidence provided at the public hearing, do you have any further comments regarding ways to improve both the access and availability of palliative medicine, nursing, and care in rural, regional, and remote New South Wales?

Potential Solutions

1. Palliative Doctors – Accreditation

The palliative accreditation for doctors requires 2-3 years' experience in a major hospital that can only be found in metropolitan areas. This will typically occur around the time of life when a doctor has family and has laid down roots. If they are in the country – they are coaxed out, and if they are not in the country, it is unlikely that they will move there.

Solution – Reconfigure the accreditation process to train doctors from the country and in the country.

2. Community Nurses & Social Workers – More funded positions, training, and better procedures

(a) Upskill community nurses:

- To provide relief and back up for existing palliative staff, which will in turn attract more applicants.
- To provide better continuity of care in those towns that are serviced by fly in fly out doctors. A properly trained, consistent medical nursing professional on the ground will create more continuity of care; communicating with doctors on patient's behalf and go a long way to ensuring doctors look beyond immediate patient needs.

(b) More funded positions and better job conditions:

- Attracting Staff

Work contracts need to be reassessed. Whilst Social Worker contracts for example are funded with the cancer institute for a period of 3 years, most professionals are awarded 12 months contracts only. With so little job security, staff are unlikely to relocate. We have

spoken to professional's who have not been able to secure mortgage finance because of these contracts.

- Arranging LHDs into a single service structure

In various small towns across the State, we have highly specialized health professionals such as clinical nurse consultants carrying our menial tasks like temperature checking. The Western NSW LHD some 18 months back implemented a single service structure which avoided such resource wastage, resulted in better job satisfaction which was demonstrated by all open nursing positions being filled.

3. In home carer providers - Increase supply and upskill existing workforce in palliative care

4. Training/Education Roll out of the TGA rulings on EOL medication

Rural doctors need to be reassured – they need to better understand the legalities around pain medications. For our immigrant doctors any breach of standards could result in de registration and consequent deportation of their entire families. The risks are high. The TGA must fix this mess they have created

5. List all relevant end of life drugs onto the PBS

Pain medication needs to be accessible and affordable.

Summary

Palliative care is under resourced and underfunded in rural, regional, and remote NSW. Whilst our health professionals are of high quality, they are over worked with little or no back up services. Hospitals have a limited number of palliative beds and hospices are few and far between. Choosing to die at home is an expensive and sometimes impossible choice, regardless of your individual financial circumstances.

Many practical steps can be taken to alleviate the problems; changes to accreditation and training, hiring more staff, improving job contracts, streamlining services, and listing more end-of-life drugs on the PBS. Only then, will residents of country NSW have access to palliative care on terms comparable to those enjoyed by metropolitan residents.

Yours sincerely,

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BRANCH MAP

