Senate Community Affairs Committee Inquiry 2012

Palliative Care Service Provision in South West Queensland

This submission has been formed by members of the Palliative Care Advocacy Support Group (PCASG) – Roma and community members. PCASG 's objective role is to act as advocate for residents within South West (SW) Queensland (QLD) and are actively campaigning to establish a palliative care service/hospice in Roma. Group members include: Ms Jennifer Rowe RN (2010-11 Clinical Nurse-Palliative Care Coordinator, Community & Allied Health Roma); Mrs Geraldine Reardon OAM – Cancer Council QLD; Mrs Linda Hamill – Uniting Church Minister, Roma; and Mrs Marisa Grulke, Enrolled Nurse, Roma. The group is grateful for the opportunity to have a voice from rural SW QLD and make a constructive contribution to the Senate Inquiry.

The following information provides an accurate account of current service delivery, and shortfalls, in palliative care in SW QLD. Data used in this submission is drawn (in part) from a draft business plan proposal for the establishment of a palliative care community service/hospice in Roma. Terms of Reference are addressed as applicable to the district followed by professional and personal experiences and community support.

Overview

March 2012, little exists in the provision of palliative services within the SW covering 319,870 square kilometres and an estimated population of 24,000 (Brennan, & Robson, 2010). The district comprises of 15 health care facilities, a mix of hospitals, multipurpose health services (MPHS), residential aged care facilities and outpatient clinics (www.health.qld.gov.au) Non Government Organisations (NGOs) such as Blue Care (community) provide clinical End of Life (EOL) care and refer clients needing additional services to community service providers such as Home and Community Care (HACC) and Spiritus, all of which are scattered across the SW district.

Primary production in rural SW QLD is typically cattle, grazing, and cropping, however the region continues to experience unprecedented growth generated by mining and gas industries.

SW district facilities include: Augathella; Bollon; Charleville; Cunnamulla; Dirranbandi; Injune; Mitchell; Morven; Mungindi; Quilpie; Roma; St George; Surat; Thargomindah; and Wallumbilla.

SW QLD response to the Inquiry Terms of Reference:

The provision of palliative care in Australia, including:

(a) The factors influencing access to and choice of appropriate palliative care that meets the needs of the population including;

(i) People living in rural and regional areas

Negative factors influencing access include:

- Lack of adequate resources within the district (palliative care service/specific facility/sufficient beds/consultant service/equipment);

- Small/medium population numbers dispersed over wide areas;

- Distant travel, patients/clients are required to travel to Roma Hospital for treatment and/or review which for residents of Charleville, for example, means a 6 hours round trip. In addition to this, patients/clients regularly travel up to 5 – 7 hours to Toowoomba and Brisbane respectively for treatment. In some cases patients/clients travel to these centres to undergo scans purely to monitor the trajectory of their disease. Little consideration is given to the fact that they are palliative and long journeys as such often take its toll with physical and emotional discomfort and loss of precious time and expense. The Patient Travel Subsidy Scheme (PATSS) fails to keep pace with actual costs incurred by patients and carers associated with travel and accommodation;

- No visiting palliative care medical specialist, servicing the SW, similar to that provided by Dr Peter Whan in Central Queensland. No consultant west of Toowoomba, Dr John Gillett Palliative Care Medical Specialist located at Toowoomba Base Hospital (.5);

- Limitations in delivery of discharge plan/strategies implemented by tertiary care centres

- Consistent shortfalls in permanent or visiting health care professionals trained and skilled in palliative care (e.g. visiting palliative care specialist or link nurses across the district);

- Reluctance by health care professionals to up skill in providing quality palliative care, (EOL care carries little importance for some). There is also a problem with backfilling positions if professional education requires absence from a substantive position for a significant period of time;

- Fundamental lack of knowledge regarding End of Life (EOL) care by both health care professionals and within the wider community (Rosenburg & Canning, 2003);

- Failure to empower patients/clients and carers in the decision making process in regard to Health Promoting Palliative Care;

- Critical shortage of respite provision (aged care, addressed (d);

- Limited provision of grief and bereavement counselling; and

- Increased fatigue burnout by limited trained health care professionals.

Positive factors influencing access include:

- Roma patients are supported by a community based Registered Nurse (currently vacant) covering both acute and community sectors;
- Fortnightly visits to Roma Hospital by General Physician Dr Robert Brodribb who has a special interest and significant clinical experience in providing palliative care;
- Support and education workshops from Palliative Care Queensland (PCQ) Advocacy Service Brisbane;
- Support and education workshops from the Centre of Palliative Care Research and Education (CPCRE) Royal Brisbane & Women's Hospital (RBWH);
- Angel Flight – free transportation of palliative patients/clients and carers to tertiary care centres (Toowoomba/Brisbane). Those eligible to use this service must be able to sit upright in the aircraft. If they are unable, due to discomfort, they must travel by their own means by road;
- Royal Flying Doctor Service (RFDS) – free transportation of acutely ill palliative patients/clients to tertiary care centres.

In terms of choice, it is clear from the above points regarding access, that choice is severely limited to those living in the rural SW as compared (assumed) to access and choice provided in meeting the needs of the population in metropolitan areas. Population needs cannot be met when disparities regarding resources, distance, travel, lack of trained staff and patient/client/carer disempowerment are not addressed and actioned for the benefit of all.

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

Due to the limitation of knowledge regarding funding arrangements, primarily within the South West Health Services District (SWHSD) Queensland Health, we are not in a position to accurately contribute to this term of reference. What PCASG can contribute however, is some knowledge of palliative care funding allocated across the district. Clearly, funding has been inadequate in meeting the districts needs over a long period of time, as identified in access shortfalls, and/or unacceptable levels of responsibility and accountability of funding allocation e.g. palliative budgets used elsewhere.

In the first instance, it could be argued that because Roma Hospital, the largest in the district, does not have a specific palliative care bed or private room available to terminally ill patients when required is evident of inadequate or inappropriate assignment of palliative care funding. Previous to 2008, a private palliative care room was available at Roma Hospital. This room has been funded by Cancer Council QLD and Roma Hospital Auxiliary members using fundraising monies to establish the room which was used for a number of years before a decision by management lead to its closure due to staffing issues.

In the second instance, in more recent years, palliative care funding was used to purchase equipment specifically for palliative patients/clients who were to remain separate from the physiotherapy department's supply. Again, decisions by management resulted in palliative equipment being absorbed into the general equipment pool; hence numerous items were no longer available for palliative patients/clients as needed or were often unaccounted for (lost).

In terms of staff funding, the position of Clinical Nurse – Palliative Care Coordinator is currently vacant. The position has been become vacant on numerous occasions due to lack of adequately trained personnel.

(c) the efficient use of palliative, health and aged care resources;

As identified, palliative resources in the SW include single beds in smaller health care facilities, fortnightly visits by Dr Brodribb – General Physician to Roma Hospital, and limited community service providers scattered across the district. Likewise, no health or aged care facility within the district has a specific palliative care service, unit or multiple beds. Given the limitations of resources it is not possible to draw conclusions of efficiency.

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

Hospital Care

Currently, Roma Hospital, as mentioned, does not appropriately accommodate palliative care patients. Patients are admitted to the (single) general medical/surgical ward where they may be placed in a single room, however this is not guaranteed. Staff assign rooms as best they can given the facilities available. Roma Hospital is currently undergoing major renovations with 'a proposed' palliative room. The PCASG fully supports the provision of a palliative room; however we also believe that the presence of 'a bed' may also serve as a mere token which is of greater concern. Some smaller hospitals throughout the district have a specific palliative care bed/room.

Attempts were made to implement the 'Care of the Dying Pathways' (initiated from RBWH) into acute hospitals throughout the district in 2010-11 were unsuccessful. It has been suggested that this failure was largely due to a failure by senior management to recognise palliative care as core business and an essential component of health care provision in SW QLD.

It is not known whether the pathways have been implemented since that time.

Lack of training of generalist medical and nursing staff in identifying patients/carers holistic needs in the acute care setting is a major concern. This will be addressed in detail term of reference (e) (ii).

Aged Care

Queensland Health's Westhaven Aged Care Nursing Home accommodates 40 local residents (mainly high care) on the grounds of the Roma Hospital site. Westhaven has a respite bed but no specific palliative care room. Westhaven will only accept a palliative patient, if not already a resident of Westhaven, as respite. They must be assessed by the Aged Care Assessment Team (ACAT) and therefore be over 65. Those who are not over 65 and require accommodated care have little or no option but to rely on family to care for them or are forced to seek care outside the district.

Waroona Aged Care Nursing Home at Charleville accommodates 30 aged care residents. The same process for admission of palliative patients who are not already a resident, applies as with Westhaven.

Attempts to implement the 'Residential Aged Care, Care of the Dying Pathways' (initiated from RBWH) into QHealth Aged Care facilities throughout the district in 2010-11 were unsuccessful. It is not know if the pathways have yet been implemented.

Residential/Community Care

- The sole community residential aged care facility in Roma is the Rotary owned Pinaroo Aged Care Home. Pinaroo accommodates 51 local residents (mainly low/med care) and has implemented the Palliative Care in the Aged Care Setting Principles.
- Mitchell, 1 hour west of Roma, had until the recent floods, accommodated 8 residential aged patients who are now dispersed throughout various aged centres within and outside the district.
- Churches of Christ at Injune accommodate 13 aged care residents while Warrawee at St George accommodate 35 before inundated by flood waters in February 2012. Residents will remain in other temporary centres until the facility is rebuilt due to severe damage.
- Blue Care receives referrals from QHealth on patient discharge providing clinical aspects of EOL care while Spiritus provides social and supportive services to clients and carers.

Overall, the effectiveness of the range of palliative care arrangements within acute hospitals, community service providers and residential aged care facilities could aptly be described as inadequate compared to that experienced in metropolitan areas.

(e) The composition of the palliative care workforce, including:

(i) Its ability to meet the needs of the ageing population,

Composition of the palliative care workforce within the SW district, in relation to the ageing population, consists of:

- Hospital based doctors and local general practitioners with varying degrees of exposure and/or experience in palliative care;
- Dr Robert Brodribb – General Physician, fortnightly visit to Roma Hospital;
- Acute ward, aged care, and community nurses with limited holistic knowledge and skills. Sadly, often provision of care by community service provider's results in patients/clients admitted to hospital due to a lack the basic fundamentals and/or training in order for the client to be cared for at home should that be their wish. Unwanted admissions in turn lead to senseless psychological and social issues.
- Clinical Nurse – Palliative Care Coordinator for the SWHSD, currently vacant;
- Transient health professional workforce;
- Strong reliance on personal carers from non-English speaking backgrounds;
- Allied Health workers including, Social workers, Physiotherapists and Psychologists who have limited exposure or knowledge of specialist palliative care; and
- Personal care givers/carers with limited scope of practice and often no specific training in the provision of end of life care.

There is no specific 'specialist palliative care team' or workforce within the SWHSD but rather an eclectic multidisciplinary health care teams endeavouring to provide basic care to the ageing population without the supervision of a palliative care medical specialist or qualified local palliative coordinator.

It is assumed that all health care professional listed above empower patients with information regarding Advanced Health Care Directives, Power of Attorney, Acute Resuscitation Plans (ARP) and their role in the decision making process, however there is no evidence to suggest this is the case. To the knowledge of the PCASG, there have been no community palliative care information sessions, or facility visits, advocating to aged persons within the district, **and**

(ii) The adequacy of workforce education and training arrangements;

Education and training opportunities for hospital doctors, locums, and general practitioners exist however they are rarely utilised due to extremely busy workloads. CPCRE recently funded and invited Prof Janet Hardy, Palliative Care Medical Specialist to address a PEPA (Professional

Education Palliative Approach) dinner in Roma for district doctors. Unfortunately, the dinner was cancelled due to lack of interest however this response appears typical of previous responses, possibly because doctors within the district view palliative care as a low priority.

The PEPA program is available to all health care professionals but not regularly taken up due to the need to travel considerable distant to a palliative service/facility, time spent away from family and organisational issues (dependent children/animals etc).

Much of the districts training in palliative care presently relies on organisations such PCQ and CPCRE to deliver education and training workshops which in term has more recently been organised in partnership with Southern Queensland Institute of TAFE (SQIT) Roma Campus. SQIT Roma established a Health Studies Unit, with a fully equipped clinical simulation ward, in April 2010. The unit offers Certificates III & IV in both Aged Care and HACC which include palliative care competencies. The unit also offers the Diploma of Nursing (external) as well as a Schools Program. To date the workshops have been well attended from all health care sectors (QHealth, Blue Care, Spiritus, Churches of Christ) across the district and demand for further education continues to grow. It is essential that the districts recognises the need to 'grow our own' health care providers whether doctors, nurses or personal carers and equip them with the necessary knowledge and skills in providing holistic quality EOL care.

Other than visiting education and trainers in palliative care skills, there is nothing provided regularly on a district level. Overall, major issues relating to education and training include: travel; time; cost; availability of trained educators; and inability to backfill staff. Videoconferencing is utilized when and where available. Industry sources within the SWHSD Workforce Development Unit (Charleville) have informed the PCASG that no in-house palliative care education or training has taken place within the district since early 2011.

(f) The adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality care to all Australians;

Clearly, adequacy of standards cannot be determined in the SW given the limitations to provision of care. Implementation of National Standards is not a legal or contractual requirement in the provision of care.

(g) Advance care planning, including:

(i) avenues for individuals and carers to communicate with health care professionals about end-of-life care,

Within the district, individuals and carers can discuss EOL care with their treating doctor, ideally early in the trajectory of the disease. Given the sensitivity of discussing such issues, health care professionals should have some background or communication skills in order to ensure the information they are giving is correct and conveyed empathically. Given the Clinical Nurse –

Palliative Care Coordinator's position for the district is currently vacant, this further reduces avenues for potential discussion and/or referral to PCQ, a counsellor or social worker.

(ii) national consistency in law and policy supporting advance care plans, and

PCASG support law and policy that endorses or mandates the use of advance health directives (QLD) and advanced care planning. We agree that it would be optional that all Australian citizens of retirement age have a current advance health directive in place.

(iii) scope for including advance care plans in personal electronic health records; and

The PCASG fully supports such a move including integration of hospital medical records and general practitioners records.

(j) the availability and funding of research, information and data about palliative care needs in Australia.

Whilst the response to this term of reference may not be specific, we believe it provides insight into issues we have encountered in our ongoing advocacy role in providing quality palliative care within the SW. As mentioned initially in this submission, information and data provided has been drawn from a draft proposal to establish a community palliative care service/hospice in Roma. It became evident very early in the project that there was virtually no statistical data available (apart from ABS) to support the need for a rural community Hospice. A great deal of academic research was accessed and presented resulting in numerous suggestions of service delivery models tailored for the rural sector. However, not all communities 'fit' into such models and we do not have the luxury of accumulating 10-20 years of data in order to implement suitable services models. Admittedly, the number of deaths in rural SW QLD is a fraction of those experienced in metro Brisbane. However, a death is a death and regardless of location every Australian should be provided with quality palliative care services. Whilst we are aware of QUT's (Prof Patsy Yates) PCOC and the PCRAM model used in Victoria, for aged care and rural communities, we welcome any opportunity to assist with gathering data or pilot site studies.

Whilst the group have had preliminary discussions with an Aged Care NGO regarding the potential of establishing a service/hospice within the organisation, we are only too aware that it cannot function without the guarantee of recurrent funding.

Professional/Personal Experiences

As a health care professional, with a background in both acute and community palliative care, there are many stories l could share of heartache, despair and frustration. For the purpose of this inquiry the following 2 stories are a true account of the hardship experienced by rural folk, dying of a terminal illness, in the SW.

Story 1

I received a referral from the Wallumbilla MPHS for a 62 year old man, Jeff, (not his real name) diagnosed with advanced lung cancer and cerebral metastasis. He lived alone in a rundown house with his beloved red heeler dog of 13 years. The MPHS doctor saw Jeff regularly when he visited Wallumbilla weekly. Whilst Jeff experienced little pain his enemy was fatigue and shortness of breath. He was a HACC client and had been abusive making threats of violence to the staff when they visited which was unacceptable for their safety. Obviously, visiting Jeff on my own l felt vulnerable but having gained his confidence he soon felt at ease opening up over the next few visits to share numerous fears and anger regarding his estranged family and as a Vietnam Veteran. During the last visit l made to Jeff he was extremely concerned about the welfare of his dog stating he would shot her rather than see her left behind without him. I attempted to offer strategies where HACC staff could feed and care for her until a home could be found. Jeff insisted he would 'deal with it'. As distressing as it was that he would shot his beautiful loyal companion, l knew l needed to respect his wishes also.

A few days later l received a call from the acute ward at Roma Hospital advising me of his admission. Jeff was deteriorating with increased pain, confusion, shortness of breath, minimal food and fluid intake and extreme fatigue. Within a week his condition had improved and he wanted to go home but this was considered unrealistic by the medical team in regard to providing him with the necessary care in the community. Whilst Jeff accepted the fact that his decision had been made by others, and with no way to get home, he accepted his fate to remain in the 4 bay room on the acute ward.

Jeff was 62 and therefore not eligible for ACAT (Aged Care Assessment Team) admission to the aged care facility Westhaven. He spent 7 weeks in the 4 bay room and his last week in a single room as he deteriorated further and peacefully passed away. On regular visits to see Jeff he reminded me often it wasn't his choice to be there but also agreed it was the best option of a bad situation.

Jeff's story is one replayed over and over within the district. Elderly, estranged, single folk who either have no carer to care for them or they can no longer care for themselves virtually have nowhere but the hospital to go and even then they only have limited days admission. People in this position may have relatives provide care or if nothing available in an aged acre facility, are found care and pass away outside of the district.

Jenny Rowe RN

Story 2

A locum emergency doctor made contact informing me of an elderly man, Frank, (not his real name) in the ED department with end stage liver disease. He said that Frank was at EOL stage and not expected to last the night. The family were with him but did not want to talk to me or about palliative care. Later that day the doctor contacted me again to inform me that Frank had been admitted to the ward and the family had requested to speak with me. On arrival to the ward a doctor informed me that Frank was having 2 units of blood. I questioned the reasoning for the order and told it was the ED doctor who had made the decision given his haemoglobin (HB) was extremely low.

As l walked into the room l saw family members sitting around the periphery of the room, distressed and crying. I looked at Frank in the bed with blood infusion running and observation machine by the bed. He was semi reclined with a nurse leaning over him feeding him water from a teaspoon. He was clearly aspirating on the water and could barely breathe. I asked the nurse to either stop or sit the man upright. She proceeded to sit him upright speaking loudly in his ear 'we better sit you up because you might choke!' After speaking briefly with Frank and then his family, ensuring they were aware of his imminent passing and offering support and assistance, l left the ward. I was contacted less than 3 hours later that Frank had passed away and that family members were inconsolable.

This is not an isolated case of health care professional's lack of knowledge and/or skills in EOL care. Why Frank was subjected to unnecessary invasive treatment and his family unable to sit close to him, talk and touch him prior to his death is deplorable. A bad death is a lasting memory of a loved one's life that remains with them forever and instils fear regarding their own death. I am deeply saddened that such treatment continues within the SW and that people are not empowered with the information they need for decision making.

Jenny Rowe RN

In early June 2011 my husband Leslie James Ryan after spending 5 weeks in the Princess Alexander hospital Brisbane was diagonosed with AMYLOID AL SYSTEMIC

After extensive consultation with the medical staff of a number of departments the decision was made not to undertake any form of treatment mainly because of the advanced state of the condition, the relative unknown of the condition and Les's age- 77yrs -he himself agreed with this decision- in fact initiated it saying that he " just wanted to go home'

The medical teams agreed with this and stated they would hand him over to the Palliative care team who would then be responsible for his care. Discussions were held with this team as to the best options- whether Les would go to Toowoomba or Roma, but after a few days we were told that Roma had agreed to his return to the Roma Hospital where he would be cared for - for as long as was necessary- his condition being such an unknown quantity that this could not be determined

Les subsequently was returned to Roma by plane and admitted to Roma Hospital. We were told in Brisbane that a care plan would be forwarded to Roma hospital for their guidance as to Les's future needs this however either never happened or was not followed by Roma hospital. Because of the rarity of Les's condition no one was able to tell us how the Amyloid was progressing or even if it was and it soon became apparent that the hospital was keen for him to 'move on' as he was not exactly an acute patient and the requisite number of days stay was fast approaching

Discussions were taking place to try to move Les home but this to my understanding was not really a good alternative as he was a tall man, over 6ft and weighing just over 90 kgs. Because of the Amyloid he had no strength and was on oxygen and he was extremely difficult to move-requiring at least 3 people — I was apprehensive as to how we were to manage his condition at home- as outside help would be minimal as we live "out of town'

Before the move was made Les passed away very quickly on Saturday 9th July 2011.

I would like to record that the care from both the Roma and Brisbane hospitals was excellent and I commend the nursing staff at both hospitals for their dedication and help

The availability of a dedicated Palliative Care Unit in Roma would have been greatly appreciated and used by Les. His condition was such that he needed feeding help and this I was undertaking each day , as well as helping in any way I could to lighten the burden of the nursing staff

The more homely surrounds of a Palliative Unit and the ability to not be as regimented as in a hospital environment would I am sure make the time — whether long or short of a persons last days much more serene and peaceful

I would urge the Government to give consideration to setting up such a unit in Roma The idea when mooted of going to Toowoomba which is a 4hr drive from Roma was although not ideal a better option than Brisbane but to have a unit in Roma where areas west to Charleville Quilpie , Cunnamulla etc could access would be much easier for families from these parts than accessing Toowoomba or even Brisbane

I fully support and offer my services to the committee in their endeavours to have a Palliative Care unit established in Roma

My Story of my Mothers experience in the last 6 weeks of her life.

She was diagnosed with Lung & Breast Cancer after an X-Ray ordered by the Local Doctor. The first Report about the X-Ray came back as nothing wrong but when the Dr saw the actual X-ray she recognised that his report was incorrect and requested that the Radiographer take another look and rewrite his report.

Although my 85 year old Mother wanted to stay in Roma she was persuaded to go to Brisbane for treatment on the advice of the Doctor as well as Family members going on the strong recommendations of the Doctor.

We drove the 7 hour trip to Brisbane which was very tiring on my Mother and admitted her to the Wesley Hospital in Brisbane that night. She had been in full cover Medical Benefits for many years and her membership was current.

My two sisters and I had Enduring Power of Attorney & Advanced Health Directive but it seemed to be of little use. The Doctors was also aware of this as they and the nurses had a copy.

She was put in a General Ward with 6 other people with very little if any privacy. The Family visited her every day twice a day. We were waiting at the Ward doors when they opened and we were mostly the last to leave when the doors were closed having been asked to leave on previous occasions.

We didn't have any privacy to be with our Mother in her final days. There was very little room and not enough chairs and we were not allowed to sit on the bed so we stood up most of the time. It was very hard for all the family to visit her all at once in the last weeks of her life because there was simply no room in the ward and we dearly wanted to share great memories together with our Mother at her end of life. Being a country woman and being from the bush there was no natural light or window that she could see outside which she found most distressing. We were ordered out at 2pm every day till 4pm as the Ward was closed to visitors and we couldn't get in before 10am in the morning.

Parking fees were costing us a small fortune as we had to pay twice a day for six weeks.

We found it very hard to get any information from the Doctors who were treating her. The only way we could find out any information from them if we happened to see them in the corridor and that was not very often.

She was subjected to constant X-Rays, MRI's & CT Scans which she complained about them as the movement and positions they required her to be in hurt her considerably but they didn't seem to listen to her. She had nobody advocating for her at a time when she desperately needed them.

When she became unconscious in the last 2 days of her life she was actually moved into a Private Room with only 2 chairs. She was put on oxygen No 12 on the scale and it just about lifted her out of the bed. No one seemed to care.

I now wish that she had never been sent away from her home town of Roma and that she had been able to die with peace and dignity which she so rightly deserved as does every Australian.