Submission to the Australian Senate Standing Committee on Community Affairs Inquiry into Palliative Care

Response to the Terms of Reference

Tasmanian Association for Hospice and Palliative Care Inc.

(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: this is generally well-covered in Tasmania. The specialist PC teams work closely with the primary care providers to give a comprehensive service.

(ii) Indigenous people: Specialist PC receives very few referrals in spite of good support for, and interest in, the programme "Providing culturally appropriate PC for Indigenous Australians" rolled out in 2004.

(iii) People from culturally and linguistically diverse backgrounds: Readily accessible interpreter services are important as family members are not always in the best position to provide this service. As these formal interpreter services are usually private, funding needs to be available from PCS monies to meet this need.

(iv) People with disabilities: It is very difficult to access funding for clients with conditions such as MND through the disability sector which is very short of funds in Tasmania. Some clients may already have a package in place on referral. However the CPCS does not discriminate on grounds of chronic disease/ disability in accepting referrals. Each referral is followed up on being received and care offered in accordance with need. A degree of specialisation in the care of people with MND has been achieved within PCS services in Tasmania, with support from MND Victoria in particular.

Recommendation 1: Support for the MND Regional Adviser position needs ongoing funding. This has been funded by a Victorian philanthropic trust for 2 years, but this will run out shortly. The regional Adviser has initiated early referral to Palliative Care services which has greatly improved the care to these patients.

Recommendation 2: Further experience in managing other chronic diseases in the form of education for palliative care service staff should be funded as chronic disease now accounts for 40% of referrals in the South (PC service internal statistics).

(v) Children and adolescents: Paediatric referrals to palliative care services are fairly rare in all areas, and the impression is that many children continue to be cared for by the paediatric team from the hospital, and interstate specialist paediatric hospital-base services with some referrals to the PC Community teams when end of life is near and the children are to be cared for at home. Whenever referral is made, there is shared care between the paediatric services and the palliative care services.

General point on access for all groups: A big problem with access is a lack of general knowledge of the services available, or realising the relevance of the PC services. There is also the fear that suggesting palliative care will impact negatively on a patient. Sadly this seems to apply to some GPs, as well as to the general public. Another barrier is that Specialist Community PC services are sometimes unable to respond to new referrals as quickly as they would wish due to high workload in comparison to staff numbers.

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

South:

State Government funding covers the 3 Community Palliative Care Services and the 10 beds on Whittle Unit (through the Federal Government health and Hospitals agreement), including all staff wages.

There is a designated palliative care bed at Oatlands Multi-purpose centre and Esperance Multi- purpose centre, which are State Government funded, and 2 sub-acute beds at Eldercare (RACF) which are frequently used for PC patients. Rural hospitals/facilities also accept PC patients.

One Clinical Nurse Consultant liaison position at the Royal Hobart Hospital is funded by the State Government and a second is currently funded by the Commonwealth as a temporary position for 3 years. Funding from the Federal Government's National Partnerships agreement has also supported a PT music therapist in the South and an OT in the North.

North-West:

There are no designated PC beds in the NW. There are 3 beds that can be used for palliative care patients on the medical ward at the NWRH, Burnie. All the rural hospitals will take palliative care patients for admission. .

North: Has 4 publicly funded beds and 3 privately funded beds at St Luke's, Calvary Healthcare. There are no designated PC beds in Launceston General or in any rural facilities, but all the rural facilities will accept PC patients.

There is a Liaison CNC at the Launceston General Hospital.

The Review (see reference at end) in 2004 highlighted several areas of increased need for funding:

Designated palliative care beds across the State were 50% short of the national guidelines. Since then only a few designated beds have been created in MPCs in rural areas.

A Medical Specialist shortfall of 3 positions (57%). This has been resolved in the South but a permanent new Specialist in the North-West has been appointed but not yet started practice.

A shortfall in Specialist Community Palliative Care Nursing positions of nearly 5 EFT positions. (25% below national guidelines) The nursing establishment in the South at the time of the review was 6.1 EFTs and this has not changed substantially since 2004, but the number of client referrals overall has increased by 82%. (440 in 2002/3 and 802 in year July 2012- June 2011 - internal PCS statistics).

No Allied Health positions except for the 3.28 social work positions, which almost meet national guidelines, but have to be set against lack of psychologists. There are very limited hours paid for a music therapist, and a pastoral care worker in the south, an OT in the north, but claims that Palliative Care Services work in a multi-disciplinary team is not reflected in the current lack of allied health staff employed as specialist palliative care practitioners in their disciplines. (ref 1)

Volunteer Services: The Northern Volunteer co-ordinator is also funded directly by the palliative care service while the NW and Southern volunteers are managed by two NGOs which are dependent on Community sector grants from the State Government.

Privately funded services are provided through the Little Company of Mary at Calvary Healthcare with 20 mixed Oncology/Palliative Care/Medical beds at St John's Hospital in Hobart, and 3 beds at St Luke's hospital in Launceston. (Plus the 4 publicly funded beds at St Luke's indicated in "North" above).

Specialist Community Palliative Care funding (State Government):

As stated, clinical positions on the Community teams fell well short of national planning guidelines in 2004, and this situation has not improved. The lack of increase in nursing positions is having a negative effect on current staff who have been working over capacity for many years. Funding for attendance at Conferences is virtually dependent on donations to the service. In an isolated State this attendance is vital to maintain practice and standards.

Recommendation 1: An increase in nursing establishment is well overdue. Clinical Nurse Educator positions within each of the 3 Specialist Community PC services would enable all clinicians to deliver better educational outcomes for non-specialist providers of PC. A programme of education for the SPCS personnel could also be organised.

Recommendation 2: Funding be organised as packages for the delivery of education to the RACFs, or an activity based funding model be set up. In this way clinical staff can be released for planning and presenting educational programmes.

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

Good relationships between the different services in each region of Tasmania supports good patient care and an efficient use of limited resources is possible given the constraints of staff shortages, demands on services and geographical factors. A high degree of cooperation and good will between staff means that as far as possible the provision of education and information, sharing of equipment, timely response to issues that arise is achieved. However, this situation is unsustainable and tenuous as staff come under increasing pressure to achieve more with fewer resources.

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

Reductions in primary care provision, including less after hours support from GP practices, has a direct impact on palliative care clients, with an increased need for forward planning to counteract unexpected events and OOH clinical need. While this forward planning is to be applauded, it is time consuming and an extra burden on SPCS staff.

Lack of medical support (GPs) in the aged care sector, particularly out of hours, has a negative impact for residents and staff, and can lead to unnecessary presentations to hospital emergency departments. Palliative Care Services who have contact with RACFs in managing residents at end of life facilitate proactive decision making and preparation for deterioration, but specialist PCS cannot sustain involvement, especially OOH, with significant numbers of such clients.

Reductions in beds at the 3 major hospitals in the State has meant longer waiting times in Dept of Emergency medicine for PC patients and longer waiting times for admission.

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

(i) its ability to meet the needs of the ageing population:

The 2004 Review (ref) noted the ageing and chronically sick population in Tasmania is higher than in other States and Territories, and that a regionalised population increases problems with travelling time and provision of services. Apart from the NT Tasmania has the lowest index of relative socioeconomic disadvantage.

While for most people, being cared for at home in the terminal phase is the preferred option, in Tasmania there are a high number of people who live alone, approx 30%. In this situation it is very difficult to receive adequate care at home, although it can sometimes be managed. With more family members leaving the State, it would appear that we will see an increase in the number of elderly people in particular, either living alone or with an ageing partner.

Referral numbers from RACF to CPCS nurses and medical staff have increased markedly over the last 3 years. The 2004 Review noted that Tasmania had a 25% shortfall state-wide of community-based nursing staff and as a result educational programmes to primary health providers had been reduced. This situation has not improved, and this has especially affected education to Care Assistants in RACF.

Recommendation: If Clinical Nurse educator positions were funded (as mentioned in (b) above, keeping the aged care workforce up to date on palliative care practice could recommence on a more regular basis.

The North-West community based service is partnering with University of Tasmania and the NW Area Health Service in piloting the UK Gold Standards Framework in 4 of the 17 RACFs in the NW area. The staff in the pilot Nursing Homes sites, are acquiring new skills in assessment and communication and benefitting from the reinforcement in the programme.

The disadvantage to the project is the amount of paperwork involved, and concerns about its resource intensity.

As a general comment on workforce issues it should be noted that the Out of Hours service in the North-West has ceased due to lack of staff and in particular a permanent medical specialist. The primary community health nursing service has increased its hours to manage clients up until 10pm. GPs have commented that with most GP practices closing at 5pm OOH crises now have to go through Dept of Emergency Medicine in Burnie where they may have been resolved at home in the past. The constant turnover of locums in the medical Specialist position has also been difficult.

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

PEPA has been a tremendously successful programme in Tasmania. However the provision of a single study day for PC staff has been welcomed but inadequate. The PC professionals need continual training and updating in order to teach others. PEPA also has an impact on clinical staff as supporting colleagues on PEPA placement is fitted around the normal clinical load of specialist staff – medical, nursing and allied health.

Recommendation: At least 2 study days/seminars a year per region would both educate and rejuvenate the Specialist PC workforce.

CPCS (South) runs education programmes for RACFs, but has to fit these in alongside the clinical work, with only 8 hours /week out of existing establishment designated for planning, preparing and delivering education to other health professionals. Hence attempts to re-introduce a comprehensive education programme (other than PEPA) have been very difficult.

In the North West provision of education to RACFs occurs mostly on an informal, ad hoc basis. In the North there is a programme of short sessions offered.

Recommendation: Under activity based funding a provision should be made for educational activity . This is core work for a specialist team and an expectation from the non-specialist providers. Regular ½-1 hour sessions can immensely improve palliative care provision in RACF, for primary providers and the disability sector.

(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:

The current standards are a good document into which a lot of work was put by knowledgeable people They are due for review, but should continue to provide the basis from which we work.

Support for NSAP to monitor the application of the standards should be supported.

(g) advance care planning, including:

ACP is being pursued by the Healthy Dying Initiative of the DHHS and by some of the individual services, including quite a number of RACFs in the south of the state particularly. There is a long way to go in training staff in holding conversations on ACP and in filling in the ACD forms.

A Goals of Care form is now completed for all patients in the RHH. Those whose goals of care include some limitation of treatment decision, or are deemed to be either palliative or terminal, should be discharged back to the community with a completed Goals of Care plan to guide future decisions by GP and ambulance crews. Many RACFs in the south are now quite familiar with seeing GOC plan forms for residents coming from RHH.

As Advance Care Planning is increasingly accepted as best practice in the RACF sector there is a real need for proper training and support for staff in RACF, ACAT and Palliative Care teams etc in assisting people in writing an ACD.

Advance Care Planning and end of life direction are an important response for the community who have concerns about receiving unwanted treatments at end of life and see that voluntary euthanasia is the only answer to this anxiety. This impacts not only on those clients of palliative care services and RACF, but on the wider ageing population.

Recommendation: funding for roll out of ACP needs to continue as this is a critical time in the process when a lot of ground work has been done, and the impetus needs to continue

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

The Healthy Dying initiative of the State Government is currently commencing a peer support programme to spread information and assistance with completing an ACD. However it is highly likely that funding to this programme will cease after June 2012. TAHPC has grave concerns that as stated above, all the initial work done on ACDs will be wasted if funding is cut off at this stage.

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

Many states have had advance care directive type documents and processes, (including provision for substitute decision maker nomination), in place for many years.

In the AHMAC National Framework for Advance Care Directives (September 2011) it is acknowledged that a national ACD document is unlikely. However the Framework states that Advance Care Planning is an important step in addressing appropriate care at end of life, engaging the community in decision making about end of life care needs and services, uniformity of language and terminology, inter-state recognition of ACDs prepared in other States and Territories. There is a need for both the medical and legal professions to understand that ACDs have common law status in Australia, and the patient's right to refuse burdensome treatment in advance of need is binding. The level of misunderstanding and anxiety amongst medical professionals is confusing for the community and hinders the widespread acceptance of end of life planning. Medical staff need access to training and education in understanding ACDs and communication around end of life.

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

There is a pilot, Commonwealth funded e- health project currently underway in partnership between the NW Area Health Service, Gold Standards Framework project and Cradle Coast Council to investigate implementation issues for e-health records including advance care plans.

In the South of the state the ACD being developed through the Healthy Dying Initiative is bar-coded for scanning into the hospital based digital medical record. Community provider access to that record should improve reach of ACDs

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

No comments

References: Eagar K, Gordon R, Quinsey K and Fildes D (2004) Palliative care in Tasmania: current situation and future directions. Centre for Health Service development, University of Wollongong

Volunteers:

I attach a report from the NW volunteer co-ordinator with recent statistics on her service: “Currently we have registered with us approximately 70 volunteers however of that number at any given time we have between perhaps another nine to twelve off on holiday, sick, family leave etc. 10 are fairly inactive.

Last year we had 80 admissions, did a total of 484 visits/transports, equalling 1110.25 hours – 80.50 night sits hours, 49.75 evening hours , 159 transport hours and 817 day visits hours. Since inception we have performed 43,564.11 hours with clients”. Ref Gaylene Reid, Manager, Burnie Hospice Programme. (NGO funded with Community Sector grant from DHHS.)

- Southern Co-ordinator’s report is in a different format but informs us that
- There are currently 80 volunteers registered.
- 52 referrals from July 2011 Jan 2012.– i.e. expect to receive approximately 100 referrals in a twelve month period.
- The majority of referrals come from CPCS, Community Nursing, The Whittle Unit (Hospice), the Royal Hobart Hospital and the private Gibson Unit.

- We see clients in four locations: Whittle Ward, the private Gibson Unit, at the Royal Hobart Hospital and in the community where the need for volunteers remains great.

- There is an increasing demand for palliative massage to be offered. We do offer basic training for this in our training course.

- Our volunteer training courses are offered twice a year – we have no difficulty filling places of 10-12 recruits per course.

- Since the ‘Walking through Grief’ bereavement group started six years ago, we have had 60 clients. Many of the clients who ‘graduate’ from WTG go on to form lasting friendships with each other. Volunteers also assist with the ‘Hands and Hearts’ bereavement group at the Hospice (Whittle Unit)

Hospice administers a grant from the Jim Bacon Foundation which assists clients in financial hardship.

Client diagnoses

89	cancer
5	motor neurone disease
8	chronic medical conditions

Plus 34 clients from previous year’s stats.

DURATION OF CARE (clients who died during the year with whom volunteers were involved)

Less than 1 month	18	1 - 3 months	19
4 - 6 months	7	6 - 12 months	4,
and 1-2 years	3		

End of Submission. 2.9.2012