

# **2012 Senate Inquiry into Palliative Care**

## **Response from the Australian Association of Social Workers NSW Palliative Care Social Work Practice Group**

### **Background**

The NSW Palliative Care Social Work Practice Group is made up of social workers working with palliative care patients in community and hospital settings, in Sydney and regional and rural New South Wales. Palliative Care Social Workers provide ongoing counselling, support and assistance to people with a life limiting illness and their carers and families. This submission identifies gaps in the service that have been experienced by these social workers in their differing work environments. It has been developed through a consultation process with the membership of the group, comprising over 50 social workers.

### **(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**

Health care staff who had worked both in the city and regional areas report that services for rural/regional clients at home are not as available or as flexible as for their city counterparts.

Health care workers in rural/regional areas have found that referrals to Carer Respite can be easily blocked. Intake workers describe respite services as those only accessible in emergencies and only for a total of 48 hours. Palliative Care clients are not seen as a special category.

#### **(iii) People from culturally and linguistically diverse backgrounds (CALD)**

There is a need for better access to interpreters for palliative care patients from CALD backgrounds. Interpreters can be block booked a year ahead and this can impact on access to interpreters for palliative care patients and their families who often need to be seen at short notice. A delay of even a day can be too long when dealing with palliative care patients and their families. CALD clients have access to the social work service -seen with health interpreters (as inpatients and at home). However few are seen for bereavement counselling.

Bereavement information in one regional service is sent out to families of patients that pass away with translation in seven languages-however there has been little response/ uptake from this.

#### **(v) Children and Adolescents**

Children and adolescents in regional and rural areas of NSW have ongoing treatment support and follow up through major Sydney children's hospitals (local facilities do not offer paediatric specialist oncology). They are not linked into local services until late in the palliative journey. For the child and family this can mean disruption and upheaval travelling to and from and staying over in Sydney. It also means that local palliative teams are not linked in until end

stage which makes it difficult for workers to form a meaningful therapeutic relationship.

We need to develop a range of services to meet the needs of children who have a parent who is facing a life limiting illness. These services are required before and after death. Canteen has done excellent work in this area for children from aged 12 but for younger children there is a lack of service provision. This requires partnerships with the education system and the family support services and a wider provision of targeted Bereavement services.

#### **(vi) Socially Isolated**

Elderly patients who live on their own and have no family or their family members don't drive can spend a substantial amount of their money on taxi fares and community transport to get to medical appointments. There is a need for more access to hospital transport to attend hospital/medical appointments especially for the elderly. There needs to be expanded eligibility for taxi subsidy scheme to include palliative patients who may not currently fit the strict criteria.

The socially isolated who don't have a carer or partner and don't have family support can struggle in being able to afford to pay the cost of their funeral. There is a need to look into a Centrelink's bereavement payment for these people to help with the cost of their funeral, which could also reduce the number of contract funerals.

### **(b) The funding arrangements for palliative care provision, including the way in which sub acute funding is provided and spent**

1. Funding arrangements: the move to activity based funding for Specialist Palliative Care Services may not be responsive enough to meet the complex psychosocial needs of our patients. Social Work interventions are often long and multi faceted in the home or in inpatient settings but may be invisible in the data collection systems in place or the proposed new models. We believe that palliative care social workers should be employed in all specialist teams across Australia, and in remote areas funding arrangements be in place to ensure access is available for all patients and families to receive high level psychosocial services.

In addition, many initiatives are funded short term only through COAG funds and even though they allow us to improve services and develop new models of care, they are not ongoing and when funds cease the improvements cease too. An example is the Calvary Health Care Sydney Palliative Aged Care Program which uses COAG funds for a nursing and social work position to work with palliative patients in local RACFS in St George and Sutherland Shire for a 3 year period. This program is a result of social work research and service development conducted by Julie Garrard over many years at Calvary as well as other evidence about the benefits of input into TACFs by specialist palliative care teams.

2. More inpatient beds required: The requirement for inpatient palliative care facilities should be reviewed and units opened where necessary, especially in rural and regional centres that are predicted to experience a significant increase in their ageing population and/or cancer incidence and mortality (for example, the Southern Local Health District of NSW). An increase in either demographic will correspond with an increase in demand for specialist palliative care services. At present, those individuals living with a life limiting illness who require specialist symptom management for advanced disease are often required to travel hundreds of kilometres intrastate or interstate (Canberra, ACT) to metropolitan facilities. This causes additional psychological and social distress to the patient, their family members and community. Also, experience shows that in some instances, patients may decide to remain at home with a sub optimal outcome rather than leave their social supports.

3. Specialised Community Care Services: There is a need for access to COMPACs for palliative care patients in more subacute hospitals. Currently many subacute palliative care units do not have access to COMPACs. The wait for other home care services and for commonwealth-funded aged care packages is too long for many palliative patients as they need services to commence straight away following discharge home and will often die before they receive such care. The wait for EACH packages and CACPs is often 6-12 months.

In addition to more COMPACs on discharge from hospital, we have identified the need for specific Palliative EACH packages. These could include respite or nursing care overnight to give carers a break and will allow patients to go home for terminal care if that is their wish. A number of other countries have nurses available to allow palliative patients to remain at home for the last few days of their life. An example of this is the UK model of the Macmillan Nurses. There is also a need for more Attendant Care Program Packages for those with palliative conditions such as Motor Neurone Disease to allow care to be provided at home for these high needs clients.

### **(c) The efficient use of palliative care, health and aged care resources**

1. Long stay patients: Younger palliative care patients who cannot return home due to their high care needs (such as brain tumours) are also usually not eligible for entry to a residential aged care facility. They can end up taking up a hospital bed long term even though they may be stable medically. There is a need for long stay hospice beds for such patients which may be funded at a reduced rate or a step down model of care for long term patients. Younger palliative care patients who don't fit into the aged care category also cannot access EACH Packages or CACPs.

2. Partnerships with RACFs: A step down model is needed for long term high level care patients regardless of age. A useful example is Bond House (run by HammondCare in Sydney) which has set up palliative beds in an existing residential aged care facility. They have modified rooms to be appropriate for

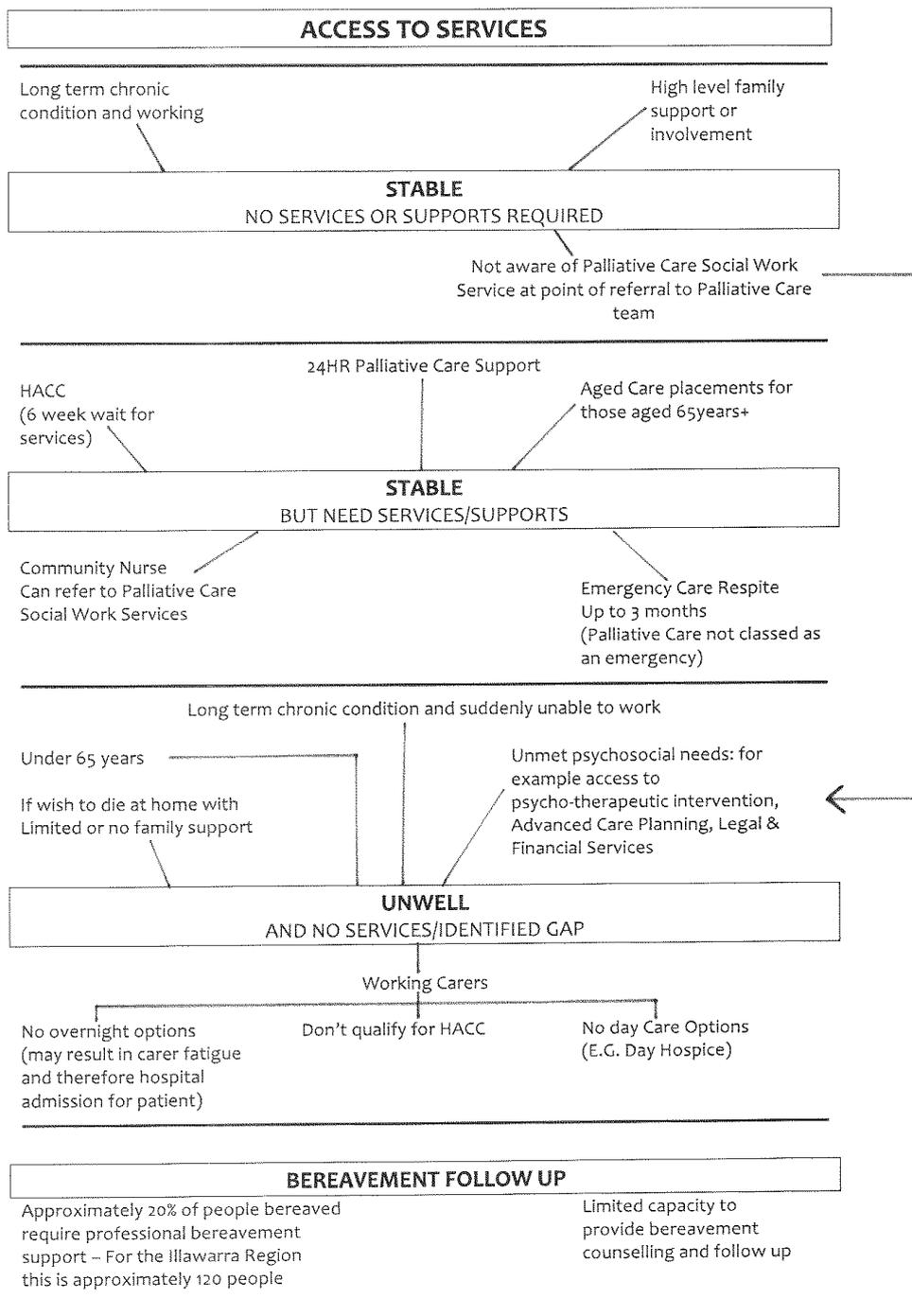
end of life care and will endeavour to have funding at appropriate levels and staff trained to understand the needs of such palliative care patients . Partnership with the local Specialist Palliative Care team is essential for this model to work effectively and must include support visits from social workers as well as consultation from nurses, doctors and other allied health. (This is the model developed at Calvary Health Care Sydney, the Palliative Aged Care Program

3. Palliative Care Respite RACF entry criteria: we propose a new category to be included on the Aged Care Assessment Record completed by the ACAT teams. This would be a three month palliative care respite category in RACFs which would serve palliative patients whose care needs are too high to return home but who are ready to leave hospital. This would save families of palliative patients the stress of completing the Centrelink financial assessment for entry into residential care when their family member has a very limited prognosis. If the patient did survive in the RACF for over 3 months a permanent assessment could be completed and the appropriate fees assessment undertaken at that stage.

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

1. Hospital and aged care interface: Once a client is deemed medically stable and not needing specialist palliative care as an inpatient, the practical support services available at home are limited. There is a COMPACS service which consists of three services offered to the client for a period of 6 weeks. If these services are not enough- the client is requiring high level care. As there is often a waiting time of 6-12 months for an EACH package then the usual pathway is an ACAT assessment and placement in residential aged care. The transfer of palliative patients to RACFs is a complex process –the distress caused to patients and families at the end of life can impact negatively emotionally, practically and financially on the patient and family. Research into the impact of transfer to RACFs from palliative care units conducted by social worker, Julie Garrard at Calvary Health Care Sydney, has demonstrated this and led to advocacy for a more cautious approach to transfer of these patients at the end of life and for better support after transfer. Some strategies to improve this distressing process have been mentioned already in sections above, including step down units, slow stream/longer stay in palliative care units or hospices (funded differently to sub-acute beds) or partnerships with RACFS who set themselves up to offer palliative care appropriately, including a consultancy with a palliative care social worker.

2. Community care services. The following chart illustrates the short fall in community service provision. The chart was designed by one of the social workers from the AASW NSW Palliative Care Social Work Practice Group



Although theoretically there is choice as to whether someone dies at home or in the Palliative Care Unit it is often restricted by availability of practical help, especially overnight.

The carer is commonly aged or frail. If there could be an extension of the palliative community team workforce to include an AIN /EN who was available to care for clients at home overnight especially in the last few days of life, then many hospital admissions could be prevented.

3. Younger carers and partners: there are limited service options for younger clients and partners or carers at home. There is inadequate flexibility or help to allow the carer to keep working and to maintain their career options. If a family cannot afford to pay for private community services (as they usually do not qualify for any subsidised assistance) while he/ she is at work, then they have to stop working to be a fulltime carer. It is important for carers to be able to maintain their skills in the workforce especially prior to the death of a partner or family member. For example, the case of a 58 year old man staying home to care for his wife. When she dies he has no job to return to and he remains on Newstart with little chance of reemployment. There is also an issue of cost of medications for patients whose partner is working and they miss out on eligibility for the health care card due to their income being just above the limit. Some medications can be quite expensive and this can take a big toll on the patient and their carer.

4. Rural and regional issues: There is a gap in service provision at the transition of clients from the oncology team (acute, prognosis focus, hope of a cure) to Palliative Care Team (comfort, choice, focus, no hope of cure). Oncologists particularly are an over stretched resource, with little time to assist clients absorb and adjust to "There's no more we can do" information delivered in their office. A support person is needed - social worker or trained counsellor. **Rural and regional clients** and their carers often have to drive home after such traumatic and life changing, yet brief conversations, often including an unprepared for prognosis pronouncement (about how much time they have left to live) asked for or not.

Social Workers provide psychosocial care, practical support and counselling to patients, their families and other carers. The need for this type of support is amplified in **rural and regional** Australia where patients have no choice but to travel long distances for treatment and investigation. This results in financial hardship associated with travel and accommodation costs. Although programs such as the Isolated Patients Travel And Accommodation Scheme (IPTAAS) can assist with these costs, these subsidies are often inadequate. Regional and rural patients may require additional support and counselling due to these stressors and the isolation associated with undergoing treatment away from usual social supports.

## **(e) The composition of the palliative care workforce**

### **(i) Its ability to meet the needs of the aging population**

Current and predicted increases in demand for palliative care services warrant a corresponding increase in resources in order to meet this demand. This ought to include the development of new specialist palliative care positions such as a Palliative Care Social Worker particularly in rural and regional centres.

Much has been said throughout this submission that is relevant to the aging population, in terms of aging carers, more community services needed, long stay beds in hospices or palliative care units and models of care in RACFs etc.

## **(ii) Adequacy of workforce education and training arrangements**

1. Rural workforce: There are far too few Palliative Care Consultants leaving many positions unfilled especially in rural and regional areas. Something needs to be done to persuade doctors to take up this important speciality. Is there a way of using this resource more equitably?

2. RACFs: Attending VMOs, GPs and nursing staff at RACFs need to be skilled to provide adequate palliative care, since this is where many people die. The situation will increase due to predicted demographic changes.

3. Training and education: the training and education of workforce is linked with ***point H –availability and funding of research***. Many palliative care staff have not had the training nor have the time to access/ liaise with researchers or adequately evaluate best practice for the palliative care community. E.g. To evaluate what is best practice in providing bereavement support and counselling for CALD clients; to research therapeutic strategies in working with children and families; to assess what is most effective in working with partners of women who are left not only grieving but also caring for young children.

Professional development training opportunities in palliative care are offered regularly in metropolitan areas however, the distance from rural/regional centres and costs associated with travel, accommodation and course registration hinder attendance by rural and regional staff. Also, in many rural/regional areas, staff members are employed on a part time basis making it more difficult to prioritise education and training over busy client caseloads, especially when substantive positions are not being backfilled during periods of absence.

Increased Government assistance is required in the form of rural scholarships, especially for allied health, to ensure rural staff attend training courses. Funding should allow the backfilling of positions while staff attend such training.

Government assistance could be given to those organisations who currently provide metropolitan based education in palliative care to allow for outreach education into rural and regional centres. These outreach programs can be face to face and also use video and teleconference link ups.

4. Clinical Supervision: all palliative care social workers need access to regular professional clinical supervision. A network of supervisors and peer supervision could be developed between metropolitan and regional and rural areas to ensure this occurs. This requires adequate resourcing to allow senior social workers in busy metropolitan palliative care services to provide such supervision.

## **Conclusion**

In conclusion with the aging of the world's population it is essential that the future health care needs of the population are addressed. It is important that the World Health Organisation Guidelines (2004) are upheld so that people who have a diagnosis of a life limiting illness are enabled to have their 'preference for place of care and death'.

## **Recommendations**

1. To increase hospice/palliative care beds to meet the needs of the aging population.
2. To increase palliative care specific packages/services to provide appropriate care overnight, during the patient's illness and for end of life care.
3. There is a need to address the gap in access to services for palliative care clients between rural/regional areas and city areas.
4. To expand the aged care entry requirements to take into account the needs of palliative care clients.
5. There is a need for increased assistance for people without family support.
6. To increase the number of interpreters to cater for the needs of the CALD population.
7. There is a need for increased support for children who have a parent with a life limiting illness.
8. To assist carers to be able to continue working or to return to the workforce once their family member has passed away.