eastern
palliative care
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Eastern Palliative Care Association Inc A0036991M ABN 62982157121

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Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Committee Members,

Re: Enquiry into Palliative Care from Eastern Palliative Care Association Incorporated

Eastern Palliative Care Association Incorporated is the largest community based palliative care service in Victoria. We developed over many years in the 1980's from the great work of volunteers in the local community to now being a professional holistic and respected specialist palliative care community based service. We supported over 1260 new clients in 2010/2011, 83% of whom had a malignant disease and 36% who were under the age of 69.

Specialist palliative care is our passion. Supporting clients to die in their place of choice with symptoms well managed is our ultimate aim. We do not have access to hospital beds but have great relationships with the hospice in our region, Caritas Christi and the various inpatient palliative care units including Wantirna Health.

In order to provide clients with a choice of where they wish to die, we need to fully support the carers who will ultimately be providing the "hands on" daily care for the client. Carers are coming to terms with the news that the person they care for is going to die and at the same time they need to be practical and resourceful in order to be able to provide care 24 hours per day, 7 days per week. Care for carers is critical. Understanding at all levels of Government as to what 'caring' means is essential. Support for carers needs to be thoroughly understood by service providers, not to limit caring, but to support carers and family to care. The role of palliative care volunteers in providing informal support to carers needs to be recognised and enhanced.

The emotional and physical struggle of caring can place undue stress on families particularly as greater than 64% of our clients are over the age of 70.

The image of a caring family with many helpers rostered so that there is always a member of the family present is not always a reality. In the eastern region of Melbourne 30.2% of clients live alone and 25.8% of clients have no carer.

The number of clients and or family members with mental health issues has also increased significantly over the past 5 years. This adds to complexity of care required and increases our need for support from other agencies.

Client care complexity has also increased as medical care lengthens life expectancy.

Recent figures regarding the 5 year survival rates of people with cancer in our society indicate five-year cancer survival has increased from 47% to a record high of 64% in the period from 1985 to 2009 (Cancer Council Victoria, 2011). Aspects of these improved survival rates could be attributed to improved treatments and access to cancer services. As a result clients whom have benefitted from these improved treatments often experience a higher degree of complexity at end of life.

Many of our clients come on to our program with multiple issues and need regular hospitalisation to:

1. Support and relieve the carer/s
2. Investigate unexpected symptoms
3. Control medication regimes or initiate medications that need to be provided as an inpatient
4. Provide palliative radiation or chemotherapy

The integration between hospitals and specialist community palliative care services is essential and needs to go above and beyond the good will of individuals to be a requirement of the system. Returning clients home after hospitalisation also needs to be an expectation. Many clients are reluctant to go to hospitals because they feel they will not get an opportunity to be home again, when in fact a short hospital stay may increase their quality of life. We constantly keep in touch with hospitals when clients are admitted to ensure they know we are involved and the services we can provide.

A true understanding of the interdisciplinary approach to care and the need to be client centred is essential. It is not about medical care but about what the person sees as important in their life. Palliative care talks about the quality of life of clients but without being client centred this cannot happen. Public hospitals are often limited in being client centred and interdisciplinary due to tight resources and limited ability to access the appropriate professional resources.

Access
Over the past 3 years Eastern Palliative Care has undertaken to ensure referrers understand our services and how we can assist clients who are dying. Our Intake Team have visited public and private hospitals, consultants, GP's surgeries to inform, provide brochures and support referrers ringing for advice. We have also undertaken a project with the Royal District Nursing Service where if a referrer is confused as to who does what they refer to us and we sort it out. We have also undertaken an Ambassador Program where we have provided training to 4 volunteers to talk at service clubs, churches and community groups about our work and how specialist services can be used.

From this work we have experienced 6% growth for each of 2 years and 9% growth for the 2010/2011 year. This work is on-going and needs to be constantly updated.

We have worked very closely with the Indigenous Health Service at Healesville to ensure our services are culturally appropriate to the local community. This work is built on relationship and we have had some very successful outcomes for clients through this work.

We have worked with the Migrant Information Centre to ensure our brochures and information, including our Consent Forms, is available in the 10 major languages in the region. We have attended Community Expos and community days to ensure we can get the message across that we are there to support the community and that there is an alternative to dying in a hospital.

Staff have worked with the Royal Children's Hospital to ensure our services meet the needs of children. At any one time we will have 1% (10 – 12) of our clients below the age of 24. We also have a significant number of clients with young children and they also need to be supported when a parent is dying. As with all our bereavement programs these children are then supported for up to 13 months following the death of the parent if that is the wish of the remaining parent/guardian.

Funding
Until June 2013 community palliative care services in Victoria are funded under an annual grant. This has been indexed at 3.5% for the past 3 years. Increased funding has been provided every few years for growth.

Although this funding allows us flexibility for client care, it has not kept pace with our increasing client numbers. Staff rosters have been increased (to cover this increase in client numbers) and the increased complexities of clients and carer issues. Our funding has not covered these costs.

Example: A recent client was reluctant to have services in the home and yet was incapable of managing her own pain independently. A family member lived with the client. The family member had significant mental health issues and was very protective of the client. There were no other family members involved. Reluctantly they allowed our staff into the home, but because of the situation 2 staff always went together. It was not safe to send just one staff member at the time. The family member had serious behavioural issues. For the last 5 days of her life we visited twice per day with 2 staff. The client died peacefully at home. The son then refused bereavement support.

Comments. Under our current funding system we can have 2 staff attend visits but under Activity Based Funding this will account for just 1 contact leaving the organisation having to fund staff safety issues and complex psycho social situations where we deem it necessary to have more than 1 staff member in the house at any one time.

In 2010 Eastern Palliative Care commenced a new service called our Priority Assessment Services. Our data showed that a number of clients each month were dying before we could get to visit them. This new service, which ran as a pilot for 12 months, 3 days per week, allowed us to prioritise clients who were at risk of dying within 7 days to be fast tracked and seen within 4 hours of referral. The pilot was very successful with 41 clients in the year strictly fitting the admission criteria and 41 % of these clients not having cancer as a primary diagnosis.

Priority Assessment Team Non-Malignant Conditions. Of the clients who did not have a malignancy the following conditions were more frequent.

Cardiac failure/disease	35%
Dementia	24%
Multiple medical	12%
CVA	12%
Other	17%

Deaths prior to first assessment dropped from 10 per month to less than 4 per month over the pilot period and now stands at 2.5 month. The figure will never be 0 as some clients never make it out of hospital because of an acute event.

This pilot project was funded by Eastern Palliative Care at a cost of approximately $130,000. No funding could be found from Government Departments or philanthropic groups to assist. Because of the success of the pilot project this has now been incorporated into our normal services 3 days per week leaving Eastern Palliative Care to find the funds annually.

We fear that Activity Based Funding will never allow us to trial new innovations in service provision or allow us to double staff as needed.

Activity Based Funding in sub-acute care as proposed, pays no attention to the needs of carers. As stated previously, the needs of carers are critical to allowing the clients to die in their place of choice. To only count face to face treatment with the client does not acknowledge the support needed for the carer. Work with the carer needs to be recognised and funded accordingly in the new funding system.

Efficiency of Service Provision

Currently, community based palliative care services work in collaboration with public and private hospitals focussing on the needs of clients while they are in hospital. I feel that if Consultancy Services, which currently work in public hospitals were actually managed by the community sector this could better support integration of community and hospital services. Consultancy services not only work with clients who are recognised as palliative but they work with acute services to support clients who move from an acute treatment plan to a palliative treatment plan.

Many clients seen would have end stage chronic illnesses and would be known to the community providers, Royal District Nursing Services, HARP or specialist community palliative care providers. By integrating the Consultancy Services more generally with the community services, particularly the specialist community services the support of clients with a chronic condition could be better streamlined.

This could mean a different role for Consultancy Services moving them to being more the pivotal information collectors of clients with a chronic condition working across both hospital and community services.

Effectiveness of Current Services

There is a lot of pressure on aged care facilities to provide quality end of life care but without the appropriate staffing levels this will never occur. Turnover of staff is also high and this exacerbates the issue. Owners of aged care facilities need to value highly their work force and develop strategies for retention of appropriate staffing. Where Eastern Palliative Care have developed the Link Nurse position with aged care facilities this only works as long as these staff are:

1. Employed by that service
2. Valued for their role
3. Allowed to organise GP's, pastoral care workers and volunteers
4. Provided with the resources to develop strategies within the facilities – e.g. training volunteers
5. Constantly upskilled and supported

Our experience is that facilities initially run with the program but a change in management or a change in budget restricts the program and then the program disintegrates.

The tightness of funding in aged care is the principle reason for this. Aged care providers have so many demands on their services that they have to be mindful of their very tight budgets. Regulatory Compliance, Spot Check Visits and mandatory reporting have affected the culture in aged care facilities so much so that the whole system needs reworking.

Without registered nurses division 1 employed by the aged care facility we find it hard to provide the required services in aged care facilities. Some services will have a nurse on call for out of hours when a client is terminal and this is most effective, but the nurse needs to understands the client and the use of medication in palliative care – the nurse cannot be an agency nurse.

Palliative Care Workforce
Specialist community based palliative care organisations need to train staff constantly in so many areas, this has the potential to impact the ability to provide care to clients.

Mandatory

Training includes:

- Bushfire Safety
- Emergency Training
- Safe Driving Program
- Infection Control
- Bullying and Harassment
- Manual Handling
- Medication Management (Nurses Only)
- Syringe Driver Management (Nurses Only)

And other training as deemed necessary each year. On top of this, training in specific areas such as Advanced Care Planning, Mental Health issues and medical issues which staff may be unfamiliar with is regularly offered. Constant education is also provided in medication use as the use of medications in palliative care is sometimes 'off label' and outside normal use.

Compliance issues remain a constant risk for organisations and needs to be factored into daily routines of staff in order for the organisation to remain compliant.

Eastern Palliative Care employs a number of bank or casual staff in order to be able to provide the mandatory training that all staff need each year and at the same time provide the daily care to clients that is needed.

Increasingly, we need to educate staff on the mental health issues we are seeing more and more in community palliative care. Mental Health issues are a separate specialist area but staff need to know and understand the basics as they support clients and their families at this time.

Eastern Palliative Care also supports the training of Nurses, Physicians and Social Workers. We also assist with the training of Palliative Care Registrars undertaking community experience. This is undertaken in conjunction with St. Vincent's Hospital and the Australasian Chapter of Palliative Medicine. Although beneficial to staff and the trainees, this again places pressure on staff who usually have a lesser client load on any day where they are supporting students. Little recognition is given for this work, however we are committed to the further development of the palliative workforce.

In the past 12 months we have experienced few problems with recruitment however, in the past many months have passed before we have been able to recruit the right people. Some staff are recruited with no specialist qualification and we support their professional development.

Any discussion of the workforce needs to include the value and work of Volunteers. Without Volunteers we could not provide the support we do to clients and their families. From in home respite, taking people to appointments or writing a client's biography these are all highly valuable skills that will be increasingly needed now and in the future. In a recent survey 45% of our volunteers identified that the reason they volunteered in palliative care is because they have experienced this in their own family. Ongoing training and support of volunteers is necessary to ensuring volunteers remain connected to services and continue to provide such valuable care.

Standards

Eastern Palliative Care is required to be fully accredited and chooses to use the Australian Council on Health Care Standards (ACHS) organisation to meet this requirement. We have also voluntarily undertaken the National Standards Assessment Program (NSAP), an initiative of Palliative Care Australia to measure our services against the National Palliative Care Standards. We are also submitting data 6 monthly to the Palliative Care Outcome Collaborative (PCOC) to measure and benchmark our clinical services.

Our service is constantly looking at ways of improving and all three mentioned measures help us to undertake improvements based on external views of our service.

The fact that NSAP is voluntary is a concern. As a specialist service we believe NSAP must be mandatory to fully understanding the national standards for specialist services. This could assist services in understanding their role in client care. Some services call themselves a specialist service and have no specialist trained staff available. All organisations should also be encouraged to submit PCOC data, however, with the change in funding to Activity Based Funding a conflict will exist in the use of Phase of Care. Services will receive 1.3 units of care for an unstable client and 1 unit of care for a stable client (proposed). For PCOC the objective is to have the client in the unstable phases as short a time as possible and this will conflict with the payment system.

Aged care facilities do not have to comply with the national palliative care standards but need to comply with the Aged Care Standards which do not prescribe the emphasis on palliative care but on the lifestyle and general clinical care of the client. The average length of stay of a client in aged care is less than 12 months – and for most clients admitted it could be foreseen that death will occur within a 12 month period and therefore an emphasis on palliative care should be made.

The fact that there are different standards for different areas of care provision in Australia is something that should not be addressed. Generic standards are not specific or relevant enough and therefore should not be attempted. Specific standards for different areas of care provide more emphasis on practical and person centered care.

Advanced Care Planning
Eastern Palliative Care has over the past 9 months developed a kit and education package for our staff on Advanced Care Planning. Specific education is being rolled out over March to ensure all staff understand the principles of this activity. The need for an advanced care plan is obvious but people in the community have little interest in this activity unless they are faced with a crisis in their health.

Much education needs to take place for people to understand the benefits of an Advanced Care Plan. Ask any health professional who understand the benefits of an Advanced Care Plan and see if they have prepared one – most will tell you “no”. If we in the industry are not preparing, how can we convince the community to do this. Although not a reason to not educate the community on advanced care planning, it provides an understanding of why everyone does not automatically comply.

Research and Data
Funding for research and data analysis is required to understand how and why people use palliative care – from both the professional’s perspective and the community perspective. Eastern Palliative Care has an electronic health record in operation for 6 years. Data is available for analysis but we do not have the resources to undertake this work. The focus of our work is service provision and all increases in recurrent funding over the past 4 years have been targeting at front line care, not on management or research. Although we understand the power of data, priorities must be directed to care provision.

Thank you for the opportunity to make this submission. We look forward to your report.

Yours sincerely

Jeanette Moody
Chief Executive Officer
Eastern Palliative Care Association Inc.