Inquiry into Palliative Care in Australia

Submission by Blue Care to Senate Standing Committees on Community Affairs

1 March 2012

Signed by and with the authority of:

Robyn Batten
Executive Director
Blue Care
T: 07 3377 3300
E: r.batten@bluecare.org.au

Submission enquiries:

Kerrie Storey
Community Care Advisor
Blue Care
T: 07 3377 3345
E: kn.storey@bluecare.org.au

Tracey Silvester
Director Community Services
Blue Care
T: 07 3720 5424
E: t.silvester@bluecare.org.au

1. Key Issues and Recommendations

Blue Care is one of Australia's largest not-for-profit providers of residential aged and community care. We support community based clients, residents of our aged care facilities and their families, throughout Queensland and northern New South Wales, through all the stages of palliative care.

Our palliative care program provides ***primary care palliative services*** including:

- clinical management and care coordination; including assessment
- triage and referral using a palliative approach for people with uncomplicated needs associated with a life-limiting illness
- end of life care.

Factors identified throughout this submission affect all recipients of palliative care, whether from rural, regional or metropolitan areas. It is the ***current system of funding and delivery of palliative care***, which is reliant on secondary funding through hospitals, that ***requires reform.***

Blue Care's submission to the Senate Inquiry into Palliative Care in Australia is in respect to both residential aged care and community care as set out in the following sections under each term of reference. The following key issues and recommendations are a summary of our full submission (enclosed) which includes details of Blue Care's experiences as well as case examples.

Term of reference (a): 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:*
    - People living in rural and remote areas are often required to travel to specialist appointments and services. ***Utilisation of technology and increased support of current primary level providers*** could provide improved access in the rural or remote setting.
    - Families often have inaccurate expectations of available support before admission and then get shocked when faced with the reality of service capacity and accessible support. In many areas, there is no relief for over-stretched carers, such as access to overnight respite care. ***Funded overnight respite services will assist in supporting choice for people with life-limiting illnesses and reduce long-term carer stress.***
    - Constraints such as inadequate remuneration, safety concerns and difficulty accessing medical advice impact on the ability of community services, such as Blue Care, to provide after hours care or advice. This could be ***improved through adequate funding*** for services providing after hours care and ***improved access to specialist medical/clinical phone support***.

  - Professional development opportunities for doctors and nurses in regional and remote areas are limited. Staffing pressures reduce the ability of these professionals to travel to in-service training. ***E-learning opportunities, videoconferencing and web-based training*** would increase education accessibility for regional and remote clinicians.

  - Equipment is often more difficult to access in rural areas as there are limited private providers and hospitals only carry small equipment stocks. Rural and remote pharmacies don't always carry the drugs required for end of life care in the home.

  - Blue Care services often receive referrals for care late in the disease process.

  - An effective ***interdisciplinary model of care*** involves primary care palliative care providers such as Blue Care and GPs, working collaboratively with a visiting palliative physician and a dedicated Palliative Clinical Nurse Consultant (CNC) employed by the hospital.

    The ***improved communication resulting in the cooperative palliative approach improves continuity of care*** for people with life-limiting illnesses who transfer in and out of hospital through the course of their illness.

    It is recommended that ***primary care models*** such as these ***are expanded and implemented in other areas across Australia.*** This should be ***supported by adequate funding*** for GPs and community nursing staff, and access to appropriate medication and equipment.

- *(ii) Indigenous people:*

  - Clients may require a more ***flexible approach*** to care delivery, which can be difficult to achieve under current funding arrangements. Assistance from Aboriginal-controlled health organisations is difficult to access in many areas. It would be ***beneficial to utilise technology to make education and support*** from Aboriginal-controlled health organisations more accessible to primary care providers and residential aged care facilities.

- *(iii) people from culturally and linguistically diverse backgrounds:*

  - Difficulty accessing interpreters consistently in a timely manner can lead to communication breakdown and misunderstanding regarding care and choices. ***Continued support and expansion of current interpreter services*** is suggested. Accessibility could be expanded through the ***use of communication technology.***

- *(iv) people with disabilities:*

  - Younger people with a disability who also have a life-limiting illness have complex needs and their carers, often aging parents, need a lot of specialist support. ***Improved access to additional carer support such as overnight respite support and manual handling equipment*** will assist in reducing carer stress, enabling longer management in the home.

  - Our residential services find providing care for younger people with a life-limiting illness, with or without a disability, challenging as their programs and care are developed for older people who have different interests. Where residential facilities are palliating young disabled people, ***improved access to specialised resources***, particularly covering lifestyle support, would improve outcomes for disabled residents and their families.

- *(v) children and adolescents:*

  - ***Palliative care for children and adolescents is well funded by hospitals in terms of equipment, supplies and outreach treatment.*** There is, however, limited educational opportunities covering paediatric palliative principles available for primary care palliative care staff. Counselling and de-briefing for our staff that are providing end of life care and support for children and their families is limited. This could be improved through ***utilisation of technology to make education and support specific to paediatric palliative care available to primary care providers***.

  - Resources for families in rural and remote areas are limited, which may require children and adolescents to be sent to Brisbane for treatment or end of life care. Implementation of ***models of care that promote access for primary providers to specialist paediatric palliative care clinical advice*** has been a successful strategy to minimise this outcome in some areas.

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

- Funding for the provision of palliative care in the community setting is fragmented and can be difficult to access. There is ***no specific funding available for early intervention, after hour's on-call services, or Grief Recovery Programs.***

- End of life care services are funded by Queensland Health and managed by the local Health Service District. Community care providers, which include not-for-profit providers such as Blue Care, apply to the hospital for funding when they determine that the person may have entered the terminal stage of their illness and are ***within their last three months of life***. As it is difficult to determine when someone will die, people with life-limiting illnesses often receive significantly less than the allocated three months available, or occasionally "run out of funding" at the very end-stages of life. The average Blue Care hospital-funded palliative admission in 2011 covered only 20 visits which represents ***less than three weeks*** of seven-day-a-week services. At the other end of the scale, where time until death is under-predicted and clients live longer than the three month timeframe, funding may be ceased.

- Provision of hospital funding can be affected by available funds in the individual hospital palliative budget. This can result in different funding availability in different areas across Queensland.

- Funded care is often ***limited to one hour of care per day*** however one nursing visit for an unstable, deteriorating or terminal palliative client can take up to three hours. ***Personal care, domestic support, allied health services and respite support are often not funded.***

- Blue Care's residential services are experiencing an increasing resident acuity level, with a 6% increase in average acuity since 2009. Adequate and timely funding for complex end-of-life care is difficult to access.

- ***A more accessible, equitable approach to funding community-based palliative care is recommended.*** This funding should be able to be ***accessed directly*** by the organisation providing care, rather than brokered through the local hospital, and ***should not be determined by estimated prognosis***. Once a palliative diagnosis is determined, ***funding could be staged*** to cover increasing needs and ***be flexible*** to incorporate clinical care (nursing and allied health), after hours care and lifestyle support. Funding could also include the ***ability to access time-limited interventions*** such as overnight respite services and Grief Recovery Programs.

- In assessing ACFI claims for residential services, ***claims should be able to be back-dated*** to the time of a valid palliative directive.

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

- ***Implementation of the primary care model*** that is supported by appropriate funding; access to training and professional development; and access to specialist consultancy services will promote a cost-effective and equitable solution for palliative funding in Australia.

- ***Access to consultancy services and education*** could be enhanced by web-based and video link technology. The ability of all care providers to ***access eHealthcare records*** would improve communication across services and enhance seamless holistic care.

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

- A ***primary care model*** including informal and formal relationships with specialist palliative care providers, GPs, hospitals and residential providers needs to be robustly established across all geographical areas.

- ***Utilising currently skilled community nurses***, with provision for ongoing professional development, to coordinate an adequately-funded interdisciplinary approach to palliative care in the community is a ***cost-effective*** way to provide this level of care in the rural and remote setting, and to utilise specialist palliative care services more effectively in the metropolitan environment.

Term of reference (e): the composition of the palliative care workforce:

- *(i) its ability to meet the needs of the ageing population:*
    - As a provider of residential and community services, Blue Care is well placed to participate in primary care interdisciplinary teams to meet the palliative care needs of ageing clients. Our staff team includes clinical staff such as nurses and allied health clinicians, and lifestyle support staff such as personal carers, domestic assistants, disability workers, respite workers, chaplains and diversional therapists. Blue Care works collaboratively with specialist palliative care services, GPs, hospital staff and other stakeholders.

- *(ii) the adequacy of workforce education and training arrangements:*
    - Workforce education and training program accessibility would be improved through the ***utilisation of e-learning opportunities, videoconferencing and web-based training.*** Specialist palliative care services can provide an exceptional resource to support primary care teams, through clinical consultancy and education.

Term of reference (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 National Standards for Providing Palliative Care should be used within a quality improvement framework, not integrated into the existing Accreditation Standards or Community Care Common Standards.

Term of reference (g): advance care planning:

- *(i) avenues for individuals and carers to communicate with health care professionals about end-of-life care:*
    - Advance care planning is crucial in meeting the needs of individuals at the end of life. A ***nationally-funded education program for staff working in residential and community*** on advance care planning will enhance the opportunity for individuals and carers to communicate their wishes with health care professionals.
    - A national community awareness program should be provided to ensure that individuals are well informed prior to or at the time of needing health care regarding end of life decisions.

- *(ii) national consistency in law and policy supporting advance care plans:*
    - Advance care directives are one way of formally recording an advance care plan. Not all advance care plans will result in the completion of an advance directive. Blue Care supports ***national consistency in law and policy for advance care directives and advocates national consistency, policy and training for individuals and staff in advance care planning.***

- *(iii) scope for including advance care plans in personal electronic health records:*
  - As indicated above, the distinction between advance care directives and advance care plans is required. Blue Care ***supports the inclusion of advance directives in personal electronic health records***.

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

- The National Palliative Care Strategy has been successful in providing funding for research, largely as one-off projects that have not been translated into practice across the sector. Some target areas have received substantial and ongoing funding, such as clinical trials or outcome measures, while others, such as carer or bereavement research, despite clear need, have not been supported to a similar extent.

- There is limited research funding for capacity building within the sector such as research scholarships and fellowships across the career span. ***Collaborative research centres with target areas identified under the National Palliative Care Strategy would address this imbalance and build future capacity.***

- The Palliative Care Outcomes Collaboration (PCOC) has been established to provide outcome data for specialist palliative care services and is currently being extended to primary care. PCOC is not designed for residential services or for primary care clients who are not identified as palliative. ***Independent evaluation of the impact and usefulness of PCOC as an avenue for palliative care data should be undertaken.***

- There is no national and publicly available data on place of death, reasons for transfers from home to specialist palliative care or acute care services and transfers from residential services.

Table of contents

2. Preface

2.1 Blue Care's scale of care

Blue Care is a service group of UnitingCare Queensland. An overview of Blue Care's scale of services is shown in the table below:

Table 1: Overview of the scale of Blue Care's services

Staff employed	8,396
Volunteers	2,200
Residential aged care	
Number of Aged Care Facilities	50
Number of residential aged care beds (approx. 2.5% of funded residential aged care beds)	4,340
Days of residential aged care provided per annum	1,500,079
Provisional	278
Number of Independent Living Units	1,110
Community care	
Number of client home visits per annum	2,873,549
Number of occasions of service per annum	3,465,568
Number of community care centres	80
Number of respite centres	55
Number of day therapy centres	9
Number of Commonwealth Respite and Carelink Centres	4
Number of Community Aged Care Packages (CAPS)	1,431
Extended Aged Care at Home Packages (EACH)	207
Number of National Respite for Carers Programs (NRCP)	22

Source: Blue Care as at 30 June 2011

Table 2: Blue Care's scale of palliative care in 2011

Number of clients receiving Queensland Health funded palliative services in the Community	1,228 (27% of these under 65 years old)
Percentage of HACC funded clients receiving palliative care	6.2% (27% of these clients are under 65 years old)
Number of hours of palliative care delivered to community based clients	234,940

NB: Some data extrapolated from Brisbane cluster data due to data collection anomalies.

2.2 About Blue Care

Blue Care is one of Australia's largest not-for-profit providers of residential aged and community care. We support community based clients, residents of our aged care facilities and their families, throughout Queensland and northern New South Wales, through all the stages of palliative care.

Our passion is to assist people to remain independent for as long as possible. As part of UnitingCare Queensland, we are committed to providing quality holistic care services that express the Uniting Church's Christian values and address the physical, intellectual, emotional and spiritual needs of the people we care for.

Our palliative care program incorporates recommendations made by Palliative Care Australia, which has been active in the development of a number of palliative care best practice documents.

Blue Care aims to provide:

- physical, psychological, emotional and spiritual support for clients and residents
- coordinated medical, nursing and allied health services for people who are terminally ill
- social support, including respite and information
- support for families and friends
- grief and loss support for the family and other carers during the life of the client or resident, bereavement support and grief recovery continuing after death
- service delivery, where possible, in the environment of the person's choice.

Blue Care has adopted the recommendation made by Palliative Care Australia regarding service levels and provides ***primary care palliative services*****,** as defined within the *Palliative Care Services Guide: a population approach* (refer *Appendix One*).

3. Term of reference (a)

The factors influencing access to and choice of appropriate palliative care that meet the needs of the population

3.1 (i) People living in rural and regional areas

Factors identified as affecting people living in rural and regional areas, also affect people living in metropolitan areas. This is because it is the current system of funding and delivery of palliative care, which is reliant on secondary funding through hospitals, that requires reform.

3.1.1 Issues

3.1.1.1 Access to treatment and care

People living in rural and remote areas are often required to travel to specialist appointments and services. This is stressful for very unwell people and their families. A rurally-based Blue Care Service Manager has said:

"In our experience clients have difficulty getting to urban areas for tests and specialist appointments; and there is no access to chemotherapy or radiation therapy locally."

Not-for-profit community care providers who visit in the home environment are not provided with additional funds for the significant travel often required in rural and regional areas. This puts financial pressure on these providers and potentially impacts their ability to provide equitable care or support for people with life-limiting illnesses that reside significant distances from their service base. Care provided at end-stage illness, which may involve pain and symptom management devices such as syringe drivers, often requires daily support visits.

Recommendations

Utilisation of technology and increased support of current primary level providers could provide improved access in the rural or remote setting. For example, an appropriately funded community nurse, who is part of a primary multi-disciplinary team, may be able to assist access by other team members and specialist consultants through facilitating on-line video access appointments whist attending the client's home.

3.1.1.2 Adequacy of support for rural carers and families

Families often have preconceived ideas and expectations of available support before admission and then get shocked when faced with the reality of service capacity and available support in rural areas. Families may be asked to complete tasks such as changing syringe driver batteries or breakthrough medication delivery, which can be intimidating for people who are not medically trained.

In many areas, there is no relief for over-stretched carers, such as access to overnight respite care. This can result in the "breakdown" of informal carer arrangements leading to an inability of end-stage clients to remain at home, or perhaps even within their own town/community.

Case study

Blue Care staff in Burdekin try to develop a roster with families to minimise carer stress on single individuals. However, a lot of their clients are elderly and do not have enough extended family to make a roster viable to assist them in remaining at home. Where there are limited family numbers available, the Service has attempted, with variable success, to recruit volunteers from the local church or community to supplement the role of carer.

It is common in rural and remote areas of Queensland, such as Cunnamulla, Murgon, Lockyer and Stanthorpe, to have difficulty in obtaining a GP who will make home visits, especially after hours. Yates and Connell (2010) identify that time constraints, inadequate remuneration, and safety concerns for GPs undertaking house visits at night, present barriers to GP home visits.

These constraints, along with difficulty accessing medical advice, also impact on the ability of community services, such as Blue Care, to provide after hours care or advice. After hours support may be required for events such as syringe drivers problems, catheter changes, symptom management, or carer support in final hours. Clients may be too unwell to attend the hospital as an outpatient for this care, or be fearful of admission, when their desire is to die at home.

As after-hour care is unfunded, there are issues both in staff availability and the ability to pay award on-call allowances. Services in rural and remote areas have smaller staff teams and no dedicated “on-call staff”. Some houses in rural and remote communities are isolated, in a mobile phone “black spot”, or in a state of disrepair, presenting Workplace Health & Safety challenges. Day nursing teams may also be adversely affected as staff who have worked overnight are unable to work rostered day shifts, and there is limited access to casual replacements.

Recommendations

- Funded overnight respite services will assist in reducing long-term carer stress.
- Adequate funding will support Primary Care palliative care services providing after hours care and advice. Improved client outcomes will also be achieved through an increased ability for these providers to access specialist level medical and clinical phone support.

3.1.1.3 Clinician knowledge and access to professional development opportunities

Professional development opportunities for doctors and nurses in regional and remote areas are limited. Staffing pressures reduce the ability of these professionals to travel to in-service training. Training requirements include medication regimes and syringe driver use in pain management and end of life care.

Recommendations

- E-learning opportunities, videoconferencing and web-based training would increase education accessibility for regional and remote clinicians. Some of our services report that videoconferencing and webinar facilities need to be upgraded to allow regional centres improved access to metropolitan education providers.

- Resources for training delivery within the organisational setting that is suitable for all levels of educational background regarding palliation would be beneficial in supporting access to training for non-clinical staff, informal carers and volunteers.

3.1.1.4 Equipment and medication availability

Equipment is often more difficult to access in rural areas as there are limited private providers and hospitals only carry small equipment stocks. Not-for-profit providers find it difficult to fund appropriate maintenance of large pieces of equipment, so often do not keep this equipment within their Service. Our staff report clients experiencing difficulty obtaining supplies such as home oxygen.

Rural and remote pharmacies don’t always carry the drugs required at end of life for syringe drivers, so there may be a day or two wait for drugs to become available. This leaves the person with a life-limiting illness without appropriate pain relief unless “loan” medications can be sourced from the local hospital, to be replaced when the pharmacy stock arrives. Out of hours medication is very difficult to obtain from pharmacies or hospitals, with most only operating during business hours.

3.1.1.5 Timeliness of referrals to Blue Care services

Although palliative care includes addressing the needs of people as they die and providing bereavement support for families, the emphasis is on improving *living*. Palliative care should be introduced gradually as life-limiting disease progresses *earlier in the care continuum* (Schofield et al, 2006).

As hospitals do not make home visits, rural Blue Care services often receive referrals for care late in the disease process when care for these clients is transferred to them. Trusting relationships that contribute to quality end-stage care have less time to develop between Blue Care staff, family/informal carers and clients.

Due to isolation there may also be a delay in referral to our service because the person with a life-limiting illness does not seek any medical support until they are very ill. This is more often the case for people suffering from end-stage chronic disease rather than cancer.

3.1.2 What works in a regional setting?

In the North Burnett, a multidisciplinary model of care that involves Blue Care working in conjunction with the Palliative Access program provided by the Bundaberg Base Hospital (and funded by Queensland Health) was started 10 - 15 years ago.

This program funds regular monthly or bi-monthly (as required) visits from a palliative physician from the Prince Charles Hospital to the North Burnett. Blue Care nurses work on the principle that patients are seen in the early phase of their palliative diagnosis. The physician then works closely with the GPs throughout the progression of the illness regarding symptom and medication management. Blue Care nurses are also able to contact the physician when required. This not only improves client care and outcomes, but also offers professional development opportunities for GPs and Blue Care nurses.

A recent example in the North Burnett involves a lady with breast cancer and metastases in brain who was able to remain at home during the end-stages of her illness. The local GP visited her at home every second day and was able to access physician advice as required. When the GP was away, the Blue Care nurse was able to contact the specialist physician by phone for symptom management advice, even after hours (a nurse is rostered on the weekends to cover palliative clients).

As a result of the success of the North Burnett experience a similar program has been established in the Fraser Coast, utilising a visiting palliative physician (who visits three times per month) and also supported by a dedicated Palliative Clinical Nurse Consultant (CNC) employed by the Hervey Bay Hospital. Blue Care community nurses, local GPs, the palliative physician and hospital-based CNC work together to provide best practice outcomes for people with life-limiting illnesses in the area. Home visits are organised and planned for physician visits to the area through a case conferencing approach between GPs, the hospital CNC and Blue Care nurses. Blue Care nurses are invited to attend home visits with the physician and CNC, allowing for comprehensive care planning with the client and family, and professional development opportunities for Blue Care staff.

Blue Care Hervey Bay has three designated Palliative Care nurses and provides seven day a week care for clients at home. The improved communication resulting from the cooperative palliative approach described above also improves continuity of care for people with life-limiting illnesses who transfer in and out of hospital through the course of their illness. Even with this very positive example of a successful program, Blue Care staff in Hervey Bay report that patients and families often remark that a 24 hour nursing hospice service would be beneficial, especially for overnight respite.

Recommendations

Expansion of care models described above to other areas will result in:

- best practice, quality care
- increased equity for rural and remote communities
- informal professional development opportunities for rural and remote GPs and nursing staff
- efficient use of available resources in rural and remote areas.

This should be supported by adequate funding for GPs and community care staff, and access to appropriate medication and equipment.

3.2 (ii) Indigenous people

It is identified in the *Standards for Providing Quality Palliative Care for all Australians* (Palliative Care Australia, 2005) that although the health care provider's relationship with the patient and their family should be based on trust and collaboration, the "past experience of the Aboriginal peoples, particularly the experience of the *Stolen Generations* has led many to distrust government services including health care services."

Our staff report experiencing difficulty as health care providers in gaining acceptance from Indigenous clients and their families. Clients may require a more flexible approach to care delivery, which can be difficult to achieve under current funding arrangements. If clients are also rural and remote this can be compounded by reduced staffing numbers.

Many Indigenous clients have a lot of family support, which can lead to Blue Care staff struggling to communicate effectively with large groups of carers. Differences in cultural approaches to death and dying can be intimidating for staff, and assistance from Aboriginal-controlled health organisations is difficult to access in many areas.

Recommendations

Utilise technology to make education and support from Aboriginal-controlled health organisations more accessible to primary care providers and residential aged care facilities.

3.3 (iii) People from culturally and linguistically diverse backgrounds

Provision of palliative care to people with life-limiting illness from culturally and linguistically diverse backgrounds is made challenging as a result of language barriers. Difficulty accessing interpreters consistently in a timely manner can lead to communication breakdown and misunderstanding regarding care and choices. This can be a very frightening experience for the client or resident.

Family support becomes essential in supporting effective communication and language translation, as well as care support. People from culturally and linguistically diverse backgrounds often more easily accept our staff and develop a trusting relationship when this family support is available.

In the Metropolitan area there is often multiple services involved in care for people from culturally and linguistically diverse backgrounds due to the availability of culturally-specific non-clinical support services. This can provide challenges if organisations don't communicate well with each other or are working towards different goals (based on different skill levels, qualifications and comprehension).

Recommendations

Continue to support and expand current interpreter services. Consider if accessibility could be expanded through the use of communication technology.

3.4 (iv) People with disabilities

As a provider of disability services Blue Care is experienced in providing lifestyle support for people with disabilities. Staff experience difficulty in obtaining additional resources and equipment for palliative clients with a disability who may have increased equipment needs related to mobility challenges, speech or swallowing difficulties. One of our metropolitan nurses reports that *"clients who are palliative for any other reason than cancer are poorly supported by Palliative Care services from hospitals; whose focus is on cancer."*

Younger people with a disability often have complex needs, and their carers, often aging parents, need a lot of specialist support. The potential for carer stress for people with a disability and also a life-limiting illness is increased as a result.

Residential services find providing care for younger people with a life-limiting illness, with or without a disability, challenging as their programs and care are developed for older people who have different interests. Whilst staff try to accommodate younger resident's individual needs, they can, at times, be treated as "older people".

Recommendations

Improved access to additional carer support such as overnight respite support and manual handling equipment might assist in reducing carer stress, enabling longer management in the home.

Where residential facilities are palliating young people with a disability, improved access to specialised resources, particularly covering lifestyle support, would improve outcomes for residents with a disability and their families.

3.5 (v) Children and adolescents

Overall, our services find that palliative care for children and adolescents is well funded by hospitals in terms of equipment, supplies and outreach treatment. GPs tend to ensure children and adolescents are referred to specialised Cancer and Palliative Care facilities. There is, however, the challenge of providing access to appropriate skilled paediatric staff in the community. As primary care providers, there is a broad spectrum of ages and care needs covered by our nursing teams and the majority of our clients are adults.

Additional educational opportunities would be beneficial in overcoming staff hesitation and ensuring up-to-date knowledge of paediatric palliative principles.

Dealing with the emotional impacts of providing end of life care and support for children and their families is another challenge our staff face. Counselling and de-briefing for staff is limited and in some areas support for families is difficult to access, placing additional pressure on staff. Children with life-limiting illnesses often have siblings, and parents may have additional respite requirements to enable adequate time to be spent with the rest of the family.

Resources for families in rural and remote areas are limited, which may require children and adolescents to be sent to Brisbane for treatment or end of life care. This can be a long way from home, and dislocation from their community can be a traumatic experience for children and their families.

Blue Care Case Examples

Our Toowoomba community care service has cared for six palliative children in the last 12 months. Access to speciality support for these children through the Mater Children's Hospital has been of great benefit to the children, their families and our staff. After hours, the family are able to talk to palliative care specialists and Blue Care is only contacted by the specialist to conduct after-hours visits if required.

In Brisbane North most palliative paediatrics are cared for by the Royal Children's Hospital (RCH), who have their own outreach service. Blue Care Northside Community Care was engaged to care for a child with a life-limiting illness in consultation with the RCH and nursed the little girl at home until she passed away. This positive outcome was enabled through well-managed and adequate care funding from the RCH, with minimal limitations on number of hours or cost of consumables. RCH also provided all required equipment.

Blue Care's Mundubbera Community Care has cared for a child who was born with a brain tumour. Due to issues outlined in this submission regarding funding, rural staffing and education, the family were not able to receive adequate support from Blue Care, who is the only provider in the area. The little girl died at two years of age. It was a long and difficult battle. The child's parents have set up "Monte's Foundation" and a website to increase awareness and support for rural families with a child who has a palliative condition.

Recommendations

Utilise technology to make education and support specific to paediatric palliative care available to primary care providers. Implement models of care that promote access for primary providers to specialist palliative care clinical advice.

4. Term of Reference (b)

The funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent

Funding for the provision of palliative care in the community setting is fragmented and can be difficult to access. There is no specific funding available for early intervention. People in the HACC target group may be eligible to receive complimentary (non-specialist) HACC services (basic support and maintenance level), however the HACC eligibility criteria does not always apply to the younger person.

In 2011, Blue Care provided HACC-funded services to 51,843 clients, with **6%** of these receiving palliative care services. The division of HACC funding between Federal and State governments being implemented in July provides funding uncertainty for those clients who will or currently receive HACC-funded palliative care from the State government. In the absence of appropriate funding, the costs of early intervention care might have to be met by the person with a life-limiting illness or their family. Alternatively, access to multi-disciplinary care support may be postponed; with Medicare-supported GP access or hospital in-patient and out-patient care only in the non-terminal stages. The benefit of early intervention, such as the building of positive relationship with interdisciplinary primary care palliative care providers, is then reduced or absent.

In 2011 Blue Care also received funding from sixty-five Queensland hospitals for 1,228 palliative clients across Queensland and northern NSW:

- 37% of the Queensland Hospital-funded clients were under 65 years of age
- 26% of Queensland Hospital-funded clients also received HACC services either concurrently or preceding this funding.

End of life care services are funded by Queensland Health and managed by the local Health Service District. Community care providers, which include not-for-profit providers such as Blue Care, apply to the hospital for funding when they determine that the person may have entered the terminal stage of their illness and are **within their last three months of life.** As it is difficult to determine when someone will die, people with life-limiting illnesses often receive significantly less than the allocated three months available, or occasionally “run out of funding” at the very end-stages of life. The average admission in 2011 covered only 20 visits which represents **less than three weeks** of seven-day a week services. This data is consistent with the average number of hours provided in Queensland by community organisations where average length of service is 19 to 22 days (Yates and Connell, 2010).

Provision of hospital funding can be affected by:

- available funds in the hospital palliative care budget
- knowledge of the person’s diagnosis and condition by the medical officer or clinical nurse consultant managing the funding
- the ability of the community provider to determine an expected date of death.

This can result in different funding availability in different areas across Queensland, even down to a variable hourly rate paid to Blue Care staff from one hospital district area to another.

At the other end of the scale, where time until death is under-predicted and clients live longer than the three month timeframe, funding may be ceased. There is very little negotiation in these circumstances, and clients and carers are presented with significant uncertainty and stress at an already difficult time. Similar three month restrictions apply to provision of equipment and funding for consumables.

Funded care is often limited to one hour of care per day. Blue Care often has to supplement with other sources of funding (e.g. HACC, fee for service) in order to meet the most basic care needs.

Example of visit to a palliating community client

One nursing visit for an unstable/ deteriorating/ terminal palliative client can take up to three hours if the following tasks are required:

- *Bed sponge/ continence care/ oral care*
- *Pressure area care*
- *Symptom management*
- *Medication titration*
- *Syringe driver change*
- *Subcutaneous cannula change*
- *Breakthrough medication preparation*
- *Family support/ education*
- *Liaison and coordination with GP/ palliative specialist team*
- *Documentation*

Hospital funders of palliative care in the community expect 24 hour on-call services for deteriorating and end stage clients. On-call allowances and after hours care provision is unfunded.

In addition, this linking of prognosis to funding results in an increased administrative and documentation burden for the community provider. Each episode of Queensland Health palliative funding is applied for individually and involves documenting the stage of illness, equipment required and additional support for travel if the client is rural. There may be agreement to fund the nurse's time but not personal care, domestic support, allied health services or respite support, which then need to be funded through other avenues.

Residential services also experience a lack of funding for residents receiving palliative care. Residential services are experiencing an increasing resident acuity level, with a 6% increase in average acuity since 2009. ACFI provides access to palliative funding for residential services, however, to receive this funding, the care provider is required to obtain a directive by a Palliative Clinical Nurse (specialist palliative care services) or medical practitioner, which can take significant time to acquire. As funding is dated from the submission date rather than the assessment date, it is delayed for these very ill residents. In addition, funding claims for palliative care are frequently challenged and sometimes withdrawn because the Palliative Care Plan does not meet the requirements of the auditor.

Recommendations

- A more accessible, equitable approach to funding community-based palliative care is recommended. This funding should be able to be accessed directly by the organisation providing care, rather than brokered through the local hospital, and should not be determined by estimated prognosis. Once a palliative diagnosis is determined, funding could be staged to cover increasing needs and be flexible to incorporate both clinical (nursing and allied health) and lifestyle support interventions. Funding could also include the ability to access time-limited interventions such as overnight respite services and Grief Recovery Programs.

- After hours care needs to be adequately funded to promote choice for people with life-limiting illness and ensure equity through supporting care delivery in the home.

- Improved access to appropriate equipment will support manual handling and safety for family/informal carers and paid community care staff.

- In assessing ACFI claims for residential services, palliative claims should be able to be back-dated to the time of a valid palliative directive. This directive from appropriately qualified practitioners (Medical Practitioner or Clinical Nurse - palliative specialist) should provide sufficient validation for the claim, which is then supported by the resident’s pain assessment and care plan.

5. Term of reference (c)

The efficient use of palliative, health and aged care resources

Blue Care provides primary care palliative care services as outlined in *The Palliative Care Services Guide: A Population Approach* developed by Palliative Care Australia in 2005 (see *Appendix One*). These primary care services include clinical management and care coordination such as assessment, triage and referral using a palliative approach for people with uncomplicated needs associated with a life-limiting illness and/or end of life care.

Community nursing, allied health and lifestyle support services offered by Blue Care (or other not-for profit providers), in conjunction with the GP and pharmacist, provide an ***interdisciplinary team approach to primary level palliative care support in the community that is cost effective and resource efficient.***

Formal and informal links with specialist palliative care providers should ***support these primary level palliative care services through specialist consultancy, clinical education and access to specialist care*** as necessary. This would provide a cost-effective way to effectively utilise limited specialist services available in Australia, increasing equity and access in the community.

> *When care needs extend over longer periods in older people with life-limiting conditions, the most appropriate roles for specialist palliative care providers may be as consultants to aged care service providers (Kite et al, 1999; Evers et al, 2002) or as providers of (or advisors on) staff training (Higginson et al, 1998)…In this way, specialist palliative care services can be an exceptional resource for aged care providers who provide a palliative approach to care (Guidelines for a palliative approach for aged care in the community setting, DoHA, 2011, p. 60).*

Recommendations

- Implementation of a primary care model across all areas will promote a cost-effective and equitable solution for palliative funding in Australia. This needs to be supported by:
    - appropriate, accessible funding
    - access to training and professional development for primary care providers
    - access to specialist consultancy services.
- Access to consultancy services and education could be enhanced by web-based and video link technology. The ability of all care providers to access eHealthcare records would improve communication across services and enhance seamless holistic care.

6. Term of reference (d)

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

Provision of effective palliative care in the home without the help of family or a carer is difficult, particularly in the terminal stage of illness. "Therefore, people who live alone are much more likely to die in a hospital, aged care facility or other institution." (Grande et al, 2003; Jakobsson et al, 2006; *Guidelines for a Palliative Approach for Aged Care in the Community Setting*, DoHA, 2011, p. 63). The effectiveness of in-home care in the palliative setting is related to access to carers or family support, including support for carers, accessible funding and access to equipment.

Palliative clients and their families have identified that they would like to access a range of care options and environments and be able to move with as little disruption as possible between these environments. Overnight respite resources, educational support for carers, and early intervention grief management/counselling are useful in sustaining informal carer arrangements in the community.

As covered in Section 3.1.2 of this submission, the interdisciplinary primary care model of palliative care delivery currently in place in the North Burnett and Fraser Coast is working effectively in enabling clients to palliate at home, despite the current funding arrangements. Other areas of the State, including metropolitan areas, have adopted similar models successfully.

It is entirely appropriate that residential care facilities provide palliative care to their residents with support from the acute sector. Often, the family and resident have built up a positive, trusting relationship with the staff before end-stage care is required. Liaison between the palliative care services and onsite visits from specialist nurses as needed would be of great benefit to palliative residents, although this level of support is often difficult to access.

Recommendations

- An interdisciplinary team approach including informal and formal relationships between specialist palliative care providers, primary care palliative care providers (not-for-profit organisations and GPs), hospitals and residential care providers needs to be robustly established across all geographical areas. This will promote cost-effective continuity of care for people with life-limiting conditions and their carers as they transition in and out of acute and residential settings; and enable effective symptom management and psychosocial support in the home.

- Utilising existing skilled community nurses, with provision for ongoing professional development, to coordinate an adequately-funded multi-disciplinary approach to palliative care in the community is a cost-effective way to provide this level of care in the rural and remote setting, and to utilise specialist palliative care services more effectively in the metropolitan environment.

- Funding for specialist palliative care services to provide consultation and education support to residential services will reduce inappropriate hospital admissions and improve quality of care for older Australians.

7. Term of reference (e)

Composition of the palliative care workforce

7.1 Ability to meet the needs of the ageing population

The *Guidelines for a Palliative Approach to Aged Care in the Community Setting* (2011, p. 248) state that “psychosocial care, treatments and support have many potential benefits for older adults in community settings, who are in failing health. In some instances, these options can be as beneficial as pharmacological therapies” or can increase the effectiveness of medical treatments and improve the client’s overall well-being.

As a provider of residential and community services, Blue Care is well placed to participate in primary care interdisciplinary teams to meet the palliative care needs of ageing clients. Blue Care currently employs over 8,000 staff and has over 2,000 volunteers who provide services across community and residential settings. Our staff team includes clinical staff such as nurses and allied health clinicians, and lifestyle support staff such as personal carers, domestic assistants, disability workers, respite workers, chaplains and diversional therapists. These staff are supported through comprehensive quality systems, assessment documentation and educational opportunities.

The philosophy of our care centres on client choice, building on strengths and promotion of independence. Blue Care services provide end of life care to maintain the comfort, choices, and quality of life of a person who is recognised to be dying (in the terminal phase), to support their individuality, and to care for the psychosocial and spiritual needs of themselves and their families. This may involve reduction of inappropriate and burdensome healthcare interventions and to offer a choice of place of care when possible.

Blue Care supports the role of aged care providers outlined in *Guidelines for a Palliative Approach to Aged Care in the Community Setting* (2011, p. 60):

> *When care needs extend over longer periods in older people with life-limiting conditions, the most appropriate roles for specialist palliative care providers may be as consultants to aged care service providers (Kite et al, 1999; Evers et al, 2002) or as providers of (or advisors on) staff training (Higginson et al, 1998)… In this way, specialist palliative care services can be an exceptional resource for aged care providers who provide a palliative approach to care.*

Blue Care provides services in an interdisciplinary model, through the development of palliative care teams and networking with a range of community services including other palliative care services, GPs, hospital staff and other stakeholders.

7.2 Adequacy of workforce education and training arrangements

Access to palliative care educational and professional development opportunities is an important aspect in maintaining best practice palliative care services. Blue Care supports staff and volunteer education, and attendance at palliative care network meetings.

Blue Care staff routinely attend Centre for Palliative Care Research and Education (CPCRE) skills sessions and other palliative educational opportunities offered. As identified earlier in this document, it is often difficult for clinicians and care providers from rural and remote services to attend training due to cost, travel requirements and limited numbers of staff for backfill in the care setting.

Recommendations

- E-learning opportunities, videoconferencing and web-based training would increase education accessibility for regional and remote clinicians. Resources for training delivery within the organisational setting that is suitable for all levels of educational background regarding palliation would be beneficial in supporting access to training for non-clinical staff, informal carers and volunteers.

- Specific topics such as:
    - supporting carers
    - discussing end-of-life care and care planning (directives)
    - utilising psychosocial interventions
    - a multidisciplinary approach to care
    - end-stage dementia and chronic disease
    - grief counselling
    - supporting cultural and spiritual beliefs

  would be beneficial in the aged care setting. Education to support paediatric palliative care and clinical competencies (such as PICC line management) has also been specifically identified as ongoing training requirements by our services.

- As identified earlier in our submission, there are also specific professional development benefits from utilising specialist palliative services to support primary care multidisciplinary staff in the delivery of care as clinical consultants, and in primary care staff participation in case conferencing and palliative physician consultations.

8. Term of reference (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 National Standards for Providing Palliative Care have been designed and are applicable to specialist palliative care services. The National Standards Assessment Program (NSAP) has been successful in proving education and support for specialist palliative care services to meet these standards using a quality assurance framework. This is voluntary and there is no penalty if a specialist palliative care service does not meet the Standards or engage in the quality assurance process.

At present NSAP has not been available to primary providers or residential services and revision of the audit tools and implementation process would be required for these settings, particular residential services. Current funding arrangements also do not provide primary care or residential services with the capacity to meet all of the National Standards to the same level as specialist palliative services. In particular Standard 8 – *Access to Bereavement Care and Services* would be difficult to achieve for many primary care services and not achievable for residential services.

In community and residential care there are Common Standards and Accreditation Standards that must be met and there are serious implications particularly in failure to meet the Accreditation Standards. While there is no specific Common Standard for palliative care, there are a number of outcomes of the Accreditation Standards – *Pain Management* and *End of Life Care* that address this. A current review of the Accreditation Standards indicates that a new outcome, *Advance Care Planning*, will be added. This addition is supported by Blue Care but must be accompanied by appropriate training for all staff in residential services.

Therefore, while the Standards are adequate and apply to all Australians, without significant increases in resources in primary and residential services these Standards cannot be achieved.

9. Term of reference (g)

Advance care planning

9.1 Avenues for individuals and carers to communicate with health care professionals about end-of-life care

Advance care planning is crucial in meeting the needs of individuals at the end of life. Blue Care has policies on substitute decision makers and withdrawing and withholding life sustaining measures. A nationally funded education program for staff working in residential and community on advance care planning will enhance the opportunity for individuals and carers to communicate their wishes with health care professionals.

A national community awareness program should be provided to ensure that individuals are well informed prior to, or at the time of, needing health care regarding end of life decisions.

9.2 National consistency in law and policy supporting advance care plans

Advance care directives are one way of formally recording an advance care plan. Not all advance care plans will result in the completion of an advance directive. Blue Care supports national consistency in law and policy for advance care directives and advocates national consistency, policy and training for individuals and staff in advance care planning.

9.3 Scope for including advance care plans in personal electronic health records

As indicated above, the distinction between advance care directives and advance care plans is required. Blue Care supports the inclusion of advance directives in personal electronic health records.

10. Term of reference (h)

The availability and funding of research, information and data about palliative care needs in Australia

The National Palliative Care Strategy has been successful in providing funding for research in palliative care in particular target areas. In some instances, this funding has been targeted to a particular area, for example the Palliative Care Outcomes Collaboration (PCOC) or Palliative Care Clinical Studies Collaborative (PaCCSC). National funding for social research or research specific to the aged care sector has not received the same attention.

Given the importance of family in providing palliative care there is limited funded research into the psychosocial impact of caring and appropriate interventions for family carers, including the effectiveness of bereavement interventions. Aged care clients are more likely to have non-malignant disease, particularly dementia, and a more national and coordinated approach in research in these settings is required.

There is limited research funding for capacity building within the sector, such as PhD scholarships, postdoctoral fellowships, early career development and senior career development awards. Start-up and ongoing funding for collaborative research centres similar to the Dementia Collaborative Research initiatives would address some of these issues.

The Palliative Care Outcomes Collaboration (PCOC) has been established to provide outcome data for specialist palliative care services and is currently being extended to primary care. Blue Care is supporting PCOC in their community services. In a geographically dispersed organisation such as Blue Care there are considerable challenges in providing sufficient staff training and program support required for the comprehensive implementation of PCOC, which has resulted in only partial implementation of this program organisationally to date. PCOC is not designed for residential services or for primary care clients who are not identified as palliative. Independent evaluation of the impact and usefulness of PCOC as an avenue for palliative care data should be undertaken.

There is no systematic national approach to information about palliative care services use and outcomes across the various sectors that provide palliative care. This includes lack of available data on place of death, reasons for transfers from home to specialist palliative care or acute care services and transfers from residential services.

11. Bibliography

Australian Government- Department of Health and Ageing (2011), *Guidelines for a Palliative Approach for Aged care in the Community Setting*, National Health and Medical Research Council, Canberra.

Commonwealth of Australia (2007), *National Program Guidelines for the Home and Community Care Program*, http://www.health.qld.gov.au/hacc/docs/pdf/hacc-nat-guidelines.pdf

Evers C, Drennan V & Roberts J (2005), Practice nurses and older people: a case management approach to care, *Journal of Advanced Nursing* 51(4):343-352.

Grande GE, McKerral A, Addington-Hall JM and Todd CJ (2003). Place of death and use of health services in the last year of life. *Journal of Palliative Care* 19(4):263–270.

Hegney D, McCarthy A, de la Rue MB, Gorman D, Martin-McDonald K, Fahey P & Pretty G (2003), The interface of acute and aged care: the role of the nurse in a provincial area, *Australian Journal of Ageing* 22(2):85-90.

Higginson IJ, Astin P & Dolan S (1998), Where do cancer patients die? Ten-year trends in the place of death of cancer patients in England, *Palliative Medicine* 12(5):353-363.

Jakobsson E, Johnsson T, Persson L and Gaston-Johansson F (2006), End-of-life in a Swedish population: demographics, social conditions and characteristics of places of death. *Scandinavian Journal of Caring Sciences* 20(1):10–17.

Kite S, Jones K & Tookman A (1999), Specialist palliative care and patients with noncancer diagnoses: the experience of a service, *Palliative Medicine* 13(6):477-484.

Palliative Care Australia (2005), *Standards for Providing Quality Palliative Care for all Australians*, Deacon ACT.

Schofiled P, Carey M, Love A, Nehill C & Wein S (2006), Would you like to talk about your future treatment options? Discussing the transition from curative cancer treatment to palliative care, *Palliative Medicine* 20(4):397-406.

Yates P, Connell S (2010), *Scoping of palliative care services in Queensland project*, Requested and funded by Queensland Health- Strategic Policy, Funding and Intergovernmental Relations Brach, Queensland University of Technology, Brisbane.

12. Appendices

12.1 Appendix One

Palliative Care Services Guide: a population approach

Palliative Care Service delivery is categorised in Australia in the following way:

Primary care	• Clinical management and care coordination including assessment, triage and referral using a palliative approach for patients with uncomplicated needs associated with a life limiting illness and/or end of life care. • Has formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care as necessary. • General medical practitioner, nurse practitioner, registered nurse, generalist community nurse, aboriginal health worker, allied health staff. • Specialist health care providers in other disciplines would be included at this level.
Specialist palliative care level 1	• Provides specialist palliative care for patients, caregiver/s and families whose needs exceed the capability of primary care providers. • Provides assessment and care consistent with needs and provides consultative support, information and advice to primary care providers. • Has formal links to primary care providers and level 2 and/or level 3 specialist palliative care providers to meet the needs of patients and family/carers with complex problems. • Has quality and audit program. • Multidisciplinary team including medical practitioner with skills and experience in palliative care, clinical nurse specialist/consultant, allied health staff, pastoral care and volunteers. A designated staff member if available coordinates a volunteer service.
Specialist palliative care level 2	• As for level 1, able to support higher resource level due to population base (e.g. regional area). Provides formal education programs to primary care and level 1 providers and the community. • Has formal links with primary care providers and level 3 specialist palliative care services for patients, caregiver/s and families with complex needs. • Interdisciplinary team including medical practitioner and clinical nurse specialist/consultant with specialist qualifications. Includes designated allied health and pastoral care staff.

Specialist palliative care level 3	• Provides comprehensive care for the needs of patients, caregiver/s and families with complex needs. Provides local support to primary care providers, regional level 1 and/or 2 services including education and formation of standards. Has comprehensive research and teaching role. • Has formal links with local primary care providers and with specialist palliative care providers level 1 and 2, and relevant academic units including professional chairs where available. • Interdisciplinary team including a medical director and clinical nurse consultant/nurse practitioner and allied health staff with specialist qualifications in palliative care.

** Palliative Care Australia. Palliative Care Services Guide: a population approach 2005.*