Stanhope HealthCare Services

Submission to Senate Community Affairs Committee's Inquiry into Palliative Care on behalf of Stanhope Healthcare Services (part of the KinCare Group)

Contact:

Gary Hudson
General Manager
Stanhope Healthcare Services
P: 03 9090 6902
Gary.Hudson@kincare.com.au

Peter Loughnane
Queensland State Manager
Stanhope Healthcare Services
P: 07 344 22601
peter.loughnane@stanhope.com.au

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Background

Stanhope is one of Australia's leading providers of Home Health Care services with over 27 years experience in the provision of Community Care. Stanhope was initially established in Victoria and has subsequently expanded its operations to New South Wales, Queensland, Tasmania, Western Australia & South Australia reflecting the success of our service models and partnerships.

Stanhope is an approved service provider with:

- The Department of Health and Ageing
- The Department of Veterans' Affairs (Community Nursing)
- The Department of Veterans' Affairs (Veterans' Home Care)
- Dust and Diseases Board NSW
- The Victorian Transport Accident Commission (TAC)
- Local Area Health Authorities for Sub-Acute Programs including; Transitional Aged Care Programs and Community Sub-Acute Programs
- Many other Community Health organisations on a brokerage basis.
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Our staff of 700 provides approximately 40 000 hours of care per month to over 3500 clients nationwide. Stanhope has extensive experience in the delivery of Domiciliary Palliative Care through the programs and services operating across Australia.

(a) What are the factors influencing access to and choice of appropriate palliative care that meets the needs of the ageing population?

This varies from area to area based on relationships and the availability of services and resources. There is no one standard approach to palliative care in Australia. From the viewpoint across Stanhope Healthcare Services the following key points are:

Key points:

- Patient Knowledge - To ensure support and information is made available and accessible to all clients with differing levels of knowledge and understanding of palliative care, as patient needs can vary and be different to previous experiences or expectations of others.
- Knowledge of clinical staff, particularly those with limited contact to palliative care needs
- The partnerships that palliative care services have with their community influences access and choice
- Capacity for home visits
- Access to appropriate medications
- Waiting times to access specialised services
- Access to after hours services
- Knowledge and use of the palliative care standards as identified by Palliative Care Australia. Auditing of these standards by services who provide palliative care is not consistent.
- The formula for which services in regions are funded is not working due to inequity that it creates

What are the particular issues for:

(i) People living in rural and regional areas.

- Access to services ie Home visits by specialist teams, drugs, after hours calls
- Natural disasters and weather events have significant impact on service access and support
- Generalist services do not provide home visits causing family and patients to wonder how they will ever get palliative care services
- The potential for palliative care nurse practitioners in rurally isolated and remote areas
- The boundaries that exist in current Government Health programs that restrict palliative care due to their funding criteria. This inhibits access to service types that could easily be overcome. An example of this is sub-acute services versus palliative care. Whilst there are some sub-acute palliative care services this is restricted and still a new concept. Palliative care patients do not typically meet the traditional sub-acute services criteria. This restricts needed services for these patients and does not support the philosophy of supporting people in their home. This can lead to higher re-admission rates.
- Service structures in service models across non palliative care services does not allow for support to palliative care patients. This does lead to the patient moving across services to find the right or better fit whilst putting the patient at risk.
- Reliant on remote teams and clinics. Quote often inexperienced nursing staff with limited to no allied health support. Disparity to metro areas where there are specialised teams.
- Lack of specialist skilled staff – how do we educate staff
- Overseas models of care that include home visiting in rural and remote should be explored.
- Greater use of over the web or video telephone calls should be explored.

(ii) Indigenous people.

- Appropriate staff that understand the culture, work in with the community and provide treatment regimes suitable to the ability of the client / carer to manage
- Ethics behind sending someone home to an often overcrowded house with people malnourished and the limited supports available through family and community
- Culturally appropriate, access to services
- Support for staff is critical for their own well-being and longevity working in that region. For example, how staff deal with people who are starving (worker perspective) and what can be done to support this.
- Ensure case management and coordination of services is working well. Access for support for staff.

- Engagement of elders within the community. Expectation they come to service provider versus worker going to them.
- Indigenous people’s understanding of treatment and drug regimes is remote areas can be limited. This leads to higher risk factors due to appropriate care

(iii) People from culturally and linguistically diverse backgrounds.

Key point is the understanding of treatment and drug regimes and how this is implemented. Similar to that of indigenous people the CALD group should have access to culturally appropriate access to services.

(iv) People with disabilities.

- Advocacy of the patient is critical with people with disabilities, for them it is about choice. This leads to a requirement that palliative care teams need to work in with specialist disability services to provide appropriate services that meet patient need
- People with disabilities are likely to have other additional health issues that palliative care staff will need to deal with. There is no workforce education and training for supporting people with disabilities.
- Remote services are largely only via phone. Inexperienced palliative team member/s trying to deal with these can lead to the ethical considerations being overlooked.
- Aged and disability – greater focus on developing models or service rather than being concerned about logistics and costs. What is reasonable in terms of sending people home in palliative state.

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

- “In community” palliative care is provided through generalist community nursing services, ie primary health care. Packaged care and of course specialist community palliative care services which are not aged care specific.
- Sub acute aged care funding is more used in Transitional aged care programs which generally palliative care clients do not meet the criteria for. There is some availability of community options for palliative clients. A sub-acute palliative care program is currently commencing on the Sunshine Coast. These types of services are limited in size and are still new in their development.
- Palliative care patients typically do not meet the criteria of other sub-acute funded programs
- Health Funds – clarity of and the role of Health Funds needs to be explored further. These groups should have greater engagement in the process and responsibility in delivering palliative care services.

(c) How efficient is the use of palliative, health and aged care resources?

- This varies from area to area; Government needs to identify different models of palliative care that meet the needs of the communities including cultural needs and rural / remote models
- There has been a tradition to rely on charities and foundations to support the sector in an unfunded state. This does lead to inconsistency of practice,

training and support to both staff and patients. The limited funding through these networks also can put the patient at risk

- Communication and coordination of services is critical and doesn't always work well, leads to duplication and resources wasted. Providers talking to each other. There should be funding for coordination of services.

(d) How effective are palliative care arrangements, including hospital care, residential aged or community care facilities?

- Stanhope's experience across Australia in Capital Cities is that specifically in aged care that hospital to community discharge is often slow with the right triggers not addressed. For example the home assessment is delayed. The outcome is the patient often has diminished life at home.
- Family often has a utopian view of spending the last days with a loved one at home. The reality is there is limited preparation of the family through discharge process for example the family understanding the transition from a 24hr care in the hospital to that of a small level of support through community services. Families/carers being appropriately prepared and supported after patient returns home is a priority.
- The practicalities of transitioning from hospital to community is often not thought through with palliative patients pushed to aged care packages due to lack of palliative care resources. Once a patient is transferred to a packaged care place, the support from the palliative care team diminishes increasing risk and life expectancy of the patient.
- Stanhope's experience is that aged care packages funding does not allow capacity for 24hr drug support. Partnerships are needed to ensure this support. This is not always well known.

(e) Can you comment on the composition of the palliative care workforce?

Again a local response. You need to identify what disciplines are available in each area that you service. Ideally you need to have access to a social worker, nurse consultant, Dr that is a PC specialist AND bereavement services (this may or may not be part of the team but needs to be accessible. Other allied health such as OT, physiotherapist or speech pathologist will be a bonus.

- There are pockets of specialised groups within specific smaller organisations and larger groups.

- There is some State based and Commonwealth funded services. These typically deliver services like a primary care provider. This is not always appropriate for community based work

- Not enough specialist staff, how do you upskill generalist staff.

Including:

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

- For an ageing community a speech pathologist is needed for CVA's, dementia care and just general decline in swallowing that comes with ageing. Diversional therapist to support longer term conditions (particularly dementia) and respite care preferably in the home programs eg. Over night / weekends etc.

- Palliative care services need to work closely with psychogeriatric and geriatric services for palliative care to be effective for the ageing communities

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

- There have been a few different initiatives at commonwealth level for community services one was PEPA.
    - Assessment tools to exist such as PCOC (palliative care outcomes collaboration).
    - These are specialised activities and not generally given as training priority in non-direct palliative care services. This has obvious implications in knowledge of staff
- Within the community aged care sector, staff need training in grief and loss and how they support families/carers.
- Where there is not a social worker attached to the palliative care team, there is less likelihood of the family being supported for end of life experience.

(f) How would you describe 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?

- Again a local discussion about how well PC services are provided in the region – do they meet the national standards AND do your PC services use the standards to guide practice – if yes comment how useful they are if no comment why not
- Are they relevant to remote areas. There is "guidelines for palliative approach for aged care in the community setting" by DoHA. No training around the manual on how to use and implement.

(g) Advance care planning.

(i) What avenues are there for individuals and carers to communicate with health care professionals about end-of-life care?

- The aged care packages do not provide well enough for end-of-life care. The packages do not fund high level support that is required. The difficulty is that once a patient is in a packaged care placement, the palliative care team is less likely to respond due to waitlist and the knowledge that the patient is receiving some care at home.
- Unless the patient has been discharged direct to the palliative care team then at no point along the patient journey is this process discussed. For example, who provides information to the family/carer "when should the care giver seek help", this is unclear.
    - Where there is not a social worker attached to the patient, there is less likelihood of the family being supported for end of life experience.

(ii) Should there be national consistency in law and policy supporting advance care plans? What are the consequences of there not being consistency?

- YES: There is much written about advance care planning. Consequences not being consistent:
    - Unplanned admissions to acute care resulting in deaths in ambulances en route or in emergency departments
    - Acceptance by families of the impending death – ie time to adjust and have those precious conversations. Unresolved grief is starting to show in mental health statistics and crime
    - We have a death denying society having consistency in the law where advance care planning is the norm would help considerably
    - Less older people ending up in intensive care units being kept alive by families in denial or expectations of long term feeding and services at home against the clients wishes.
    - Unless you are part of the specialist group then you won't necessarily know about the standards, therefore the Community won't know about this.
    - Staff need to be trained to do this, at least an understanding what this means. Lack of knowledge can lead to inaccurate information

(iii) What scope is there for including advance care plans in personal electronic health records?

- It is about educating society about advance care plans and getting people comfortable with them. This requires investment in education similar to that of health promotion
- We all do wills why can it not be part of that thinking I need to do my will and while I am at it I will do my advance care plan.
- GPs could be doing advance care plans
- Existing recording tools do not capture this information and need to be adapted.

(h) What are your views on the availability and funding of research, information and data about palliative care needs in Australia?

- Funding needs to go into changing societies perception about death; this will assist more in the bigger picture issues that health care professionals face daily with relatives denying the impending death and placing unrealistic expectations on the health budget OFTEN against the wishes of the client.
    - Not every dying person needs a palliative care service a great deal more can be done if people stop denying death
- Funding and research needs to be more transparent and openly available

For any further detail or clarification please contact:

Gary Hudson
General Manager
Stanhope Healthcare Services
P: 03 9090 6902
Gary.Hudson@kincare.com.au