



hospice  
@HOME

# The District Nurses

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*A division of Hobart District Nursing Service Incorporated*

Response to Green Paper – Delivering Safe and Sustainable Clinical Service and Building a Stronger Community Care System.

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# Delivering Safe and Sustainable Clinical Services

## Green Paper Response

### Foreword

**Hobart District Nursing Service Inc. (HDNS)** are writing in response to the Department of Health and Human Services Green Paper to highlight the current changes we would recommend in ***Community Palliative Care***.

Hobart District Nursing Service Inc. (HDNS) is a not for profit organisation that has provided holistic and high quality in-home nursing and allied health care to the Tasmanian community since 1896. Throughout these 119 years HDNS has delivered palliative care services as part of its core business and was the only provider of professional nursing services to Southern Tasmania until the 1970's.

The success of HDNS' palliative care services has been largely due to its comprehensive care planning and capacity to coordinate and deliver the full range of services required including, nursing, personal care and domestic assistance, allied health, specialist nursing and medical advice/consultant services, as well as assessment and referral for more complex needs.

In response to the Green Paper HDNS have taken some of the following into consideration;

- 70% of the State is classified as rural and remote and 50% of the population live in small rural communities so we have a dispersed population for a small state.
- Tasmania has the highest rate of people living alone and has the highest overall incidence of Cancer Nationally. It is estimated that 1 in 2 males and 1 in 4 females will develop cancer by the age of 75. By the age of 85, the prevalence is 1 in 2 males and females.
- Having people in small rural communities requires a different response to deliver Palliative Care. With people living alone they are more likely to require a hospice or hospital based care than home based care. We are more of a hospital based system as we have very limited after hours and weekend community services and restricted resources for people to utilise to manage in their own home.
- Tasmanians have only 4 main public hospitals in the State.
- Tasmania has an ageing population with the highest proportion of people aged 65 years over at 16.1%, just ahead of South Australia at 15.9%.
- When asked where they would prefer to die, most healthy Australians nominate their home as their preference. However, data on place of death indicate that only 14% of people die at home, while 54% die in acute care facilities with the remainder 32% Aged Care facilities. This data suggests, not only, that many people do not receive care where they would prefer, but also that the cost of

providing care is being incurred in the most expensive part of the health system, namely hospitals.

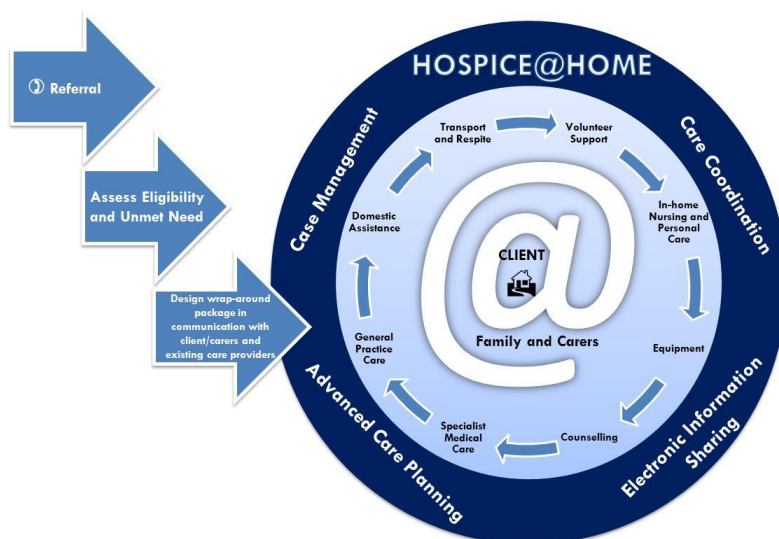
(National Palliative Care Strategy 2010, Supporting Australians to Live Well at the End of Life).

HDNS are currently delivering hospice@HOME (h@H) care within the Better Access to Palliative Care Program.

h@H has a strong emphasis on case management and care coordination, integrating and coordinating with existing services and networks – both building on the strengths of existing services and also delivering, or brokering improved access to, an additional network of services to meet identified gaps.

h@H are committed to addressing identified barriers to accessing community based palliative care (such as poor continuity of care, inadequate family support and limited access to services in rural and remote areas) and expand capacity to deliver multi-disciplinary home based palliative and end-of-life care services through: education and training of health professionals; improvements in shared care; provision of rural and regional outreach services; an increased number of trained volunteers; and enhanced communication between services, service providers, clients and their families and carers.

The H@H model is illustrated below.



h@H has currently delivered 704 packages of care in Tasmania and aims to meet and extend on the amount of packages over the 3 years of funding. There have been 371 deaths during the funding period and all of the deaths have been reviewed through a Mortality Review process. h@H are evaluating all of the processes in a continuous quality framework and evidence is suggesting the program is making cost savings to the hospital through reducing Length of Stay (LOS) and decreasing presentations to the Emergency Department and providing quality of life outcomes.

## Recommendations:

### **1. *The White Paper support the shift to primary care services and implementation of strategies for Care Co-ordination to strengthen and add purpose to the discharge process for end of life in the hospital system;***

- HDNS support the review of a “Pull out” of hospital concept. Evidence tells us “More co-ordinated end of life care is needed to support people to die the way they want to... Dying people are often admitted and discharged from hospital into community care, creating an end of life journey that is disjointed and confusing for patients” (Swerissen and Duckett, 2014, p17). End of Life retains an “Acute Care” focus within the current healthcare system. A shift is required to cease this and review people in an end of life focus to stop prolonged acute beds utilisation affecting length of stay (LOS). Bringing in an external discharge focus (pull out) for end of life develops a pathway for transition of care to be timely and effective. Planning for care co-ordination across the multidisciplinary teams and developing effective strategies before discharge allows better outcomes for those at home to not re-enter the acute system multiple times. The h@H co-ordination has started this process at the Royal Hobart Hospital (RHH) and Palliative North Unit (Melwood) and North West (NW) Regional and is in the early stages of reviewing the effectiveness and outcomes. Anecdotally the outcomes evidenced are shortening LOS, decreasing the representations to Emergency Departments and enabling safe transition into the community with responsiveness to peoples care requirements. Currently the “Pull Out” is supported through a monthly meeting with all units at the RHH identifying possible people who are end of life in each of their units and developing strategic planning for their safe and efficient discharges. At Melwood a weekly ward round is attended by h@H reviewing all eligible referrals for people wishing to transition home. The NW team attends discharge planning at NW Regional twice a week, leading to discussions surrounding discharges to enhance a smooth transition home. h@H reports to the meeting the amount of referrals received from the units in each of the departments to identify a gap in referrals.

The establishment of a focus on “in reach” functionality should become part of normal operations. According to *Standards for Providing Quality Palliative Care for all Australians* (2005, p.28), “Standard 4 - Care is Coordinated to minimise the burden on patient, their caregiver/s and family” which states;

“Recent studies and other feedback indicates that lack of coordination of care and services increases the stress experienced by the patient, their caregiver/s and family and that alleviation of this would add significantly to their quality of life”.

Evidence supports the concept for care coordination and the pull out creates a pathway for the process to be adopted. We would welcome the opportunity to continue to develop the role of care co-ordination h@H are delivering at end of life and build and strengthen upon the strategies being implemented across the State.

- A single referral point for end of life primary care services should be established where all service providers can integrate through that platform. A single entry point would allow clients not to tell their history multiple times.
- HDNS do not support the role of the Community Assessment and Referral Services (CARS) in Queensland for all end of life admissions. HDNS would propose the complexity for the end of life planning into the community requires integration and coordination with the primary services which will not be met in this structure. CARS continues an acute care focus and not palliative in home focus required to deliver complex coordination in discharge. In these environments evidence tells us that professionals are conflicted and provide life prolonging treatments even when they are of little benefit and delay the hard discussions that prepare people for end of life (Swerissen and Duckett 2014, p.12).
- HDNS acknowledge the Care Coordination work of Tasmania Medicate Local (TML) and their role in Chronic Disease Management. End of life care coordination is not met by this role in the primary care service.

**2. A National position on General Practitioners (GP's) identifies GP's at the centre of care in the primary care setting. The White Paper should support an increased commitment to enable GP's to carry out that role for their patients at end of life.**

- In the Tasmanian model for Palliation we recognise the role of GP's has been diminished.
- *Standards for Providing Quality Palliative Care for all Australians* (2005) Standard 10 identifies that patients should be referred back to the primary

care provider. The GP should be recognised as the primary care participant in end of life.

- HDNS support the submission to the Green Paper from TML in regards to strengthening the role of the GP in the primary services.

**3. *The role and responsibilities in the primary care services setting of the Specialist Palliative Care Service (SPCS) be reviewed and aligned to the National Palliative Care Standards.***

- SPCS should deliver equitable access to their service across the whole of Tasmania.

During the delivery of h@H packages across the State we have identified models of community palliative care that are very different in each region. The White paper has the opportunity to align the practices in these regions through review of the model of care and the equity in access through the role delineation concept. The Tasmanian Palliative model does not align succinctly to the *Standards for Providing Quality Palliative Care for all Australians* (2005) and integrate appropriately with the primary care services. With a focus to deliver services further in the primary care sector this review is a priority. According to Standard 4 of the *Standards for Providing Quality Palliative Care for all Australians* (2005, p.28) one health care provider should lead the care in the primary care services.

The model in Tasmania moves away from this as SPCS transitions the lead according to symptom management, creating a disjointed and confusing pathway for people. The below is the current model explanation;

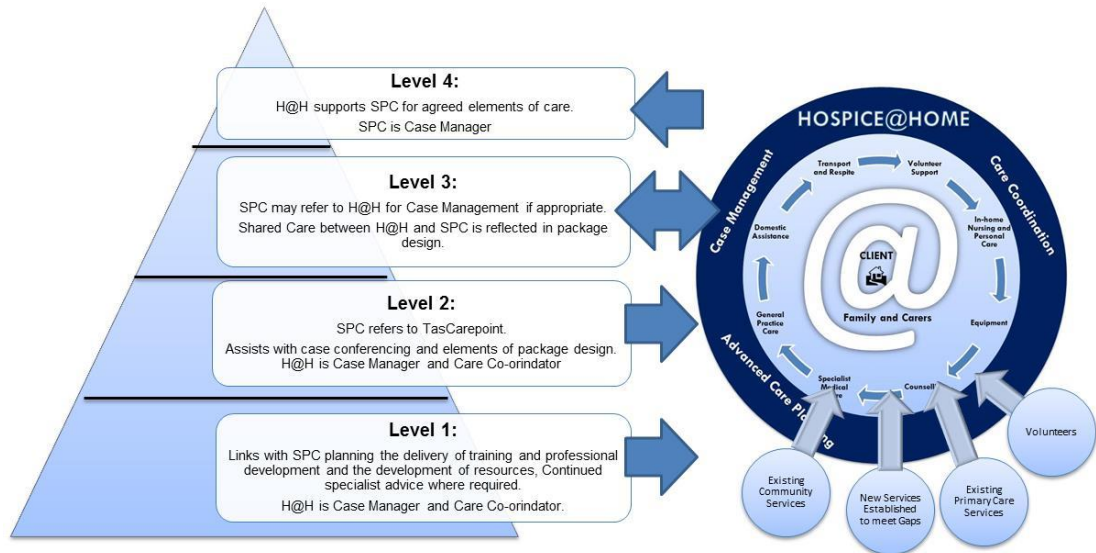
Patients with life-limiting illnesses require different levels of involvement from the specialist Palliative Care Service based on their needs and the primary care provider's capability and capacity to meet those needs;

Many patients receive primary palliative care without having any contact with the specialist Service (Level 1). There is a clear distinction between consultation-liaison (Level 2), shared care (Level 3) and services provided directly by the Specialist Service itself (Level 4).

[http://www.dhhs.tas.gov.au/palliativecare/health\\_professionals/model\\_of\\_care](http://www.dhhs.tas.gov.au/palliativecare/health_professionals/model_of_care)



## Linkages between HOSPICE@HOME and Existing Service System



As Horsfall et al point out;

The concept of a good death has been superseded by the concept of a managed death, one that requires professional support and knowledge ... and takes place in a hospital, or more rarely a hospice, resulting in modern death becoming 'cellular, private, curtained, individualised and obscured.

The research by Gratton Institute recommend SPCS should be extending the scope and quality [of] palliative care through a greater emphasis on training, research and capacity building, and providing more information for the public and patients on end of life choice and options (Swerissen and Duckett, 2014, p.17).

The white paper has the opportunity to adopt the model of care for primary services to retain the lead in all community palliative care, which will align to the national standards and provide a clear pathway and eliminate peoples disjointed and confusing experiences.

- The burden for families in caring for end of life people is not being currently met by the funding models and the need for further primary care services to support end of life within home and community care is required. h@H are meeting the extra services through the Commonwealth Funded packages of care through Better Access to Palliative Care (BAPC) and these will need to be replicated and supported outside the funding to continue to meet the care requirements for people to remain in their own homes. Currently spending is not targeted to support people in their own home and their choice of setting.



Although data in Australia is not readily available it does suggest strongly that much less money is spent in aged community care for people than in aged care facilities and hospitals. It is important to develop policy that align to a cost efficient services for end of life as the crude death rate sharply increases and the current aggregate of health costs associated to dying will double if the policy does not change (Swerissen and Duckett, 2014, p.21).

**4. *The White Paper should address an individual's decision to die in the setting of their choice. A culture shift needs to be supported with an end of life focus delivered in communities where individuals live and where they wish to die.***

- As stated previously end of life can be institutionalised and the acute focus diminishes the coordination and support people and their family and care givers require. As Tasmania is a regionalised State we must also recognise that end of life in these institutions often takes people away from their communities and displace the family and care givers for these people as well. The ability to ensure we do not medicalise and institutionalise end of life is important and we should integrate it into the primary care service as a priority. Currently the culture is for acute presentations that take people out of their community. We need to support primary services through policy and packages of care to have better support to die in their setting of choice.

**5. *Development of innovations to support the primary care services models and develops better co-ordination in maintaining status at home. Innovation to support the transition to primary care services being sustainable.***

- Telehealth and appropriate in home monitoring is recognised to have benefits which range from decreasing ED visits, unnecessary hospitalisation and cost savings through maintaining people in their homes and improving quality of life. The current funding mechanisms do not allow for appropriate assisted technologies to be maintained in people's homes. It would be likely that with the influx in aged care and the need to reduce costs that the telehealth assisted technologies could provide tangible and cost effective solutions if appropriate policy and funding was implemented to support these being established. The ideal is to "integrate these technologies to manage the changing cost in care delivery in a structured, innovative way." (Medical Technology Association of Australia Limited, 2012).
- Development of an Emergency Medication Kit (EMK) has been acknowledged as an innovative tool to support end of life in the home. One reason palliative clients are transferred to acute care facilities afterhours is due to symptom crisis. Research suggests that timely access to medications to manage symptoms in the home can prevent unwanted admissions to emergency

departments and acute care facilities. The use of Emergency Medication Kits (EMK) to support anticipatory prescribing and access to palliative care medications, can avert symptom crisis by providing rapid symptom relief in emergency situations in the home and thus avoid patient transfer to hospital/ED. The use of EMKs seeks to avoid distress associated with access to medication by anticipating symptom control needs and ensuring appropriate medications are prescribed, dispensed, and available in the home to cover the afterhours period. It also includes processes for administration of the medication when needed, either with pre-arranged access to RNs or by ensuring the kin carer is appropriately trained to administer the medication after discussion with an afterhours RN using an afterhours number.

- In December 2013 a review was conducted of the Patient Controlled Electronic Health Record (PCEHR), which developed recommendations for the future focus for all Australians. The paper has developed 38 recommendations with great detail behind these supporting the decisions. The overarching consideration for the PCEHR is the opt out, not opt in option. Tasmania has a opportunity to be at the forefront of adopting these recommendation and delivering an opt out option for the PCEHR as part of reforming our States Health System to develop a record that is shared has international evidence identifying the benefits to all health care.  
[http://health.gov.au/internet/main/publishing.nsf/Content/46FEA5D1ED0660F2CA257CE40017FF7B/\\$File/FINAL-Review-of-PCEHR-December-2013.pdf](http://health.gov.au/internet/main/publishing.nsf/Content/46FEA5D1ED0660F2CA257CE40017FF7B/$File/FINAL-Review-of-PCEHR-December-2013.pdf)
- HDNS would welcome the opportunity for Tasmania to develop an Opt out for PCEHR to allow information sharing currently not achieved. Following is a statement from the Australian Bureau of Statistics, which offers a compelling case on the practical applications for the PCEHR relating to coordination of care.

#### COORDINATION OF HEALTH CARE

The coordination of a person's health care is an important factor in ensuring the best possible health outcomes. This is particularly true for those people who have seen several health professionals for the same health condition. Ensuring the correct information is passed between health professionals will serve to minimise errors and limit the possibility for symptoms to be overlooked. The coordination of health care enables a person to access the full range of services they need to treat their health condition.

In 2012-13, around one in six people aged 15 years and over (16.3% or 3 million people) saw three or more health professionals for the same condition. Females were more likely than males to have seen three or more health professionals for the same condition (18.6% compared with 14.0%).

The proportion of people who saw three or more health professionals for the same condition generally increased with age. Almost one in four people (23.6%) aged 75-84 years had seen three or more health professionals for the same condition, compared with almost one in ten (9.3%) people aged 15-24 years. Those who had a long term health condition were more likely to have seen three or more health professionals than those without a long term health condition (27.6% compared with 7.2%).

Of those who saw three or more health professionals for the same condition, 68.8% reported that a health professional helped coordinate their care. Of this group, the health professional most likely to coordinate the care was a GP (53.7%), followed by a medical specialist (29.6%) and then a nurse (6.4%). The coordination of care helped to a large extent for 69.0% of people, while 27.4% reported that it helped to some extent.

Those living in areas of most socio-economic disadvantage were more likely to report that a health professional helped coordinate their care compared with those living in areas of least socio-economic disadvantage (73.3% compared with 64.3%). Among those whose care was coordinated, those living in areas of most disadvantage were then less likely to report that the coordination of care helped to a large extent compared with those living in areas of least disadvantage (66.5% compared with 73.9%). Major cities were similar to other remoteness areas of Australia.

Among those who saw three or more health professionals for the same condition, 12.8% reported that there were issues caused by a lack of communication between the health professionals. Those living in areas of most socio-economic disadvantage were more likely to report that there were issues caused by a lack of communication between health professionals compared with those living in areas of least socio-economic disadvantage (13.8% compared with 10.3%). Those living in outer regional, remote or very remote areas of Australia were more likely to report that there were issues caused by a lack of communication between health professionals compared with those living in major cities of Australia (16.5% compared with 11.7%).

Australian Bureau of Statistics

Source(s): Patient Experience Survey: Summary of findings

#### 6. ***After Hours better utilised to assist people in their homes during Palliative and end of life phase;***

- Extended Care Paramedics are a model to be further rolled out to support the maintenance in the home at end of life. A recognised model of best practice in the UK is Marie Curie Cancer Care. The organisation has established rapid response teams who can, like an ambulance service, provide immediate support to people in homes and hospices. The results of these teams have been significant in supporting people having end of life in their own home.
- h@H have developed an After Hours response as part of its funding through BAPC. The after hours service follow a Palliative Care Telephone Triage Model developed from the Grampians Region Palliative Care Consortium.

The use of the h@H client management system and policy developed means that all clients records are available for the after hours staff and the clients pathway for after hours support is known to the after hours staff member. An example is if the SPCS is managing the client after hours then an alert is provided to the staff member and the person would be “warm” transferred to the SPCS so they do not need to repeat their conversation. h@H is able to triage the need for the call through their triage model and provide timely support meeting the clients need and knowing the clients pathway. The *Dying Well* paper acknowledges that when people are connected to someone after hours and are made to feel comfortable it often will avoid emergency department visits. It is important people have a clear pathway and know who to access after hours. *Standards for Providing Quality Palliative Care for all Australians* (2005, p.28) outline that people need clear written instructions about how to seek help after hours or in unanticipated situations. h@H is trialling further technology in the near future in the use of video conferencing after hours with the Registered Nurse on duty as part of managing calls received and providing the comfort required to reduce Emergency admissions.

- Statistic’s from h@H. In December 2014 - January 2015 we had 42 deaths. 22 deaths in Acute and Palliative Care settings at hospitals and 20 deaths at home.

Of the 22 deaths that were in Acute or Palliative Care Settings;

- 11 had no Symptom Action Plans (50%)
- 8 used h@H After Hours Service (36%)
- 20 had contact with Tas Ambulance (90%)
- 17 presented to Emergency Department (77%)

Of the 20 deaths that were at home;

- 14 had Symptom Action Plans (70%)
- 11 used h@H After Hours Service (55%)
- 2 had contact with Tas. Ambulance (10%)
- 1 presented to Emergency Department (5%)

The results above identify that when a clear pathway through the AH telephone triage model within h@H is communicated and support is available evidence demonstrates that the attendance to an Emergency room or use of a Tasmanian Ambulance is dramatically reduced.

In conclusion HDNS would like to acknowledge their support of the Tasmanian Medicare Local submission to the Green Paper and the Better Access to Palliative Care Program. HDNS hope that the findings presented assist in the development of strategies to support the white paper and the need for strengthening the community

palliative care and primary care services. The appropriate care in peoples setting of choice is a priority for the cost benefit and also the quality of life outcomes that can be achieved. We are happy to expand on any of these recommendations through the process if that would assist.

Written and submitted on behalf of Hobart District Nursing Inc.

Fiona Onslow

Director of State Operations

The District Nurses

A division of Hobart District Nursing Service Inc.

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