

ATTENTION:

House of Assembly Standing - Committee on Community Development

Inquiry into Palliative Care Submission

Submission From:

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Introduction

The District Nurses (TDN) is submitting the information to the House of Assembly Standing – Inquiry into Palliative Care. The submission will be a reflection of the work being achieved via their recent project, which has been aimed to assist all Tasmanians to die at home in their place of choice. The submission will provide the background to the project and the projects achievements. We will then address as per the Terms of Reference of the inquiry areas of Advanced Care Directives, Medical treatment of minors, emergency medications and will finally outline some of the issues and imperatives for future funding to support a state wide approach in delivering palliative support to people in their place of choice.

Background

The District Nurses, a division of the Hobart District Nursing Service Inc (HDNS), is an autonomous, not for profit organisation providing professional nursing, personal care, residential aged care and allied health services to the general and veteran community. The Hobart District Nursing Service is one of Hobart's oldest and best-loved philanthropic organisations. The Service was founded in 1896 by the wife of the Governor of Tasmania at a time when there was increasing concern about public health, when women were becoming more active publicly, and when nursing was beginning to be accepted as a profession.

In 2013 The District Nurses welcomed the announcement of the organisation being the successful tenderer for the provision of Statewide in-home palliative care program; Better Access to Palliative Care in Tasmania.

The new program to be delivered by The District Nurses was called hospice@HOME and provided, for the first time, **easy** access to palliative care in their own homes.

Previously in Tasmania the delivery of in-home palliative care services has been fragmented and difficult for people to access. We have been aware of the problem for some time and we have been working on a model of in-home palliative care where the patient is central.

The District Nurses have vast practical nursing experience, including in emergency, and fully understand the needs of dying people as they approach the end of life. More often than not, what they really want to do is die in their own home surrounded by family and friends.

Unfortunately until now it has been very difficult for families to be with their loved one at home during the end of life, and to have the support of professional and non-professional palliative care practitioners and carers to do so.

Based on our experience, hospice@HOME, provides wrap around care and support for patients and their families.

There are many benefits for Tasmania from hospice@HOME. Firstly and most importantly families and patients are fully supported, and secondly hospital beds, Ambulances and Emergency Departments have been freed up in the acute wards and other facilities. And thirdly, there are fifty seven organisation who are contracted to provide a new workforce focus who are engaged in the palliative approach to care in the home, employing and educating the workforce to achieve the h@H outcomes.

Aligned with the World Health Organisation definition of Palliative Care, The District Nurses are committed to providing impeccable in-home care that neither hastens nor postpones death.

The District Nurses operate hospice@HOME across all corners of Tasmania, including the Bass Strait Islands, and the service has offices in Hobart, Launceston and on the North West Coast.

hospice@HOME achievements;

The program is a dynamic one that has been continuously growing and developing since its launch in late 2013. Much has been achieved in the past three years and we are confident that the next twelve months of funding will demonstrate that the program is an essential element of the palliative care sector in Tasmania.

Some of the achievements are as follows:

- 63.2% of people who wanted to die at home achieved this goal. This value is up from the 50% value stated in June 2015. Of the clients who wanted to die at home, but did not achieve this, 42.6% had avoidable hospital admissions (deterioration, end of life care, symptom management).
- 44.1% of all hospice@HOME clients died at home, compared to about 14% of the general Australian population. (many people are choosing to spend as much time at home, before dying within an insertional setting).
- By end of May 2016 a total of 1651 packages of care had been provided to clients around Tasmania.
- hospice@HOME clients who died in hospital were able to stay longer at home.

- hospice@HOME has enhanced the quality of life and quality of care - clients and carers rated the program particularly highly in terms of the friendliness and helpfulness of staff and their concern for client comfort and confidentiality.
- hospice@HOME is cost-effective – it is reducing unnecessary and inappropriate use of ambulance services and emergency departments
- the hospice@HOME model, based on a maximum of 12 months length of stay, has proved to be appropriate for the client group, with the average stay in the program being three months
- the program is successfully reaching rural communities and is addressing regional imbalances regarding access to palliative care

hospice@HOME has established a strong evidence base to support its sustainability into the future and contribute to national and international knowledge on end of life care. The model will be presented at the upcoming International Palliative Care Conference in Montreal, Canada.

The service model is based on continuous quality improvement, with a strong focus on service coordination and collaboration. The program has made significant inroads in breaking down some of the barriers that have characterised the palliative care sector in Tasmania.

Any reduction or curtailment of funding at the end of the current funding cycle will result in the breakdown of a large service network and could potentially affect every person in Tasmania. We are confident that the program can be a model rolled out across Australia.

NOTE: Data presented as part of this inquiry comes from several data date sources and any discrepancies are due to time frames of when the data has been reviewed. Data set numbers will be provided.

(i) Advanced Care Directives

Advanced Care Directives and Medical Goals of Care are important pieces of documentation that support a person's wish to be achieved. Not all people are able to or willing to complete these documents. We also find that clinicians are unwilling to support clients to begin the end of life conversation and therefore clients are left with unrealistic expectations of their end of life trajectory. I have included a Case Review, which reflects upon these comments and is a typical presentation within Tasmania. The case review demonstrates a concern that clinicians are not and have not prepared a client or their family for their end of life and the dilemma that ensues with the case progresses.

CASE REFLECTION

I reflect on a case that I have been involved with prior to the client's death and the subsequent post bereavement work that I undertook. For the purposes of anonymity and confidentiality I have used pseudo names.

Margo was a 62 year old single mother who was diagnosed with ovarian cancer about two and half years ago. She lived alone in her three bedroom house in the northern suburbs. Her only daughter Chloe, a single mother with five children (ages ranging from 2 years to 18 years) lived in a rented property also in the northern suburbs. Margo has had a close relationship with her daughter Chloe.

My initial involvement with Margo occurred in August 2014 when I was approached by the RN at h@home, with some concern that Margo was having financial difficulty as she was unable to access her funds apparently being 'controlled' by her daughter.

I visited Margo to introduce myself and to ascertain what her financial difficulties were. Understandably, Margo was quite guarded with her responses. My conversations with Margo did not in any way suggest that her daughter was holding her account. She explained that she was saving up her money for refurbishment of the interior of her house and was therefore reluctant to over spend on heating. At this period, she was being assisted with home care support (someone who lit her fire place for her regularly).

I was able to elicit information relating to the psychosocial aspects of the family and discussed briefly about Advance Care Directive. She had agreed for me to send the relevant document and information in the mail. She also revealed that she had made a Will at the local post-office and nominated her daughter as the sole beneficiary. She also explained that her condition had improved tremendously according to her GP and that she did not require any additional supports. Subsequent to this home visit, I was later informed that Margo has had a fall in the house and she was unable to lift herself up or reach her telephone until a friend arrived to help her. She had not contacted her daughter for assistance as she did not wish to cause her any stress.

The RN at h@Home approached me with a request for information on the costs of purchasing an alarm which Margo could use to alert someone in an emergency. Another concern was that Margo was not preparing her meals as she found this to be problematic. On these matters, I discussed with Margo and proceeded to obtain the costs of alarms from two

suppliers and also enquired on costs of 'Mums' meals from Claremont and 'Meals on Wheels' from Glenorchy. When the costs of these items were presented to Margo, she rejected all of them because she considered them to be expensive. She agreed to carry her mobile with her at all times so that she could contact someone in an emergency. She also explained that she will attend to preparing her meals.

Principles of Social Work and Theoretical Approaches

From a social work perspective, adopting the principles of individuality; acceptance; and confidentiality; a non-judgemental attitude; empowerment of the client and client self-determination are all appropriate principles of social work. Theories of task-centred/problem-solving and strength-based approaches were all considered to be appropriate in working with the client and her daughter.

In December 2014, all support services for Margo was cancelled at her request following her appointment with her GP who apparently suggested that her condition had improved.

In May 2015, at the request of the CNM, I visited Margo by prior arrangement and she subsequently agreed for me to contact her daughter Chloe for a joint discussion on Advance Care Directive (ACD). At the joint meeting with Margo and Chloe, both confirmed that Margo's Oncologist had provided a good prognosis of her condition and therefore she did not consider it necessary to be concerned about her health. Her comment was, 'I am 100% well'. Nevertheless, the ACD and also bereavement planning were discussed. Margo did not display any emotions at that stage and both agreed to undertake the agreed tasks and receive the written version in the mail.

Subsequent follow-up telephone calls made between July and October 2015 had ended with excuses about one thing or another for not being able to see me. In October 2015, Margo finally put the receiver down as soon as she heard me over the telephone.

I subsequently contacted Chloe to explain her mother's response. She apologised for her mother's behaviour and explained that her mother had declined to follow up on the ACD as well as plan for her bereavement, as she believed that her condition had improved and she will continue to live. At this point, I made the decision not to follow through on these matters.

Client's Denial and Coping with Reality

It was difficult to know what Margo's Oncologist had explained to her about her condition. Perhaps, Margo may have adopted an attitude to be in total denial of her condition and avoid acceptance of her imminent death and thus shield Chloe from any undue stress. She had displayed resistance to any suggestion of an imminent death and therefore it was not possible to address her 'fears', 'emotions' or 'spiritual' needs (if any).

A week before Christmas 2015, Margo was admitted at the RHH, and Chloe, when contacted over the phone, expressed her anxieties as she had learnt that her mother's condition had deteriorated rapidly and that her mother was asking to be discharged home. Chloe was anxious over her mother's imminent death and how she might be able to cope with arranging her funeral since this had not been addressed. She was also ambivalent about being able to care for her mother as she had responsibility for her own children. Margo was subsequently transferred to the 'Whittle' ward. At that stage, Chloe had been approached by the social worker to sight Margo's original Will which Margo subsequently had agreed to and was found to be invalid due to erasures and inadequate witnesses. A new Will was prepared at 'Whittle' which was signed and appropriately witnessed. Given my involvement with the family, it was agreed that I continue to provide social work support for both Margo and Chloe.

On 27th January 2016, Margo had insisted on being discharged home and Chloe had agreed to care for her mother by moving her children to stay at her mother's house and with a greater level of support to be brokered by h@Home. She did so, because her mother had expressed her wish to return to her own home. It was unclear if she had in insight into deteriorating her health condition. Given my part-time role, my own anxiety over this sudden development was ensuring Chloe was able to make immediate funeral plans in readiness for the imminent death of her mother. Her own anxiety was how she might meet the funeral costs. It became evident based on conversations with Chloe that there were insufficient funds in her mother's account that she could access to meet the funeral costs.

Just a day before her mother's discharge home, I was able to arrange for Chloe to meet with a Funeral Home Coordinator, with whom I have had prior discussion of the circumstances. The meeting was actually held at h@Home. The Coordinator accepted the proposition that settlement of the funeral costs would be met with the proceeds of the sale of her mother's estate. It was at this point that Chloe became quite distressed when she was handed an album of caskets and costs to select from.

Ethical Issue

An ethical issue emerged at this stage about planning for bereavement without Margo's input. I had discussed this very ethical issue with the social worker at Whittle, who expressed the view that while Margo was in total denial of her condition, it would prove to be unproductive and hinder anyone from making forward plans, if she had to participate in her funeral arrangements. Chloe's own response to this question was that she did not wish to cause her mother any more distress and she was prepared to proceed to finalise the arrangements. A suggestion that was put to Chloe by the Coordinator was that she gradually breaks it to her mother when appropriate that she had discussed her funeral arrangements with the Coordinator. She agreed to do this. My professional advice received on this issue was that, Chloe's decision to proceed with the funeral arrangements without her mother's input was appropriate under the circumstances and was not in conflict with ethics.

Death

Margo passed away in the early hours of the morning on 3 February 2016. I contacted Chloe and expressed my condolence as well as on behalf of h@Home. She had contacted the 1800 A/hours number and SPCS for support. She had contacted the funeral Coordinator and her mother's body was removed. The funeral was held on the 9th February 2016 and I attended the service. She had also contacted h@Home and requested for equipment to be removed.

Disposal of Margo's estate and Probate Matters

Chloe was introduced to a local law firm and she has approached them with concerns about loss of property title and her mother's outstanding debts as well as application for grant of probate. The property was uninsured and I introduced her to APIA who kindly negotiated a premium on an instalment plan for the vacant property. She is now preparing her mother's house for sale, so that she could settle funeral and other outstanding debts with the proceeds of the sale.

I have reflected on this case, because I was involved in a previous similar situation in which there had been no bereavement planning by family members despite efforts by the social work staff to engage in bereavement planning and the matter was being decided while the body remained in the house. Whereas, in this case, Chloe, who was unprepared for her mother's sudden death, became overwhelmed with issues surrounding bereavement planning and arranging her mother's funeral. She accepted that it was her responsibility to plan for her mother's bereavement. With support and guidance, Chloe was able to plan for her mother's funeral and manage this as best as she could. The timing of this planning and the actual death of her mother seemed all too coincidental. Chloe seemed to have had the emotional strength to see these things through with the support from the social worker. It is still early days since the funeral. She may require post bereavement support and this will be provided in accordance with the agency's bereavement support policy.



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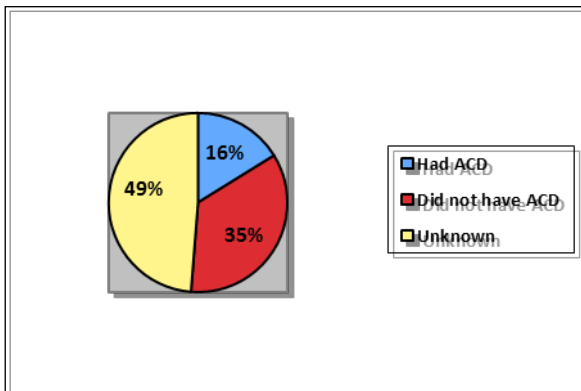
A division of
Hobart District Nursing Service Incorporated

Name withheld (Social Worker)

Data that we have captured reviewing the use of Advanced Care Directive's (ACD's) is as per below;

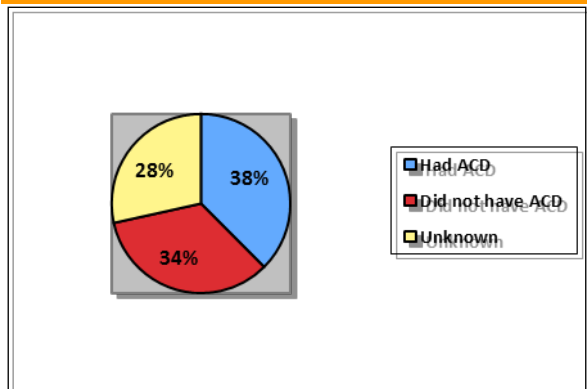
Early Data Set;

n=716



Present Data Set;

n=288



The data we have gathered demonstrates that we have had an increase in the amount of ACD's that have been taken up by our clients. What it does not tell us presently is if that relates to clients wishes being met and outcomes. Anecdotal information and research to date informs the discussion that the ACD does create better outcomes for choice, as per our case review.

Future options that should be addressed is the eligibility of the hospice@HOME packages picking up a responsibility for the ACD and Medical Goals of Care (MGoC) and making these documents a part of an eligibility criteria, a challenge that has not been met to date. What this would mean is that if clients wished to receive h@H packages of care they need to have an ACD and MGoC in place. The ramifications from this are a concern as we could find we are then discriminating clients from services if they feel incapable of making these decisions in a timely fashion, also we have the challenge of people acknowledging their end of life trajectory, a dual challenge when the medical profession also do not recognize this with a client in a timely fashion, as represented in the case reflection. Although these are challenges we would review the option to implement a eligibility linked to ACD and MGoC and an opt out option as required. The aim in doing this would be to raise the profile of these discussions with the medical professionals and raise awareness of ensuring earlier conversation about end of life.

(ii) Administration of medical treatments to minors

To note that in the last two and a half years there is a very minimal amount of terminal minors. h@H have been minimally involved with two minors and a brief overview is provided. Minor's treatment has been well managed as far as their terminal phase and access to services as per the h@H clients.

Two patients;

- Aged 7
 - o Male aboriginal
 - o Referred by GP

- Client of South hospice@HOME, require home cleaning and gardening support,
 - Passed away at home
 - Two older siblings.
 - Admitted in 28/7/2014 died 1/8/2014
- Age 16
- Female
 - Downs Syndrome with cognitive level of a five year old
 - Referred by a friend,
 - Client of North hospice@HOME, currently do not require services but appreciate afterhours phone service and may like assistance with the ACD and emotional support for parents and brother.
 - Admitted in 01/03/2016
 - Diagnosis Myelodyslasia Syndrome

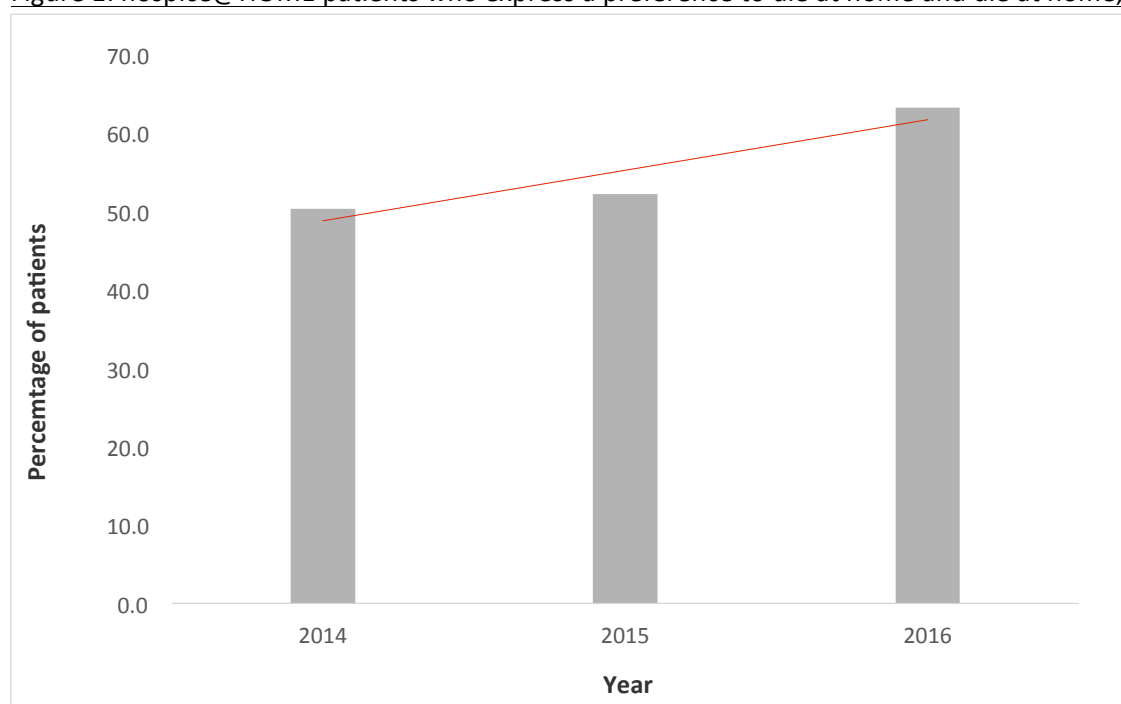
(iii) The administration of emergency medical treatment

The District Nurses have been heavily involved in the review for an Emergency Medication response in the end of life, terminal phase. The District Nurses have done the needs assessment and have been in consultation for over two years in regards to addressing this matter. TDN are now in an implementation phase over the next 12 months introducing an Emergency Medicine Kit and as per below is the needs assessment completed as part of the review:

Access to terminal symptom emergency medications in the community for people that wish to die at home

It is well known from the literature that one component that may help accessing symptom medications in the home is an Emergency Medical Kit (EMK) which are currently used widely in primary care in the UK (Gold Standards Framework 2006), Canada (Harlos & Embleton 2012) and to a greater or lesser degree in the majority other states and territories in Australia (Brisbane South Palliative Care Collaborative 2009; State Government of Victoria 2012; Calvary Health Care 2014; Bullen et al. 2014; Ms et al. 2014; Palliative Care WA Inc 2012). However, in Tasmania, there has been resistance to the implementation of an EMK. The reasons stated for this resistance is scant evidence objectively measuring the size and scale of the problem upon which to measure change. hospice@HOME examined the literature and scrutinise their patient database in order to determine a baseline which to measure the effectiveness of any changes in practice such as the implementation of an EMK.

Figure 1: hospice@HOME patients who express a preference to die at home and die at home, 2014-2016.



As a first step, hospice@HOME retrospectively examined their database identifying all patients who received their services in 2015 who subsequently died in the same year and had verbally expressed a preference to die at home but died elsewhere (hospice, hospital and/or Residential Aged Care Facility, public and/or private). There were a total of 488 patients, receiving hospice@HOME services, recorded as

having died in 2015. 391 patients of those patients, or approximately 80%, verbally expressed a preference to die at home. This is higher than the national data of 70% but not surprising given that the patients who are referred to hospice@HOME are accepting packages from a service that actively facilitates home deaths as a choice. 52% (n=203) of those patients died in their own homes and 48% (n=188) died elsewhere.

When the study sample (n=188) was explored in depth, it was observed that a large proportion (n=108) of the cohort that died elsewhere were admitted between 0 and 7 days prior to death (Figure 2). This observation led to a refinement of the sample size to exclude those admitted 8 days or longer prior to death. This was to allow for greater in depth analysis of reasons for admission for those patients who were (a) confirmed to be terminal and (b) most likely to have needed emergency access to medications for end of life symptom control.

When that group was investigated, it was found that the most likely reason for admission was for management of terminal symptoms, followed by active treatment, respite and lastly sudden death (Figure 3). Unfortunately, due to limitations in the hospice@HOME data at that time and an inability to access medical records from other services, it was not possible to confidently conclude the precise number of admissions caused by difficulties accessing end of life medications for symptom relief in the terminal stage. It was possible however to highlight several case studies where it was a causative factor in admissions at end of life and two examples are given in Table 1. There were also many further cases where medication access for symptom management were related to the admission, but it was not clear how much it factored in to the decision making process at the time.

Figure 2: Time in days from facility admission to death in 2015 for hospice@HOME patients who expressed a presence to die at home but died elsewhere.

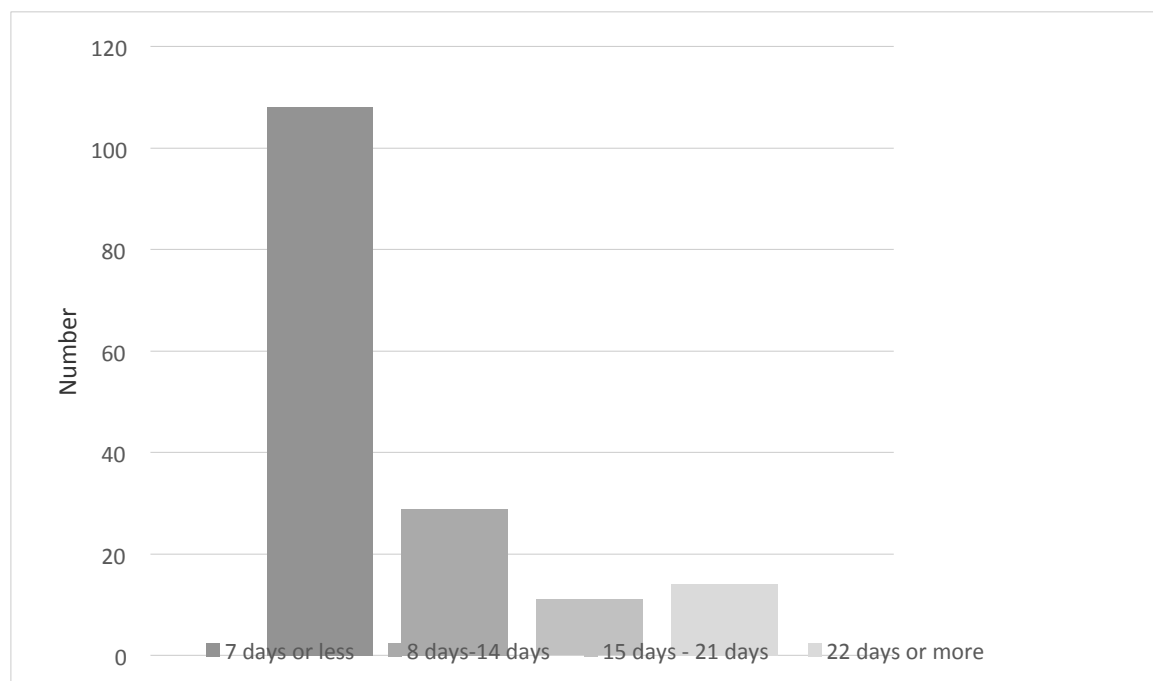


Figure 3: Reasons for admission to a facility as recorded in hospice@HOME database in 2015

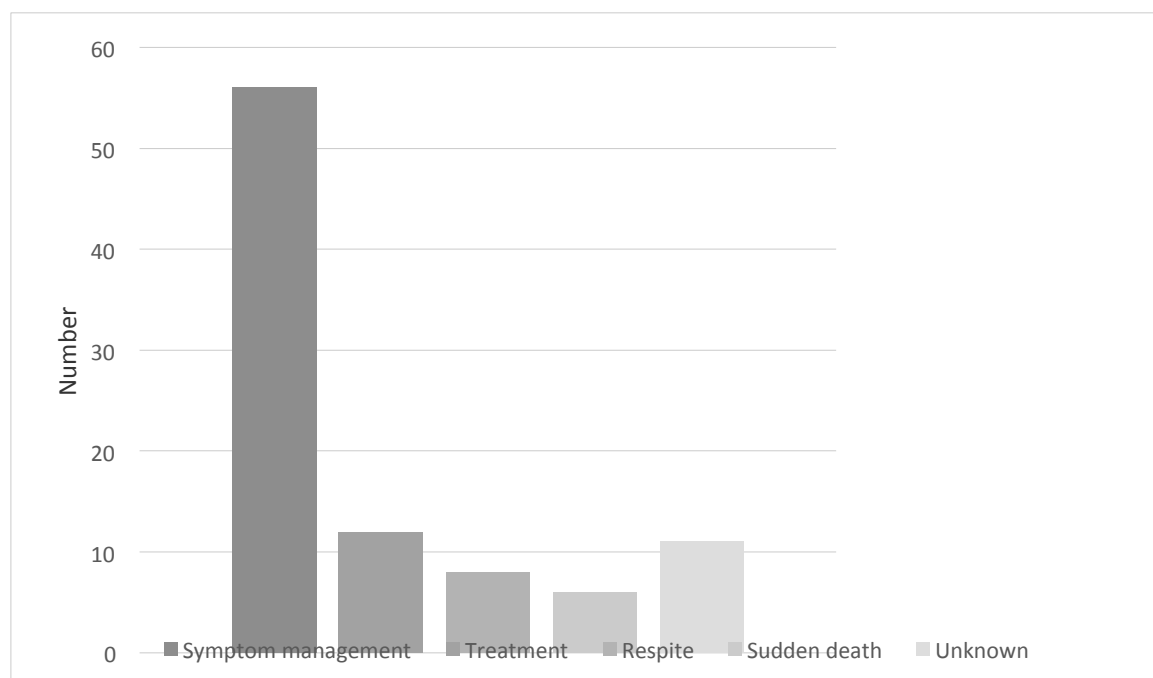


Table 2: Examples of emergency access to medication problems in the study cohort

Case Study 1	<i>When Mrs Y started to approach end of life she become restless and a syringe driver was started to ease her symptoms. Her General Practitioner prescribed further medications for breakthrough symptoms over the weekend, but the family did not know where to access them. She was admitted to hospital on the weekend and died one day following admission with the prescription still unfilled on the coffee table.</i>
Case Study 2	<i>As Mr X became terminal, prescriptions for a syringe driver were written however it was difficult to access medications he needed for the</i>

syringe driver in the community as his pharmacy did not stock some of the medications he needed. He was admitted to hospital for symptom control before a syringe driver was started and died two days following admission.

The hospice@HOME data and the international and national literature support the notion that Tasmanian patients and families requesting end of life care at home, may benefit from the implementation of an EMK. The introduction of an EMK with supporting policies, frameworks and governance, may also reduce unwanted hospital admission at end of life and may increase primary care workforce efficiency and capacity

(Wowchuk et al. 2009). hospice@HOME have provided evidence and established a baseline measure to assess any changes to emergency symptom management in the home for end of life patients prior to the implementation of an EMK. By comparing the data post implementation to the 2015 cohort hospice@HOME hope to be able to objectively measure the effectiveness of an EMK for reducing avoidable hospital admissions and to ensure that patients have control of their preferences at end of life.

In July 2016, hospice@HOME will shift into an implementation phase with 40 EMKs being delivered to support patients wanting to die in their own homes. Those patients currently have little or no access to emergency symptom relieving medications at end of life and often die in a place that was not their choice. It is envisaged that the results from the EMK evaluation will provide evidence for Tasmania that ongoing access to emergency medication in the community avoids the unnecessary hospital admissions that are current practice.

Access to emergency palliative care support for patient and carers during after hours

The provision of 24 hour care to palliative patients is the gold standard of health care in Australia (Palliative Care Australia 2005). However, until the commencement of hospice@HOME, after-hours palliative care support in the state of Tasmania was highly fragmented. The North-West region of Tasmania with a population of just over 87,000 (ABS, 2012) had no after-hours telephone palliative care support, while palliative care patients in the Northern and Southern regions could only access palliative care after-hours support if they were classed as having complex needs. Patients who required after-hours support in the North-West region of Tasmania, or those who lived in the Northern and Southern regions who were deemed to have simple palliative care needs were required to contact hospital palliative care wards or their general practitioner (GP) for after-hours support. The strained after-hours workforce of GPs (especially in rural areas) and the fragmented standard of after-hours palliative care limited the ability of patients and

their families to receive adequate round-the-clock support at home. This support is essential to community based end-of-life care, especially when a patient is actively dying. After-hours palliative triage models have been shown to be readily accepted by patients and their families (Jiang & Gentry 2012).

To address inequitable access and wide regional disparities in after-hours service provision, hospice@HOME initiated a state-wide palliative care after-hours number called 1800HOSPICE in 2014. Currently this after-hours service is coordinated and provided by registered nurses (RNs) and a clinical nurse specialist employed by hospice@HOME. All call handlers have been trained in palliative care telephone triage, and follow evidence-based palliative care triage models (established by Wimmera Health Care Group; Victoria, Australia). The training has been pivotal in ensuring calls ranging from general enquires to medical interventions are correctly handled. The after-hours service is available to patients, carers, professionals and the public, and operates 24 hours a day seven days a week. Any contact outside of business hours (after 16:00 Monday to Friday, and weekends and public holidays) is classified as after-hours.

Patients who engaged with the after-hours service, were less likely to contact the ambulance service than patients who had never called after-hours (Two-way Chi-squared 70.0941 $p < 0.01$). In addition, patients who engaged with the after hour's service were less likely to present at ED than patients who had never called after-hours (Two-way Chi-squared 78.2865 $p < 0.01$). When looking at a subset of patients who stated that they wanted to die at home (established during admission), it was found the patients who did die at home were more likely to utilise the after-hours service than were patients who were admitted for end-of-life care in an institutional setting (Kruskal-Wallis test, $p < 0.001$).

The impact on cost savings that the after-hours service has had on calls to AT and ED admissions was estimated. The data for the period under study showed that patients who called the after-hours number ($n = 458$) had a significant difference in rate of AT calls (six per 100/six months) and ED admissions (five per 100/six months) when compared to those who did not call the after-hours number using AT (41 per 100 patient/six months) and ED (33 per 100 patients/six months).

Using those rates, it was estimated that for every 100 patients that called the after-hours service, 28 ED presentations were potentially avoided during that six month period. That meant that for the 459 calls, there were potentially 129 less end-of-life patients presenting to ED which equates to a cost saving of

~\$121,647 AUD (using The Independent Hospital Pricing Authority [2012] average ED admission cost - \$943 AUD).

Additionally, for every 100 patients that used the after-hours service, 35 calls to AT were potentially avoided in six months. That meant that for the 458 calls, there were potentially 161 less end-of-life care calls to AT which equates to ~\$112,700 AUD savings (using Ambulance Tasmania [2007] average ambulance call-out cost - \$700).

It may be noted that under the current structure, total after-hours costs including wages for RN's staffing the after-hours service and direct intervention costs (if needed), were less than the acute health care savings. In light of these estimates, it can be put forward that after-hours palliative care support lowers acute health care costs by reducing unnecessary ambulance call outs and emergency department admissions, through the employment of registered nurses trained in palliative care telephone triage staffing the after-hours service.

The state-wide after-hours palliative care support number was utilised by palliative care patients in all regions of Tasmania. The need for an after-hours palliative care support service in the North-West region of Tasmania was highlighted by the North-Weats over represented of call (by 15%) in comparison to the population distribution of Tasmania. The distribution of calls was similar to that described in other publications (Phillips et al, 2008; Jiang et al, 2012), with the majority of calls on weekdays occurring between 16:00 and 23:00, indicating hospice@HOME should increase operation hours until 17:00. Weekend and public holiday calls peaked at 09:00 and decline steadily until 23:00. The distribution of calls in combination with the reason for calls, indicated family and carers will generally call during waking hours to ask for services, primarily calling at unsocial hours (23:00 – 05:00) if there is a medical issue or death. This indicates the need for service providers receiving calls during this time to be prepared to provide appropriate advice for these circumstances.

The after-hours service was primarily utilised by family and carer's of palliative care patients, who were the main providers of care for home-based palliative patients. The majority of calls from family and carers were seeking additional personal care encompassing a range of activities for the patient. Studies indicate that home-based palliative care may cause families and caregivers to feel 'pressured' to provide continuous physical and emotional support to the patient (Hudson, 2003). Moreover, research suggests that the act of caregiving for a palliative patient can exceed a family or carer's ability to cope (Broback and Bertero, 2003; Morris et al, 2015). When this occurs a family member or caregiver may admit the patient to hospital, reducing the patient's chance of dying at home (Stajduhar, 2003). It is speculated that the 24 hour access to personal care support for palliative patients and their caregivers may relieve some of the stress of caregiving associated with end-of-life care and increase their confidence and ability to cope at home. A qualitative assessment of the benefits that after-hour support provides to patients and carers, would provide greater validity to this assumption.

In addition to being an important service to patients and caregivers, the after-hours service demonstrated a causal link between using after hours telephone support and reducing ambulance use and preventing end-of-life care hospital admissions; as seen in other research (Fry 2008). It is acknowledged that there are patients who called an ambulance or presented at ED without calling the afterhours service, and the reason

for individuals not contacting the after-hours service (at this current time) cannot be established. Those individuals were most likely experiencing a palliative care emergency that demanded more specialist care than the telephone service could provide. Nonetheless, in instances when a caller made contact with regard to a medical issue, the on-call RN was generally able to avoid contacting the AT and preventing ED admissions by providing over-the-phone advice or arranging medical assistance via an on-call doctor, thereby reducing acute health care costs.

An interesting finding from the evaluation of the after-hours service was that patients who were identified as wanting to die at home were more likely to die at home if they and their caregivers proactively sought help from hospice@HOME after-hours in the form of personal care, medical advice and equipment when compared to patients and caregivers who rarely utilised the after-hours call service. While there are many factors involved in the facilitation of a patient dying at home (Gomes and Higginson, 2006; O'Brien and Jack 2009; Morris et al, 2015), the significance of this result cannot be overlooked and suggests that access to 24 hour support is an additional variable in determining if a patient dies at home. This paper puts forward the suggestion that in addition to proactive planning and services, 24 hour reactive involvement of primary healthcare professionals to the sudden rapid deterioration of a patient during end-of-life care within the community, prevents unnecessary hospital admissions allowing the patient to actively die at home rather than in emergency departments or an acute care ward.

(iv) Other matters incidental thereto

The delivery of the h@H packages within the Tasmanian Health System has built the knowledge and understanding of the palliative approach of care across the whole of Tasmania. Working in collaboration not only has the Tasmanian Health Service (THS) and TDN built further knowledge and capacity but also the NGO's and Private providers affecting all health care providers. The h@H packages have also had significant affects in the implementation of equipment and an after hours response.

The outcomes in having the h@H packages in place allows the state to meet the Australian Palliative Care Standards in a way that it has not in the past.

The information provided in *Palliative care in Tasmania: current situation and future directions* (Centre for Health Service Development, 2004) was used to benchmark the pre-BAPC model against the Palliative Care Australia (PCA) guidelines. It found:

- SPCS had No staff with qualifications in psychology, physiotherapy, occupational therapy, speech pathology or music/art therapy Tasmania were employed by the Tasmanian palliative care service
- Lack of access to allied health therapists had flow-on effects for the palliative care nursing workload
- The Tasmanian palliative care service was only servicing about 52% of estimated need
- Demand for palliative care in Tasmania was likely to grow more rapidly than in other jurisdictions because Tasmania had the highest overall incidence of cancer in Australia and a rapidly ageing population.
- high incidence of cancer and the high number of older people who live alone meant that Tasmania needed a staff ratio above the national average in order to provide an adequate service
- Staff turnover rates in Palliative Care were significantly higher than the average for other staff within the Department.
- High risks of staff burnout and limited opportunities for collegial support, professional supervision and professional development were evident (Centre for Health Service Development, 2004).
- The regionalisation of services saw slightly different services evolve along with different interpretations of the service delivery model.

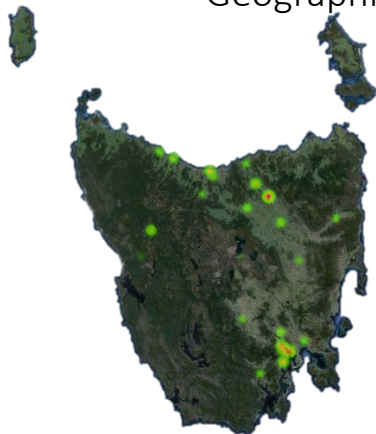
A current review would see a changed environment and a positive future for service delivery with the implementation of the hospice@HOME program and the Better Access to Palliative Care implementation.

In New Zealand, US and France they have twice the amount of **non** institutionalised deaths than we do in Australia. Swerrison and Duckett in their Dying Well paper have exposed this difference, yet it has not been further explored.

People want choice, control and dignity and they want their symptoms to be well managed and personal social and psychosocial support. But dying has become highly institutionalised and deaths in hospitals has increased yet paradoxically the likelihood and timing of death is now more predictable. There is more time to prepare for death but dying is not discussed and we are not taking the opportunities we have to help people prepare for death, rather than creating an experience of people being disconnected, confused and distressed as an array of services, interventions, and health professionals intervene when people are dying.

The hospice@HOME packages are reaching the broad range of stakeholders in all areas of Tasmania. As the maps below demonstrates;

Geographical heat map of clients



hospice@HOME



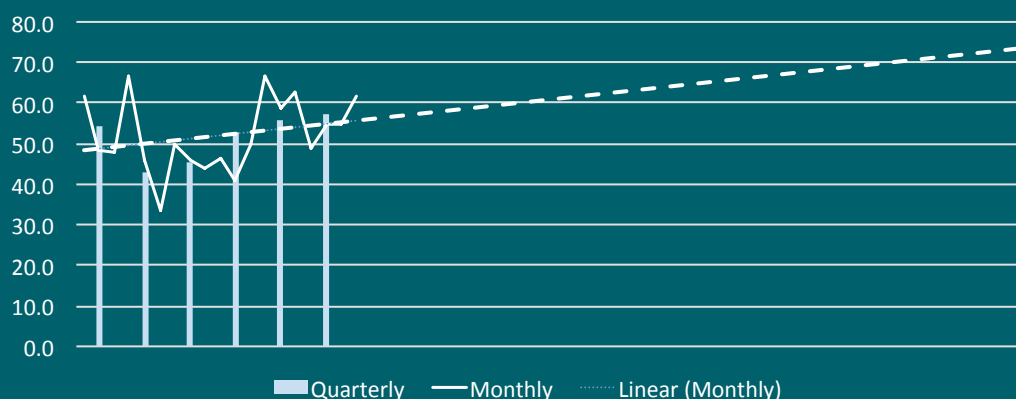
Tasmanian population

Our projections tell us that in 5 years that 73% of people will be achieving their goal to die at home. A significant shift out of acute facilities would be achieved.

We would also have achieved a significant turn of the statistics, when 70% of people wish to die at home and only 14% have been achieving this to date, the change to the predicated rate will be significant in just 5 years.



Five years of hospice@HOME 73%



As demonstrated in the reform agenda review Tasmania has a strong culture in the way that's services are delivered. h@H now have a Collaborative Protocol with THS which is key in the development of packages and ongoing support of Collaborative practices.

Service providers in the NGO and private space have embraced the packages and have worked very closely with The District Nurse's and have demonstrated their understanding of the concept to deliver the care in a collaborative manner.

What we do know is that dying at home is a choice AND dying at home can be a reality when we meet the gaps that incur in fragmented care arrangements.

h@H are implementing a system and partnership approach which requires collaboration across varying health and care providers aimed to maintain the focus on the individual who inevitably has complicated issues and challenges. The project has overcome challenges and broken down the silos that exist to achieve what an individual wants and be responsive, flexible and adaptable. h@H are striving for not only sustainability of this program for Tasmania but hope that the rest of Australia can learn and adapt from the journey we have taken.

Case Study;

Case Study

Demographics

Age: 76

Gender: Female

Region: Anglican

Diagnosis: Systemic Sclerosis

Patient information (names have been changed)

Length of stay:

Gwen was referred to h@H on 09/05/2016 by RHH – older person's unit – first visit attended in hospital. Gwen died at home 4 days later on 13/5/2016.

Social history

Gwen lived with her husband of more than 50 years – Bill in their Goodwood home. Together Gwen and Bill had one child – a daughter, three grandchildren and 5 great grandchildren. They were a close knit family and Gwen was well supported by them until the end.

Past medical history

Gwen had a history of COPD. Weight Loss also occurred due to diagnosis of Systemic Sclerosis.

Service information

Why were they referred?

RHH referred client for Palliative Care assistance in the home, equipment subscription – hospital bed specifically to enable Gwen to be cared for at home for end of life cares and to assist in

arranging Personal Care – either by increasing current services or putting in immediate services for end of life.

What services did they received, and why?

Personal Care – h@H brokered support through IHCS (although Gwen was a District Nursing client, TeamCare were unable to facilitate referral at time) to provide Mon/Wed/Fri Personal Care – Gwen received two visits for this when services were cancelled as client passed away – this was implemented because client was not mobile at time of h@H admission and required two support staff to bed bathe her.

Registered Nurse – h@H brokered 2 x night sits to ensure family were able to care for client at home comfortably on 11th and 12th of May. Due to client's condition these were provided as needed and reviewed daily, also assisting with breakthrough medications.

**This was not done without delay however as a h@H RN had arranged to broker this but Bill cancelled prior to shift ending, however later that night he decided he did in fact need some assistance as Gwen was very unsettled with increased/unmanaged pain again – h@H afterhours RN home visited client and arranged an overnight sit at late notice.*

After Hours – h@H after hour's assistance was used on numerous occasions with the RN on duty also visiting the client's home to assist brokered support to assist client, supporting with break through medications as client was agitated at times.

h@H RN/Non-Clinical Care Coordinator: h@H assisted in liaising with client's GP regarding Syringe Driver implementation and medication, visiting client's home and setting up Syringe Driver to enable ongoing pain relief, drawing up break through medication to ensure family had enough supplies to keep Gwen comfortable, h@H RN and NCCC turned and educated family on how to move client, provided family with a Care Pack and educated on the use of items within this, offered but did not need to bathed client as brokered support had visited.

Any issues with the services?

The biggest issue in Gwen's scenario was the discharge from hospital. During Gwen's first night at home Bill was extremely concerned with Gwen's level of pain as she was screaming out to him in pain. Bill went to the hospital at 6 am to obtain break through medication for Gwen but he believes by this time it was really too late as her condition had deteriorated rapidly by 6am. Bill and his granddaughter Alissa assisted Gwen overnight and were very upset that break through medication was not offered prior to discharge to enable to discharge home to be easier on Gwen.

Summary on case study

Besides an unsettling discharge, the assistance at home for Gwen was very well received by client's family.

After Gwen's first night at home Bill had booked her into the Whittle Ward – a decision he did not like to make but one he felt he couldn't help as he advised that he could not bear to hear her in pain another night. Bill became quite emotional on the phone to a h@H RN and through tears advised that 'he wanted what was best for her' and he felt like he was letting her down. Clearly he felt that the Whittle Ward whilst not her choice for EOL care was his best option to ensure she was well cared for. As the Whittle Ward were unable to accept Gwen on the ward until the following day h@H attempted to arrange an overnight sit with an RN to allow break through medication to be handled and to allow Bill to get some rest – at first this was declined, however later at night Bill decided he could not cope with Gwen's condition and the h@H after hours RN visited and assisting in arranging an RN to provide a night sit at very short notice and stayed to provide assistance to client, family and brokered RN until everyone was settled.

Seeing how well this worked overnight Bill made the decision the following day to cancel the Whittle Ward booking and subsequent ambulance and to again try to assist Gwen for EOL care at home, as per her wishes.

The client's GP ordered medication to allow Gwen to have a Syringe Driver inserted to allow for better pain relief and a h@H RN visited to set up Driver and draw up further break through medication to ensure the family felt well prepared and well supported.

The h@H RN and Non-Clinical Care Coordinator provided assisting in moving client – to ensure pressure sore was not worsened, provided education to family re: moving client, provided care pack and education re: how to use items within this and general support to family.

It was also decided that we would arrange another overnight RN sit to allow Bill to rest and his granddaughter Alissa to go home and see her family for the night.

h@H afterhours RN visited client again as Gwen was again agitated and in obvious pain, break through medication given, client settled prior to overnight RN sit arriving.

Gwen died, peacefully, at home the following day.

Following Gwen's death Bill has called to thank The District Nurses/h@H/SPCS/Tas Community Clinic - Nurse Practitioner - numerous times.

Upon attending Gwen's funeral service the h@H RN and Care Coordinator were moved by Bill's personal dedication to support received. When Bill saw them he tearfully told them "You know who you are? You are everything!"

As published in the Mercury:

Smith.

A Service for Mrs Gwen Smith will be held at the Graham Family Funeral Home Chapel, Cnr Risdon and Bay Roads, New Town, on Wednesday at 1.00 pm.

Family and friends are warmly invited to attend.

In lieu of flowers donations may be made to the Hobart District Nurses and will be gratefully received at the Service.

Private Cremation.

Funerals

Published in The Mercury on 16/05/2016

Conclusion

The District Nurses are committed to delivering in home palliative care packages that demonstrate best practice principles and meet the Australian Palliative Care Standards. TDN has built an innovative system model that educates and innovates a whole system approach to improving palliative care outcomes in the community. The District Nurses have achieved their outcomes through collaboration across the entire sector and building a knowledge base that dying at home is achievable.

The District Nurses are aiming to review their ability to increase the ACD and MGoC uptake through a future recommendation for eligibility to be inclusive of these elements. A opt out option will be available to ensure access to all Tasmanians so packages can be maintained as available for all Tasmanians. The adoption of ACD have increased immensely over the time of the packages which indicates that when h@H are involved that this is viewed in positive terms. We do acknowledge that when clinicians are reluctant to pursue the end of life conversation it becomes increasingly difficult to make ACD's meaningful for the family in a timely manner.

The care for minors has been minimal for the h@H program, indicating the population of terminal ill minors is relatively low in numbers. The need for care is also low and after hours and social support has been a positive impact within the packages for families.

The Emergency Access for the terminally ill has been a large proponent of the work done through TDN. As discussed the needs assessment has identified that the issue with access had many ramifications including representation to hospital and increased use of ambulances. The h@H package implementing a supportive Emergency Medication Kit (EMK) is in its infancy but is to be evaluated and assessed in the coming 12 months. h@H believe that the support developed from an evidenced based need and evidenced based implementation process will meet the emergency requirements for patients and further reduce representation and calls to ambulances, and reduce family burden of care.

As the Specialist Palliative Care Teams move to deliver their role more succinctly as per the Palliative Care Standards as consultants to health professionals will support the packages aims into the future. The h@H program has reached such a broad population and varied clients needs, we assert, that the removal of it will affect all Tasmanians. The outcomes are exemplary and the reduction or ceasing of these packages in the community for the future will have dire effects in the delivery of Palliative Care for everyone that meet the Palliative Care Standards.

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