

Dying at home is a choice

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Abstract

In 2013 the desire to die at home became a more realistic goal for Tasmanians as a project entitled hospice@HOME (h@H) commenced through Commonwealth funding to deliver "Better Access to Palliative Care". The project is a first in Australia and aims to ensure all Tasmanians who wish to die in their own home are supported and resourced to do so.

Tasmania is ideally situated to provide evidence based results and systems based approaches that can be replicated in other States and Territories. Tasmania has a dispersed population, rural and remote communities, and a high rate of people living alone with limited after-hours and weekend support systems.

The project to date has delivered 600 packages of care and is aiming to deliver 2000 over the three year funding period. The delivery of care is through established organisations and h@H is identifying the current gaps in services that impede people achieving their wish to die at home. h@H aims to deliver a quality of life change to the care that can be delivered in the home when meeting that gap.

To deliver this in an evidenced based approach that can be replicated in the future h@H are capturing the qualitative and quantitative data to deliver a systems based approach. Data is captured through the electronic based Client Management System, Mortality Reviews and Collaborative Practice outcomes.

The project team is working with 25 organisations across Tasmania to deliver the in home care approach with care co-ordination a strong link to the delivery of consistent practices across the State. The main aim has been to shift the method delivery of care away from a 'clinical approach' to 'individual client driven care' thus providing a unique wraparound model of care with a focus on meeting the gaps in care and provisions required for in home palliation at end of life. The gaps identified vary from equipment, support workers, gardening, walking pets, cooked meals and clinical support after-hours.

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 is about how to overcome these challenges and break down the silos that currently exist to achieve what an individual wants and be responsive, flexible and adaptable. h@H is delivering this outcome and is striving for the rest of Australia to learn and adapt from the journey.

Introduction

People want to die in their own homes, they want to be comfortable, supported by their family and friends, be in their own community and have access to effective services¹. The reality is that people in Australia are not achieving this option as we have provided an institutionalised care environment that is medically orientated. People are unable to access the care they need in the community setting of choice and family as the carers are being left with the burden of the care. Seventy percent of Australian people want to die in their own home yet only 14% are dying at home.¹ In 2000-01 more than 1 in 5 palliative patients were dying as admitted patients and in 2009-10 that increased to 1 in 3 people.² In other countries such as New Zealand, Cyprus, Croatia, United States, France and Ireland people are twice as likely to die in their own home.¹ The reasons why this is not being achieved here in Australia is concerning. In 2013 when funding was received by The District Nurses, the aim was to ensure mechanisms were developed to provide wrap around care for people to be in their homes and communities and relieve the burden to carers. Commonwealth funding was provided to deliver "Better Access to Palliative Care", and hospice@HOME (h@H) created packages that aim to work within the existing health care structure. The packages have an interdisciplinary approach and specifically focus on care co-ordination, after-hours support, equipment availability and extra "in home care" service

delivery for all people. The aim is therefore to provide a “hospice” like environment for people in their own home, as hospice is defined;

Hospice is not a place, but a concept for healthcare delivery to those dealing with life-limiting illness. Hospice focuses on creating a natural and comfortable end-of-life experience for those confronted with a terminal condition. Through a range of palliative, medical, nursing, psychosocial, and spiritual care provided by an interdisciplinary team of experts, hospice seeks to manage symptoms and provide comfort when cure is no longer possible.³

The packages of care commenced in 2013 and an evaluation structure was adopted to enable continuous review and quality improvement. A Mortality Review process was developed and for the purposes of this paper 266 deaths have been reviewed. The results have reflected quantitative trends and further research opportunities have now been identified for qualitative and cost benefit review.

Literature review

In depth research has recently been conducted through the Gratton Institute with the release of the *Dying Well* paper in September 2014.¹ The Standards of Palliative Care have been reviewed as well as the Australian Institute of Health and Welfare. The findings from these form the Palliative Care Service Review with recommendations to support the findings. Further literature has been reviewed from the USA and examination of their palliative care in-home delivery mechanisms demonstrates similar barriers and issues to that of Australia

Method

A whole of a system change is required but review of the current data in Tasmania found limited evidence on preference for place of death, or amount of people who died in their own home. There was no specific data indicating the wish of Tasmanians to die in their own home, nor the evidence as to where the majority of Tasmanians were dying. It was evident that this lack of specific data created an environment which challenged the Tasmanian health system with regards to the need for a program such as h@H. But the State of Tasmania is ideally situated to provide evidence based results. Tasmania has a highly regionalised population with 70% of the State classified as rural and remote and 50% of the population live in small rural communities. Tasmania has a dispersed population for a small state and has the highest rate of people living alone and the highest overall incidence of cancer nationally with a 1 in 3 chance of developing cancer before the age of 75.⁴

Having people in small rural communities requires a different response to deliver Palliative Care, and with people living alone they are more likely to require inpatient hospice or hospital based care than home based care. Tasmania provides more of a hospital based system as we have very limited after-hours support, weekend community services, and restricted resources for people to manage in their own home. Tasmania has only four main public hospitals in the State, and has global service provision challenges. The methodology implemented is targeted so that the findings from the h@H project can be replicated in any State or Territory in the future.

The h@H packages were developed to meet any individual's need at end of life. h@H began working with current service providers who were delivering end of life care in the community by enhancing their role to provide extra services. The aim was to not duplicate services but rather bridge services together so we can achieve the concept of wrap around care. The identified fragmentation of current services and 'silos' of care was evident; end of life choices were not discussed and the services were variable and inconsistent. h@H adopted one referral access point already in existence in Tasmania known as TasCarepoint, and implemented an after-hours service following the Wimmera After-hours Palliative Care Framework.⁵

An equipment gap analysis was undertaken and a significant gap in equipment availability was identified as well as inefficiency in the Tasmanian Community Equipment Scheme (CES). An attempt to integrate with the CES, as initially intended, failed and a process for delivering equipment through another private organisation ensued. A gap also identified access issues to emergency medication for symptom control. The opportunity for an 'Emergency Medication Kit' was highlighted and a project commenced. An opportunity for telehealth was also recognised and a "Clientranet" telehealth project was initiated. A collaborative practice model of care was developed with the Tasmanian Specialist

Palliative Care Service (SPCS) and Community Health providers, and contracts were implemented to provide brokered services across the State.

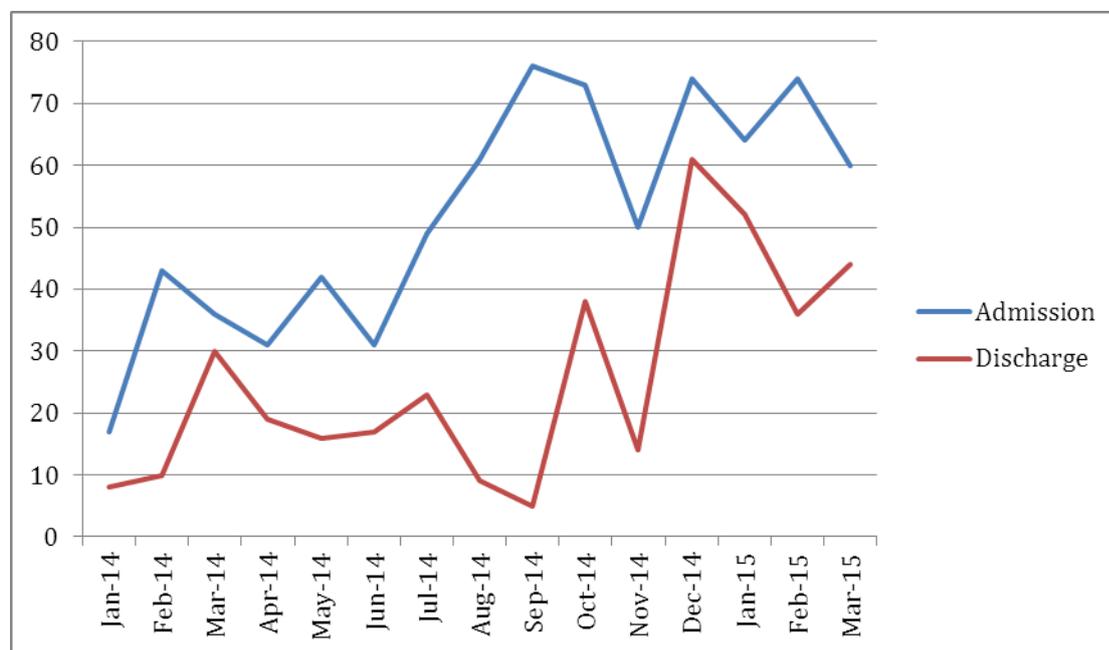
h@H developed policies and procedures and packages of care were made available for people across the State with an agreed eligibility – ‘hospice@HOME is available to any Tasmanian residing in the community with an end of life or life threatening outlook, who is assessed to be within the final 12 months of life, or as determined by a Medical Doctor’. The packages were provided at no cost to the patient and with no age limitations. A Mortality Review was established for data collection and the Commonwealth appointed an evaluator for active evaluation throughout the project.

Results

The results identified in this paper have been collected from the h@H Mortality Reviews and through the electronic ‘client management system’ at The District Nurses, known as Uniti. Interim results are available but presently lack patient/carer feedback and quality of life measures, as well as a cost benefit analysis for Tasmania based on hospital avoidance data. The District Nurses will further their evaluation process to address these areas.

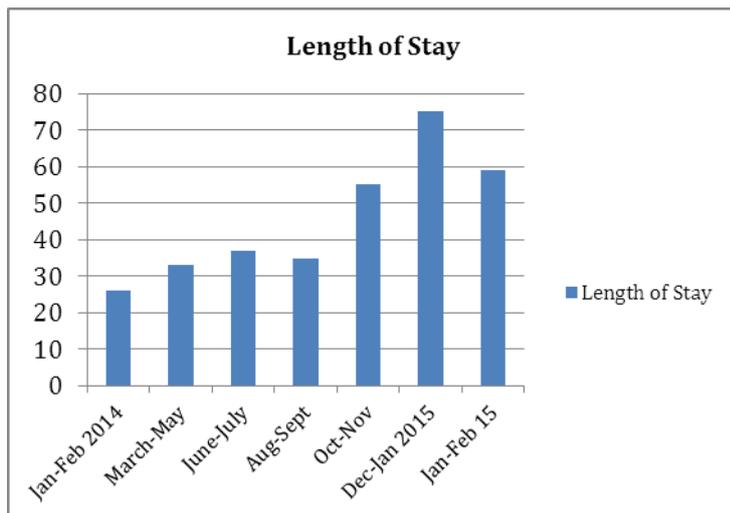
The current number of patients referred to h@H is 781, with 382 discharges. The packages commenced in December 2013 and Graph 1 demonstrates the admissions and discharges to the end of March 2015. From July 2014 we have doubled the h@H packages across the State. We do see some plateauing of the rate per month of referrals and expect that this may change through some strategies outlined further in the paper.

Graph 1 Admission and Discharge 2014-15



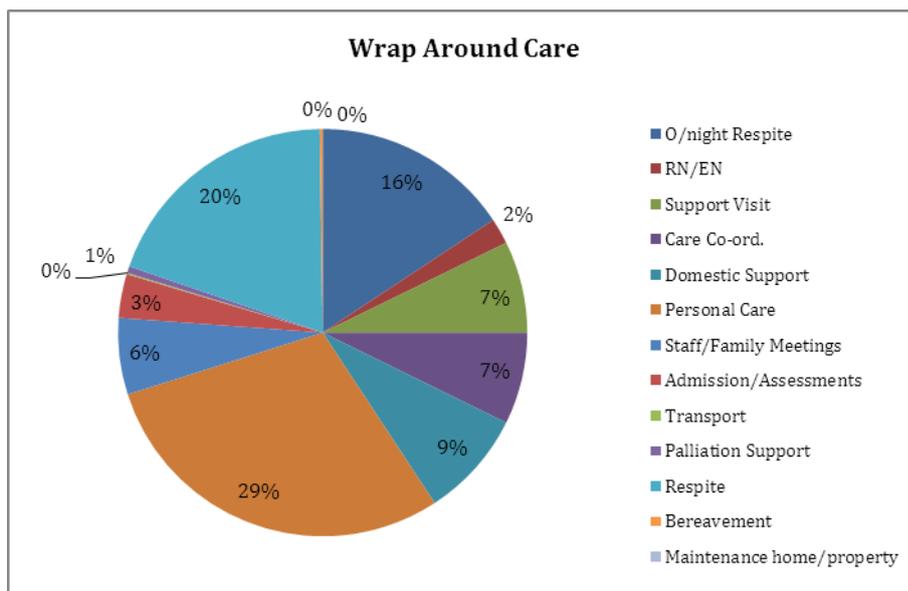
Length of stay (LOS) for the h@H packages has been captured bi-monthly from the Mortality Reviews as per Graph 2. LOS has increased incrementally since the beginning of the service with the h@H LOS currently 64 days. The Palliative Care Outcomes Collaboration (PCOC) National Report in 2014 demonstrated that the average inpatient LOS was 10.9 days and the community episode of care was 35.8 days.⁶ The h@H episode is longer indicating we are keeping people at home longer than the identified palliative cohort in the PCOC.

Graph 2 Length of Stay



Graph 3 outlines the wrap around care that has been brokered for the h@H packages. As you can see the majority of care required for patients is overnight respite, personal care and domestic assistance. It is recognised that for people to stay in their homes there is currently insufficient formal home and community care for the person.¹ The lack of formal carers has put pressure on the informal carers such as family and friends, but undoubtedly this will create its own problems in the future as the carers will require care. Evidence tell us that a well co-ordinated and interdisciplinary approach to care can have a positive impact on reducing carer burden, with lowered levels of anxiety and depression, and leads to perceived increase in quality of life amongst patients and care givers.⁷

Graph 3 Wrap Around Care



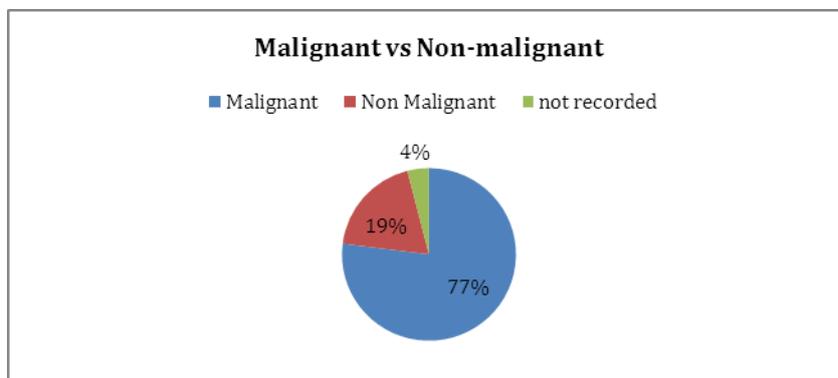
Bi-monthly Mortality Reviews have been conducted since the beginning of the project. The reviews look at each patient and capture the GP details, date of referral, date of death, LOS, social history, region, diagnosis (malignant, non-malignant, HIV/AIDS), assessment date, location of assessment, participants in care, referrals to the SPCS, completion of Advance Care Directives and/or Goals of Care, preferred place of death, actual place of death, expected or unexpected death, presence of a symptom action plan, access to the after-hours service, contact with Ambulance Tasmania, presentation to Emergency Departments, bereavement plan, bereavement delivery, feedback from participants in care, unintended consequences and comments.

The following is a summary of results for 266 deaths. 328 deaths were recorded but 62 of these had insufficient data available.

83% of h@H patients identified that they wished to die at home. To date the actual place of death recorded as home is 44% for our patient population. 56% of our patients died in Acute/Palliative Units or Residential Aged Care Facilities. The recent PCOC data however, identified that 77% of the palliative patients died in hospital and 27% died in the community.⁶ h@H is looking at further opportunities to support patients with h@H packages to achieve their wish to die at home.

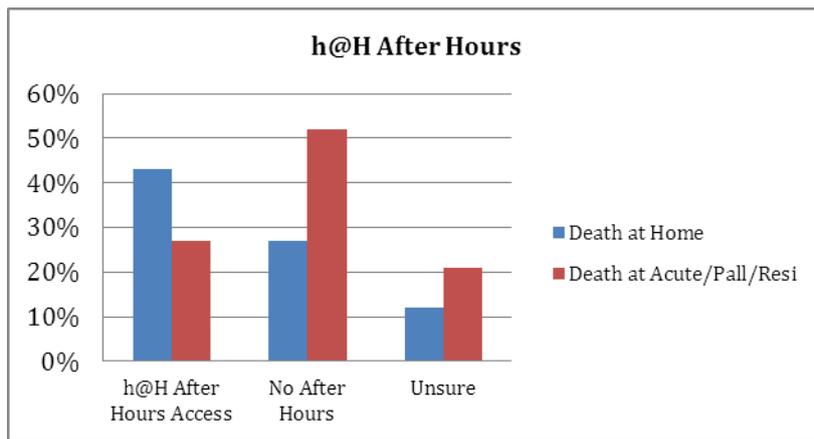
The number of patients with a malignant versus non-malignant diagnosis is captured in Graph 4. We have a 'not recorded' section where the data was not captured. The malignant numbers are high and reflect a similar cohort captured in the PCOC data across Australia. The latest PCOC summary identified 77% of the palliative patients had a malignant diagnosis.⁶ As the project has worked in close collaboration with the SPCS in Tasmania the statistic reflects the profile related to a palliative service, as evidenced in the PCOC. It should be noted, however, that the leading cause of death in Australia is Coronary Heart Disease followed by respiratory system diseases and then cancer and dementia.⁸ Therefore the high malignancy rate is not aligned to the leading causes of death. As mentioned previously, Tasmania has the highest level of cancer per capita in Australia, but with the large malignancy cohort evident in the h@H packages we acknowledge that we lack referrals for non-malignant patients.

Graph 4 Malignant versus Non Malignant Diagnosis



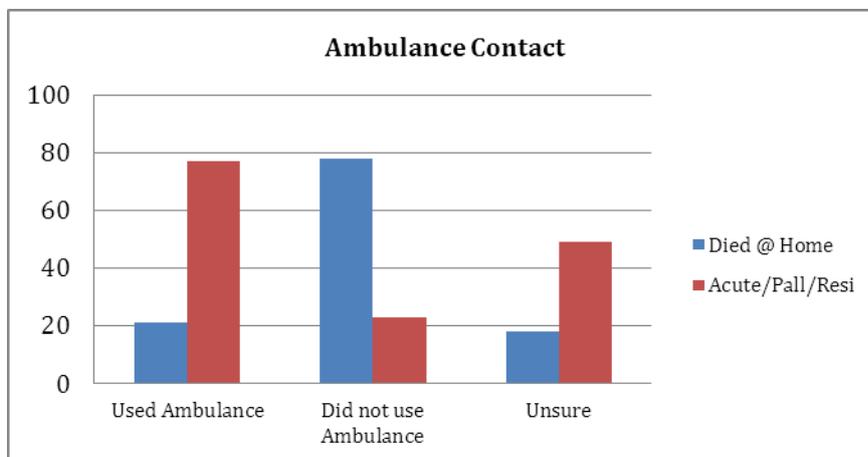
The Mortality Review enabled h@H to review the effectiveness of the after-hours service delivered through a telephone triage model of care developed initially by the Wimmera Hospice Care Group.⁵ As identified in the Palliative Care Standards, Standard 4, when a patient has a clear pathway for knowing who to call after-hours and care co-ordination is in place, burden is minimised to the patient and caregivers.⁹ The after-hours service supported this Standard and aimed to reduce confusion and deliver a Palliative Telephone Triage approach. As per Graph 5 we have found that when patients have contacted the h@H after-hours service there is a correlation of them achieving their wish of staying at home. The majority of people who have died in the Acute/Palliative or Residential Aged Care Facilities have not contacted our after-hours service. It is also cited as part of the *Dying Well* research that home help lines assist and help patients and carers feel someone is there for them. Emergency Department visits can be avoided by connecting patients and carers to assistance when problems emerge after-hours.¹

Graph 5 h@H After-Hours Contact



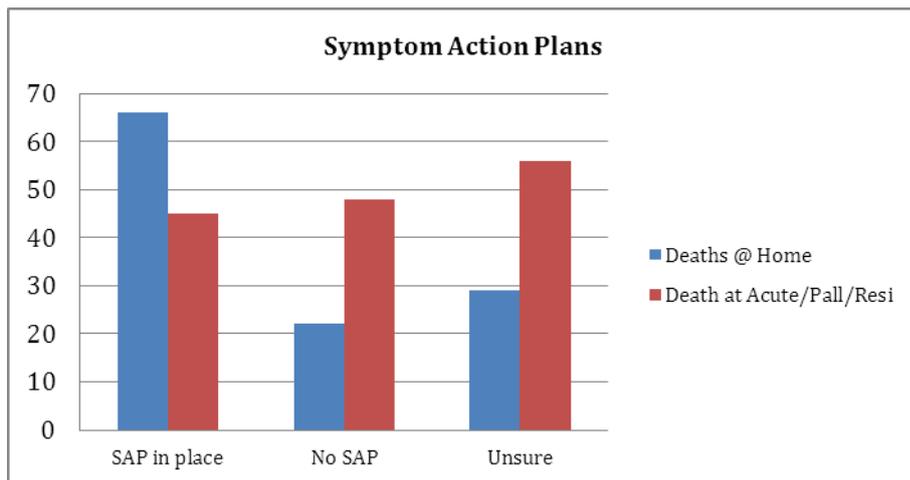
Ambulance contact was a measure developed to capture any contact with the Ambulance Tasmania service. It can be argued that its reference is suboptimal as the episode of care is not specified. As per Graph 6 the Ambulance had been used less frequently by those who died at home compared to those who died in hospitals and residential facilities. There is a high unknown factor still evident and this is an acknowledged area for further research. The cost of dying is affected through the use of these resources as well as the impact on Quality of Life.

Graph 6 Ambulance Contact



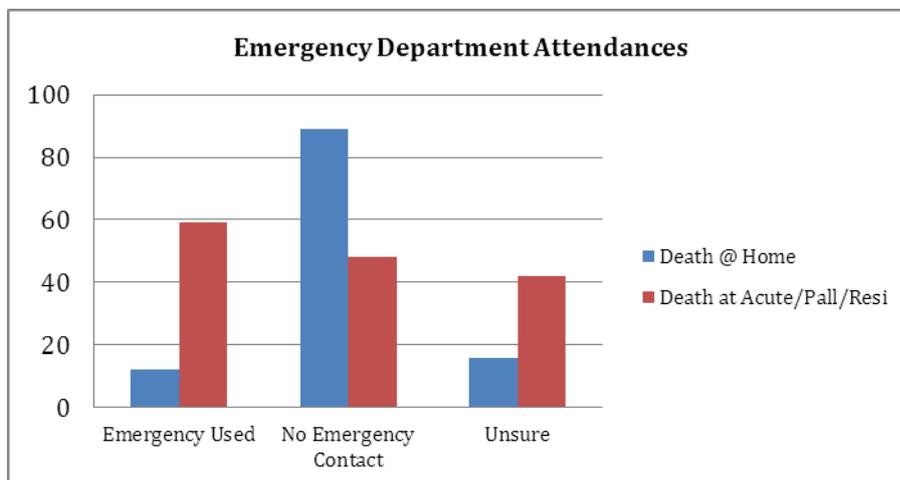
The results also indicated that when a Symptom Action Plan (SAP) is available and appropriate that a person has better outcomes and more likely to die at home. From a patient's experience the factors to delivering a good death are managing symptoms, avoiding prolongation of dying, achieving a sense of control, and relieving burdens placed on the family.¹⁰ It is clearly evidenced throughout literature that in end of life symptom control is a priority for patients, their family and carers. To ensure that people feel safe to deliver the care at home it is imperative that these issues are proactively addressed and plans are in place to support symptom changes. Graph 7 demonstrates that when a SAP is in place the person has better outcomes in their ability to stay at home. But as we can see in the graph the data captured has a high "unsure" result. The measurement of "unsure" is likely to indicate that there is not a clearly articulated SAP in place.

Graph 7 Symptom Action Plans



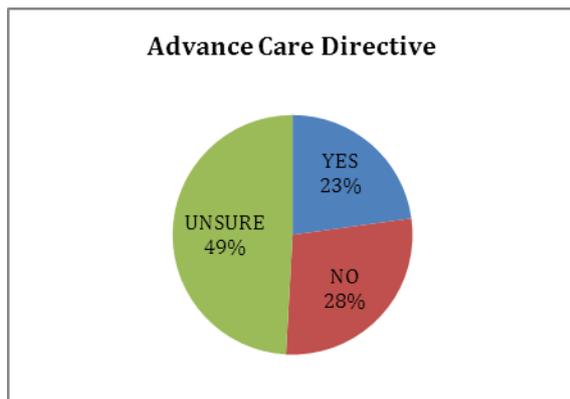
Emergency attendances are clearly correlated to Ambulance use. We have recorded the amount of patients who have had contact with an emergency department versus those who have not. The research has demonstrated that there is a decreased use of the emergency department when people die at home rather than in the Acute, Palliative or Residential Aged Care facility. The *Dying Well* paper suggested that the ability to provide increased services in the home is likely to reduce the burden on hospitals and our results have supported this notion.

Graph 8 Emergency Department Attendances

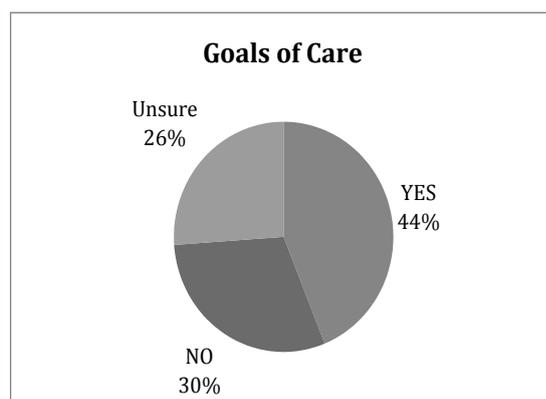


As part of the BAPC funding it has been acknowledged that further support is needed for people to complete Advance Care Directives and have Goals of Care in place. Promotion through the community and further health professional education has been introduced. Literature supports advance care planning as being most successful when a whole of a system approach can be adopted and should include strategies such as community engagement, health professional education and training, documentation processes and organisational policies and procedures.⁹ The District Nurses and our partners in BAPC are all implementing these strategies to ensure wishes at end of life are understood and adhered to.

Graph 9 Advance Care Directives



Graph 10 Goals of Care



Discussion/conclusion

Through the delivery of the h@H packages, the Mortality Reviews and collection of patient data, the evidence is indicating that h@H is achieving the outcomes to support people with wrap around care to die in their own home. The key findings indicate there are some trends that require further investigation and supporting research. However the most significant of the results indicate that if a patient has a SAP in place and access to an after-hours service for planned support they are more likely to die in their own home, .

The Tasmanian primary care providers and SPCS teams are integral in the development of a systems based approach to continue to support the increased SAP in the community setting. h@H will focus on education and training and a whole of health professional approach underpinned by policies and procedures to support the use of SAP in end of life care.

Access to the h@H after-hours service indicates a better planned pathway for support in avoiding admission to the Acute/Palliative and Residential settings for end of life care. The literature as indicated supports the co-ordination for after-hours care to be lead from one centralised area and patients and family know that utilising the service will assist them. The results indicate that having an after-hours service with the use of the palliative telephone triage model has supported people to die at home. Direct quality of life and qualitative review is required for a better understanding of this finding, but early details indicate the use of a clear after-hours pathway is effective for in home end of life care support.

A link has been identified showing that when people are supported to die in their own home they have reduced contact with Ambulance Service and emergency departments. The overall cost then would be expected to be reduced for the health system. The burden reduced on emergency services and then reduced admissions for palliation should be evident. Currently the flow on effect of this are yet to be proven and the review needs to capture if that is a tangible cost reduction and what the differences are to the episodes of care being delivered and what that cost, if any, is to the acute care sector and emergency services.

In conclusion, the h@H project has identified that in delivering wrap around person centred care they can support people to die in their own home. The main mechanism supporting this is the increased care being delivered in the home with associated care co-ordination. The after-hours service has been delivered with a clear pathway of support and a triage model that assists people to stay at home. A well co-ordinated and collaborative practice working across many organisations is delivering a positive impact for people and relieving carer burden. Further research has been identified to support the findings to date, and future research will include a cost benefit review to the acute care sector and qualitative / quality of life review for patients and carers.

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Presenter

Fiona Onslow is the Director of State Operations at The District Nurses in Tasmania. Fiona is a Registered Nurse with a Postgraduate in Family and Community Health, and is currently completing her MBA. Fiona has worked in rural, regional and metropolitan facilities in Western Australia and Tasmanian across her 18 year career. Fiona more recently secured funding for her organisation to deliver hospice@HOME packages of care across Tasmania in a project for Better Access to Palliative Program.