



hospice@HOME  
INTERIM REPORT

...achieving our vision

October 2015



hospice  
@HOME

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# Message from the Executive

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 for people in their own homes.

Previously in Tasmania the delivery of in-home palliative care services was 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 staff and I have vast practical nursing experience, including in emergency, and we 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 palliative care practitioners 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 bed, acute wards, other private facilities, plus ambulances and emergency departments, have been freed up.

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

hospice@HOME is aligned with the World Health Organisation definition of Palliative Care and The District Nurses is committed to providing impeccable in-home care that neither hastens nor postpones death.



Kim Macgowan  
Chief Executive



Fiona Onslow  
Director of State Operations

# Summary



*'[Thank you] for the incredible care and love you showed to Mum and Dad over the past weeks and many, many months. The service provided was exceptional and so was the genuine compassion given to them. The emergency care you put into place straight after Dad's death was brilliant and the night time assistance was a godsend. Thank you for your support and assistance that was there when we needed it. Thank you also for helping us understand all the service providers.'*

This interim report provides an overview of hospice@HOME and how it is achieving its vision to give Tasmanians nearing the end of life the choice to die at home. 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 two years and we are confident that the next eight months of funding will see the program fully established as an essential element of the palliative care sector in Tasmania.

Some of these achievements were as follows:

- By end of June 2015 a total of 884 packages of care had been provided to clients around Tasmania.
- 46% of hospice@HOME clients died at home, compared to about 14% of the general Australian population.
- 50% of clients who said they wanted to die at home fulfilled this wish.
- 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.
- Waiting times between referral and admission to hospice@HOME are relatively quick, averaging between 3.7 and 9.6 days.

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 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 could result in the breakdown of a large service network and could potentially affect every person in Tasmania. We are confident that the program makes such good sense that the future will see the Tasmanian hospice@HOME model rolled out across Australia.

# Introduction

The hospice@HOME program is a new model of care for people approaching the end of life in Tasmania. It has been designed to give them, their families and carers optimal dignity, choice and control in this most significant journey.

The current program is a pilot, developed by The District Nurses in Tasmania and funded by the Australian Government until the end of June 2016. Its first two years have been a dynamic undertaking to get quality, coordinated care packages in place for those who are most in need of them. While often challenging, both for the organisation and for the existing health and community care system, the establishment of the program has been a journey of rapid learning and adaptation, with much achieved to date towards realising the program's aims.

hospice@HOME was launched in March 2014 by the Honourable Fiona Nash, then Assistant Minister for Health. It is part of the Better Access to Palliative Care (BAPC) program (included in the Tasmanian Health Assistance Package) that has been funded for the three years from July 2013 to end of June 2016. The program has had widespread support from across the political spectrum as well as within the Tasmanian community.

Other components of BAPC have included funding to the Department of Health and Human Services to enhance palliative care services and policy, and to the Tasmanian Association for Hospice and Palliative Care (TAHPC) for infrastructure support such as community development approaches towards death and dying, promotion of Advance Care Directives, volunteer training, and professional development.

Intrinsic to the development of hospice@HOME has been the establishment of a solid infrastructure, a competent workforce, strong partnerships with 40 contracted services and other components of the BAPC, and an extensive evidence base to ensure sustainability into the future.

While the program still has over half a year to become fully established and demonstrate its effectiveness, this report provides a brief overview of what has been achieved to date.

*'hospice@HOME enabled [my father] to fulfil his wish and die at his home. Without them, it simply couldn't have happened.'*

# Dying in Tasmania: the case for change

## Why die at home?

When asked where they would like to die most Australians nominate home as their first preference. While 70% of Australians would prefer to die at home, only about 14% achieve this goal. The remainder die in hospital or residential care. This propensity to die in institutional care is a relatively new one. Death at home used to be the accepted norm. Hospitals provide intensive near death clinical management but care at home can provide a better experience for many patients and their families. This is also a more cost-effective option for the health system.

hospice@HOME provides people nearing the end of life with the choice to die at home, or stay at home for as long as they wish. Packages of care provide a mix of clinical and other services through face-to-face visits and 24/7 telephone advice, ensuring patients and their families have optimal support at this critical time. Packages are adapted to individual needs and are designed to complement, not duplicate existing services. They give patients, their families and carers a sense of control and the necessary care to enable them to manage this intense time in the best way possible – in other words to have 'a good death'.

*A good death gives people dignity, choice and support to address their physical, personal, social and spiritual needs.<sup>1</sup>*

Other characteristics of 'a good death' that are promoted by hospice@HOME are an understanding of what is happening and what can be expected, control over pain and other symptoms, access to help and advice at any time of the day or night, information about the various roles of services that can help, and assistance with the bereavement process.



## Why Tasmania?

Tasmania is well-placed to trial the hospice@HOME style of service delivery. Its population of just over half a million people is a good size for trialling systems based approaches and conducting evidence-based research.

With Tasmania's rapidly ageing and highly dispersed population and high costs of hospital based care, hospice@HOME offers a cost effective way of providing palliative and end of life care to a growing number of people who would otherwise miss out on quality palliative care because of locational disadvantage.

The profile and needs of the Tasmanian population are changing. Tasmania has the most regional and dispersed population of any state in Australia, with 58% of the population living outside the greater capital city area.<sup>2</sup> It also has the oldest population of all Australian jurisdictions and is ageing more rapidly than Australia as a whole. All projections for Tasmania suggest that its population structure will continue to age faster than anywhere else in Australia with 25% of its population anticipated to be aged 65 and older years in 2030, up from 16% in the 2011 census. This equates to 60,000 more older Tasmanians in 2030 than in 2011. The rapid ageing of the population and increasing longevity are leading to larger numbers of older people with disability and severe or profound activity limitation.<sup>3</sup>

As the State's older population increases so too does the number of older people living alone. In 2011, 27% of Tasmanians aged 65 and older lived alone (as compared with 12% of all Tasmanians) with this proportion increasing to 38% for those aged 85 years and older. This is well above the Australian average of 34% for this age group.<sup>4</sup>

The average life expectancy for Tasmanians is slightly lower than for Australia as a whole. The most common causes of death are cancer, ischaemic heart disease and cerebrovascular diseases.

A significant number of hospitalisations in Tasmania occur in people aged 65 years and over. The rate of hospitalisation for this group increased by over 50% between 2002 and 2011, and there was a similar increase in palliative care admissions.

<sup>1</sup>Swerissen, H. and Duckett, S. *Dying Well*, Grattan Institute 2014.

<sup>2</sup>Australian Bureau of Statistics (ABS) Regional Population growth Australia, Tasmania, 2011-2012.

<sup>3</sup>State of Public Health 2013, Population Health, Department of Health and Human Services 2013.

<sup>4</sup>ABS 2011-12

# Our program

## hospice@HOME wrap around packages of care

hospice@HOME packages offer individually tailored services to meet a client's specific needs, enabling them to remain at home for their end of life care. The hospice@HOME model is intended to build on existing services and minimise the number of service providers and complexity of the care coming into the home.

Following referral, a hospice@HOME Care Coordinator contacts the Clinical Teams involved in the care of the client, in particular the General Practitioner and Specialist team, and then the client is contacted and hospice@HOME explain their role in supporting ongoing care coordination for the end of life phase. The Care Coordinator then visits the home and, in consultation with the client, family and other service providers, develops an individual package of services and support options.

A package of care can include a wide range of services such as in-home nursing, personal care, physiotherapy, respite, domestic support, transport, equipment, massage therapy, art therapy and pet therapy. Services are provided at no cost to the client.

The Care Coordinator brokers services from a wide range of organisations around Tasmania with which the program has developed service contracts. These contracts specify the quality of services to be provided. Most services fall into the general area of Support, which includes personal care, respite, support visits for shopping and meal preparation, and domestic support. Other service areas include care coordination and support for family. The packages have required only a small amount of input from Registered Nurses and Enrolled Nurses and it appears that the extra support services assist the current Clinical input (Figure 1).



*'Thank you for your support and assistance that was there when we needed it. Thank you also for helping us understand all the service providers.'*

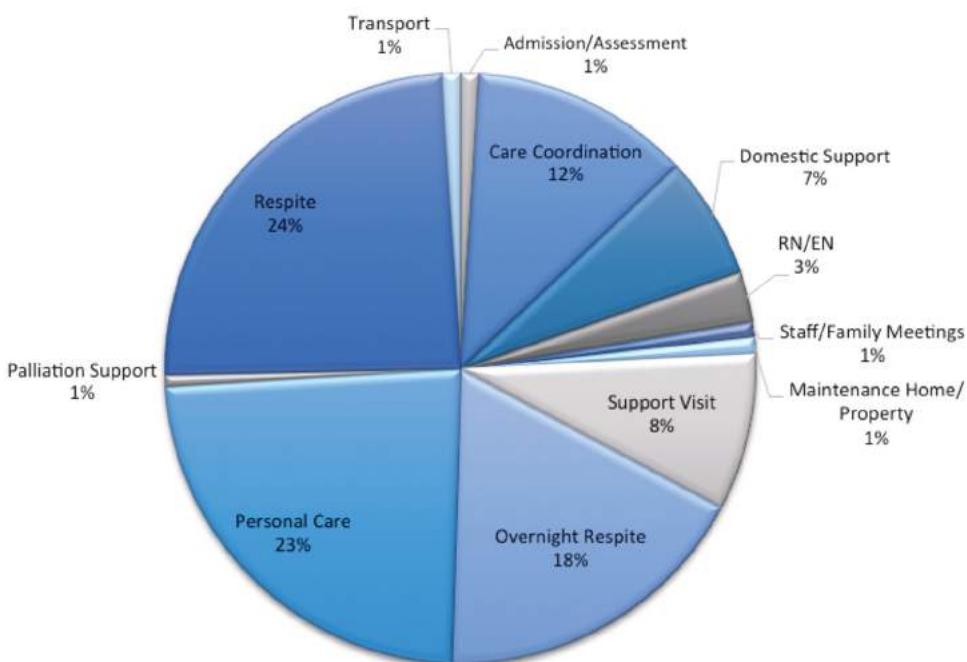


Figure 1. Percentage breakdown of brokered intervention services

# Our program

## 24/7 telephone support 1800HOSPICE

hospice@HOME provides a free, coordinated, single statewide call centre for advice and deployment of local on-call nursing staff 24/7 called 1800HOSPICE. Prior to the introduction of this service, after hours palliative care support was fragmented and variable depending on the region and locality in which it was sought. The aim of the service is to provide quality after hours support so that patients and their carers can make informed choices about their end of life care regardless of where they live.

1800HOSPICE is staffed by specially trained nursing staff who use the evidence based Palliative Care Telephone Triage Protocols. Staff provide feedback to the client's primary care providers on how the client is managing and any other issues that are impacting on their physical, social, mental or spiritual health. The service can coordinate rapid increases or decreases in care service provision.

*'I was on the phone with you the night dad died. You were a tremendous help to me and supported me to navigate the final hours of dad's life with dignity and control. Thank you for being empathic when I was crying, for walking me through the pain assessment process, for calling and getting top up pain relief approval through the GP on call and always keeping me in the loop. Later you helped me to recognise when dad was actively dying and when you visited our house your respect and professionalism blew me away.'*

## Our clients

Since the first intake of clients in December 2013 until 30 June 2015, hospice@HOME has had a total of 884 clients on its books. Some selected statistics are outlined below:

- 43% of clients lived in the South; 33% in the North; and 24% in the North West. In terms of overall population, the North was over-represented.
- 56.6% of clients lived in inner regional areas, 42.4% in outer regional areas, and 1.0% in remote or very remote areas. This compares with the Tasmania population breakdown of 64.7% inner regional, 33.2% outer regional, and 2.1% remote and very remote, indicating that hospice@HOME is achieving a good reach into rural areas.
- The average length of stay in the program is 91 days, or 3 months.
- The average length of time between referral and the client being admitted to the program is 6.4 days, with this figure varying from 3.7 days in the North West, to 6.6 in the South and 9.6 in the North of the State.
- There were slightly more male clients than female clients but this difference was not significant.
- As at 30 June 2015, 619 clients, or 70%, had died. The average age of death was 73 years, with the age range being 7 to 99 years.
- 26% of clients lived alone, 61% lived with family, and a further 13% live with others.
- The three primary causes of death were cancer (over 50% of clients), heart disease and respiratory disease.

A sample of 516 clients who were reviewed by the service indicated that:

- The average length of stay of hospice@HOME clients who went to hospital was 8 days, varying from 9.4 in the North, to 7.7 in the South, and 4.6 in the North West. This compares with an average of 12.9 days in inpatient Palliative Care in Australia.<sup>5</sup>
- 93% of clients indicated a wish to die at home, with almost 50% of them achieving this wish. 26% died in a Palliative Care ward, 22% in an acute hospital setting, and 2% in a Residential Aged Care Facility.
- hospice@HOME packages of care average three months in duration. Only 15 people remained active in the program for longer than 12 months, some of whom had Motor Neurone Disease where the disease trajectory is difficult to predict.

<sup>5</sup>Australian Institute of Health and Welfare 2012. Palliative care services in Australia 2012. Cat. no. HWI 120. Canberra: AIHW. P 79.





*'My experience was very beautiful with my husband. I thought they were amazing, all of them. If they had not come and made [my husband] so comfortable he would have had to die at the hospital which was not his wish.'*

## Our infrastructure

hospice@HOME was developed by The District Nurses, a Tasmanian community-based nursing service, and is co-located with this service in the South. Offices were opened in the North West (Burnie) in late 2013 and in the North (Launceston) in January 2014.

Current staffing is 21 full time equivalent. Clinical Nurse Managers are located in the South and North/North West and are supported by Registered Nurses, Care Coordinators, Social Workers and administrative staff.

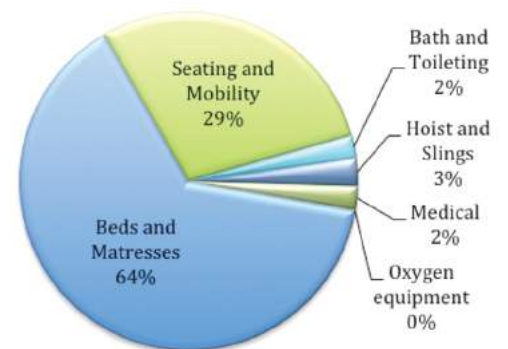
Communications systems (phone and electronic) have been developed and a client management system, UNITI, has been adapted for use by the program. A new client management system that better fits the needs of the growing service is currently being trialled and will be implemented in the near future.

## Equipment

The hospice@HOME equipment scheme has been invaluable in assisting people to realise their goal of remaining at home. Equipment is provided through Aidacare and includes a total of 674 items (Figure 2).

Clients access an average of 3 items, with the length of use averaging 45 days.

**Figure 2.** Breakdown of the type and amount of equipment held by hospice@HOME



*'The equipment provided [by hospice@HOME] made it easier to have Mum at home for the time that we did. All dealings with hospice@HOME staff were professional and caring.'*

# Our program



## Collaboration

An extensive range of policies and protocols have been developed and service contracts with 40 brokered organisations have been put in place. Between 25 and 40 organisations are brokered to provide services each month. hospice@HOME thus supports an extensive network of palliative care services.

Various forums have been established to ensure ongoing internal and external communication and these are helping to develop a stronger, more coordinated palliative care sector, where once there were gaps and duplication.

## Research/evidence focus

hospice@HOME is establishing a strong evidence base for the program. The research focus is on quality, cost effectiveness and supporting people to remain at home for their end of life care. This information will provide a platform for future development of palliative care in Tasmania as well as contribute to national and international knowledge on end of life care.

Analyses of data available through the existing data collection systems are being undertaken to answer questions regarding the quality and quantity of service delivery, service reach, and client pathways and experiences.

Other current research activities include:

- A comprehensive internationally benchmarked client and carer satisfaction survey of 260 clients has been conducted by Press Ganey and this will be repeated in early 2016.
- An analysis of acute service use by hospice@HOME clients as compared with clients not receiving hospice@HOME services is being conducted by KPHealth to look at actual and potential cost savings resulting from hospice@HOME intervention.
- A Reflective Analysis of the development of the hospice@HOME program is looking at barriers and enablers to its formation, and critical milestones and events from the perspective of key players involved in its establishment. This information will inform the evaluation of the program and the further refinement of the service model, as well as provide valuable insight for others considering the establishment of a similar end of life program
- An analysis of the After Hours service throughput and costs is being conducted.

hospice@HOME has an ongoing interest in best practice and innovative models of care occurring elsewhere and actively uses this information to inform and adapt practice. Staff keep up to date through participation in conferences (both as presenters and attendees), involvement in communities of practice forums and through literature scans.

## Special projects

### Just in Case

An action research project is looking at the introduction of an end of life symptom management package, based on the UK 'Just in Case' model. This will include carer education and support as well as a medication kit. The action research is being planned in collaboration with the Specialist Palliative Care Service (SPCS) and in consultation with other key service providers.

### Clientranet

Clientranet is a digital platform based on a Samsung Galaxy Tablet. It has been designed for client and carer use, providing them with clinical information and enabling communication with family, friends and professionals. The device will be set up based on the client's needs and will be supported through h@H. While the project has had some limited rollout in the North West, it has yet to be fully trialled. This will likely occur in conjunction with the 'Just in Case' project.

*'[Our] family very impressed with the level of expert and compassionate care provided to [my mother] during her short illness. All of the support services combined to make her time at home as comfortable as possible. Our family are very grateful to all concerned.'*



# Our achievements: the story so far

*'We would like to thank you all for the extremely excellent support you provided. Your care, support and professionalism was impeccable and greatly appreciated. Your service allowed us to grant our mother's last wish, which was to be at home.'*

## Meeting client needs

In the period up until the end of June 2015, 50% of hospice@HOME clients who said that they wished to die at home achieved this wish. Overall, 46% of hospice@HOME clients have died at home. This compares favourably with only 14% of the general Australian population who die at home, and countries such as New Zealand, the United States, Ireland and France where people are twice as likely to die at home than in Australia.

It is also evident that hospice@HOME clients who did not die at home managed to stay at home longer at end of life than people who were not part of the program.

The assessment criteria for hospice@HOME, which requires a doctor to determine that a client will die within 12 months, has been demonstrated to be appropriate for the client group. While the average length of stay in the program is only three months, 12 months allows for clients such as those with Motor Neurone Disease, where the trajectory towards death cannot be predicted, to receive much needed services in their last months.

A review in 2014 of the after hours 1800HOSPICE service introduced by hospice@HOME demonstrated that clients using the service achieved better outcomes in terms of client experience and there was a reduction in the use of Tasmania Ambulance and Emergency Departments. There was also a correlation with people achieving their wish to remain at home. It is estimated that over a year hospice@HOME saved the acute health care service a total of \$120k.

A client and carer satisfaction survey conducted by Press Ganey, the world's largest provider of healthcare satisfaction services, has provided evidence of hospice@HOME's success in filling service gaps and improving quantity and quality of care. The results of the survey were benchmarked with international and national palliative care peer groups. hospice@HOME received an overall benchmark ranking of 88.8 which compared favourably with other services, particularly given the fact that the program was still in an early stage of development at the time the survey was conducted. It was rated particularly highly with regard to friendliness and helpfulness of staff and their concern for the client's comfort and confidentiality. Also very highly rated was the degree to which services support quality of life and overall quality of care. Most clients and carers would have recommended the service to others. A follow up client and carer satisfaction survey is planned for early 2016.

## Developing innovative approaches towards service delivery

From a patient and carer's perspective, factors associated with a good death include managing symptoms and achieving a sense of control. hospice@HOME has been encouraging the use of Symptom Action Plans (SAPs) with end of life patients, which increase their likelihood of dying at home.

The use of Advance Care Directives that enable patients to document their wishes regarding end of life care are also encouraged. The Tasmanian Association for Hospice and Palliative Care is promoting the use of these Directives in the broader community.

## Service coordination and collaboration

Carers and clients tell us that they find it difficult to navigate through the maze of health and community services that are out there and have difficulty in finding the right people to talk to in order to get the services that they need.

Service coordination and the development of a culture of collaboration have perhaps been the most challenging aspect of program implementation. When BAPC was first conceived, the palliative care sector in Tasmania was fragmented and uncoordinated. Service models in each of the three regions were quite different and specialist services were, for the most part, limited to urban areas and their immediate surrounds. hospice@HOME, along with its partner BAPC organisations, has been actively working to reduce fragmentation across the palliative care sector in Tasmania.

hospice@HOME has also been working to improve coordination with ambulance services and hospital emergency departments. Both services are now able to identify hospice@HOME clients through a wallet card and pathways have been developed to help clients stay at home or return home rather than be admitted to hospital. hospice@HOME also works with hospital staff to identify patients who no longer need intensive clinical care and for whom discharge to home based care may be appropriate.

## Continuous quality improvement

hospice@HOME has implemented a continuous quality improvement (CQI) approach from the commencement of the project. As a project in a highly developmental phase, rigorous reflective practice and enquiry have been supported by processes of review and learning. Following closure of their package of care, a review of patients is undertaken to identify any system or care improvements required in the program.

The hospice@HOME program strives for best practice at all times. A Risk Improvement Plan (RIP) is regularly monitored to ensure any issues identified result in changes to practice.

Staff are supported to maintain currency of practice through professional development opportunities and a journal club within the organisation.

## Stakeholder engagement

hospice@HOME has been very committed to building strong relationships across the breadth of service providers as well as consumer groups involved with the palliative care sector. The importance of building connections, understanding the sector and the roles that others can play in supporting people fulfil their wish to die at home is recognised and acknowledged as part of the staff roles. Significant time, effort and resources have gone into engaging with others, providing information about both the hospice@HOME and BAPC program.

hospice@HOME recently hosted a statewide forum to build stronger connections, coordination and collaboration between services to meet patient needs. A further forum is scheduled for November to continue the work of overcoming challenges and building collaboration as well as sustainability.



# Costs of care

The District Nurses received a total of \$35mill to operate the hospice@HOME program and provide 2,000 packages of care over a three year period. The budget included extensive set up costs – e.g. office fitouts, establishment of phone systems, development of new client management systems, and purchase of in-home equipment - and a substantial investment in research and the development of a strong evidence base.

Approximately \$3.5m of hospice@HOME's annual budget is allocated for purchase of brokered services through a network of 40 community organisations.

Actual ongoing expenditure has yet to be fully determined but is anticipated to be in the region of \$6 -\$13k per package. This is in line with Swerissen and Duckett's costing of approximately \$6k (at 2013/14 levels) for a three month end of life package of care.<sup>6</sup>

The ongoing number of packages required for Tasmania is anticipated to be in the region of 800 per annum, therefore annual costs would be between \$4.8million and \$10.4million.



## The future

The establishment of hospice@HOME has entailed a massive effort by a team of very dedicated people with the enthusiasm, vision and organisational skills to project manage it from conception to implementation. Should the program funding cease at the end of the pilot phase in June 2016 much would be lost not just for those providing services and their clients but also for the network of organisations brokered through hospice@HOME, the program's BAPC partner organisations, and the health and community sector as a whole. If the option of a supported death at home were to be curtailed or reduced, every Tasmanian could potentially be adversely affected.

*Palliative care and aged care should not primarily be the province of the hospital and the acute care system, and our continued acceptance of this and the concentration of health care spending in the last months of life is no longer tenable, It represents both bad care and a waste of money.*

From 'Time to rethink end-of-life care', Medical Journal of Australia, 6 June 2011, p 563

We are confident that the next eight months will enable us to fully realise our vision for the program and will see a continuous increase in the number of Tasmanians who are able to fulfil their wish to have a good death at home.

We also believe that the program makes such good sense on all levels (and the evidence we are collecting supports this contention) that the future will see the Tasmanian hospice@HOME model implemented across Australia.

<sup>6</sup>Swerissen, H. and Duckett, S. *Dying Well*, Grattan Institute 2014, p 21.

*'I hadn't realised that such comprehensive support existed to support families [and their] loved ones at their end life phase. When dad was dying he had a spike in pain and this happened over the weekend. The hospice@HOME nurses were incredible. I was on the phone with you the night dad died. You were a tremendous help to me and supported me to navigate the final hours of dad's life with dignity and control.*

*Thank you for being empathic when I was crying, for walking me through the pain assessment process, for calling and getting top up pain relief approval through the GP on call and always keeping me in the loop. Later you helped me to recognise when dad was actively dying and when you visited our house your respect and professionalism blew me away.'*



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