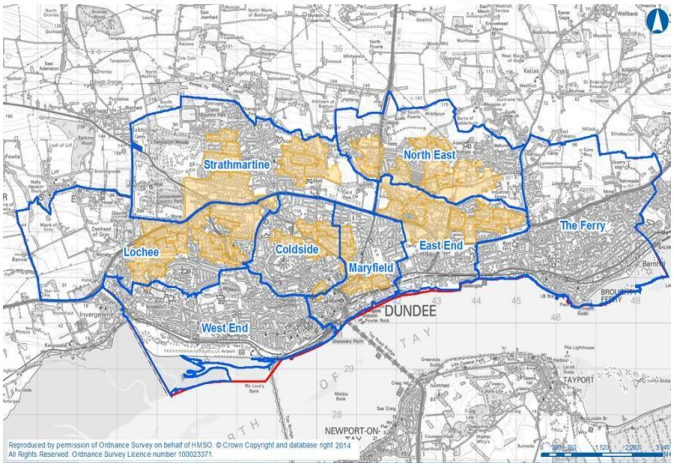
Dundee: Living and Dying Well in Care Homes

A local story



Source: Map produced by Dundee City Council using data from Scottish Index of Multiple Deprivation 2012, Scottish Government

Introduction

The Scottish Government's Strategic Framework for Action on Palliative and End of Life Care states that everyone in Scotland who needs palliative care will have access to it by 2021[1]. To support this 10 commitments were developed, with Commitment 1 focusing on identification and care coordination for people with palliative support needs.

In relation to dementia and palliative care the following two commitments in Scotland 3rd National Dementia Strategy, 2017 – 2020 were also developed:

- Commitment 5: We will test and evaluate Alzheimer Scotland's Advanced Care Dementia Palliative and End of Life Care Model, and
- Commitment 6: We will work with stakeholders to identify ways to make improvements in palliative and end of life care for people with dementia[2].

Dundee Health and Social Care Partnership worked with Healthcare Improvement Scotland's Improvement Hub (ihub), specifically the Living Well in Communities and Focus on Dementia portfolios, from November 2017 to November 2019, to support the implementation of the three commitments. Two care homes in Dundee were selected for this work, Harestane Care Home (Nursing) and Craigie Care Home (Residential). This story highlights the work undertaken and the results.

Dementia and palliative care – the evidence

It is estimated that 90,000 people are living with dementia in Scotland. Dementia is the second leading cause of death in Scotland, accounting for 11.3% of all deaths, and the leading cause of

death among women[3]. The proportion of people dying with dementia is growing due to increasing life expectancy.

A third of people living with dementia live in care homes[4]. A study by Lithgow et al (2011) found that almost 90% of people in the care homes they studied had some form of dementia, with 35% of those likely to be in the advanced stage[5].

Average life expectancy for people living with dementia has been shown to be 4.5 years[4]. Due to the gradual trajectory of decline in dementia there is a great deal of uncertainty in understanding when a person with dementia is actively dying[6]. This can lead to individuals' needs not being met and lead to unscheduled hospital admissions. McCarthy et al (1997) found 67% of people with dementia had been in hospital during the last year of their life, with 26% staying for a period in excess of three months[7]. Sleeman et al (2014) investigated the trend in hospital deaths for people with dementia in England and found two in every five people with dementia die in hospital[8].

People with dementia are much less likely to receive palliative care, and those who do typically do not begin receiving it until around two weeks before death[9]. The most complex phase of dementia requires a multidisciplinary co-ordinated and planned approach to support those providing day-to-day care[4].

Methods used in the Dundee project

The focus of the project in the two care homes was to test two identification tools: one for assessing advanced dementia, and the other a functional assessment tool for palliative care, and to test the Advanced Dementia Practice Model[4]. In addition to testing these core components, Anticipatory Care Planning was the underpinning method for capturing the individual's wishes*.

Alzheimer Scotland's Advanced Dementia Practice Model[4] provides a framework so that the care and support given to people with advanced dementia and at the end of life is integrated and comprehensive. It incorporates the 8 Pillars Model of Community Support[10] and introduces an Advanced Dementia Specialist Team for optimum care (see Figure 1).

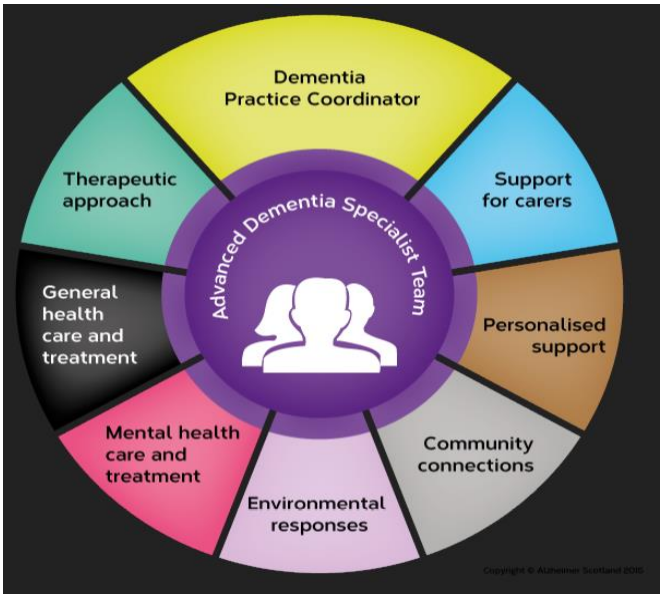


Figure 1: Advanced Dementia Practice Model, Alzheimer Scotland[4]

What did the two teams do?

- Engaged in and completed training in Foundations in Palliative Care
- Engaged in identifying individuals for journey mapping to extract themes from pathways.
- Captured thoughts and views of the staff groups through a series of focus groups
- Identified carers that would be willing to share their story of care
- Tested identification tools – The Functional Assessment Staging Test (FAST) scale and the Palliative Performance Scale (PPS)**
- Developed a pathway to reflect the Advanced Dementia Practice Model[4] and Care Coordination for testing with the identified care homes and Dundee's Care Home Team.

* See further information on Anticipatory Care Planning from the ihub website.

**There is further information on identification tools in the Palliative Care Identification Tools Comparator on the ihub website.
https://ihub.scot/media/6484/palliative-care-identification-tools-comparator.pdf

Findings from staff and carer interviews

Early identification of palliative care needs are essential to focus on a person-centred, proactive thinking ahead approach to support a person to achieve the end of life that they want. It also ensures that the people closest to the person are aware of what may occur as the individual moves towards end of life. To deliver this, staff need to be skilled and confident in their roles, linking with other areas of health and social care services to support the individual to die in the place of their choosing.

"The team were very good at having difficult conversations over end of life care and wishes for my husband. They cared for my husband with consideration and dignity – This was very important to me and our family"

Carer

"We need to do something differently' to impact on person centred care"

Care Home Staff

"The team were able to help facilitate time for me to be with Mr A on my own, I really appreciated that"

Carer

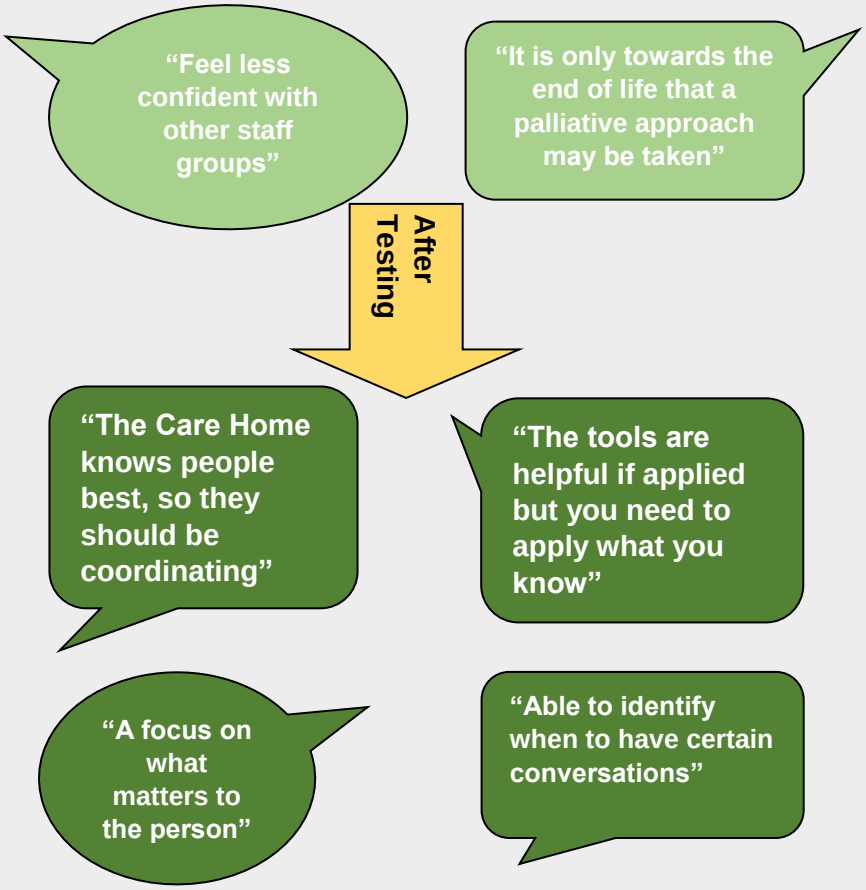
Learning for the project

- Staff teams wanted to do the right thing for people, but highlighted gaps in their confidence and knowledge when approaching identification of palliative care needs and end of life. They also expressed a desire for improving partnership working across the wider health and social care system.
- The review of the journeys of care supported the experience of staff and late identification of palliative care needs. Although individual personal outcomes plans reflected end of life wishes, this information was frequently not shared or recorded in an Anticipatory Care Plan.
- For carers, it was important to feel involved and part of decision-making and to feel confident in care home staff supporting their relative. It was also important for there to be openness about what may happen towards the end of life.

What the teams did and what they found

Testing of identification tools: FAST and PPS	Coordination of care	Care at home or within a homely setting
Where identification tools were applied robustly and considered as part of key information as a support to clinical decision-making and review they were useful to assist planning and conversations regarding care. Both care homes felt that the FAST tool was more suited to their needs, with one care home identifying that it was more helpful in supporting conversations with carers about future wishes, as the tool identified what people could expect towards the later stages of dementia Where identification tools are robustly applied and considered as part of review and considered as part of review they may be useful in supporting 'whole sight' review of complexity and trigger conversations for future planning	The core team focused on developing a pathway of care to support integrated care delivery across the Care Homes and Care Home Team The pathways identified key stages in a resident's journey as: • 6-week review • Where deterioration is identified • Multidisciplinary review Structure of the pathway enabled the individual, family and care providers to consider care and treatment preferences and share across all areas of service through Anticipatory Care Planning Care home Personal Outcomes Plans were linked to the Advanced Dementia Practice Model[4] and the care home staff developed a structured review document to capture information and plan from review	Where identification tools are routinely applied and earlier conversations are prompted through clinical discussion they: Reduced transactional response to deterioration Worked to help people to stay in their preferred environment for longer and prevented unnecessary hospital admissions

Language and perceptions of care home staff have changed:



KEY LEARNING

Developing and maintaining a skilled and competent workforce should not be underestimated and is essential in shaping models of service that put the individual at the centre of care

Key Themes

- Shared understanding
- Behaviours
- Decision-making
- Leadership
- Achieving outcomes that matter

What the teams achieved

Harestane Care Home (Nursing)

In January 2019, 38% of Anticipatory Care Plans had been completed.

By September 2019, **70%** of Anticipatory Care Plans had been completed and shared on electronic systems.

This was a percentage increase of **46%**

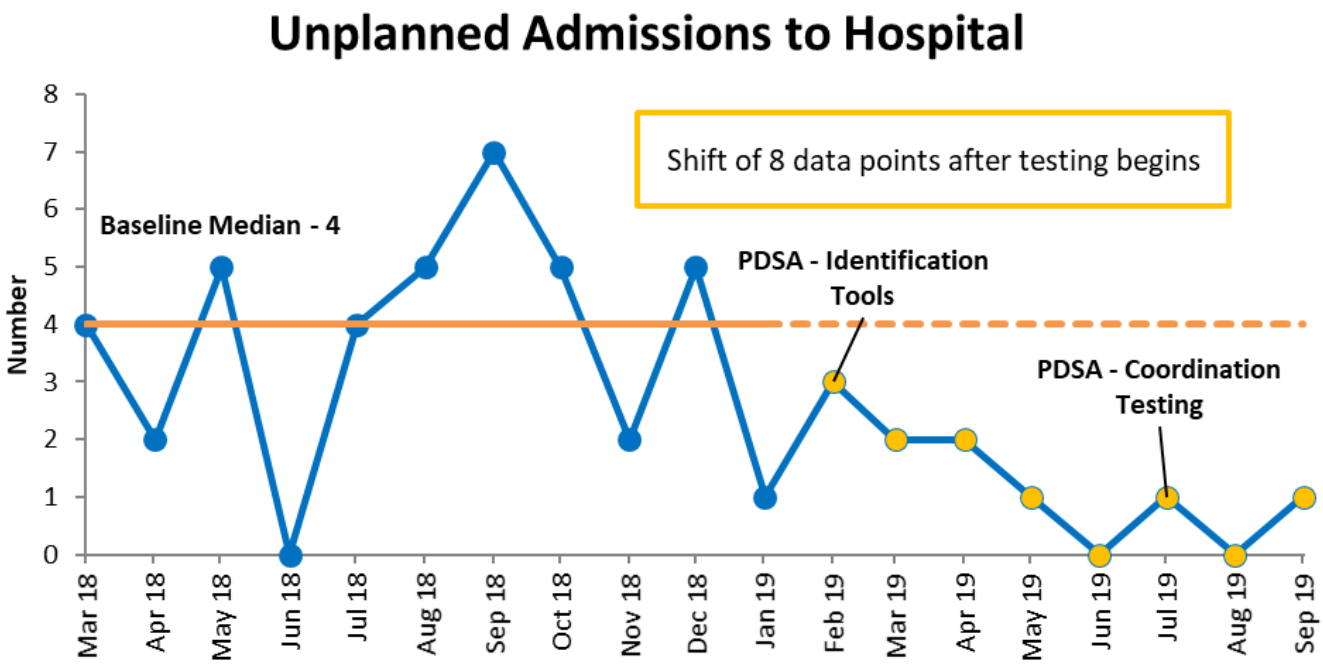
73% of people achieved their preferred place of death during the tests

Craigie Care Home (Residential)

From the 17 beds occupied, the FAST tool identified that nearly two thirds of residents scored a rating of 6 or above, indicating advancing stages of dementia.

Application of the structured document supported increased confidence and skill in the coordinating role.

In January 2019, 18% of Anticipatory Care Plans had been completed, with an increase to 59% in September.



Learning going forward

- Frontloading Quality Improvement Teams engaging in education and training is critical in developing knowledge, understanding and, importantly, to give confidence to act on developing services.
- The value of a skilled and competent workforce should not be underestimated, and has been a critical factor in the learning achieved throughout the life of the project.
- Use of identification tools, when applied robustly, may highlight a shared understanding of current presentation, trigger timely care interventions and future planning.
- A focus on models of service and pathways that support the individual and develop shared decision-making through earlier collaborative conversations are essential.
- Work with all agencies to shift focus and develop preventative anticipatory approaches, and reduce inequalities in care by creating a shared culture of language and understanding.
- Leadership at all levels of care working collectively to build a cooperative integrative leadership, where the success of the person's care is every leader's priority, not just relevant to the success of individual areas of service.

What informs continuous future improvements?

- Learning from the project has highlighted many areas of complexity that are critically relevant in the context of how they influenced our change efforts, such as a different understanding of what palliative and end of life means.
- Developing and sustaining a healthy organisational culture is essential to create the conditions for high-quality delivery of health and social care systems. This has been reflected in the learning. From testing new ways of working and developing a new approach to attaining collective leadership, to sustaining and seeking to embed quality improvement within the culture of health and social care.
- A commitment to extend Foundations in Palliative Care Education to care homes in Dundee and identification of care homes that want to be engaged in taking learning forward.
- The learning from the project has supported thinking from all teams about transitions in care and what aspects of care it may be beneficial to consider at each point.

In conclusion

- Education and developing skills are essential to develop confidence in the workforce to act on a person's wishes, and Dundee has committed to offering the provision of training to all care homes within the city.
- The use of identification tools may support a timely response to deterioration.
- Developing person-centred pathways and models of service contribute to coordination of care, but also there is a need to acknowledge that care coordination and care integration present challenges in aligning care.
- Identification tools, and also Anticipatory Care Planning, are key components that can drive people's experiences of care, but coordination through supportive pathways and developing models of service are the mechanism to deliver the right care at the right time.
- The learning from nursing and residential care homes may suggest that different levels of intervention may be required depending on the blend of shared understanding, behaviours, decision making and, crucially, leadership.
- There were no referrals made to the specialist team during the phase of testing coordination. Further testing would be required to ascertain reasons for no escalation beyond the Care Home Team.
- The benefit of a healthy organisational culture is essential to create the conditions for high-quality delivery of health and social care systems, where people from different service areas are brought together to deliver the care that matters to the individual.

Find out more

For more information on the work in Dundee, please contact Hilary Provan, hprovan@nhs.net

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