



## End of Life Care Service for People with Dementia Living in Care Homes in Walsall

Published to coincide with Dying Matters Awareness Week 2016, this case study focuses on an innovative end of life care service in Walsall initiated through collaboration with Pathways 4 Life (partnership between the Accord Group and Age UK Walsall) and St Giles Walsall Hospice.

The core service consists of two community-based Dementia Support Workers (DSWs) who work in care homes across Walsall in order to provide expertise, insight and knowledge to further improve dementia and end of life care. The DSWs strive to empower care home staff, people with dementia and their families through development sessions, support and guidance, along with a strong partnership working ethic.

The DSWs use a range of evidence-based tools, including the 'Namaste Care' approach, to advance a more holistic approach to dementia and care. This involves helping to create safe and relaxing spaces, and providing a broad spectrum of meaningful person-centred activities, some suitable for using with individuals even at the very end stages of their lives.



*"Your help has been tremendous"*  
Care home Care Manager

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## Introduction, Aims and Objectives

There is a well-documented pressing need to improve care within settings where people with dementia are living (e.g. CQC, 2014<sup>1</sup>). Providing good quality end of life care, especially for people with dementia in care homes, can prove particularly challenging. This includes enabling people to die in their own home rather than in acute hospitals, which is still the experience of many (e.g. EoLCC, 2016<sup>2</sup>). The Pathways 4 Life and St Giles Hospice end of life service was set up as a response to these challenges.

Key service objectives include:

- improve staff awareness of the importance of meaningful engagement
- increase the type and levels of meaningful activity and engagement
- encourage the adoption of the Namaste care approach<sup>3</sup> which advocates a holistic, person centred approach to care
- improve staff awareness of the importance of Advance Care Planning for residents and ensure that end of life care plans are carefully considered and tailored for each individual
- increase the amount of resources and signposting available to care homes
- improve staff awareness of, and confidence in working with, useful tools such as the Abbey Pain Scale, PAINAD, MUST Screening Tool and Care Fit for VIPS
- increase the use of assistive technology
- decrease the amount of unnecessary hospital admissions.

The service was funded by the NHS Walsall Clinical Commissioning Group, initially for one year until May 2016. Funding for a further year has also been secured.

## How the Service Works



Two Community-based Dementia Support Workers (DSWs) provide specialist evidence-based advice, development sessions and support to care home staff across Walsall. Their role is to actively promote best practice approaches to dementia and end of life care. They work with care home staff, residents and their families and identify areas for potential improvement which will provide a positive outcome for residents and their families. The service has a strong joint working ethos. The

DSWs not only work in partnership with people in the care home but also alongside hospice staff, nursing case managers, ambulance teams, community groups, occupational therapists and the voluntary sector.

1 CQC (2014) *Cracks in the pathway: Our review of dementia care*. Care Quality Commission, October 2014.

2 End of Life Care Coalition (2016) *On the Brink: The Future of End of Life Care*. Macmillan Cancer Support, 2016.

3 Namaste Care is a programme designed to improve quality of life for people living with dementia and/or a terminal illness, by creating safe and relaxing spaces, whilst providing a broad spectrum of meaningful, person centred activities that include sensory stimulation and advocate a more holistic approach to care

The DSWs begin their engagement with a care home by carrying out a series of observation studies. During these observations they look for signs of person centred care, effective communication from staff and whether homes utilise assistive technology to better support their residents. They then deliver a series of in-depth development sessions focusing, for example, on supporting care staff to develop their existing skill set and working practices. Together with care home managers, they will work on formulating an improvement plan for homes using Care Fit for VIPS.<sup>4</sup>

The DSWs also make recommendations on how to improve the environment (such as the use of appropriate signage and orientation aids) and to increase opportunities for socialisation, activity and meaningful engagement. They will promote and support care homes to adopt the Namaste care approach and to ensure that they are providing care which is fully person centred. They can deliver tailored development sessions for care home staff and work towards improving their understanding, their approach and their communication skills through role modelling activities. Typically the DSWs' work will encourage the use of: reablement and positive risk taking principles; 'This is Me'/Life Story work; wellbeing action plans; end of life care plans; engagement in dialogue with families and friends; outside activity where possible; individual management strategies for behaviour that challenges; nutritional screening tools such as MUST; Dementia screening tools such as 6CIT; and pain and depression screening tools. If signs of pain or depression are observed, information is passed on to GP.

These guiding principles help to steer the service:

- make sure that the people with dementia are always at the centre of everything
- maximise partnership working
- utilise an evidence based practice approach
- empower and engage volunteers, staff and family to maximise their contribution.

## Effects the Service is Having

### Evidence of Impact

Findings from an ongoing evaluation study are providing evidence that the service has led to:

- a decrease in unnecessary admissions to hospitals
- an increase in engagement activity among many residents with dementia
- care home staff feeling more confident in their abilities
- strengthened links between Health and Social Care
- an improvement in continuity of care across the borough by increasing communication between care homes and other relevant services



<sup>4</sup> Based on the internationally recognised 'VIPS Framework' developed by the Association for Dementia Studies with Professor Dawn Brooker, University of Worcester.

- staff having a better understanding of what constitutes an emergency and what does not
- the introduction of more effective and efficient documentation / paperwork.

Changes resulting from the implementation of the Namaste Care Approach include:

- improved quality of life and sense of wellbeing for residents
- increase in socialisation between residents
- staff developing and exploring additional ways of communicating with residents
- improved engagement with family and friends
- staff feeling more enthusiastic and motivated about their role: *“we’ve needed this for a long time!”*
- staff feeling more confident
- greater appreciation of residents’ capabilities
- fuller understanding from staff and families of what advanced needs entail
- less task-driven working practice
- improved understanding of the importance of creating meaningful moments for residents
- improved understanding from staff of how important it is to make the, *“sunset as good as the sunrise”*.



## Case Example

### ***Beryl***

Beryl has:

- a diagnosis of mixed dementia
- limited communication with others
- only ever used one word - “Birmingham”
- lacked confidence to socialise with others within the care home
- appeared to be very frustrated and anxious within herself.



### ***Challenges***

Staff at the Home where Beryl lives:

- had a lack of understanding of the importance of activities, in particular music
- lacked confidence to deliver activities
- lacked confidence in identifying ways in which they can communicate with Beryl
- did not have an in-depth understanding of Beryl’s dementia
- did not have a good knowledge about her interests, past history or likes and dislikes
- were risk adverse.

### **Changes Made Included:**

- DSWs spend time with staff to help support a deeper understanding of Life Story work and the benefits this can bring
- each staff member being asked to identify one piece of important information about Beryl and from this information being able to each introduce a meaningful activity
- discovering that Beryl loves music
- DSWs providing a wide variety of activities around music, i.e. music quizzes, musical instruments
- offering Beryl an iPod.

### **Outcomes**

- Beryl immediately took to 'Le Fabuleux Destin d'Amelie Poulain' soundtrack and continues to listen to this a lot
- she is now communicating much more, asking others: *"Can you hear this?"*, *"Listen to this with me"*, *"This is fantastic!"* – whilst clapping her hands and tapping her feet
- Beryl is now making friends for the first time since moving into the care home
- she has started smiling.

### **Further Examples**

A resident who displayed agitation by shouting loudly at a similar time late each evening, was offered the opportunity for a hand or foot massage from a member of staff before it got to that time wherever possible. This, together with instigating other interventions from the Namaste approach, led to a significant decrease in the resident's levels of agitation, distress and boredom. She now no longer shouts out and other residents have started to spend more time in her company.



During a Namaste session with one gentleman, a very moving and powerful moment occurred. As part of the interaction, staff used a perfume that his wife used to use which he had not smelt for many years since she had passed away. Whilst the gentleman did not verbalise his feelings, staff witnessed a tear fall down his cheek as a broad smile stretched across his face. One of the staff team explained that many of their residents have limited recognition of many places, faces or moments from their past but, "since introducing Namaste, we have seen a distinct increase in residents being able to identify certain smells, personal items and photographs from their earlier lives."

Staff at another home had a misconception that the Activity Team's only role was to organise large events such as bingo or entertainment. Following the Namaste programme being introduced they all have a fuller appreciation that activity with residents is not just about group events but as much about a series of meaningful exchanges and collaborations which are tailored to each individual within the setting.

In addition, all staff, from senior nurses to domestics, are showing a much greater interest in what the Activity Co-ordinators are doing and, as a result, now have a much better awareness about what meaningful activity should and can entail.

During care planning discussions, a new resident was asked if she would also like to have an Advance Care Plan (ACP). These had been recently introduced by the home following one of the sessions from the DSWs. The lady, who had capacity, decided that she would like to complete one and the home staff were able to discuss and document her end of life wishes and preferences.

Sadly and unexpectedly she passed away only a few days later. Her family were shocked and upset and did not know where to begin planning the funeral. They were therefore incredibly relieved and grateful to learn of the ACP, be given full access to the paperwork, and to be able to make fully informed decisions about their relative's funeral and service plans. Without having had the ACP, both the home and the family would not have been able to have put the lady's genuine preferences and best interests at the forefront of their care.

## **Recognition of Achievement**

Several care homes which have utilised this service have been awarded recognition certificates by Walsall CCG at the Mayor's Parlour in acknowledgment of their improvements in dementia and end of life care. These recognition awards are significant as they highlight how successful the service can be when care homes embrace and engage with the support available.

## **Learning Points from Working with Care Homes**

### **Need to be aware that:**

- end of life symptoms are commonly misunderstood and may not be picked up by care home staff
- professionals, including care home staff and GPs, can be unaware of what dementia support is available, such as dementia cafés, carers' centres and day opportunities
- clinical staff, such as Ambulance staff, District Nurses, and Nursing Case Managers, going into care homes do not necessarily have an understanding of dementia
- there is often a lack of collaboration between services providing support for people living with dementia and/or end of life care needs.

## Important Ingredients for the service have been found to be:

- a requirement that the DSWs are highly experienced in both care and dementia in addition to working with people at end of life
- providing a service that is 'needs led' and not 'provider led', with recognition that every person with dementia is different
- having the confidence to challenge attitudes and behaviour where there is a need (e.g. with a GP)
- support and engagement from care home management and other key professionals is essential in order to maintain momentum and make improvements.

## Moving Forward

The service has been re-commissioned for a further 12 months and, alongside their current work within care homes, the DSWs will begin to extend the support they offer to people living in the community as well. It is anticipated that they will provide guidance to individuals with dementia and end of life care needs living in their own homes, as well as to their families and the social care and health professionals assisting them. It is hoped that by widening the service's reach, better end of life care can be provided to as many people as possible across the borough and individuals can be supported to live as well as possible, until their death. The service will give guidance on how to provide comfort to those living with end of life care needs, how to achieve dignity in death, and help people to ensure that their wishes and preferences are realised.

In a further bid to reduce the number of unnecessary 999 calls made by care homes across Walsall, the DSWs, Clinical Commissioning Group, and Walsall Ambulance Team leader have developed a working group to conduct a review of this. Further work is also being conducted locally to set up an End of Life steering group for a range of community, health and social care providers to agree best practice approaches for Walsall.

## About Pathways for Life



Walsall Clinical Commissioning Group

## Accord Group



The Accord Group is a not for profit and one of the largest housing and social care organisations in the Midlands, providing 13,000 affordable homes and health and social care services to 80,000 people, employing nearly 5,000 staff.

## Age UK Walsall



Age UK Walsall is an independent charity, registered in November 1996, aiming to support all elderly people aged 50 years plus across the Walsall borough by providing relevant services, information, advice, and advocacy.

## St Giles Hospice



St Giles Hospice was established in 1983 and has sites in Walsall and Whittington. It is a registered charity providing high-quality medical and nursing care for local people living with cancer and other serious illnesses. St Giles has over 400 staff, over 1,500 volunteers and 31 charity shops, with over £9 million spent on providing care every year.

## Note

The views expressed in this paper are those of the authors and not necessarily the Housing Learning and Improvement Network.

If you would like more information about the DSW EoL service, please contact Nicole Beeching at [nicoleb@accordha.org.uk](mailto:nicoleb@accordha.org.uk)

## About the Housing LIN

The Housing LIN is a sophisticated network bringing together over 40,000 housing, health and social care professionals in England and Wales to exemplify innovative housing solutions for an ageing population.

Recognised by government and industry as a leading 'knowledge hub' on specialist housing, our online and regional networked activities:

- Connect people, ideas and resources to inform and improve the range of housing choices that enable older and disabled people to live independently
- Provide intelligence on latest funding, research, policy and practice developments, and
- Raise the profile of specialist housing with developers, commissioners and providers to plan, design and deliver aspirational housing for an ageing population

For information about the Housing LIN's comprehensive list of online resources on housing and end of life care visit:

[www.housinglin.org.uk/Topics/browse/CareAndSupportatHome/EndOfLifeCare/](http://www.housinglin.org.uk/Topics/browse/CareAndSupportatHome/EndOfLifeCare/)

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