

# Real stories: Real insight

## Help for others to replicate

March 2013



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Developing key worker competences for domiciliary care workers to support an integrated pathway for end of life care.

May 2011

  
the bottom line is better care

  
**National End of Life  
Care Programme**  
Improving end of life care



# Extract produced in March 2013 from the full report published in May 2011

This document is an extract from the full report. It is intended for use with the film of domiciliary care workers (DCWs) in a training pack produced by Skills for Care.



This (9 page) extract provides the ‘Help for others to replicate’ section.

## It includes:

- insights
- a list of six activities to help others replicate the approach and findings
- recommendations for your local services:
  - 1 the development of a generic worker role across health and social care
  - 2 apply person centred thinking as a key element of advanced care planning
  - 3 consider whether your local end of life care is commissioned around institutions or the person.

For readers who require a more detailed explanation, a separate (29 page) document entitled “Real stories: Real insight competences” is contained within the training pack.

# Conclusion with recommendations

Through gathering stories from people and workers in health and social care it became apparent that the perception of end of life being totally a ‘health’ responsibility needs to change and that a person should be able to ask any visitor to their home for help and information.

The term ‘end of life’ is not always clear for relatives or carers, and they seem to believe this is within the last week or days for a person. This is echoed across both health and social care staff as well in their reluctance to have conversations early on about preparing and planning for death. This is borne out as, too often, we see admission to hospital because planning has not been discussed adequately and clinicians do not offer people their choice of care as they concern themselves with ‘saving life’. One carer quoted that doctors and nurses do not know about what people need when they are dying as they are only trained in making people better. The presence of a key worker should support all agencies to understand the wishes of people at end of life.

What we have found is that through these stories some of the differences that mean the most to people in being able to manage and benefit from support is more about the smaller, often not recognised aspects of care. People maintain their confidence and dignity if they feel their expressed needs are being listened to, the benefit this has to their overall ability to manage at end of life is currently immeasurable, but confidence in their carer is key.

The public and care staff both said they would want someone to be cared for with the right attitude and at a high standard or level of dignity that you would want for yourself. Underpinning competency and skill is the understanding that what makes an ‘excellent worker’ for people at end of life and their families are the human principles of caring, wanting to help, interaction and listening. Through person centred thinking we can understand what a person feels happy about and what they would like to change, these are not the advances of medical science or expensive treatments but the skill of a person to listen and to adapt to a circumstance or a wish.

This project has enabled focused discussions and linkages to happen to allow us to better understand the current state of partnership working across health and social care in relation to end of life care.

The key to determining if we have in fact delivered on the social care framework objectives and changed care for the better, will be the delivery of Wakefield and Hull’s sustainability plans, the fact that we now have such plans means we have partly achieved our objectives.

# 6.1 Insights

This section includes insights gathered in relation to specific objectives that are in the social care framework.

## Insights grouped into:

- what the public would like to see included as key competences for domiciliary workers
- emergent themes from social care managers and staff.

## Local insights on making the project sustainable

The table below looks at learning from the project with reference to the social care framework.

Objective from Social Care Framework	What we have learnt about delivering the objective
<p>Identify and raise awareness of the role of social care in supporting people at the end of life, among the public, social and health care workforce and management.</p> <p>Promote understanding and best practice in holistic assessment of individuals, their carers and families at the end of life.</p>	<p>In using various methods to seek understanding of the role of DCWs we have seen that DCWs could have the skill and competency to work as a key worker for people at end of life. This is more effectively done when part of a multi-agency approach to planning care.</p>
<p>Promote early engagement with end of life care planning that builds on a holistic understanding of wellbeing.</p>	<p>In using person centred thinking and planning tools DCWs have gained a more in-depth understanding of the needs of people and their families at end of life. This is based on listening and supporting people.</p>
<p>Create a supportive work environment that enables social care workers to maximize their contribution to quality end of life care.</p>	<p>DCWs are well placed to spot ‘trigger points’ in a person, these may not be medical or symptomatic signs but more subtle and individual to the person. They can also occur at any time not just the last weeks or days of life.</p>
	<p>Supervisors and managers of DCWs recognise the contribution the workforce has to supporting people at end of life. DCWs display many of the competences to ensure quality care is received. What is required is the system change that allows time and flexibility to meet changing needs of people at end of life and their families.</p>



- To be caring... just care about the patient – that's all families want to ensure is happening.
- Someone who loves the job, is experienced and has the right attitude.
- To concentrate on a patient's needs for as long as the patient needed them. If arranged to go for one hour, stay with the patient for one hour.
- Treat the person as a whole, use a holistic approach.
- Listening and responding skills are key for clear communication between the staff member, patient and the patient's family.

**Following engagement with social care managers and staff the emergent themes are:**

- Certain individuals within a culture can make a difference, leadership and attitude to change experiences is a key driver to supporting staff.
- The use of person centred thinking tools supported the domiciliary care worker to have the discussions about end of life with their client.
- There is benefit in the domiciliary care worker being part of a wider team to support the needs and care a person requires at the end of life.
- The knowledge a care worker has about the day to day needs a person has can assist in the planning of care.



# Sustainability of the project

## Hull

The Primary Care Trust (PCT) has been working with Hull City Council to develop joint plans to utilise the Department of Health reablement monies which are being issued to PCTs to spend with local authorities to enhance reablement and support social care. One of the schemes that has been put forward is a 24-hour palliative and end of life domiciliary care service.

Hull PCT currently commission a health and social care team which supports people to leave hospital with the support they need to facilitate end of life care in their own home. The service can respond quickly to provide low level domiciliary interventions and signpost to other services. The investment to the local authority would be used to expand and integrate the existing service with more social care and third sector support. The aim is to increase the number of people who die in their preferred place of care and could result in an extra 25 people a week being supported to live well and die with the required support in their place of choice.

The PCT intends to use the learning and outcomes of the key worker competences project to inform recruitment to this extended and newly integrated team and build a workforce development plan which incorporates the learning from the project. The particular areas of interest are the competences and the conditions required to foster closer working between health and social care to improve end of life care for the patient.

## Wakefield

NHS Wakefield District is working with health and local authority providers to action the implementation of the recently finalised end of life care strategy. Discussions have included advanced care planning and the definition of a key worker to develop a shared understanding across health and social care.

A common advanced care planning tool is being agreed across the locality and an action plan devised. Task and finish groups and trials are beginning and training will include key worker competences identified during this project in order to include domiciliary care workers as part of the multidisciplinary team caring for patients in a holistic way.

The involvement of domiciliary care workers in GP practice Gold Standards framework meetings will be tested out.

A critical case review meeting will be held to explore issues raised by a recent actual client's experience of care which has been identified as requiring improved communication between health and social care. An action plan will be developed.

The findings of the report will be shared with the social care director and local strategic partnership board with the intention of shaping future joint commissioning approaches and service delivery.

## 6.2 Help for others to replicate

- Consider the role of domiciliary care workers within a more integrated team with primary care, look at how systems are set up within your area for working between health and social care. Actively listening to people is important and the action to specifically address the barriers to good quality care. For example, the time taken to feed someone may exceed the time allocated for the visit, but person centred care is about the conversations during this routine care and taking the opportunity to support the person through listening. This takes time and the flexibility in the system to be able to action change.
- Identify and develop the social care workforce aspects of core competences in recognising the start of end of life and developing practice, the use of person centred planning and thinking supports the start of advanced care planning and links into personalisation for people requiring additional support at end of life.
- Use established partnership boards to agree a set of principles across all sectors, consider integration for health and social care that does not involve full scale re-design but just simple and effective communication methods.
- Establish and agree effective methods for the selection of individual stories across health and social care that support the needs analysis for your area, allowing you a greater understanding of the wider picture and what will make a difference.
- Use the individual stories and related case study, informed by any learning need analysis, to test opportunities for a more integrated Multi Disciplinary Team (that includes care staff) working to identify end of life trigger points.
- Communicate with all stakeholders what your definition of “key worker” is, and be specific about the requirements of the role. Understandable and simple routes of communication between partners of care mean the DCW can discuss any front end/trigger point conversations, and alert and signpost needs to all relevant partners.



## 6.3 Recommendations

### The development of a generic worker role across health and social care

When considering the themes arising from this project, the similarities displayed between the level of end of life care competences of experienced domiciliary care workers and health care assistants working in end of life care settings cannot be ignored. It raises the question again about how to develop more integrated approaches at this level for end of life care delivery such as a generic role spanning health and social care.

The concept of integration in the form of the generic worker regardless of employing profession is nothing new and with the current climate of limited resources putting increased emphasis on the need for quality improvement, productivity and innovation, it could be considered an opportune time to revisit this. The further policy drivers for broader partnership working between the statutory and voluntary sectors (at a time when voluntary sector end of life care providers are reviewing their business models in order to weather the storm of the financial downturn) could provide an opportunity for integrating approaches and roles.

The context of what we mean by the term generic worker is a person who can work at assistant level across organisations, this is a big step to really implementing partnership commissioning.

There is a care workforce of around 350,000 in Yorkshire and the Humber who are well placed to enable care to improve for people approaching end of life.

### Regional Key Statistics Report: Yorkshire and the Humber, April 2011

Total	Care home services with and without nursing			Domiciliary care services (adults) -DCC		
All	Registered Manager	Senior Care Worker	Care Worker	Registered Manager	Senior Care Worker	Care Worker
342,799	9,239	31,389	169,726	2,342	6,592	123,511

Source: National Minimum Dataset: Social Care Part 7. Workforce: Worker Summary by Main Service Type.





### **Person centred thinking as a key element of advanced care planning**

Within this project we saw real benefits to people and their families when approached to do the person centred thinking and complete the tools. Advanced care planning is seen as a crucial element to support people at end of life. Within this project the GP who experienced the information contained within the Living Well document used the person's wishes to discuss hypothetical scenarios ensuring quality of life is maintained with the person's wishes. DCWs, once trained in the use of the tools, felt confident to start conversations with people about care and this is something that many health professionals still feel uncomfortable about.

### **We should consider whether we commission end of life services around institutions or the person**

End of life care is difficult in terms of provision for health and social care, the complexity of emotions, symptomatic management, communication skills, diagnosis, and ultimately the skill and knowledge by medical staff to agree that no more medical intervention would enhance a person's life or prevent death. What we do know is people at end of life sometimes go through unnecessary journeys and procedures without their knowledge or understanding.

Sometimes current procedures are inflexible and inadequate to deal with end of life care, the project identified that from the social care perspective, end of life care outside of hospital can be delivered. However, this does not seem to be factored into commissioning decisions, where services are commissioned within institutions e.g. hospitals and hospices. Financial drivers influence decisions on where the responsibility of care is led - for example, continuing health care money implies that care responsibility is health rather than social care. Commissioning should be integrated between health and social care as this would go a long way to affording excellence in care for people and this is not a care pathway that health can tackle on its own.

What we would recommend is when people's needs change due to physical (medical) or social support, the use of person centred thinking as a way of planning care, along with engaging those workers within the care services, may mean that supportive end of life care can continue within the person's usual place of residence. Problems can be dealt with or avoided earlier if DCWs are engaged fully within the care process, the alerting or signposting this workforce could do would enable real proactive planning to overcome problems for people at end of life and their families.