
Improving end of life care through better integration: supporting front line workers

A Health Education North East Central and East London (HENCEL) funded project delivered by Skills for Care in London and the South East with Skills for Health and the National Council for Palliative Care

July 2014

“we share information about the social care sector”



Improving end of life care through better integration: supporting front line workers

Published by:

Skills for Care, West Gate, 6 Grace Street, Leeds LS1 2RP www.skillsforcare.org.uk

Skills for Health, 1st Floor, Goldsmiths House, Broad Plain, Bristol BS2 0JP www.skillsforhealth.org.uk

National Council for Palliative Care, 188-194 York Way, London N7 9AS www.ncpc.org.uk

Skills for Care, Skills for Health and National Council for Palliative Care are pleased to acknowledge the contracted work of Melissa Balman in researching and compiling this publication.

© Skills for Care, Skills for Health & National Council for Palliative Care 2014

Reference no. DS046

Copies of this work may be made for non-commercial distribution to aid social care workforce development. Any other copying requires the permission of the publishers. Skills for Care is the employer-led strategic body for workforce development in social care for adults in England. It is part of the sector skills council, Skills for Care and Development. Skills for Health is the sector skills council for all health employers; NHS, independent and third sector. National Council for Palliative Care is the umbrella organisation for all those who are involved in providing, commissioning and using hospice and palliative care services in the UK

Bibliographic reference data for Harvard-style author/date referencing system:

Short reference: Skills for Care, Skills for Health & National Council for Palliative Care [or SfC, SfH & NCPC] 2014

Long reference: Skills for Care, Skills for Health & National Council for Palliative Care. (2014). *Improving end of life care through better integration: supporting front line workers* www.skillsforcare.org.uk www.skillsforhealth.org.uk www.ncpc.org.uk

Contents

Project summary	3
What we did	3
How we did it	3
Next steps	4
Project aims	5
Project stages	6
Methodology	7
Co-production	7
Project partners	8
The project group	8
Strategic partnership	8
Champions	8
The products	10
The network	10
Learning and development sessions	10
The film	11
The Pyramid: an electronic tool for sharing the key messages for about frontline practice and working together	11
Conclusions	11
Aims	11
The principles	13
Recommendations	14
Post script	15

Project summary

What we did

We worked with practitioners to create a set of key messages to help individuals work in a more integrated way, and then delivered the messages to other front line workers. We began to create a network of people who could support each other when working in end of life care. We also produced a film, and developed an e-learning tool to support people's thinking and learning.

How we did it

A [project group](#) steered all of the work throughout the life of the project. Membership included people from Skills for Care (and Skills for Care associates), Skills for Health, and the National Council for Palliative Care, who were also partners to the project.

We identified [a group of strategic leaders](#) across the project area to make sure that this piece of work was delivered to enhance other learning and development, and that it linked to other relevant initiatives.

Using contacts from the strategic group, contacts known to Skills for Care, and contacts we sought out working with Skills for Health, we sent an open invitation to people to participate as champions. We were looking for anyone with experience, expertise or enthusiasm in end of life care.

We did not ask for a long term commitment, just that people would attend one event. We held [four events with champions](#). Each event had a mixed audience (social care, health, carers, voluntary and private sector) as we wanted people to find out about each other's work and experiences. At the events participants were asked to share experiences of working together in end of life care, people talked about what had worked and what had not. The groups then looked at these experiences to identify the most important messages about working together.

Once all of the events were finished we used the materials to produce a set of [six key messages](#) for people working at the front line, to help them in their everyday practice. The key messages were also developed into an [e-learning tool](#).

Those messages were used to underpin [a learning and development session](#) that was developed to deliver to front line workers.

The stories that people told were used to [create a single story that was made into a film](#). The film illustrated the key messages.

As the materials were developed, champions and the strategic group were consulted to ensure that what we produced reflected what people said.

All of the champions agreed to share their contact information with each other, and that formed the basis for the development of the [network](#).

We then used all of our contacts to invite people to attend a [free learning and development event](#). We told people we wanted mixed groups, but said we were happy to run sessions in a workplace so long as other people could attend. The training session was delivered at least twice in each participating borough. To maximise people's ability to attend we offered the programme at different times of the day, and kept it short (1 ½ hours).

A [project report](#), giving more detail about what we did and people's experiences has also been produced.

Next steps

We have been successful in securing further funding which will enable us to continue work on establishing an electronic network, and hold three champion events over the next year to help support the network. The additional funding will also allow us to offer further learning and development sessions, working with some of the boroughs not included in the original project.

We have also commissioned a second film, which will explore the roles of different people delivering end of life care. A leaflet, describing the roles will also be developed.

We will be launching the products at an NCPC event.

We are planning to continue to offer the learning and development sessions, working with some of the boroughs not included in the original project.

All of the materials mentioned here will be available online at www.skillsforcare.org.uk, www.skillsforhealth.org.uk and www.ncpc.org.uk

For further information please contact Ali Rusbridge at Ali.Rusbridge@skillsforcare.org.uk

Project aims

This project was one of seven end of life care projects funded by the Health Education North East Central and East London. (HENCEL) Most of the other projects that involved adult social care focussed on delivery of the Gold Standards Framework. This had an impact on the shape of the Skills for Care project, which was designed to complement this already established framework of learning and development in end of life care.

The aim of this project was to improve people's experiences of end of life care by encouraging people to work together in an integrated way. Its purpose was to provide guidance to individuals in daily practice, by finding out what mattered most to people and translating this into¹:

- a set of underpinning key messages presented as e- tool (The Pyramid)
- a short one and half hour learning and development session delivering the key messages to front line workers
- a film, illustrating the key messages.

Additionally, an important aim was to create a network of champions who would be able to continue to support each other once the project was over. We also planned to offer some accredited learning and development opportunities to champions interested in developing their facilitation skills.

The project drew on the **principles of workforce integration**², in particular:

- **Principle one:** Successful workforce integration focuses on better outcomes for people who need care and support.
- **Principle four:** A confident, engaged, motivated, knowledgeable and properly skilled workforce supporting active and engaged communities is at the heart of workforce integration.
- **Principle five:** Process matters- it gives messages, creates opportunities and demonstrates the way in which the workforce is valued.
- **Principle six:** Successful workforce integration creates new relationships, networks and ways of working. Integrated workforce commissioning strategies give each of those attention, creating the circumstances in which all can thrive.

And the (updated) **principles of end of life care**³

1. Care and support is planned and delivered in a person centred way with the individual's priorities, including spiritual emotional and cultural needs guiding all decisions and actions.
2. Communication is straightforward, appropriate and timely; and is delivered sensitively, taking account of the circumstances, needs and abilities of the person and their carers. Communication reflects and understanding of, and respect for, the person's cultural and spiritual needs.

¹ All freely available on the Skills for Care website

² Due for publication in the summer of 2014 this is a set of six principles jointly being promoted and developed by Skills for Care, Skills for Health the Local Government Association and Think Local Act Personal

³ The principles were being updated as the project ran.

3. End of life care is provided through integrated working, with practitioners collaborating to ensure seamless care and support at the point of delivery. Needs are met in ways that are appropriate to the individual, rather than being service led. Workers maintain ongoing communication so that care and support is properly co-ordinated and responsive to changing circumstances and priorities.
4. Good, clear and straightforward information is provided to individuals and their carers.
5. Regular reviews and effective communication ensure that care and support is responsive to the needs and changing circumstances of individuals, and their carers. Forward planning, including advance care planning, facilitates well planned and organised care and support.
6. The needs and rights of carers are recognised and acted upon. Carers are offered support both whilst caring, and during bereavement. Employers recognise the ways in which workers are affected whilst caring for someone who is dying, and provide appropriate guidance and support.
7. Employers provide appropriate learning and development opportunities for workers to ensure that they are properly equipped to work with people at the end of their lives. Workers are encouraged to take responsibility for their own learning.

Project stages

The project, which ran from November 2013 to June 2014, was divided into four stages:

One

- identifying and working with the key players across the HE- NECEL area
- building the project plan around the already established networks, resources and priorities
- identifying champions and other resources.

Two

- working with the champions, identifying key messages through personal stories and experience, and beginning to connect champions to each other
- using the messages to develop the learning materials
- identifying participants and venues for the learning and development sessions.

Three

- delivering the learning and development sessions
- making the film
- setting up a framework for an ongoing champion network.

Four

- launching the products and sharing them via a number of website hosts
- accredited training offered to some participants
- project evaluation
- ongoing support of the network.

Methodology

Integration principle five (*Process matters - it gives messages, creates opportunities and demonstrates the way in which the workforce is valued*), six (*successful workforce integration creates new relationships, networks and ways of working. Integrated workforce commissioning strategies give each of those attention, creating the circumstances in which all can thrive*) and end of life care principle seven (*employers provide appropriate learning and development opportunities for workers to ensure that they are properly equipped to work with people at the end of their lives. Workers are encouraged to take responsibility for their own learning*) were particularly influential when deciding upon the approach to be taken with the project. Although the “specialist” focus of the work was end of life care, we were equally keen to emphasise the importance of working together in an integrated way, and listening to people. Our emphasis was on people’s experiences of care and support rather than the disease-specific management of conditions, and we wanted to ensure that we ended up with a product that reflected what people’s experiences told them (and us). No assumptions were made about what this would be. Sessions were designed to encourage free-flowing conversations that led people into thinking about what works and doesn’t. From this, the learning points that underpinned the rest of the project were developed.

In order to marry the two sets of principles, it was agreed that at every stage of the work we needed to bring people together, so that by working together they would learn from each other, and begin to create new relationships that supported integrated practice. To achieve this all sessions (expert reference group, champions and front line sessions) were run with mixed groups of practitioners. Every event included people from health and social care, people from the statutory and voluntary sector were included, and carers and people who used services were invited to participate. The project team itself included people from a similar range of individuals.

Because we wanted the learning materials to be shaped by what practitioners and people using care and support services saw as important to working together, a co-production approach was used when working with the champions. This allowed us to focus on hearing what people had to say to us and to each other, and to ensure that these stories and experiences shaped the materials we produced. These conversations also created an environment in which people could begin to find out about each other’s work and create new working links. Ultimately it also gave more power to our material as we were able to say that this was what people with experience told us.

Co-production

Co-production is an inclusive approach to working with people. In co-production participants are acknowledged as experts who bring their own rich experiences, perspectives and expertise. Also used as an approach to working with people using care and support, it harnesses people’s abilities as well as identifying needs and agreeing how these can be met. In this project it was used as a way to work collaboratively with people with expertise and experience of end of life care, to develop a common understanding of the most important messages to share with people to support better integration in end of life care.

Project partners

The project group

There were four Skills for Care employees in the project group. Other members were recruited to bring different expertise and perspectives to the work. This included two people with a social care background, one person with a health background a member of staff from the National Council for Palliative Care (NCPC), and an educational film maker. Everyone on the team had experience of end of life care. The group had regular contact (meetings or teleconference) throughout the project.

Strategic partnership

To ensure that this project complemented other work taking place, and that we were able to utilise the knowledge and experience of managers and others across the area an expert reference group (ERG) was established. Members were drawn from a wide range of settings, including local authorities, hospices, and the voluntary sector. The group also included two carers.

The reference group came together twice, to discuss the project proposals and review at the midway point. Group members were kept up to date with the project via email and reports. There was further contact with individual members of the group at various points throughout the project. The group also acted as a conduit to networks across the area, and ensured that we were aware of other activities.

Champions

The champions were the backbone of the project. Early on there were discussions about what we meant by champions, and the potential for confusion because of other champion initiatives. In the end we agreed that for this project champions were people with an enthusiasm for improving the quality and experience of end of life care. They did not need to have any technical expertise. We asked for people to put themselves forward as partners to the project, to work with us to shape what we were going to do. We did not ask for a commitment to the whole project, but invited anyone who wanted to attend one of the events being held across the area. An open invitation was sent out via the ERG and other networks. The champion sessions themselves focussed on people telling the stories that mattered to them. Through focussed discussions, champions generated a wide range of material that was used to shape the film (using the stories people told) and the key learning points (from what people said about their experiences.)

At the end of this stage a get together was held for all of the champions where they were invited to give feedback about the products being developed. (Key learning points, learning and development sessions, film). The event also had networking opportunities built in, to facilitate the development of a local end of life care network.

In total 46 people attended the events. A good mix of backgrounds was achieved, participants included:

- carers
- commissioners (health and social care)
- district and hospital based nurses
- social workers

- hospice staff
- patient representatives
- HR/trainers (health and social care)
- doctors (GPs and consultants)
- health care assistants
- social care workers
- managers (team leaders, home managers, voluntary organisation managers).

Some champions worked in an “end of life care” setting. For others, end of life care was relevant to their roles. Many participants also had personal experiences that they shared during discussions.

Along the way we continued to invite people to join the champions’ network. During the third phase of the project champions remained involved in the following ways:

Key messages and the e-tool

The key messages were developed from the contributions of the champions at each event. The draft version was shared with champions (and ERG members) before being developed into the e-tool. The tool was also sent to champions for their comments before it was finalised.

Learning and development sessions

The learning and development sessions built on the key messages from the champions. Champions were invited to act as facilitators at front line sessions, in the end only two actually undertook this role (although some champions attended the sessions as participants). Champions at the get together event were also given the opportunity to comment on the proposed content.

Film development

The stories and experiences shared by the champions were used to create a scenario that illustrated the key messages. The story outline was shared with champions for their comments, including some specific “technical questions”. As well as asking champions for input into the film scenario, the consultation was extended wider to include others, particularly those with direct experience of Motor Neurone Disease.

A local network

Some champions made new contacts with others whom they met at events. Champions were happy for their contact details to be share with other champions to help establish/maintain a network. Skills for Care agreed to host a series of events and set up an electronic network to maintain and develop these links. This work continues as the formal element of the project ends.

Towards the end of the project champions were asked to comment on their involvement in the project, including a question about networking. There were seven responses to an electronic survey sent out, with three follow up more detailed discussions. Additionally, we received a lot of verbal feedback during and at the end of sessions about the benefits of coming together. Several champions were overheard arranging to keep in touch, and others

contacted us afterwards wanting to have contact details for people they had met. This very positive experience of working together is reinforced by feedback from participants at the learning and development sessions, where a strong theme was the benefit of learning and sharing in a mixed group.

The products

The network

An important aspect of the project was the development of a champions' network. Part of the rationale for the way that champions were brought together was to build in opportunities for people to meet each other. We were always clear that creating a platform to sustain a network was a planned outcome of the project, but we also recognised that networks grow from relationships, so we created situations in which they could be nurtured.

At the time of writing Skills for Care (London and the South East) is planning to host a number of events during the next year to support the ongoing development of relationships as well as providing opportunities to develop integrated practice. There are also plans to set up an e-network to keep champions in touch with each other.

As a by-product of the work, particularly through the creation of the ERG, a number of professional links have been either established or built upon, including a much wider understanding of the range of related initiatives in the area.

Learning and development sessions

One of the main deliverables of this project was the learning and development sessions. These were built around the key messages that were developed during the champion sessions. Deliberately kept short (one to one and a half hours) the sessions were designed so that they caused minimum disruption to work commitments.

Invitations were sent to everyone on the mailing list asking for expressions of interest in the sessions. Further invitations extended through other networks. People were also asked to let us know about venue availability, as the plan was to offer the training at least once in each of the project boroughs. Sessions were timetabled throughout April and in the first part of May, at different times of day to maximise access.

To underpin the message about working together, and to give people chance to meet others, and create their own networks, sessions were planned to include participants from different backgrounds. In total 18 sessions were delivered to 296 participants. Although not everyone indicated their job role, of the 145 that did 118 (81%) were from social care backgrounds and 27 (19%) from health. However, it needs to be borne in mind that in some roles, the distinction between "health" and "social care" is becoming increasingly blurred as workers take on a wider range of tasks. We also had to make some assumptions based on job title as we did not have more detailed information.

Feedback from participants was overwhelmingly positive. An impact assessment was undertaken, and all participants indicated that their understanding of working together in end of life care had increased. The two areas where the biggest shift was recorded was in understanding other people's roles (outset 23 scored 10/10, end 50) and understanding

models of good practice (outset 34, end 71). Across all questions, there was a significant shift from people scoring in the lowest half. Participants were invited to add additional comments, and these overwhelmingly showed that the value in the experience was in being able to work with, and talk to, people from different settings. Respondents talked about learning about each other, and working together, rather than any actual “programme content”. Two participants (who were also champions) talked about the events in follow up discussions. Their comments echoed these findings, although both felt that the feedback time, whilst very helpful to learning, was a little long.

A learning and development “pack”, incorporating the key messages and reflecting what participants told us, has been developed for people to use in their own settings.

The film

The film content evolved during the discussions with champions. At the champion events people were asked to share stories and experiences, and on each occasion many powerful messages emerged. The film’s director participated at each event, and was able to pull together the different stories and messages to build the scenario that was finally used. Although the story itself is fictitious, every element within it is drawn from something we were told.

The film was scripted to ensure that it reflected the key messages, and was designed to complement both the e-tool and the learning and development pack.

The Pyramid: an electronic tool for sharing the key messages about frontline practice and working together

All of the messages from the champion sessions were drawn together to create a set of six key messages. Following consultation with the ERG and the champions, these were developed into an e-tool that takes the user through the headline messages, drilling down to more detail about what they mean in practice, and ways to work that support integration.

Conclusions

Aims

The overarching aim of the project was to improve people’s experiences of end of life care by encouraging people to work together in an integrated way. Clearly the timescale of this work precludes any testing of the experiences of people requiring care and support. We were however able to gather some information from participants to gauge whether the project had an impact on their thinking or practice.

We identified several other aims, related to products and activities, all of which were achieved:

Champions’ network (and activities)

This is still embryonic, but feedback from champions is that:

- Meeting other people and hearing their experiences is enriching and has positive benefits to practice. The champion events were positively received, on each day there was a huge amount of enthusiasm and people felt it was worthwhile.

- Understanding the roles of other practitioners was helped by the sessions; there was some feedback that more information about other roles would be welcome.
- Similarly, a lot of information about resources was shared, and there was frequent discussion about the benefit of some signposting to resources.
- Carers welcomed the chance to contribute to developments, and saw this as way to contribute to the ongoing learning of practitioners. Practitioners also commented the benefits of hearing directly from carers.
- An ongoing network would be welcomed. Already some new relationships have formed and champions are keen to maintain links.
- One of hopes of the project team was that champions would continue to work with us. Champions were asked to identify work streams they might be interested in contributing to, but in the event the amount of ongoing involvement was less than we would have liked. Feedback from champions indicates that this was less about a lack of interest and more about time and timing.

Key messages and e-tool: The Pyramid

The messages that came from the champion events were consistent, and this made agreeing the messages relatively straightforward. There were two difficulties in deciding upon what was included in the final messages:

1. Many of the messages and much of the discussion was around good practice in the broadest sense. We needed to focus the messages on working together: with other professionals, people using care and support, and their families and carers.
2. Inevitably, a number of organisational/structural factors were discussed. As before, all really important, but as our focus was in giving front line workers messages about what they could do in their everyday interactions, these were excluded too.

Initially it was not certain how the messages would be presented, but through a series of discussions the e-tool was agreed upon. As it is currently in development it is not possible to comment on its usefulness. What we do know is that:

- champions felt the messages reflected their discussions
- champions felt that the messages were right, and would be helpful to front line workers (although there were some concerns about wider issues that impacted on practice and how).

Learning and development sessions

The plan was that the sessions would evolve from the key messages. Due to the available time for the project this did not work exactly as planned. However, some of the key points in the messages were identified early on, and these underpinned the sessions.

The sessions were planned as “short and sharp” in order to maximise the number of people able to attend. Sessions were well attended, and a good mix and number of participants was achieved.

Initial hopes that the majority of sessions would be jointly led by a project facilitator and champion were not achieved, although some champions did attend.

The balance between health and social care was heavily weighted towards social care, and although not formally checked, anecdotally, there was only a very small representation from smaller, community based organisations.

Champions were keen for the sessions to continue to be supported.

Participants enjoyed the sessions, and felt that they helped them to increase their understanding of working together in end of life care. Several commented that they needed to continue to be offered, or that they would like follow up materials/sessions.

The film

The film is in production as this report is being written, but what we already know is:

- The champion sessions were a rich source of information to the film's producer, who acted as one of the facilitators at each event.
- Feedback from champions and others about the proposed scenario have been hugely positive, both about the story itself, and the ways in which it illustrated the key learning points.

The principles

The project was underpinned, in particular, by:

Workforce integration principle five

Process matters - it gives messages, creates opportunities and demonstrates the way in which the workforce is valued.

Our experience, which is supported by feedback from participants, is that this is an important principle. Feeling listened to; being part of decision making, contributing to developments creates a positive attitude. This project worked with people outside of their work setting, but it illustrates the potential benefits for an integrated and inclusive approach to workforce development and improving care and support.

Carers who joined the events talked about the importance of being part of the discussions, being able to share their stories and contribute to practice development. Given that Carers UK estimates that there are currently 6.5 million carers in the UK, their contribution to this project was invaluable.

Workforce integration principle six

Successful workforce integration creates new relationships, networks and ways of working. Integrated workforce commissioning strategies give each of those attention, creating the circumstances in which all can thrive.

We had planned the champion sessions, in part, to create networking opportunities, and were pleased to find that this was a highly valued aspect of the events. The learning and development sessions had been organised to ensure that people from different settings came together as a way to support learning. The regularity with which participants commented on the benefits of working together in this way suggests that by thinking about

how learning and development is organised can create additional benefits without extra costs.

End of life care principle seven

Employers provide appropriate learning and development opportunities for workers to ensure that they are properly equipped to work with people at the end of their lives. Workers are encouraged to take responsibility for their own learning.

Feedback from both the champion events and the front line sessions shows that people valued and learned from the opportunities provided. It also illustrates how much people want to learn for themselves, and support each other. A consistent aspect of champions' feedback was how much they learned simply by being with each other. Their wish to maintain a network provides further evidence of how this is valued, and of people taking responsibility for their own learning.

Recommendations

This project has now finished, but it has ended at a point where there are newly created resources to support people working together for better end of life care, and enthusiasm to keep the focus alive.

Along the way we have also learned of resources that people feel would be particularly beneficial to their practice.

These recommendations draw on both of these factors.

1. Maintaining the momentum

- Champions are keen to remain in touch. Additionally, others (for example some participants at learning and development sessions) are keen to join. Skills for Care is already committed to setting up an electronic network for champions, it is important this happens whilst people are still enthused.
- Champions and others are asking about the products, and are very keen to see them. It makes sense to have the network set up in time to use this to let people know when the products are available.
- The champions who responded to the electronic questionnaire were keen that learning and development sessions continue to be offered. Direct feedback from participants was positive. Although not in a position to directly fund this, Skills for Care could look at ways to market and publicise the finalised learning pack, and perhaps support people in its delivery.
- Champions attending the champion events were very positive about the benefits of talking to each other to their practice; people regularly commented on how talking to carers affected their thinking. Carers talked about the benefits of being listened to, and contributing to practice development. Developing and consolidating links with carers' organisations will help to ensure that carers remain involved in ways that work for them, and that carer perspectives are maintained in all learning.
- Skills for Care plans to run a number of network sessions for champions over the next year, these should all include opportunities for structured discussion and information exchange to support growing relationships and networks.

2. Developing resources

- The importance of information and signposting came up again and again⁴.
- Another key theme was the importance of understanding each other's roles and perspectives (highlighted as one of the great benefits of participating in the project). Currently this information does not exist (so far as we could find). Developing a resource to fill this gap would be a great benefit to practitioners, and could make a significant contribution to supporting people to work together more effectively.⁵

3. Learning and development sessions

- The learning and development session will be reviewed following the responses of participants, and a final version will be developed and made available.
- The sessions were very well received by participants, continuing to offer sessions to new audiences would be very beneficial. This could include:
 - different geographic locations (other boroughs)
 - a better balance between health and social care
 - trying to reach some of the smaller organisations that time prevented us from engaging this time.

Post script

Since writing this report additional funding has been secured. We are currently finalising plans for the next stage of activity, which will include:

- further work on developing a network
- three champion events during 2014-5
- work on engaging under-represented groups
- embedding the film and learning points into the learning and development sessions, and delivering the revised sessions to a new audience
- exploring accredited learning and development options for front line workers and champions
- commissioning a further film. This will be a talking heads format asking people to talk about their role in end of life care. We are also commissioning a leaflet to go with the film.

⁴ We hope to develop a resource signposting people to different services/sources of information.

⁵ We are hoping to be able to commission a second film, in which individuals talk directly about their roles in end of life care and support, and some written materials to support this.

**Skills for Care
West Gate
6 Grace Street
Leeds
LS1 2RP**

**tel: 0113 245 1716
fax: 0113 243 6417
email: info@skillsforcare.org.uk
web: www.skillsforcare.org.uk
ref: DS046**