

Trainning
Engagement
Services
Transferability and sustainability



Supporting people to live and die well:
a framework for social care at the end of life





In July 2010 the National End of Life Care Programme published the report of its Social Care Advisory Group 'Supporting People to Live and Die Well: a framework for social care at the end of life.'¹

Social Care Framework – Phase 1

Phase 1 of the implementation of the Social Care Framework was undertaken between September 2010 and June 2011. Roadshows took place in each of the Association of Directors of Adult Social Services (ADASS) nine regions along with the commissioning and piloting of eight social care test site projects.

A report on Phase 1 was prepared by the programme's Social Care Leads and published in November 2011². More detailed analysis of the phase is obtainable on request by email to: Margaret.Holloway@eolc.nhs.uk.

The core purpose of the test sites initiative was to develop and consolidate the knowledge base about what works in social care at the end of life. Each test site addressed one or more of the key objectives in the Social Care Framework.



¹ www.endoflifecareforadults.nhs.uk/publications/supporting-people-to-live-and-die-well-a-framework

² www.endoflifecareforadults.nhs.uk/publications/social-care-workstream-report-nov11



Test site 1: Development of key worker competences for domiciliary care workers to support an integrated pathway for end of life care

Wakefield and Hull

Lead organisation

NHS Wakefield District

Partners

NHS Wakefield District, Wakefield District Council, NHS Hull, Hull City Council, Dove Hospice (Hull), GPs, HICA Home Care and Elm Tree Court Residential Home

Aim

The aim is to change people's experience for the better and provide an evidence base that can be disseminated widely, by looking at the core competences required for front-line staff in end of life care.

History

Hull City Council had been working with their local Cancer Network and a range of partners on implementing the Living Well person-centred toolkit, a guide to help those at the end of life think about and record what is important to them and assist them to plan for the end of their life.

Summary

The project built on previous work in the two health economies in Wakefield and Hull. The project compared and contrasted the detailed circumstances in the city of Hull and Wakefield District to develop common themes. In Wakefield the project tested the idea of a domiciliary care worker (DCW) as a key worker for end of life care as part of everyday practice, including a competency analysis. In Hull, the role of DCW as an advocate in the primary care Gold Standard Framework meeting was tested.

Activities and outputs

- People's stories collected and summarised onto DVD for training purposes (www.skillsforcare.org.uk/developing_skills/endoflifecare/real_stories_real_insight.aspx)
- Social care staff trained in person-centred and Living Well tools
- Key worker competences developed for DCWs.

Tip from the test sites

Small projects working to a short timescale and with modest funding can produce valuable outputs and learning that can be easily replicated.

Tip from the test sites

Many people have a role in end of life care but may not recognise it. Awareness raising and training staff is key.



Test site 2: Mentoring workshops for adult care social workers and fieldwork support assessors

Gloucestershire

Lead organisation

Sue Ryder Care

Partners

Sue Ryder Care, Gloucestershire County Council – Adult Care

Aim

To target the social care staff who are responsible for assessment and care management of individuals and their carers at the end of life, in order to build their skills in communication and reflection on the palliative care aspects of their roles.

History

The project lead and colleagues had been working on a four-level social care model to complement the National Institute for Health and Clinical Excellence (NICE) models for psychological and other holistic aspects of care. The project aimed in part to test the usefulness of this model in supporting generalist social work staff.

Summary

Workshops, utilising the four-level social care model, were delivered to social care frontline staff and managers over a three week period. The managers were engaged to gain their support for the project and workshops. The workshops were evaluated by the University of Nottingham.

Activities and outputs

- 3-6 meetings were planned for operational managers, with further planned as necessary – one of their bi-monthly meetings was attended and telephone discussions held
- Six workshops were planned and delivered, and 66 staff participated
- The planned evaluation by the University of Nottingham was undertaken with 64 pre- and post- workshop questionnaires completed and analysed.

Tip from the test sites

Effective end of life care is underpinned by social care input at all steps of the end of life care pathway. Social care workers need to be engaged and involved early on.

Tip from the test sites

Improvements need to be sustained and a rolling programme of education is recommended.



Test site 3: Hospice at Home personal budgets pilot

Rossendale, Lancashire

Lead organisation

Lancashire County Council

Partners

Lancashire County Council, Rossendale Hospice, Help Direct

Aim

To offer people receiving social care support, who access hospice services, an opportunity to plan their support through the use of personal budgets.

History

Rossendale Hospice had moved into a new building offering the opportunity for the development and extension of their services including Hospice at Home and day therapy. Links had been made with Help Direct, a signposting organisation. Lancashire County Council, implementing personal budgets, was committed to including end of life care within their personal budget processes.

Summary

Service users with palliative care needs accessing the Hospice at Home service were offered a personal budget service. A considerable amount of the project time was spent briefing and raising awareness with key stakeholders.

Activities and outputs

- Project processes including a project board were planned and implemented
- Briefing sessions for key stakeholders were planned and delivered to around 50 people, including staff at Rossendale Hospice and social workers working with people at the end of life
- A support plan for accessing personal budgets has been prepared – three individuals took up these budgets, and three expressed an interest
- Two individuals accessed Help Direct services and seven more are considering options
- A Help Direct clinic has been established at the Rossendale Hospice.

Tip from the test sites

Funding barriers are a crucial inhibitor of good end of life care. Continuing health care budgets must be fast-tracked and personal budgets introduced early in the end of life care pathway if they are to be effective.

Tip from the test sites

Handyperson and other modest preventive services can help ensure that the home is a suitable environment for end of life care, enabling more people to die in their home.



Test site 4: The implementation of an integrated palliative care service

North Norfolk

Lead organisation

Norfolk County Council

Partners

Norfolk County Council Community Services – Adult Social Care, NHS Norfolk, primary care staff and three GP practices, North Norfolk Integrated Care Organisations, the Norfolk Hospice, three domiciliary care agencies

Aim

To identify, share and develop good practice around commissioning and delivery of person-centred integrated care, access to community support services, and development of professional expertise in supporting palliative and end of life care in North Norfolk.

History

Norfolk County Council's Adult Social Care jointly commissioned the Marie Curie Delivering Choice Programme (MCDCP) Toolkit with NHS Norfolk and NHS Great Yarmouth and Waveney. The first two phases (understanding the current state of services, and designing service models) had been completed. The project built on this previous work undertaken on the MCDCP. North Norfolk, where the project was undertaken, was one of their Integrated Care Organisation test sites.

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Activities and outputs

- Fifty interviews held with a range of stakeholders
- CareFirst data (the Norfolk County Council social care database) was analysed identifying three clients accessing personal budgets
- A survey based on end of life care competences was completed by 105 people working in adult social care and 60 working across the community and primary care. Ten case studies were collected. Survey and case study results were discussed in multi-disciplinary workshops
- Recommendations emerged in respect of commissioning of domiciliary care, the delivery of person-centred integrated care and the strengthening of the specialism of palliative care
- Examples of excellent practice were identified, but practical support was not easy to access
- Findings were shared with key stakeholders and agencies.

Tip from the test sites

Other professionals working in end of life care may not recognise the important role of social care workers. Engage and inform stakeholders at an early stage.

Tip from the test sites

Workshops can give staff a significant and measurable confidence boost, and can be an invaluable opportunity to share learning and best practice.



Test site 5: Delivery of integrated health and social care community discharge planning for people with a life limiting diagnosis who are in the last 6–12 months of life

West Essex

Lead organisation

West Essex Primary Care Trust Provider Service

Partners

Essex County Council Social Care, Princess Alexandra Hospital NHS Trust, NHS West Essex, St Clare's Hospice

Aim

To improve the quality and efficiency of discharge facilitation for individuals with a life limiting illness in the last 12 months of their life, admitted for acute care through an integrated approach through discharge co-ordination.

History

Partner organisations in West Essex had been working to improve the integrated management of end of life care but it was recognised that more had to be done. In particular, the effective hospital discharge of individuals admitted with a life limiting illness needed to be improved by integrating health and social care practice.

Summary

A discharge facilitator was appointed to work jointly with social care. Given the problems already identified in the discharge process, the appointment of a joint discharge facilitator to work operationally across professional boundaries was felt to be the most effective way to establish a new model of working.

Activities and outputs

- The discharge facilitator worked to raise awareness of their role, end of life care and preferred priorities for care, as well as actively encourage the referral of people in the target group from the hospital and the community.
- They also worked with agencies to expedite discharges and, in some cases, accompanied people home when they were very close to death.
- The project received 68 appropriate referrals (7.5 per week for the duration of the project), most of whom were discharged within 48 hours.
- The vast majority (nearly 90%) were discharged to their preferred place of care.

Tip from the test sites

To ensure sustainability it is essential to have senior buy-in and clarity about aims, objectives, roles and responsibilities.

Tip from the test sites

Many people are not aware of the end of life care pathway or that end of life care starts before the final few weeks of life. Education and knowledge are crucial.



Test site 6: The delivery of integrated health and social care operational commissioning and delivery plan

Essex

Lead organisation

Essex County Council

Partners

Essex County Council (social care, quality and development, contracts and commissioning), acute, primary care and mental health Trusts, commissioners, hospices, domiciliary/residential care providers

Aim

To facilitate a streamlined, co-ordinated health and social care pathway that is based on competency rather than professional identity. To promote timely discharge with robust access to a range of high quality individualised care and information services, planned with the person and their family and crossing organisational boundaries where required.

History

Planning had begun around the Quality, Innovation, Productivity and Prevention (QIPP) agenda and New Ways of Working in Essex, which was launched by the council to modernise services whilst generating financial savings. It seemed an opportune time to start co-ordinating Essex County Council's end of life care strategy.

Summary

The project manager worked with a wide range of organisations and agencies in the statutory and private, voluntary and independent sectors to promote, and disseminate knowledge about end of life care and to ensure that end of life care is embedded in commissioning processes, strategies and delivery plans.

Activities and outputs

- Creation of a network of 40 end of life care champions
- Commissioning of end of life care training and introduction of mandatory end of life care training for Essex County Council staff and the establishment of a workforce training pathway
- Work with the community engagement team to develop guidance on end of life care for travellers
- The development of a care pathway which incorporates end of life care with a local prison
- An end of life care delivery plan and action plan.

Tip from the test sites

Regular local networking and stakeholder engagement events provide the opportunity to discuss barriers and problems, and strengthen and consolidate good practice.

Tip from the test sites

Local end of life care strategies and action plans are crucial, as are effective integrated governance and accountability arrangements for end of life care. This includes sharing and having access to the same data across agencies



Test site 7: Exploring the role of leads in end of life care in social work teams

Lambeth and Southwark

Lead organisation

Guy's and St Thomas' Charity Modernisation Initiative End of Life Care Programme

Partners

Community, Disability and Older Persons Service, Lambeth Council and Older People's Services, Southwark Council

Aim

To identify end of life care leads in each social care team, their training needs and to clarify and test their roles. To cross-fertilise learning in end of life care through a facilitated learning network of district nurse leads and social care leads in end of life care. To increase multi-disciplinary information sharing.

History

The project lead has already been working with senior managers in adult social services in the two boroughs as part of the Modernisation Initiative (MI).

Summary

The project builds on the work of the MI, established in 2008 to examine every aspect of end of life care. The social care test site initiative provided the opportunity to develop the end of life care lead role, to identify training and support needs and to meet these needs through the training provided by St Christopher's Hospice and a range of sessions and activities arranged and/or delivered by the project facilitator.

Activities and outputs

- Sixteen social workers and social care staff end of life care leads were identified across older people and adult services and in a variety of settings including hospital and the community
- Identification of training needs (which were shared with the St Christopher's Hospice team who provided training)
- Shared learning and networking events with a range of end of life care providers
- Development of a social care end of life care lead role description which also details the roles and responsibilities of managers in supporting this role.

Tip from the test sites

End of life care leads and champions have a significant impact in their region.

Tip from the test sites

Successful training initiatives rely on auditing needs and tailoring programmes to targeted groups.



Test site 8: End of life intervention skills consultation and education

Lambeth and Southwark

Lead organisation

St Christopher's Hospice

Aim

To work towards meeting the learning and support needs of older adults social care staff in the London boroughs of Lambeth and Southwark in terms of their delivery of high quality end of life care.

History

St Christopher's Hospice has extensive experience of providing training for all professionals engaged in palliative care, including social work and social care staff. The team had wanted to do more training with statutory social work services for some time and to extend their work to the boroughs of Lambeth and Southwark.

Summary

The project worked collaboratively with the Guy's and St Thomas' team and the heads of adult services in the two boroughs to identify end of life care leads and their training needs. Although the St Christopher's team had originally proposed to focus on social work end of life care leads, it became evident that managers (including senior managers) and social work teams would also benefit from training. The project also worked with end of life care leads from a wider range of social care settings than initially proposed e.g. sheltered housing, hospitals and Care Line.

Activities and outputs

- Training, consultation and support for three groups:
 - Managers (senior and service managers)
 - Other members of these social care teams (half-day sessions and 12 team visits)
 - End of life care leads (three events over 2.5 days).
- The project also offered leads:
 - Free places on training courses run as part of St Christopher's programme of multi-disciplinary training
 - Access to St Christopher's library and the support of the librarian
 - A helpline for support on end of life care issues.

Tip from the test sites

Inviting social work teams and managers to visit the hospice or palliative care setting will familiarise them with the environment and culture and will help build strong working relationships.

Tip from the test sites

Specialist palliative care social workers can inform and engage with wider social care teams to talk about the role of specialist palliative care services, the End of Life Care Strategy and Social Care Framework.



Evaluation to assess impact

An independent evaluation of the eight test sites was undertaken by the University of York, with findings published in January 2012³.

Separately the National End of Life Care Programme commissioned the University of Nottingham to evaluate its wider social care integration activities, including the appointment of Social Care Leads, the development of the social care framework and Phase 1 of its implementation.

The evaluation's findings, published in February 2012⁴, indicate that the social care framework has established a solid base on which to build and move forward into the second phase.

Social Care Framework – Phase 2

In Phase 2 of the Social Care Framework implementation, the National End of Life Care Programme is focusing on developing initiatives across England to meet local and regional needs. The first wave of Phase 2 initiatives are:

Nationwide

1. A community response to end of life care
Creative Commissioning

North of England

2. Supporting integrated working between social care and primary health care
 - a) Hull: Raising primary care professionals' awareness of the role of social care in end of life care
 - b) Wakefield: Support the effective contribution of domiciliary care workers to end of life care multidisciplinary meetings
 - c) York: Support the effective contribution of home care staff in end of life care pathways of care delivery
Yorkshire and Humber social care end of life care strategic leads group
3. Developing a good death charter for people with dementia and their carers
North East Good Death Charter Group / North East Dementia Alliance
4. Using action learning to embed end of life care training in social work teams
East Lancashire Palliative Care Partnership / Cumbria and Lancashire End of Life Care Network / Lancashire County Council
5. Delivering integrated end of life care training through joint social and health care professional education
Merseyside and West Cheshire Palliative and End of Life Care Network
6. Developing training from 'The route to success in end of life care: achieving quality in prisons and for prisoners'
Prisons Route to Success Project Working Group / Merseyside and Cheshire Palliative and End of Life Care Network

³ www.endoflifecareforadults.nhs.uk/publications/social-care-test-sites-evaluation

⁴ www.endoflifecareforadults.nhs.uk/publications/integration-of-social-and-health-care-evaluation



Midlands and Eastern

7. End of life care within dementia care homes
Derby City Council / Derbyshire Clinical Commissioning Group / Making Space
8. A joint social and health care training needs analysis and scoping exercise for the delivery of integrated end of life care
Norfolk County Council / Norfolk Community Health and Care NHS Trust / NHS Great Yarmouth and Waveney / NHS County Workforce Group / Anglia Cancer Network

South of England

9. An approach to localised involvement and development in support of people at the end of life, including family, carers and people living and dying with dementia
South of England Health and Social Care Partnership

London

10. End of life care intervention skills: consultation and education for Bromley social care staff
St Christopher's Hospice / London Borough of Bromley

TEST

In order to facilitate the utilisation of evidence and tools already available, they have been mapped against four broad themes. This has resulted in **TEST**, a signposting and mapping tool to enhance the development of a range of initiatives for improving social care at the end of life.

TTraining

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Training

Objective 7 of the Social Care Framework identifies the need for education and training in end of life care and Objective 8 recognises the importance of creating a supportive work environment.

There are widespread calls in the roadshow feedback for improved training and better access to training, not just for front-line staff but also for managers to enable them to better understand and value social care's role in end of life care and support and supervise their staff.

Test sites 1, 2, 7 and 8 produced evidence and tools to facilitate the development of training and mentoring initiatives:

- A training DVD focusing on domiciliary care, aimed at domiciliary care workers and other professionals who work with them (*test site 1*)
- A workshop training programme for end of life care mentors utilising the four level social care model of the Association of Palliative Care Social Workers (*test site 2*)
- A training needs audit for end of life care leads in social work teams (*test site 7*)
- A half day foundation end of life care training package for senior and service level managers (*test site 8*)
- A half day foundation end of life care training package for social workers / social care workers in adult services teams (*test site 8*)
- A two and a half day training package for end of life care social work leads (*test site 8*)
- Presentations on aspects of end of life care for end of life care leads to give to teams (*test site 8*)
- A model as to what the role of social care champions looks like and their managers' roles (*test site 7*).

The following tools available from the National End of Life Care Programme website are also relevant:

- Finding the words DVD supported by a reflective practice booklet
- Developing end of life care practice: a guide to workforce development to support social care and health workers to apply the common core principles and competences for end of life care
- Common core competences and principles
- Developing skills: talking about end of life care
- Capacity, care planning and advance care planning in life limiting illness
- End of life care learning resource pack: information and resources for housing, care and support staff in extra care housing
- Preferred Priorities for Care (PPC) documentation and support tools
- The differences between general care planning and decisions made in advance.





Engagement

Effective engagement with a range of stakeholders emerged as a significant driver for improving end of life care. This relates to within one's own agency, across the health and social care network, and with community and voluntary groups including users and carers. Likewise, failure to engage significant parties such as senior managers was one of the factors most likely to inhibit success.

Objectives 1 (raising awareness), 4 (engaging with palliative care social work), 6 (early engagement in end of life care planning) and 9 (engaging with wider communities) of the Social Care Framework indicate the range of engagements which can contribute to good quality end of life care.

There are important messages and useful suggestions about engagement from test sites 2, 4, and 6. Test site 7 also developed:

- A specification of end of life care roles and responsibilities for managers of social care community teams
- End of life care providers shared learning and networking events (range of suggestions).

Services

Objectives 2 (commissioning), 3 (inspection and regulation), 5 (assessment) and 6 (care planning) of the Social Care Framework address core aspects of social care service delivery processes. The emphasis in the framework is to embed end of life care in existing mainstream structures and service delivery models.

Test sites 3, 4, 5, 6, and 7 identified and developed low-cost interventions which facilitate this process and which they consider are easily replicable. A number of specific tools were also developed and piloted:

- Key worker competences for domiciliary care (test site 1)
- The Living and Dying Well Toolkit to assist front line staff in engaging with end of life care planning and difficult conversations (Helen Sanderson Associates with test site 1)
- A support plan for accessing personal budgets for end of life care (test site 3)
- A Help Direct clinic for accessing practical support at the end of life (test site 3)
- Ten case studies of integrated palliative care in the community (test site 4)
- A joint discharge facilitator role for integrated hospital to community discharge planning (test site 5)
- A social care end of life champions network (test site 6)
- A social care end of life workforce training pathway (test site 6)
- An end of life care discussion document for work with travellers (test site 6)
- An end of life care pathway for prisoners (test site 6)
- An end of life care local delivery and action plan for social care, mapped across the Social Care Framework (test site 6)
- A social care end of life lead role specification (test site 7).

The following tools available from the National End of Life Care Programme website are also relevant:

- Care towards the end of life for people with dementia
- End of life care – achieving quality in hostels and for homeless people
- The route to success in end of life care – achieving quality for people with learning disabilities
- The route to success in end of life care – achieving quality in care homes
- The route to success in end of life care – achieving quality in domiciliary care
- The route to success in end of life care – achieving quality for occupational therapy
- The route to success in end of life care – achieving quality in prisons and for prisoners.



Transferability and sustainability

Evidence on the transferability and sustainability of social care initiatives to support people approaching the end of life is key to capacity building on the scale which is required if the vision outlined in the Social Care Framework is to be realised. It is a crucial part of developing the robust evidence base which is identified in Objective 10 of the framework.

Next steps

The National End of Life Care Programme will use **TEST** to structure ongoing work with the Association of Directors of Adult Social Services (ADASS), the Department of Health's social care directorate and to support the regions in developing local responses to implement the Social Care Framework.

Following the success of the National End of Life Care Programme's facilitators' network, which consists of over 300 healthcare staff across the country working to improve end of life care, the programme recently launched its social care champions' network. If you are keen to improve end of life care and are interested in becoming a social care champion, please get in touch: information@eolc.nhs.uk

A new Route to Success publication for social workers will be launched in summer 2012 following extensive consultation. Keep up to date and sign up to the programme's monthly newsletter at: www.endoflifecareforadults.nhs.uk

Sign up to the social care champions' network by emailing information@eolc.nhs.uk





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Improving end of life care

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