



A GOOD DEATH: THE ROLE OF THE LOCAL AUTHORITY IN END OF LIFE CARE

Forewords



IF PEOPLE want to die in their own homes then housing, be that affordable or rented, must play a much larger role in the delivery of end of life care. It's a shared agenda in which an enhanced role for housing providers and local authorities is key to unlocking the door to a system that reflects people's wishes and not bureaucratic boundaries.

With at least one fifth of NHS spending¹ relating to end of life care and large amounts of data to support the claim that end of life patients often access GP and acute services when greater support at home would meet the needs they present to doctors with, the potential for a significant improvement in the quality of care alongside savings is self-evident.

But that requires a different way of working. We must overcome the difficulty of silo-working and separate budgetary streams that only serve as barriers to delivery.

The survey results are reflective of the debate going on within the sector. There is a concern that existing schemes will not be able to cope in the future. But equally there is also real optimism with three quarters of respondents seeing a role for councils in commissioning and developing end of life services.

Within Health and Wellbeing Boards local authorities have a leadership role both in raising awareness of the end of life care agenda and promoting new ways to increase levels of home care which can deliver better outcomes for patients and savings for the taxpayer.

As a major social landlord and the UK's largest provider of care and support services we have used our experience and expertise to make practical arrangements and choices which have allowed individuals to remain in their own homes for as long as possible. Working together with local authorities care providers now have the opportunity to make sure the same opportunity is shared more widely.

Rachael Byrne
Executive Director of Care and Support
Home Group

¹ *Dying for Change*, Charlie Leadbetter and Jake Gardner, Demos (2010)



WE DON'T talk much about dying. Despite it being one of the few universal elements of the human experience we tend to shy away from it as a topic of discussion. Our fears, let alone our hopes or expectations of dying are rarely aired. Often it is seen as the province of religion or poetry rather than of public policy.

This report is part of a wider effort to change this. We know, as this research points out, that people do in fact have strong preferences about how and where they die, but few of us are able to realise them. For instance two-thirds of people would prefer to die at home but only two out of ten actually do. A majority of respondents to this research thought that their council's existing arrangements for end of life care would be inadequate for the future, and less than four in ten were confident that people could effectively plan their end of life care.

Why do we fail so abjectly to give people the deaths they want? This may not seem like an obvious question for local government, but only because we have to a large extent medicalised our view of the end of life. This too is odd: there is, after all, no cure for death. As this report shows many of the factors that affect the quality of people's deaths: good housing, integrated social care, support to stay in their homes, fall within the purview of local authorities.

At LGiU we believe that the role of good local authorities is increasingly to help people build the resilience and capacity to manage their own well being throughout their life course. Dying may not be the part of the life journey we most want to think about, but we must not neglect it. That's why it's so important that local authorities consider the findings of this report so that they can give people more choice about how they spend their final days.

Jonathan Carr-West
Policy Director
LGiU

Summary

This report considers the role of local authorities in end of life care. While the health sector has taken a strong lead role on this agenda in recent years, the engagement of local authorities has been more mixed. Nevertheless, many of their core services, including social care and housing, are important components of a high quality approach to end of life care. In the context of major reform to the framework of health and social care, councils are considering how they can move forward with the agenda.

Our survey of local authorities showed that:

- Six out of 10 local authority respondents thought that their existing end of life care arrangements would not be sufficient in future.
- Four out of 10 thought that Health and Wellbeing Boards should lead on end of life care in future. However, only three out of 10 said that their shadow Health and Wellbeing Boards had identified end of life care as a priority.
- Progress made on end of life care varied considerably across the country, but 60 per cent of respondents said that their authority intended to develop their role in promoting better end of life care in future.

There were three main conclusions from the findings:

- There is a need for more work to raise awareness in local government in relation to end of life care. Our survey results suggested a level of uncertainty and confusion about the agenda among a significant proportion of council respondents.
- There are opportunities for local authorities to take greater ownership of end of life care. Councils have an important role to play in delivering and commissioning services, and in coordinating partners locally, but some responses suggested that the health service is still regarded as holding primary responsibility for end of life care.
- Housing could still be better connected into this agenda. Less than a quarter of respondents agreed that housing works closely with social care on end of life provision, despite its often crucial role in supporting quality of life outcomes.

The issue

Research shows that 70 per cent of adults would like to be cared for and die in their own home.² But the great majority of us still die in hospital. Neither are future projections for this matter encouraging. In 2008, leading academics forecast that demographic trends could lead to 90,000 more people dying in institutions by 2030, with fewer than one in 10 dying at home by 2030. More recent research has been cautiously encouraging, suggesting a slow reversal of this trend.³ Nevertheless, it will be difficult for progress to keep pace with our rapidly increasing annual number of deaths, which is expected to rise by 17 per cent from 2012 to 2030.

These figures have urgent implications for both the quality and cost of care, and raise real questions about the role of housing in the provision of end of life care, as well as the integration of health and social care in this area.

Despite this, media attention of end of life care issues has been strongly focused on issues of assisted dying and, more recently, the Liverpool Care Pathway. Less public attention has been given to broader questions of quality in end of life care, and the integration of health, social care and housing.

Progress to date

In health circles, there has been a strong emphasis on end of life for several years. The Department of Health launched its 10-year End of Life Care Strategy in July 2008, followed by a Palliative Care Review in June 2011. Palliative care pilots based on the recommendations of the review are now under way in 11 areas of the country.

Nevertheless, end of life care is not the concern of the health sector alone. Local authorities also have a key part to play, through their provision of social care. In their broader role as place shaper, they also provide local leadership and are important players in bringing together public services in a locality.

And of course their increasingly prominent role in housing is vital to this agenda. In many cases simple adaptations and support can help people to remain in their own

homes for longer, and councils can play an important role in ensuring that health, social care and housing are all equally engaged in delivering end of life care.

The need for better local authority engagement is recognised in the work of the National End of Life Care Programme (NEoLCP), which has promoted better integration between health and social care in delivering end of life care. So far their work has included:

- Establishing a framework for social care at the end of life: Supporting People to Live and Die Well (2010). This sets out an agenda to address the role of social care in the commissioning and provision of quality end of life care.
- Appointing social care leads within

² NatCen survey on attitudes towards dying, death and bereavement commissioned on behalf of the Dying Matters coalition (July-September 2009)

³ *Reversal of the British trends in place of death: Time series analysis 2004–2010*, Higginson (2010)

NEoLCP to promote the importance of social care within end of life care work.

- Running road shows and test site pilots to focus on the objectives of the framework for social care.

Local authorities have responded positively to the programme. A 2011 evaluation of NEoLCP's work showed that authorities value the support around integration of health and social care, though health was still largely seen as leading in this area.⁴ The next steps for the Programme are to encourage councils to name their own social care leads who will progress the work locally, and to establish a new focus on the role of housing in end of life care.

Social care and housing has also been considered a key part of other organisations and charities who seek to improve palliative and end of life care. For example, the National Council for Palliative Care's recent report in conjunction with the National Care Forum notes that "we need to build compassionate communities which support people to grow older and die in the community. This requires clever use of housing and neighbourhood design,

a long-term vision and partnership working across all sectors". However, while there are several individual examples of innovative work among local authorities, practice on the ground has been mixed.

With this in mind, now is a good time to consider how councils are responding to the end of life care agenda.

- What level of awareness of end of life care priorities is there now among local authorities?
- Are elected members familiar with work around end of life care?
- What level of involvement is there from housing departments?
- What level of involvement is there from social care departments?
- What do local authorities regard as their role in this agenda? Do they see this changing in future?
- What level of integration with health has already been achieved, and how will the reform of health and social care affect this work?

Research findings

The LGiU undertook a national online survey of local authority officers and elected members, focusing on their understanding of the end of life care agenda, their perceptions of the challenges and opportunities in this area and their relationships with other key agents in the public and voluntary sectors.

The survey received 135 responses, representing 91 out of 152 upper tier authorities. Of these, 75.9 per cent were

officers (of whom 21 were directors, 35 were heads of service and 27 were third tier managers), and 24.1 per cent were councillors (of whom 14 were cabinet members and 14 were overview and scrutiny chairs).

Just over three quarters represented adult social care departments, a fifth were from public health, and the remainder was from a mixture of housing, children's services and policy departments.

⁴ *The National End of Life Care Programme: evaluating the Programme's work to support and promote the integration of social and health care*, University of Nottingham (2011)

Key findings

- 60 per cent of respondents thought that their existing end of life care arrangements would not be sufficient in future.
- Four out of 10 respondents thought that Health and Wellbeing Boards should lead on end of life care in future. However, only three out of 10 said that their shadow Health and Wellbeing Boards had identified end of life care as a priority.
- 40 per cent of respondents reported that their authority had a lead officer for end of life care. Just over half had a local plan for end of life care, either on their own, or jointly with health.
- Less than a quarter of respondents agreed that housing and social care worked together on end of life care.
- 60 per cent of respondents said that their authority intended to develop their role in promoting better end of life care.

The current position

There was evidently a level of concern among local authority respondents with the current systems of end of life care, perhaps reflecting uncertainty about the wider funding of social care, and also about the changes brought about by health reform. We asked people to agree or disagree with the following statements:

- Our existing end of life care arrangements will be sufficient for the future.
- Service users and their families in this locality are able to plan and control their end of life care.

Sixty per cent of respondents thought that their existing end of life care arrangements **would not** be sufficient in future.

Just over a third of respondents said that service users and their families were able to plan and control their end of life care. However, the majority were more

ambivalent, with 35 per cent neither agreeing or disagreeing, and 28.6 per cent disagreeing completely.

These results raise a series of interesting questions regarding progress against this agenda, which we will address here.

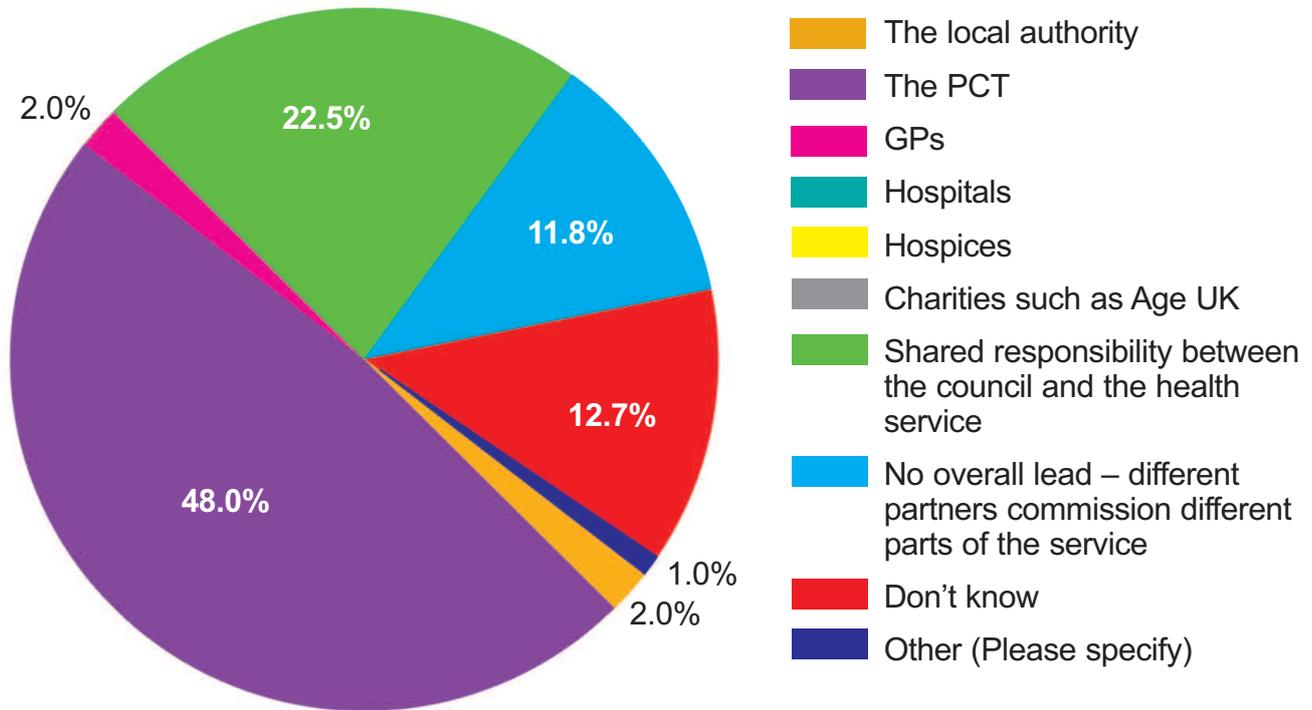
Who leads on end of life care?

There is currently some uncertainty regarding the leadership of the end of life care agenda at a local level. The NHS was still regarded as the lead organisation for end of life care in the largest proportion of responses.

While there was evidence of joint working between health and local authorities, with just over 20 per cent holding a shared lead for end of life care, the Primary Care Trust (PCT) was still identified as the lead body in just under half of the responses.

This reflects the strong lead taken by the Department for Health in end of life care, and the work of the NEOFPC, but it raises

Chart 1: Who currently leads the commissioning of end of life care in your locality?



potential concerns for the future of this work in the context of a shift away from PCTs to Clinical Commissioning Groups (CCGs).

Taking this into consideration, we asked local authorities, who they thought should coordinate end of life care in future. Just over 40 per cent identified Health and Wellbeing Boards, suggesting it is widely regarded as a shared agenda between health and the local authority.

However, 37.6 per cent said CCGs should take the lead in coordinating work in this area. This may imply that for many, end of life care remains a health issue, potentially raising concerns that councils do not have sufficient ownership of the agenda in some localities.

The division illustrated by this finding highlights a level of uncertainty and confusion in local government regarding the ownership of the end of life care agenda, and their role within it. It raises important

questions about how we exercise democratic control over the process in future.

Local authorities have a key role to play in end of life care, through their provision of relevant services in social care and housing, and in drawing together local partners on the issue. There is evidently a need for more clarity in some areas of the country.

Is end of life care a priority for local authorities?

To establish how local authorities regarded the end of life care agenda, we asked them:

- if they had a lead officer for end of life care in their authority;
- if the authority had a policy or plan for end of life care; and
- whether or not their shadow Health and Wellbeing Board had identified end of life care as a priority.

Chart 2: Who do you think should have overall lead responsibility for coordinating end of life care in your area in future?

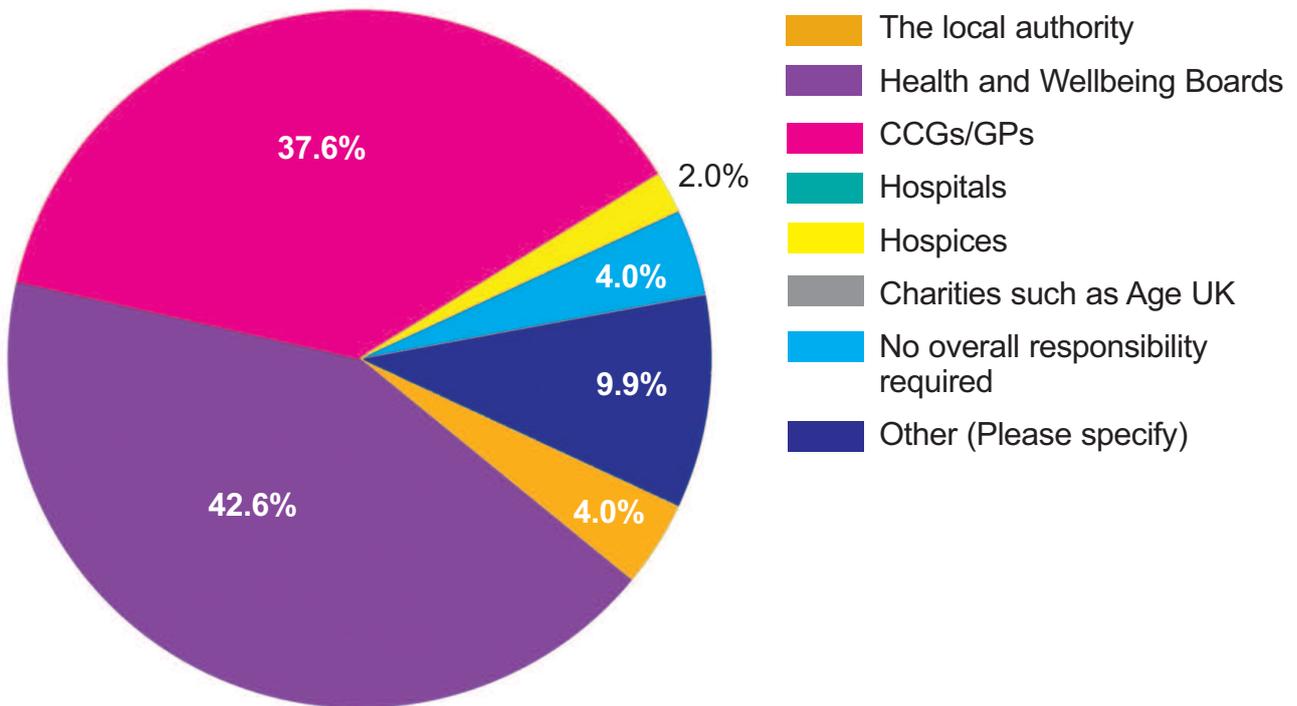


Chart 3: Does your council have a plan for supporting end of life care development?

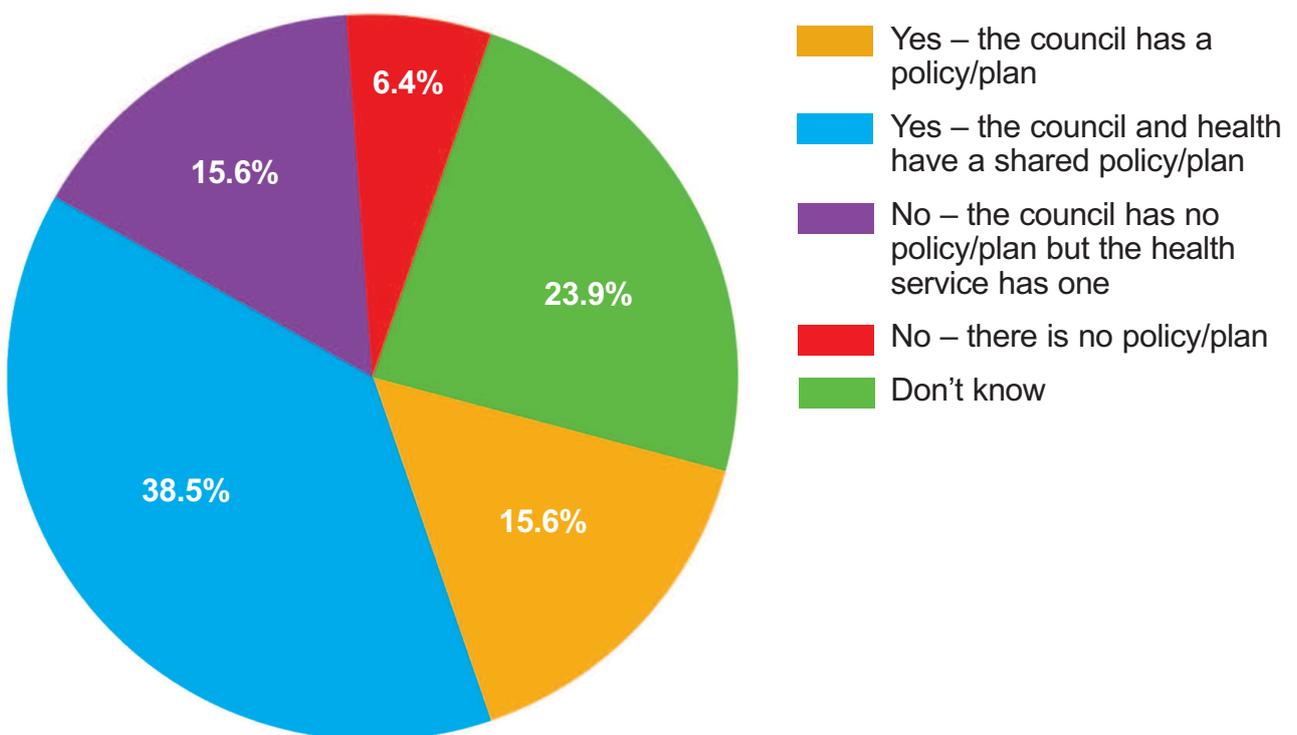
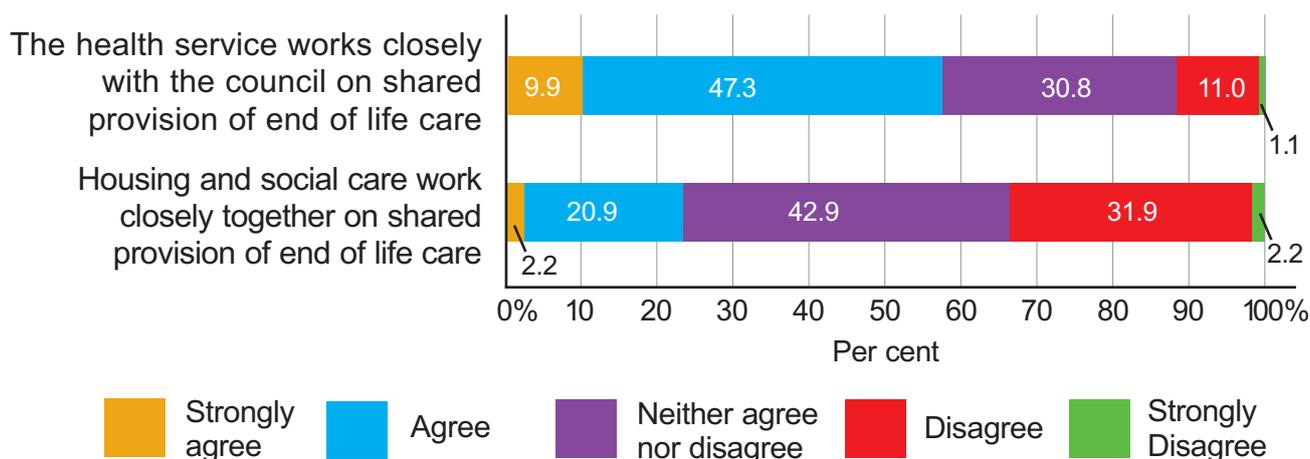


Chart 4: To what extent do you agree with the following statements?



The picture was varied: over 40 per cent of authorities had a lead officer for end of life care in their area, but 30 per cent did not, and a further 30 per cent did not know whether or not a lead had been appointed.

The majority of respondents reported having a plan for end of life care. In just under 40 per cent of cases this was a joint plan between the council and the health service.

In 15.6 per cent of cases the council had their own plan. However, a further 22 per cent indicated that the council did not have a plan, and 23.9 per cent did not know whether or not there was a plan.

It is encouraging that there are so many joint health and social care plans focusing on this area of work; further research into the contents of these plans, and the way in which other council services such as housing have been incorporated would be of value.

However, it is also clear that a significant proportion of authorities still do not have a plan, suggesting this agenda has not been identified as a priority, and perhaps continues to be regarded as the

responsibility of health. Without sufficient buy-in from all relevant partners it will be difficult to make further progress on this agenda.

32.7 per cent of respondents reported that their Health and Wellbeing Board had identified end of life care as a priority, but roughly 30 per cent had not, and the remaining respondents did not know whether or not it had been identified as a priority.

This reflects the recent findings of research undertaken by the National Council for Palliative Care, which has found that only 38 (46%) of 83 newly created Health and Wellbeing Boards with public strategies have considered the needs of dying people.⁵

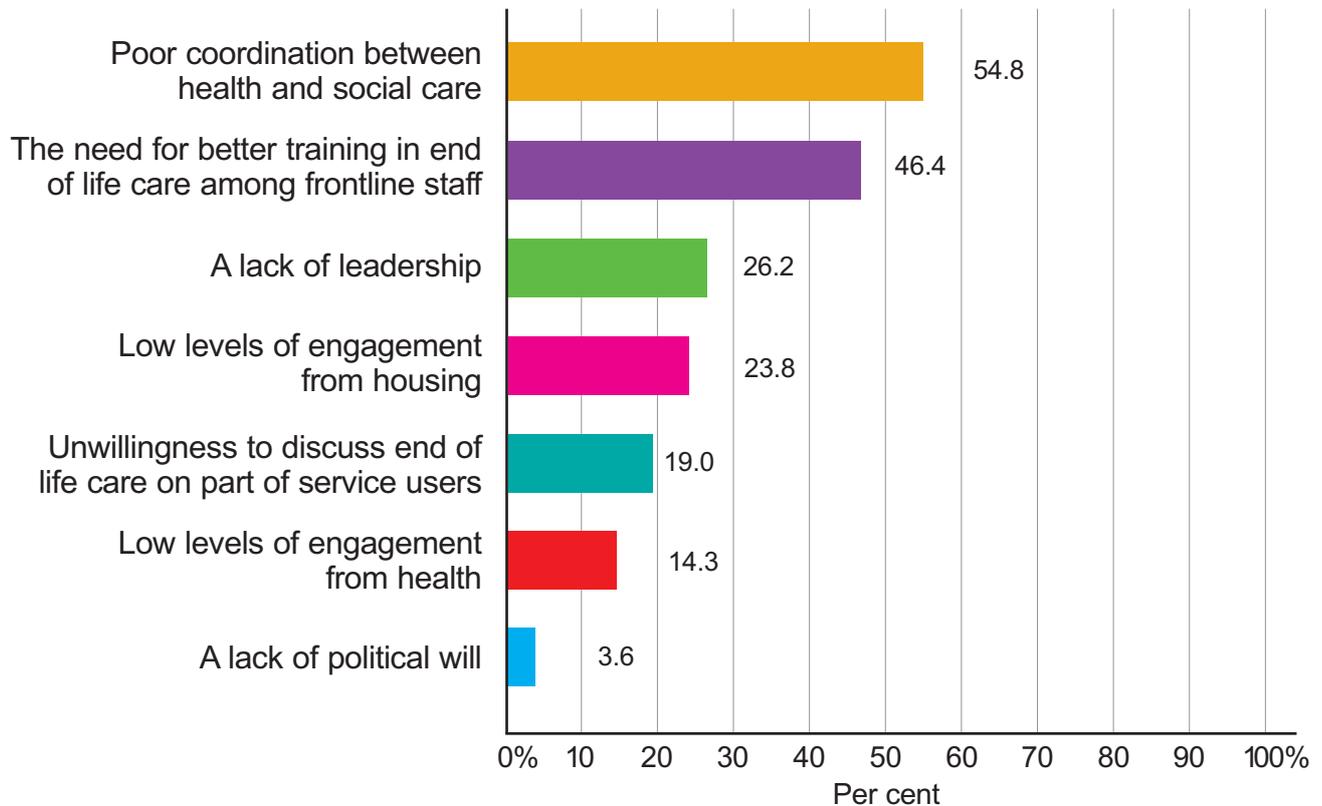
How well integrated is end of life care?

We asked respondents to agree or disagree with two statements on the integration of this area of work.

- The health service works closely with the council on shared provision of end of life care.

⁵ *What about end of life care: Mapping England's Health and Wellbeing Boards' vision for dying people*, National Council for Palliative Care (2012)

Chart 5: In your view, what are the biggest barriers to the provision of better end of life care, if appropriate?



- Housing and social care work closely together on shared provision of end of life care.

Housing was clearly less integrated into end of life provision than health and social care. While nearly 60 per cent agreed, or strongly agreed that health worked closely with the council on end of life care, less than a quarter agreed that housing and social care worked together on this agenda.

However, when we later asked respondents to identify the top barriers to better end of life care, only 23.8 per cent regarded housing’s lack of integration as a barrier.

This suggests that the vital role played by housing in delivering high quality end of life care is less recognised than the role of health and of social care services. Housing is an essential part of the end of life care agenda. Many unnecessary hospital admissions could be prevented by a more integrated

assessment of housing need alongside those of health and social care for example.

What are the barriers to better end of life care?

When asked to identify the challenges for end of life care provision, respondents identified the following barriers as their top three choices:

- poor coordination between health and social care (54.8 per cent)
- the need for better training in end of life care among frontline staff (46.4 per cent)
- a lack of leadership (26.2 per cent)

Interestingly a lack of political will was not widely regarded as a prominent issue. The concern regarding coordination between health and social care is of particular

relevance given that more than 60 per cent of respondents agreed that health worked closely with social care on end of life care in an earlier question. This suggests that although there is partnership working, other factors, such as the difficulty of aligning budgets, are preventing traction on this agenda.

Several people identified their own barriers to better end of life care, which perhaps shed some light on this contradiction.

- Availability and flexibility within the marketplace. Lack of specialist commissioned services.
- Lack of knowledge, information and understanding on behalf of service users and family carers across health and social care.
- Need to raise awareness amongst general public about end of life care.
- Lack of healthcare capacity – it is less staff resource intensive if patients are maintained in a hospital or care home setting. Resources will need to transfer accordingly.
- Better training is required for frontline staff employed by care homes and domiciliary care agencies.
- There is a willingness and appetite to work together but with adult social care unable to provide financial resource, influence is limited.
- Professional jealousy and protectionism.
- Out-dated working practices and employment contracts i.e 9-5 Mon to Fri services and lack of out-of-hours specialist provision; service gaps; a culture of paternalism and not allowing real choice and risk-taking; underlying power and accountability issues.

What is the role of the local authority in future?

The context in which services are delivered is changing rapidly as a result of reform in the sector. With this in mind, we asked respondents what they regarded to be the most important roles of the local authority in end of life care in future.

These results reflect a broader shift occurring across local government, and particularly in social care, where most authorities have moved towards assessing, commissioning and monitoring, rather than directly delivering services.

More than three quarters regard 'commissioning and developing services' as an important part of their responsibility in this area. Less than half, however, would regard coordinating partners as an aspect of their role. This perhaps reflects the prominent role health has taken in this agenda to date.

We would argue however, that one of the most important roles a local authority can play, is in bringing together the wide range of partners and interests from across the public, private and voluntary sectors, to promote better coordination and awareness of the issues that must be overcome.

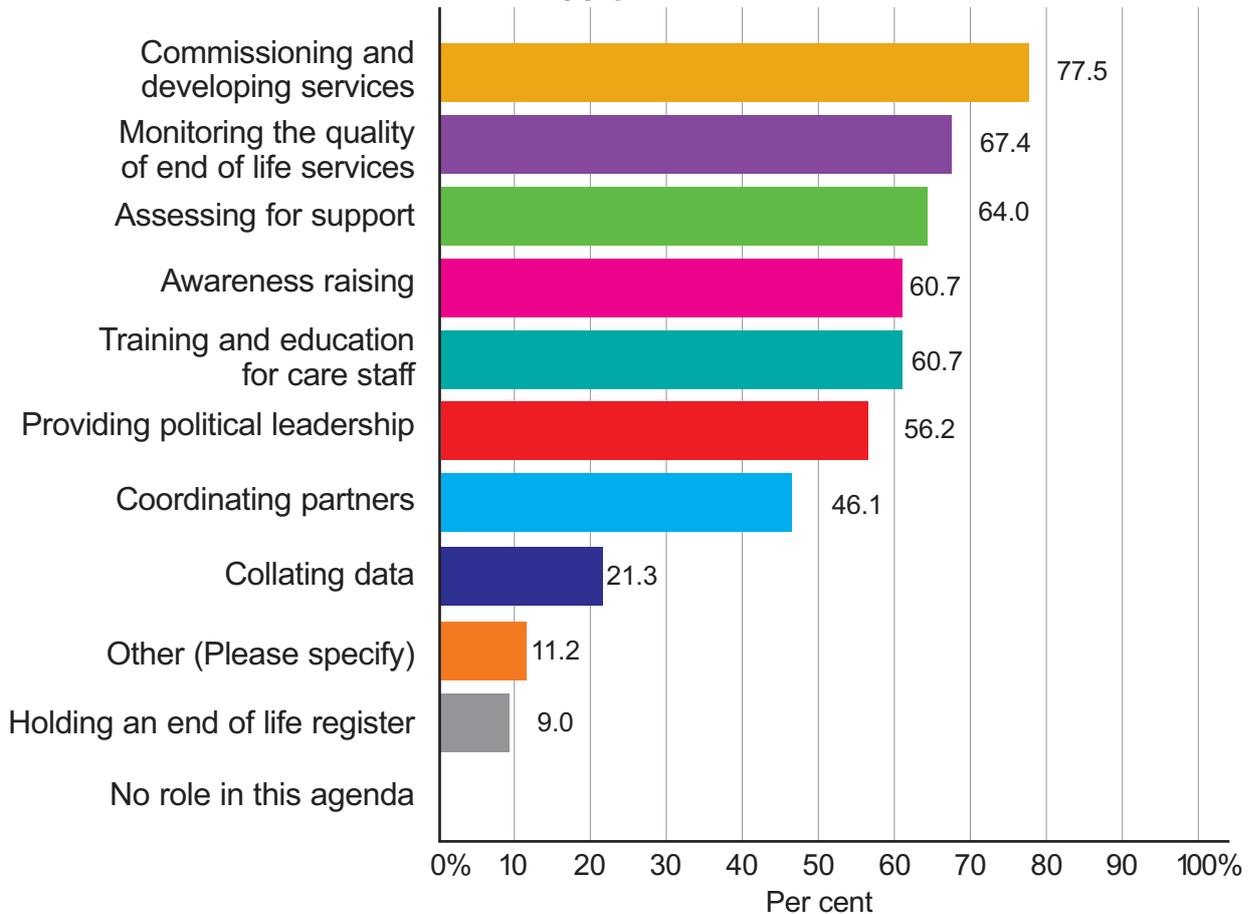
In their position as place-shaper in a local area, a council has an important role in promoting the importance of the agenda, in generating debate and developing shared understanding.

A number of respondents wrote individual responses to this question, including the following:

"Being in partnership with health having a shared vision and also responding to user feedback."

"To ensure that end of life care is embedded in all existing services."

Chart 6: What do you regard as the council’s role in end of life care? Please tick all that apply.

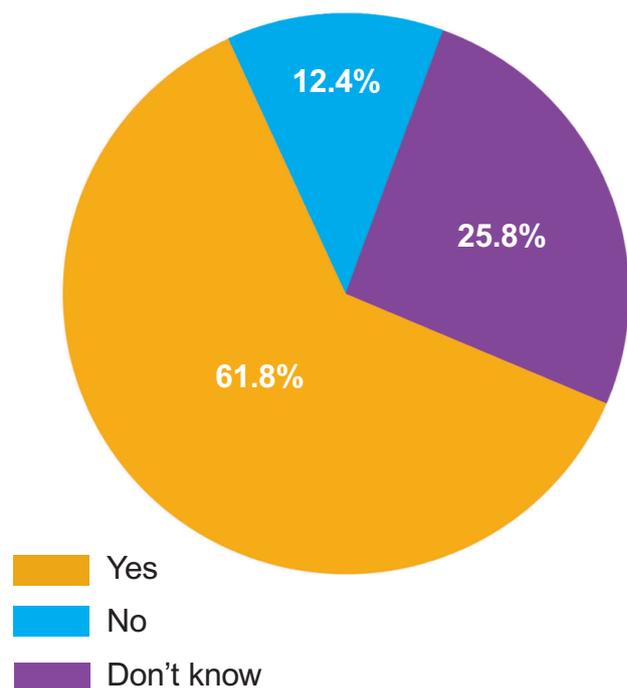


“We would see social care working with health provision in the support of an End of Life Care Pathway.”

“All the above should be a joint responsibility with respective lead commissioners within the two CCGs we are directly working with. It should be everybody’s business to ensure the wishes of people at end of life are respected and acted upon. Local authority cannot directly influence health staff, etc.”

Encouragingly more than 60 per cent of respondents said their authority had plans to develop its role in end of life provision in the future, perhaps reflecting the move towards greater partnership working between health and social care as a result of Health and Wellbeing Boards.

Chart 7: Does your council have plans to develop its role in end of life provision in future?



Recommendations

The local context for end of life care varies significantly from one authority to another. Some have established programmes of work in partnership with health services, while others have yet to act on this agenda. The findings of our survey illustrate three broad areas of work for councils in reviewing end of life care.

1) Raise awareness

There is clearly still scope to further raise the overall level of awareness of the issues associated with end of life care in local government.

The majority of respondents to the survey had some level of formal responsibility for social care, either as an officer, cabinet member or overview and scrutiny chair, but more than a third of respondents did not know if end of life care was a priority for their Health and Wellbeing Board. Around a quarter did not know whether or not they had an end of life care plan and 30 per cent did not know if they had a lead officer for this area of work.

There was no clear dominance from either officers or councillors in terms of knowledge. Nearly half of councillors responding did not know if their authority had a lead officer for end of life care, as opposed to a quarter of officer respondents. But 40 per cent of officers did not know if their Health and Wellbeing Board had identified end of life care as a priority, as opposed to 25 per cent of councillors.

2) Take ownership

The results indicate that councils are beginning to take a more prominent role in an area that has previously been primarily led by health. That more than 60 per cent of respondents report that they plan to develop their role in end of life provision is encouraging.

However, around 40 per cent of respondents identify CCGs as the lead partner for end of life care in future, rather than Health and Wellbeing Boards. This suggests that many still regard end of life care as being first and foremost an issue for health. The work of lead officers, and elected members will be to raise the profile of the local authority as an equal partner to health in this agenda.

There is some level of contradiction with regard to the relationship between social care and health. While nearly 60 per cent agreed, or strongly agreed that health worked closely with the council on end of life care, 'poor coordination between health and social care' was seen as the top barrier to better end of life care. This may reflect the changing relationships in this area as a result of health and social care reform.

3) Integrate housing

Less than a quarter of respondents agreed that housing works closely with social care on end of life provision, despite its often pivotal role in quality of life outcomes for people in receipt of care.

A recent pilot project delivered on behalf of authorities in Tyne and Wear by Home Group, has brought together housing, health and social care services to make practical arrangements for individuals to enable them to remain in their own home for as long as possible. As well as reducing unnecessary hospital admissions, and supporting better quality of life for individuals, it has also shown that savings can be made by integrating housing with health and care services.

The renewed initiative from local authorities offers new opportunities for a joined up approach that draws in health, social care and housing.

Case study: Tom, client of a Good Death programme, 2011

“I’m 38 years old, married, with a two-year-old daughter and I have terminal bone cancer. Cancer Connections, part of Macmillan Cancer Support, referred me to the Good Death project just after I was terminally diagnosed whilst in hospital with an infection.

The hospital weren’t willing to discharge me as my home had six leaks in the roof, making the property damp and unsuitable for me to live in, especially as I was very poorly at the time.

I own my property but because I was unwell and without work, I was unable to keep up with repairs or pay someone else to undertake the works for me. All I wanted to do was go home and be with my wife and young daughter as I knew I had little time left.

Home Group worked with my family to access funding, including a grant from Macmillan, which meant the roof could be fixed and I could return home to my family.

Without this support, I guess I would still be in the hospital.”

Conclusion

As we face the long-term challenge of an ageing population at a time of shrinking financial resources, it is vital that we get end of life care right. Failure to do so will result in spiralling costs for the public sector, and more importantly, a human cost for all of us who want to reach the end of our lives with dignity and control.

Getting it right will require good leadership, and effective coordination of local agencies working in this field. Councils have a crucial

part to play, both in their position as providers and commissioners of services, and in their broader role as place-shapers and coordinators in the local area.

This research shows that progress has been made in some areas of the country, but that there is further still to go in developing a fully integrated approach to end of life care that draws in the expertise in health, social care and housing to deliver joined up, personalised services.

Bibliography

Independent evaluation of NEO LCP social care Phase 1 test sites
[Centre for Housing Policy, University of York \(January 2012\)](#)

End of Life Care Strategy – promoting high quality care for all adults at the end of life
[Department of Health \(July 2008\)](#)

Where people die (1974-2030): past trends, future projections and implications for care
[Palliative Medicine, 22:1, 33-41. Gomez B, Higginson IJ \(2009\)](#)

Dying for Change
[Leadbetter, Charlie and Gardner, Jake, Demos \(2010\)](#)

A 2030 Vision: building communities and environments to support people to live and die well
[National Council for Palliative Care and National Care Forum \(2012\)](#)

What about end of life care: Mapping England's Health and Wellbeing Boards' vision for dying people
[National Council for Palliative Care \(2012\)](#)

Supporting people to live and die well: A framework for social care at the end of life
[NHS National End of Life Care Programme \(July 2010\)](#)

TEST (Training, Engagement, Services, Transferability and sustainability): Supporting people to live and die well
[NHS National End of Life Care Programme \(May 2012\)](#)

Social Care Workstream Report
[NHS National End of Life Care Programme \(November 2011\)](#)

The route to success in end of life care – achieving quality for social work
[NHS National End of Life Care Programme and the College of Social Work \(July 2012\)](#)

Evaluating NEO LCP's work to support and promote the integration of social and health care, Nottingham
[University of Nottingham \(February 2012\)](#)

Websites

Home Group's Good Death programme:
<http://www.homegroup.org.uk/news/Documents/A%20Good%20Death.pdf>

National End of Life Care Intelligence Network – Local authority profiles
http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/la_profiles_2012.aspx

National End of Life Care Programme: <http://www.endoflifecareforadults.nhs.uk/>

The National Council for Palliative Care: www.ncpc.org.uk

Dying Matters: www.dyingmatters.org

**Report author: Lauren Lucas,
Policy Manager, LGiU**

The LGiU is an award winning think-tank and local authority membership organisation. Our mission is to strengthen local democracy to put citizens in control of their own lives, communities and local services. We work with local councils and other public services providers, along with a wider network of public, private and third sector organisations. The LGiU convenes the Children's Services Network (CSN), which provides policy briefings, reports and events for children's services professionals.

www.lgiu.org.uk

Based in Newcastle, Home Group is one of the UK's leading providers of affordable and supported housing. Through our Stonham brand the group is Britain's largest provider of care and support services. Working in over 147 local authorities we provide high quality services which support 30,000 individuals to gain and maintain independence each year.

www.homegroup.org.uk

LGiU

LOCAL GOVERNMENT
INFORMATION UNIT

**22 Upper Woburn Place
London WC1H 0TB
020 7554 2800**

info@lgiu.org.uk

www.lgiu.org.uk

November 2012