



Meeting local and national priorities for adults and children with terminal and life-shortening conditions in Scotland

A Hospice UK briefing
December 2017

Acknowledgements

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Thank you to:

- Richard Meade, Head of Policy and Public Affairs for Marie Curie Scotland
- Stephen McCauley, Policy and Advocacy Manager at Hospice UK
- Dr Sarah Russell, Head of Research and Clinical Innovation at Hospice UK

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About Hospice UK

Hospice UK is the national charity for hospice care. We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life.

We work with and support over 220 local hospices to grow outstanding hospice care for adults and children across the UK, championing the expert, compassionate and free care they provide.

Published by Hospice UK in December 2017.

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Summary

Scotland's 31 new Integration Authorities ('Partnerships') have been tasked with delivering what the First Minister has described as the "most radical reform in healthcare since the foundation of the NHS": the integration of health and social care services.¹ The scale and pace of integration places huge demands on Partnerships and they have been working to establish the structures and processes by which they will deliver better outcomes for people across Scotland.

As the new structures embed and planning develops, we assess how integration is evolving for people living with palliative and end of life care needs. This briefing is designed by Hospice UK to support ongoing local Strategic Commissioning Plan (SCP) development work and local planning teams in meeting palliative and end of life care needs. It emphasises the role of hospices in solving local challenges and is intended to complement the Scottish Government's forthcoming Strategic Commissioning Guidance.²

We look at what SCPs currently say about meeting the needs of children and adults living with terminal and life-shortening conditions. We identify opportunities to strengthen planning and build links with hospice care to support the ambitions of integration, and meet the needs of local communities.

Palliative and end of life care was made a core priority relatively late in the local planning process, and it is not surprising that many of the initial SCPs produced by Partnerships have potential to expand this area. Improving planning through prioritising palliative and end of life care will significantly contribute to transforming outcomes for people and the whole health and social care system locally.

We focus on reducing unplanned hospital stays and the key role palliative and end of life care, particularly as delivered by hospices, plays in achieving this. Around a third of people in hospital in Scotland are in their last year of life, half of all deaths occur in hospital and almost one in ten people who are in hospital today will die before they are discharged.³ Many have no medical need to be there and could benefit from palliative and end of life care in the community.

There are five main ways Partnerships can work toward universal access to palliative and end of life care, deliver better outcomes for people locally and reduce unplanned hospital stays:

1. In Joint Strategic Needs Assessments, prioritise the identification of people with palliative and end of life care needs; and those with chronic and long-term conditions likely to deteriorate over time.
2. In SCPs, prioritise meeting needs of those with terminal and life-shortening conditions, and those with chronic and long-term conditions likely to deteriorate over time.
3. As part of addressing the paucity of data relating to widening access to palliative and end of life care, in statutory reporting, include metrics which capture progress on widening access to palliative and end of life care.
4. Engage meaningfully with hospice care providers across all aspects of assessment, strategic planning and delivery.
5. Ensure decision making structures reflect the importance of delivering universal access to palliative and end of life care.

Context

Experts estimate that around one in four Scottish people don't get the care they need at the end of life – some 11,000 people per year.⁴ Children's Hospices Across Scotland (CHAS) estimate there are over 15,000 babies, young people and children in Scotland with life-shortening diagnoses, but two-thirds are not known to their services.⁵ In every Partnership area there are likely to be children and adults missing out on the expert palliative and end of life care they need.

The need for palliative and end of life care is only set to grow:

- 56,700 Scots died last year and by 2037, the number of people dying each year will have risen by 12 per cent.⁶
- It is estimated that up to 82 per cent of all people who die each year can benefit from palliative care. This would equate to over 40,000 people dying in Scotland each year with palliative care needs.⁷
- The number of Scots aged over 65 is expected to increase by more than 20 per cent by 2026.⁸
- Across the UK, frailty is now the most commonly reported health condition in older people leading to death.⁹
- One in three Scots aged over 75 years was admitted to hospital at least once in 2015-16.¹⁰
- Research shows that there is a much bigger unmet need for children's palliative care than anticipated in Scotland and service planning for the future must respond.¹¹

Do SCPs address the needs of children and adults with terminal or life-shortening conditions?

The Scottish Government has set out a series of national policy priorities to improve access to palliative and end of life care that meets people's needs (see the box on page 4). The government has made it clear that it is now the job of Partnerships to deliver these priorities locally, in pursuit of the national ambitions.

The Scottish Government has:

- set out a vision that by 2021 everyone who would benefit from such care will be able to access it (Strategic Framework for Action on Palliative and End of Life Care, 2015)¹²
- committed to doubling the provision of palliative care in the community within the same time frame (Health and Social Care Delivery Plan, 2016)¹³
- said that everyone who needs the anticipatory care planning tool, a Key Information Summary (KIS), should have one (Health and Social Care Delivery Plan, 2016)
- instructed all Partnerships that it is a priority to increase good palliative care “particularly in people’s own homes, communities and where appropriate, in hospices to ensure people who would benefit from this care can access it” (Scottish Government/COSLA letter to all Chief Officers of Integration Authorities regarding draft Budget 2017/18, 15 Dec 2016)
- agreed that integration progress must be tracked across six indicators, the fifth of which relates to palliative care (Scottish Government/COSLA letter to Chief Officers of Integration Authorities, January 2017)
- committed to providing strategic commissioning guidance (at present on a non-statutory basis) to Partnerships relating to commissioning palliative and end of life care services (Strategic Framework for Action on Palliative and End of Life Care).

To assess how well current strategic commissioning processes are including and prioritising palliative and end of life care, we conducted an audit of SCPs. The Scottish Government advises that Strategic commissioning is the mechanism by which the priorities of integration will be achieved and SCPs are “the output of the strategic commissioning process.”¹⁴

As the outputs of the strategic commissioning processes, auditing SCPs provides evidence regarding the current visibility of palliative and end of life care in SCPs which is indicative of Partnership planning priorities.

What we did

In the summer of 2017 we undertook research to better understand how palliative and end of life care is being prioritised by Scotland’s new Partnerships. We:

- undertook an audit of SCPs in two parts:
 - » a key word search across all 31 existing SCPs for key terms related to palliative and end of life care
 - » a detailed review of 21 SCPs looking specifically at how palliative and end of life care terminology was used within context
- asked hospice care providers for feedback to gauge how local strategic commissioning activity is responding to national priorities.

What we found

The audit

In our key word search of all 31 SCPs, we found a lack of visibility of terms we associate with palliative and end of life care.

Across all SCPs:

- 90 per cent do not reference the Strategic Framework for Action on Palliative and End of Life Care
- 87 per cent do not mention 'terminal', or 'life-limiting' conditions; none mention life-shortening
- 81 per cent do not mention 'bereavement'
- 71 per cent do not mention 'hospice care' or 'hospice/s'
- 61 per cent do not mention 'dying'
- 23 per cent do not mention 'end of life'
- 13 per cent do not mention 'palliative'.

Looking in more detail at 21 SCPs, we found many instances where use of the relevant terms lacked substance, being either a very brief reference or inclusion in statutory lists (such as, which services Partnerships are responsible for commissioning; or of current national health and wellbeing outcome measures). Further to this, in the 29 per cent of SCPs that mentioned hospice/s it was often in the context of a list of local stakeholders or amongst place of death statistics. This is not to say that there were no SCPs with clear and detailed priorities for palliative and end of life care, but these were the exception.

We recognise that a number of Partnerships have specific plans for palliative and end of life care that sit separate but beneath the SCP. Given the importance of palliative and end of life care to meeting national priorities, it should be part of high level strategic planning and as such, referenced in the Partnership SCP.

We acknowledge that palliative and end of life care was included as a core priority for Partnerships relatively late in the planning process, making it difficult for Partnerships to rework proposals already underway. However, uneven or low visibility of planning to implement national priorities relating to palliative and end of life care and addressing community need will be a cause for concern if proposals are not improved.

Achieving good outcomes for people in need of palliative and end of life care (and realising integration aims)

Anyone with a condition that is terminal or life-shortening could potentially benefit from palliative and end of life care and support. However, too many people are not identified, assessed or referred to appropriate services, such as hospice care.

Prioritising palliative and end of life care planning to deliver national ambitions is an opportunity to improve the experiences of thousands of Scots and will support many of the ambitions of health and social care integration. In particular, we focus in this briefing on the core integration aim of reducing unplanned bed days in acute hospitals. This aligns with the Scottish Government's goal of shifting the balance of care from acute to community settings. We will demonstrate how prioritising end of life care and engaging with hospices can contribute to realising the aim and yield better experiences for people in the community.¹⁵

We know that most people wish to receive care and to die at home, or in a hospice inpatient setting.¹⁶ While this may not always be appropriate, and people can, and do, change their preferences over time, the fact that half of deaths occur in hospital indicates hopes of choice or control over the end of life are not being realised for everybody. Being admitted to hospital in the last weeks and days of life, when someone could be at home; or receiving expensive potentially traumatic medical interventions which may be of little or no benefit, can severely impact on quality of life and experiences of dying.

- In 2012/13 'unplanned palliative medicine' accounted for 27,909 bed days and £12.4 million: 95 per cent of the total expenditure on palliative medicine in Scotland's acute hospitals.¹⁷
- In England (numbers will be similar for Scotland), hospital costs make up the bulk of end of life care costs with the cost of care for the last three months of life averaging £4,500 per person – mainly due to emergency acute admissions with costs rising sharply in last few weeks of life.¹⁸

How prioritising palliative and end of life care helps

Personal outcomes

- Palliative care improves quality of life and experiences for people receiving care and those around them; and the earlier care begins, the better the outcomes.¹⁹
- People with terminal illnesses are more likely to die at home or in the community, if preferred, if they have access to palliative care.²⁰

Economic outcomes

- People receiving hospice care in their own homes experience fewer admissions to hospital and A & E (which can also have a huge personal impact).²¹
- Providing hospice services in people's homes saves around £500 per person when compared to costs of hospital care, community and primary health and social care.²²
- Healthcare Improvement Scotland says that investing in community-based palliative care will reduce time spent in hospital at the end of life; and that reducing emergency admissions by 10 per cent and reducing the average length of stay following admission by three days will "release" £104 million.²³
- NICE calculates that providing end of life care to children and young people in need within a population of 1.5 million people would yield a net resource saving of £701,000. Scotland's population is 5.4 million.²⁴
- It is estimated that costs of care for people in the last year of life are 30 per cent lower for people in receipt of palliative care.²⁵

CASE STUDY: Fast track hospice care at home

Marie Curie delivers a Fast Track Service offering short and evening visits at home to provide health and personal care to people living with terminal illness. The service is for people nearing the end of their lives who are at risk of hospital admission as well those in hospital who need more care at home to be discharged. This allows people to spend their precious final days at home, reducing avoidable hospital admissions, stays and deaths.

How hospices help

Hospices are vital community assets and resources. As well as directly investing in, coordinating and providing care, hospices support care in other settings and are unique community partners for planning services that meet people's palliative and end of life care needs.

Providing care

- Scottish hospice care represents a **wide range of local, community-based palliative and end of life care services** for people and families in, and beyond, hospice inpatient units: in 2016/17 over 20,000 Scots were helped directly by hospices, with 80 per cent of being cared for in the community or at home.²⁶ Over 18,000 people received clinical care, which represents two fifths of all people estimated to need such care in Scotland. Scotland also has a hospice provider dedicated to the care of children: Children's Hospices Across Scotland (CHAS). In 2016/17 CHAS cared directly for over 400 children and their families in two hospices, through Diana Nurses across settings and in families' homes, with plans to reach many more families in need.²⁷
- Hospices understand that **out-of-hours support** is crucial to reducing acute admissions: 75 per cent of hospices provide a 24/7 telephone advice service to clinicians and the public.

- Hospices are leaders in delivering, teaching and supporting palliative approaches to care and **Anticipatory Care Planning** – approaches that potentially mean many A & E presentations, acute admissions and readmissions, and medical interventions with limited or no benefit can be avoided.
- Bereavement can lead to poor physical health, mental health, financial and employment outcomes for people. Anxiety and depression are the leading causes of ill health in Scotland.²⁸ Scottish hospices offer **bereavement support** to children and adults before and after death, with many supporting referrals from outside their own services (where the loved one who died was not being cared for by the hospice).
- Hospices are leaders in innovation in palliative and end of life care, able to **test and evaluate new models of care** in ways not possible elsewhere in the health and social care system; offering Partnerships unique opportunities to collaborate to drive quality improvement and widen access to excellent care.
- Hospices are **important research hubs for palliative and end of life care**. 80 per cent of Scottish Hospices have a dedicated research function and the same proportion is engaged in research partnerships with universities and/or other academic institutions.

Supporting hospice care to be delivered in non-hospice settings

Scottish hospices are engaged in supporting care across a range of health and social care partners including (but not exclusively) through:

- **Working with** other community based care providers such as GPs, hospital clinicians, schools and care homes. 85 per cent of hospices are supporting care homes to increase their capacity to deliver palliative and end of life care (see the 2017 Hospice UK report: ‘Hospice care and care homes in Scotland’ for more detail on how these partnerships work and how they can be expanded).²⁹
- **Supporting carers** and families to deliver care as well as have respite from caring and through bereavement.
- **Teaching** health and social care staff to deliver a hospice model of care in other settings via formal and informal programmes and partnerships. 92 per cent of Scottish hospices have an education or practice development function and 77 per cent provide training for external staff.

CASE STUDY: Project ECHO in the Highlands

One of the challenges care providers face is how to support services across Scotland’s more dispersed geographies. Highland Hospice has responded by implementing Project ECHO (Extension of Community Health Outcomes) across a variety of care settings, including care homes. Project ECHO is a ‘hub and spoke’ knowledge-sharing network model, provided remotely over the internet that enables a safe and secure place to exchange knowledge, with distance being no barrier. As part of this work the hospice is working with around 20 care homes to support and mentor colleagues to support residents with palliative and end of life care needs. As well as care homes, the hospice has developed communities of practice using the ECHO methodology to support specialist nurses, community pharmacists and out-of-hours practitioners. Further development is being explored to support care at home and community hospital colleagues.

Unique community partners in planning and delivery

The 2014 Public Bodies (Joint Working) (Scotland) Act³⁰ places a duty on Partnerships to ensure that stakeholders are “fully engaged” in the preparation, publication and review of strategic commissioning plans. This engagement needs to be more focussed than the current Third Sector Interfaces, which are too broad to capture the specific skills and knowledge of very different organisations providing a wide range of different services.

The Scottish Parliamentary Health and Sport Committee Inquiry into Integration Authorities Consultation with Stakeholders (2017)³¹ reported that that Third Sector Interfaces (TSIs) have not been working as a reliable vehicle for third sector organisations to engage meaningfully with Partnerships, either to be part of decision making or to obtain information.

Engaging more fully with third sector organisations, such as hospice care providers, should not be a burden or undertaken only because there are duties placed on Partnerships. Rather, Partnerships will be more able to meet the targets and deliver more care to more people if they work with hospice care providers as partners and take a co-production approach.

Hospices in Scotland are major commissioners and providers of palliative and end of life care.

- The Scottish hospice movement **invests around £66 million every** year to meet local palliative and end of life care needs. Statutory sources account for, on average, 39 per cent of funding for adult services and hospices need to fundraise £3.3 million every month.³²
- Thousands of local **volunteers** power Scotland’s hospices: in 2014/15 volunteers delivered an estimated 318,000 hours of work.
- Carers need to be better supported in our communities and hospices have prioritised carer support. Hospices do not just care for the patient: **they support thousands of carers to keep caring** across Scotland every year through respite care, counselling, bereavement support and through many more formal and informal ways.
- Hospices are active in communities across Scotland with experience of planning and coordinating care in a **person-centred**, community sensitive, holistic way. Hospice care understands that a person’s physical, emotional, spiritual and social needs are of equal importance – and the people who matter to patients, matter to them.
- Hospices are **willing and prepared** to support local teams in planning palliative and end of life services; ready to share experience, expertise and to build capacity for service delivery to reach more people.

Beyond the barriers: getting care to people

There are a number of reasons people miss out on care for life-shortening and terminal conditions, or at the end of life, that could be tackled in local planning.

To date, there has been limited investigation of exactly who the 20 per cent of Scots are that it is estimated could benefit from such care but do not get it. However, evidence from a range of research show that some groups are particularly disadvantaged due to factors such as sexual orientation, older age, diagnosis (for example, those with a non-cancer diagnosis access care in proportionately fewer numbers than those with cancer), homelessness, living in more deprived areas, and ethnicity.³³ It is likely that lack of access to palliative and end of life care is a complex interaction of these and other factors.

We identify two key considerations that, if addressed, could widen access to palliative and end of life care:

Improve awareness of what palliative and expert end of life care is, and who could benefit

Both professionals and people in need of care (or those around them) can have limited understanding of the role of palliative and expert end of life care. This can lead to a failure to identify need, make appropriate referrals, or take up care. For example, although cancer causes around 30 per cent of deaths it accounts for 80 per cent of referrals to hospice care.

Modern hospice care includes rehabilitative care that is supportive of chronic long-term conditions, such as respiratory and circulatory illnesses. Stigmatisation and lack of understanding of the role of palliative care in a wide range of conditions contributes to poor access for people with a non-cancer diagnosis.

This is also true for babies, children and young people with palliative care needs. Children's hospices are able to offer long-term support to families with a child with a life-shortening condition – often for years.

Changing patterns of death and dying mean that we need new ways to identify and care for people approaching end of life. Population changes and medical advances mean that we are likely to live longer, but with multiple comorbid conditions. For example, frailty or dementia do not follow the same illness trajectory as terminal cancer, but in many cases people with these conditions would benefit from palliative or expert end of life care.³⁴

Improve local capacity to respond to need

To widen access to palliative and expert end of life care we need to improve the partnerships across all providers in the care network, ensure access to better training across the health and social care workforce, and have clear lines of accountability so that complexity does not mean people fall through the gaps.

There is a recognised deficit in the training of the health and social care workforce to understand and respond to palliative and end of life care needs. The Scottish Government intends that everyone working in health and social care will have access to the necessary knowledge to understand and, where relevant, deliver, good palliative care through the Educational Framework for Palliative and End of Life Care (as per the Strategic Framework for Action).³⁵

Joint working across the private, public and third-sector, needs to be strengthened to improve the care journey for those currently accessing care, and for those yet to be identified. Closer, more consistent, strategic working between hospices, Partnerships and other care providers is essential to identify and deliver processes and initiatives which secure wider access to care. Bolder, innovative commissioning across services is required to get care to everyone who needs it.

“Based on local priorities and working in partnership with the third and independent sectors, Health and Social Care Partnerships decide through their strategic plans how best to allocate their pooled budget to fund capacity where it is most needed, in order to improve outcomes for their local populations. By focusing on improving palliative and end of life care, reducing unplanned hospitalisation as well as delayed discharges, the Partnerships are key to ensuring the Health and Social Care Delivery Plan objectives are achieved.”

Chief Executive's Annual Report 2016/17
NHS Scotland, November 2017.

FIVE ACTIONS PARTNERSHIPS CAN TAKE TO IMPROVE PLANNING

1. Joint Strategic Needs Assessment

Good planning depends upon good data. The needs assessments which inform Strategic Commissioning Plans should assess end of life and palliative needs, services and service gaps. This process connects to wider, supporting work underway locally through the implementation of the Strategic Framework for Action relating to mapping need, service provision and individual patient journeys at the end of life. That work is being led by ISD under Commitment 9 relating to data and by HIS under Commitment 1 examining better identification of need and coordination of services across test sites.

2. Strategic planning

Focusing on palliative and end of life care will help you achieve your wider strategic objectives. The current SCPs do not consistently address how the palliative care needs of children and adults with terminal or life-shortening conditions will impact on their overall strategic outcomes. All SCPs should set out plans that demonstrate how national ambitions will be realised locally. There is opportunity to reduce unplanned admissions and widen access to palliative and end of life care by prioritising the needs of people in the last year of life and people with chronic and long-term conditions likely to deteriorate over time.

3. Performance reporting

What gets measured, gets done. Annual Performance Reports and measures aiming to qualify performance should address widening access to (community based) palliative and expert end of life care. The Scottish Government has instructed Partnerships that one of the key six integration indicators they will be expected to report against relates to palliative care. To this end, embedding access to palliative and end of life care measures in all aspects of care reporting, rather than as a discrete service type, will improve outcomes. For example, do all people with a chronic, long-term conditions expected to deteriorate over time have a palliative care assessment or referral to rehabilitative palliative care? And are referrals for palliative and end of life care made from acute services where people are identified as having repeat unplanned hospital admissions?

4. Engaging with hospices

Hospices are a resource that can help. Hospice care providers are commissioners of a large proportion of palliative and end of life care in Scotland, providing approximately £35 million per annum to services beyond statutory resources. As such, hospice care providers are essential to the co-production of services and systems at local and national levels. Their expertise and contribution to local health and care systems cannot be captured under a broad umbrella of 'third sector' representation. Consistent ways for hospice care providers to input to local decision making is essential. Stakeholders should be involved very early in planning processes and before decisions are taken, as recommended by the Scottish Parliament's Health and Sport Committee.³⁶ Hospice expertise, resource and innovative approach will support local Partnerships to deliver on Scottish Government commitments.

5. Decision making structures

Make it clear where responsibility sits. To deliver universal access to care, we recommend that Partnerships ensure the groups responsible for decision making for palliative and end of life care, such as Steering Groups or Managed Clinical Networks are transparent, effective and include hospice representation. Partnerships should also have a named lead for palliative and end of life care, or where co-hosting applies, an identifiable lead for shared decision making.

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