

Dear Colleague,

A PARTNERSHIP FOR BETTER PALLIATIVE AND END OF LIFE CARE: CREATING A NEW RELATIONSHIP BETWEEN INDEPENDENT ADULT HOSPICES AND NHS BOARDS IN SCOTLAND

Summary

NHS Scotland aims to deliver the highest quality of healthcare services to people in Scotland. This Chief Executives Letter (CEL) sets out new planning arrangements between NHS Boards and independent adult hospices. It reflects the recommendations set out in the report *A Partnership for Better Palliative and End of Life Care: Creating a New Relationship Between Independent Adult Hospices and NHS Boards in Scotland*

<http://www.scotland.gov.uk/Resource/Doc/924/0111432.pdf>

The recommendations in the report were endorsed by the Scottish Government in Living & Dying Well: *Building on Progress*. This CEL supersedes NHS HDL (2003) 18 - Funding of Specialist Palliative Care Provided by Independent Voluntary Hospices in Scotland.

Action

NHS Boards should ensure that:

- copies of the report and this CEL are made available to interested parties, but in particular to NHS Board Executive Leads for Palliative and End of Life Care
- interested parties are aware of the background and strategic context of this CEL
- commissioning arrangements for adult independent hospice provision follows the guidance outlined in this CEL
- commissioning arrangements support quality improvement, efficiency and effectiveness.

Yours sincerely

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Policy Director, the Quality Unit

CEL 12 (2012)

May 2012

Addresses

For action

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NHS Board Executive
leads for Palliative Care

For information

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BACKGROUND

1. NHS Boards and independent adult hospices have close working relationships. Increasingly, they work across boundaries to deliver more integrated and holistic care, consistent with the objectives set out in *Living and Dying Well (2008)*. The development and implementation of the Quality Strategy has also signalled a shift to a service more closely focused on offering more consistent and better outcomes for people and their families.

2. This CEL seeks to support the development of an even closer collaboration and co-operation between independent adult hospices and NHS Boards.

3. The Audit Scotland 2008 *Review of Palliative Care Services* noted the scope to improve the consistency in funding arrangements between independent adult hospices and NHS Boards, and recommended that NHS Boards put in place commissioning and monitoring arrangements which would ensure that value for money was achieved. In examining the Audit Scotland report, The Public Audit Committee of the Scottish Parliament recommended robust commissioning arrangements in the delivery of specialist palliative care services to ensure value for money, and also recommended that the Scottish Government should supplement existing guidance on what should be included in NHS Board funding allocations to voluntary sector bodies.

4 The Scottish Government accepted these recommendations and a Short Life Working Group (SLWG) was established with representation from the Scottish Hospices Forum and the six NHS Boards with independent adult hospices in their areas. This group, chaired by one of the co-chairs of the *Living and Dying Well* National Advisory Group, adopted a collaborative approach and explored opportunities, within the context of today's challenging financial environment and increasing expertise in quality assurance issues, to build a viable and enduring partnership and commissioning framework between NHS Boards and independent adult hospices in Scotland.

5 The report of the SLWG was presented to the Scottish Government in July 2010 and published alongside *Living and Dying Well: Building on Progress* in January 2011. In accepting the recommendations, the Scottish Government agreed to consider the implications for the existing guidance, as set out in HDL(2003)18 http://www.sehd.scot.nhs.uk/mels/HDL2003_18.pdf.

6 At the Scottish Government's request a Short-Life Working Group, with representation from NHS Board's and Hospices as outlined in Annex C, has considered the opportunities to refresh and update HDL(2003)18 in light of the Quality Strategy, the commissioning report and *Living and Dying Well*. The work of this group is reflected in this CEL.

7 NHS Boards and independent adult hospices should ensure that progress is made over the course of 2012-13 to support the implementation of the recommendations. It is expected that all NHS Boards with independent adult hospices will have new arrangements in place to inform funding for 2013-14 onwards.

STRATEGIC CONTEXT

8 *Living and Dying Well* advocates a comprehensive and cohesive approach to the planning and improving of palliative and end of life care. It describes palliative and end of life care as integral aspects of the care delivered by any health or social care professional, focusing on the person, not the disease, and applying a holistic approach to meet the physical, practical, functional, social, emotional and spiritual needs of patients and carers facing progressive illness and bereavement. It is essential that NHS Boards, with key stakeholders, including, for example, the voluntary sector and social care partners, work together in order for the aims of *Living and Dying Well* to be fully realised.

9 As envisaged at the publication of *Living and Dying Well*, NHS Boards and the independent providers of specialist palliative care have built a strong and effective alliance for change. The report, *Building on Progress* described the substantial progress already achieved across the NHS, and in collaboration with the independent sector, in improving the quality of palliative and end of life care.

10 A central aspect of the work of the SLWG has been to ensure that the original strategy and policy intent for HDL(2003)18 was not undermined but rather shaped to meet current circumstances. Independent adult hospices value their status, as being separate from the NHS, whilst offering a distinctive contribution to the provision of palliative and end of life care. The 50% funding formula is intended to respect this position and to ensure continuity of support for independent adult hospices.

11 The SLWG also recognised the scope to ensure clarity regarding funding and a greater focus on evidencing outcomes and value for money, within an integrated commissioning framework.

12 The **Individual Elements** set out in HDL(2003)18 are updated in Annex A. The updating of these elements reflects changes in the position of NHS bodies, legislation and accountabilities since 2003. Such individual elements should be brought into the commissioning cycle set out in the recommendations of the SLWG and considered in the determination of agreed running costs.

GUIDANCE FOR ESTABLISHING AN INTEGRATED COMMISSIONING FRAMEWORK

13 NHS Boards and independent adult hospices should take steps to establish longer-term commissioning arrangements, consistent with the recommendations in the SLWG report. It is recognised that good commissioning practices are important determinants to providing quality care. NHS Boards should ensure that the overall commissioning approach contributes to the aims and ambitions of the Quality Strategy.

14 The SLWG report referred to the need for commissioners “to view hospices more as *partners* in commissioning than simply as *providers* of commissioned services. Similarly, hospices need to have a fuller understanding of the tight financial environment in which NHS Boards are operating and the need to make difficult choices between and within priority areas.”

15 The following principles should underpin the approach to commissioning:

- transparency and openness
- a focus on outcomes
- clinical effectiveness
- cost effectiveness
- value for money

16 To maximise the value from commissioning therefore, the process needs to be owned and led by the NHS Board Executive Lead for Palliative and End of Life Care, working in partnership with Executive staff and Trustees of local independent adult hospices. Following these principles a more structured partnership approach to commissioning should be taken, that is informed in particular by:

- value for money and efficiency
- benchmarking of costs, activity and quality
- quality outcome measures.

17 The quality outcome measures should be informed by the work being led by Living and Dying Well, National Advisory Group.

18 In establishing the longer-term partnerships and commissioning cycle between NHS Board and independent adult hospices, NHS Boards should draw upon:

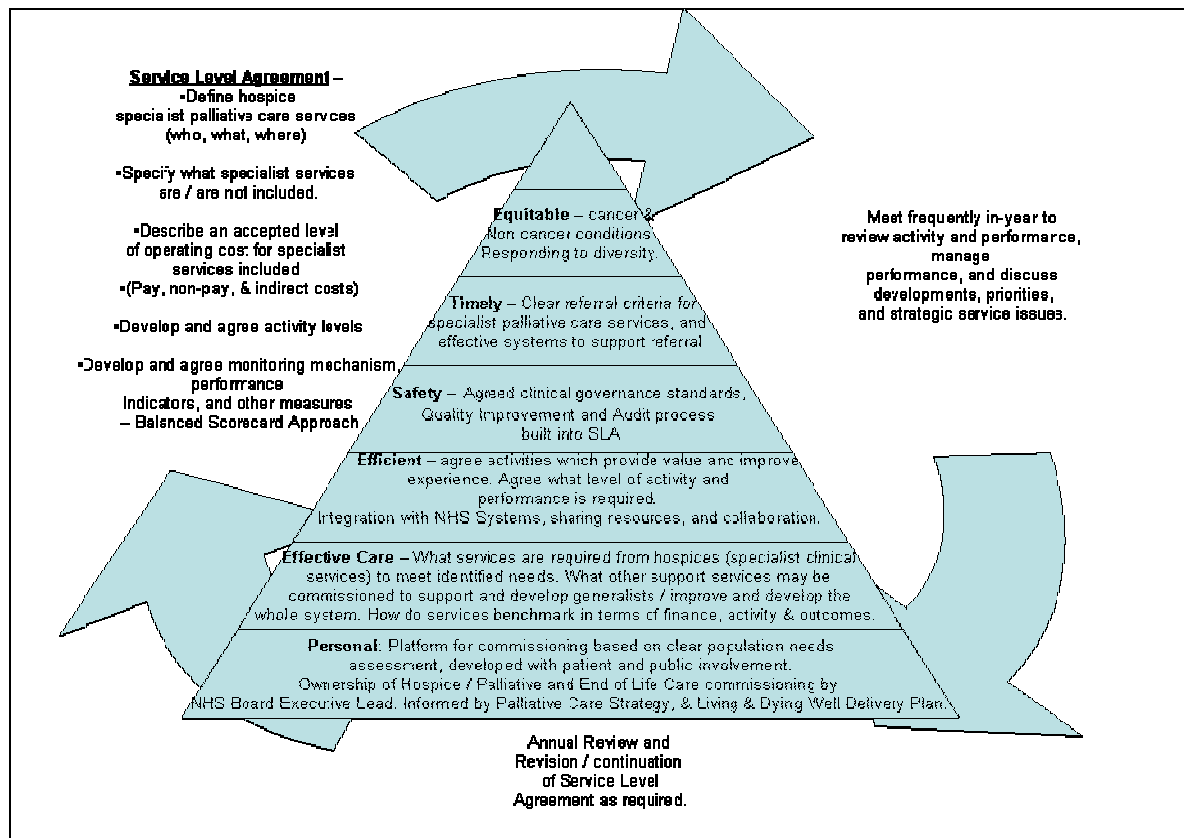
- 18.1 a common and consistent approach to commissioning between NHS Boards and the independent adult hospices
- 18.2 an explicit statement of commissioning intentions by NHS Boards of what level of service that will be purchased and which fully reflect *Living and Dying Well* and local Delivery Plans

- 18.3 an “open book” approach between NHS Boards and independent adult hospices to expenditure in the Hospices
- 18.4 a clear, consistent and detailed definition of agreed running costs
- 18.5 a balanced scorecard of level 3 measures (quantitative and qualitative) with agreed performance trajectories - measures should be consistent with the Quality Strategy and the quality improvement role of Health Improvement Scotland. The balanced scorecard is intended to underpin the commissioning framework
- 18.6 a commitment to agree and sign-off Service Level Agreements in a timely fashion, as part of the overall commissioning cycle
- 18.7 a commitment to regular, open dialogue and flow of information between NHS Boards and independent adult hospices
- 18.8 the work of NHS Boards Managed Clinical Networks for palliative care in which independent adult hospices have a key role to ensure they can help to inform service improvement and development
- 18.9 the findings of the published Healthcare Improvement Scotland inspection reports based on national care standards.

19 Funding of mutually agreed specialist palliative care services (eg drawn from the list of core specialist palliative care services in Annex B) should be reached by NHS Boards and independent adult hospices on a 50% calculation of agreed costs reflecting the intent within HDL (2003) 18 and over a 3 year period, however a longer period may be agreed if appropriate with individual NHS Boards. The commissioning principles and approach outlined (sections 15 and 16) should be used to support the agreement of costs to be included in the 50% calculation. There is further intent that NHS Boards and local authorities will jointly meet 25% of the running costs of the independent children’s hospices which provide specialist palliative care and respite services for children with life-limiting conditions.

20 The SLWG set out a proposed new commissioning framework (figure 1). The framework recognises that effective hospice commissioning requires a number of core dimensions to be developed and put in place in partnership (between independent adult hospices and NHS Boards) in each local health and social care system. These dimensions provide the platform for commissioning hospice care, and are outlined in the pyramid in the centre of the diagram. Service Level Agreements should be developed around these dimensions, clearly responding to identified need and in line with local plans. The commissioning framework should underpin service level agreements and these should be regularly monitored and reviewed on an annual cycle.

Figure 1: A new mutual commissioning framework for hospice care – for use by NHS Boards and Independent Hospices in Scotland



QUALITY IMPROVEMENT, EFFICIENCY AND EFFECTIVENESS

21 The SLWG made reference to the need to establish a Hospice Quality Improvement Forum to allow the ready exchange and development of information to support effective communication.

MONITORING IMPLEMENTATION

22 It is proposed to establish a Hospice Quality Improvement Forum, overseen by the Living and Dying Well National Advisory Group, which will bring together NHS Boards and independent adult hospices to;

- build a common set of quality measures, drawn from the work being advanced by the Living and Dying Well National Advisory Group;
- ensure an open approach to benchmarking of the cost, activity and quality of independent adult hospice services;
- share good practice between NHS Boards and independent adult hospices in the development of efficiency and productivity programmes.
- ensure a link to the Healthcare Improvement Scotland scrutiny model to support quality and service improvement.

23 The National Advisory Group for Living and Dying Well will continue to oversee progress of its action plan.

24 NHS Board Executive leads for palliative and end of life care should take responsibility for working in partnership with Executive staff and trustees of independent adult hospices. This will promote relationships between organisations based on mutual understanding, trust and openness. This will also be supported by participation in a Hospice Quality Improvement Forum which would build on and support the application of national quality performance indicators.

25 Monitoring arrangements should demonstrate mutually agreed outcomes, standards and shared objectives.

ANNEX A: INDIVIDUAL ELEMENTS

In order to promote the fullest possible mutual understanding of future plans, NHS Boards must be included at the earliest stage in the consideration of any developments which could generate running costs that would be eligible for the 50% of agreed running costs.

1. The contribution of hospices to education and training has long been recognised. For many hospices education provision may be an integral part of their role as providers of specialist services. Costs associated with education and training should therefore be considered within the service level agreement. Agreed costs should be based on the requirement locally for education and training support. The calculation should however relate to the running costs net of any income to the hospice generated by this activity.

2. Agreement on the appropriate multi-disciplinary team establishment, including any out-of-hours resource, if required, from trainee doctors where the post graduate dean has given educational approval for the trainee, should form part of the basis for funding.

3. **Depreciation.** Where the buildings and services concerned have been agreed as appropriate for inclusion in the 50% calculation of agreed costs, depreciation on the relevant assets should also be covered. Similarly, where new capital investment is not for purposes agreed as appropriate for inclusion in the 50% calculation of agreed costs, depreciation on those assets should not be included.

4. **Pharmaceutical Services.** The intention has always been that hospices would receive pharmaceutical services, which is understood as covering specialist pharmaceutical advice as well as pharmaceuticals, free of charge. These services are not covered by the 50% arrangement, and should always be identified as a separate element in the service level agreement between independent adult hospices and NHS Boards. Local arrangements for provision/supply can take a variety of forms, but all must ensure that they are cost-effective, ensure compliance with legislation and are high quality. Appropriate local arrangements need to be in place to ensure adequate governance and safety.

5. **Fundraising.** This was not an element in the original 50% calculation of agreed running costs, but it is now accepted that the basic costs of fundraising should count towards hospices' agreed running costs. These 'basic costs' relate to the employment of an appropriate level of fund-raising staff, but not the costs associated with organising individual fund-raising events and excludes charity shop and lottery staff costs. The rationale is that unless this aspect of hospice activity is recognised, hospices' ability to meet their share of the agreed running costs could be put in jeopardy. In relation to the 50% calculation of agreed costs, the 'appropriate level' of staff should be agreed between hospices and Boards.

6. **Out of area transfers.** The 50% agreement relates to the costs of providing the totality of a hospice's specialist palliative care services. It is not calculated on a cost-per patient basis, which means that hospice should not be sending invoices to Boards outwith their own area. But where a hospice provides a substantial service to people from more than one NHS Board area, the hospice should agree jointly with the relevant Boards how the 50% contribution should be shared between them.

7. **Charging for inspection by Healthcare Improvement Scotland.** There are no plans to exempt hospices, as the arrangements cover other bodies which operate on a not-for-profit basis. In view of the importance of ensuring compliance with standards, these charges should form part of the 50% calculation".

8. **Information Provision.** NHS Boards are required to ensure that information in the form of Scottish Morbidity Records (SMRs) are transmitted to Information and Services Division (ISD) for all NHSScotland patients treated in the independent healthcare sector. Hospices have their own information and IT requirements, but this additional responsibility is one imposed by NHSScotland. SMR data, especially if they cover all hospice activity, will be a valuable resource to support financial accountability, palliative care strategy development, epidemiology and local and national service planning. The funding implications stemming from the requirement to provide SMR data, and the IT infrastructure necessary to supply them, should therefore be included in the 50% calculation of agreed costs. Hospices should agree with NHS Boards the most cost-effective way to meet these needs.

ANNEX B: Palliative Care

Palliative Care

Palliative care is defined by the World Health Organisation as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.

Specialist Palliative Care

Specialist Palliative Care is the active total care of patients with progressive, advanced disease and their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support, and it will involve practitioners with a broad mix of skills. (Tebbit, 1999)

Specialist Palliative Care requires effective multi-professional working within specialist teams and co-ordination across a wide range of professions to ensure that all appropriate patients, including those with non-malignant disease, can access the appropriate service and achieve the best quality of life possible.

These teams work in partnership with those who provide generalist palliative care, to ensure that patients’ and families’ complex needs are met.

Complex needs are identified as needs that cannot be addressed through simple or routine interventions/care.

Specialist Palliative Care seeks to:

- meet complex needs through a multi-professional team that meets regularly, and where individual team members understand and respect each other’s roles and specialist expertise;
- enable team members to be proactive in their contact, assessment and treatment of patients and their families/carers;
- discern, respect and meet the cultural, spiritual and religious needs, traditions and practices of patients and their families/carers;
- recognise the importance of including the needs of families in the patient’s care, since good family care improves patients’ quality of life and contributes positively to the bereavement process;
- share knowledge and expertise as widely as possible;
- promote and participate in research in order to advance the speciality’s knowledge base for the benefit of patients and carers.

A number of essential components make up a specialist palliative care service and the lists below are not exhaustive. These include:

- effective communication
- symptom control
- rehabilitation
- education and training

- research and audit
- continuity of care
- terminal care
- bereavement support

The core clinical specialist palliative care services comprise:

- **In-Patient care** facilities for the purposes of symptom management, rehabilitation and terminal care
- **24 hour access** to the In- Patient service which includes specialist medical and adequate specialist nursing cover
- **24 hour telephone advice service** for healthcare professionals
- **24 hour telephone support service** for known out-patients and their carers
- **Day services** provided by an out-patient model or day hospice model where patients attend for a determined part of the day (eg. from 11-3)
- **Education programme**
- **Research and audit** undertaken within a framework of clinical governance
- Formalised arrangements for specialist **input to local and community hospitals**

Key Elements of Specialist Palliative Care within a Specialist Palliative Care Unit

The core team comprises dedicated sessional input from

- Chaplain
- Doctors
- Nurses
- Occupational therapist
- Pharmacist
- Physiotherapist
- Social worker

The range of integrated service components which can meet patients' needs at different stages of the disease process will include written referral guidelines to;

- Bereavement services
- Community specialist palliative care services
- Complementary therapies
- Counselling services
- Day services
- Hospital specialist palliative care services
- Lymphoedema services
- Patient transport services
- Psychological support services
- Social services
- Spiritual support services

Clinical Standards Board for Scotland (2002) Clinical Standards Specialist Palliative Care NHS Scotland.

In addition to referring onto these services externally, many Scottish Hospices provide them as part of the holistic range of integrated care and services.

Increasingly this includes services which assist with people's information and education needs (patients and carers) and also working with community groups to develop a shared understanding of care, loss death and dying.

ANNEX C: MEMBERSHIP OF SHORT LIFE WORKING GROUP

- Robbie Pearson, Scottish Government
- Peter McLoughlin, NHS Lothian
- Anne Harkness, NHS Greater Glasgow and Clyde
- Rhona Baillie, The Prince and Princess of Wales Hospice
- Carol Somerville, Bethesda Hospice
- Maria McGill, CHAS
- Kenny Steele, Highland Hospice
- Irene McKie, Strathcarron Hospice
- Marion Ford, ACCORD Hospice
- Geoff Sage, St Andrews Hospice
- Edward McGuigan, St Margaret of Scotland Hospice
- Anne Willis, Marie Curie
- Aileen Anderson, Ayrshire Hospice
- Mark Hazelwood, Scottish Partnership for Palliative Care
- Rachael Dunk, Scottish Government
- Patrick McAuley, Scottish Government

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