Update to the Review of Palliative Care Services in Scotland

Since the publication of Living and Dying Well a national action plan for palliative and end of life care in Scotland in October 2008 considerable progress has been made in implementing the actions and in undertaking the further development and collaborative work required to achieve the full range of Living and Dying Well aims. Less than two years on, there is widespread evidence that the cohesive national approach is well on the way to ensuring the provision of consistent and equitable palliative and end of life care for all people and their families across Scotland who need it.

The progress to date has been characterised by the sustained engagement of those concerned at every level of operation and the widespread progress has been achieved due to significant commitment across a range of stakeholders. This has been backed up by robust systems of governance and leadership provided by the National Clinical Leads, and Executive Leads within NHS Boards.

The Scottish Government will publish a follow up document to Living and Dying Well, titled Living and Dying Well: building on progress. It is anticipated this will be published later this year. This document will recognise the scale of the achievement to date, provide further actions and outline future developments that will support the continued improvement of palliative and end of life care across Scotland as well as identify priority areas. Progress to date includes:

- ongoing development of governance and leadership to support improvement
- ongoing national roll out of the electronic palliative care summary (ePCS)
- the publication of the NHSScotland Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policy
- the completion of Living and Dying Well working group reports
- the commitment and support of organisations including NHS Quality Improvement Scotland, NHS Education Scotland and the Scottish Partnership for Palliative Care
- strong links across national strategies and policies including the Healthcare Quality Strategy
- completion of the review of commissioning arrangements for specialist palliative care

Additional information requested by the Committee is provided below in Annex B1.
ANNEX B1

1 NHS Board implementation of *Living and Dying Well* has been characterised by the ongoing and enthusiastic involvement of those concerned at every level of operation, and the high level of progress achieved has been due in no small measure to this widespread sense of engagement and commitment. NHS Board palliative and end of life care Executive Leads have established appropriate infrastructures and communication mechanisms with their clinical communities, and many have adopted an integrated approach to the implementation of *Living and Dying Well* and related national policy areas, such as Long Term Conditions, *Better Together* and the *Scottish Patient Safety Programme*. NHS Board Executive Leads, IT Leads and Resuscitation Leads have also contributed through their engagement with and support of National Clinical Leads in the development of the electronic palliative care summary (ePCS) and the *National Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Integrated Adult Policy* as well as to the overall implementation of *Living and Dying Well*.

2 Each NHS Board has also identified a palliative and end of life care education champion to liaise with NHS Education for Scotland (NES) and to facilitate the spreading and sharing of good practice. Facilitators to support and cascade the implementation of advance/anticipatory planning have also been identified. NES provides support and resources for these education champions and facilitators, thus enhancing the local delivery of education and training related to *Living and Dying Well* within NHS Boards.

3 All NHS Boards were asked to submit *Living and Dying Well* delivery plans against the actions required in March 2009 and to review progress in October 2009. In addition, the National Clinical Lead for Palliative and End of Life care visited all of the NHS Boards in late 2009 and early 2010. These reviews demonstrate that substantial progress has been achieved across Scotland against all of the relevant actions in *Living and Dying Well*. Many of the developments and recommendations outlined in *Living and Dying Well: Building on Progress* will contribute to the continuing efforts of NHS Boards in this regard.

### The Roll Out of the Electronic Palliative Care Summary (ePCS)

4 The electronic Palliative Care Summary (ePCS), rolled out Board-wide in NHS Lothian in September 2009 following a series of successful pilots using different GP systems in NHS Lothian, NHS Grampian and NHS Ayrshire and Arran. It is now subject to national rollout on a Board by Board basis. The ePCS improves communication between patients, carers and professionals at all stages of the patient journey by allowing data to be sent automatically and on a daily basis from GP systems to Out of Hours (OOH) services. In particular it allows practices to:

- replace the fax form used to send patient information to Out of Hours services
- clearly see essential information on patients with palliative care needs
• view or print lists of patients on the practice Palliative Care Register
• set review dates to ensure regular review of patients.

5 The ePCS provides the opportunity to develop Advance /Anticipatory Care Plans which may include:

• medical diagnoses as agreed between GP and patient
• patient and carer understanding of diagnosis and prognosis
• patient wishes on preferred place of care and DNACPR
• information on medication and equipment left in the patient’s home ‘just in case’.

6 Development of the ePCS and its practical implementation has been supported by the Scottish Government’s National eHealth Clinical Lead and the Palliative Care eHealth Advisory Group, as well as by NHS Board IT Leads.

7 To date, 10 of the 14 territorial Boards have began to use ePCS. In total, across Scotland 218 practices are now using the ePCS. We are supporting NHS Boards through the, sometimes complex, practical technical implications of local roll out through which we expect a considerable increase in the uptake and usage of ePCS over the coming months.

**Progress Towards Developing NHS QIS Palliative Care Standards**

8 The Scottish Government is committed to an integrated approach to its key policies and strategies. The recently launched *Healthcare Quality Strategy for NHSScotland* provides the opportunity to bring together all aspects of patient care in a new quality improvement model (see below) which will ensure a unified approach to ensuring the best quality care for every patient every time at every stage of their lives.

9 NHS Quality Improvement Scotland (NHS QIS) has agreed that palliative and end of life care, and the continuing implementation of *Living and Dying Well* and *Living and Dying Well: Building on Progress* should be included as one of the integrated work programmes through which it will support implementation of the *Healthcare Quality Strategy*.

10 The NHS QIS approach is based on an integrated cycle of improvement (Figure 1) incorporating:

• advice and guidance
In its role of supporting continuous quality improvement within palliative and end of life care, NHS QIS will work closely with the Scottish Government, with NHS territorial Boards, Special Health Boards such as NHS Education for Scotland, the Scottish Partnership for Palliative Care and other partner organisations to promote integration and alignment of national initiatives and programmes of work. It will liaise closely with NHS Boards regarding further priority areas of activity and will ensure that any future developments are taken forward in partnership with SPPC and NES through the Living and Dying Well National Advisory Group. The strengths of NHS QIS (quality improvement), NES (education and workforce development) and SPPC (sharing of expertise within the palliative care community) will collectively maintain the development of palliative and end of life care which will bring together best practice and support improvement in a continuous cycle.

The implementation of the Directed Enhanced Service for Palliative Care

The Scottish Government introduced the Palliative Care Directed Enhanced Service (DES) in Scotland in November 2008 as part of its cohesive and integrated approach to meeting the palliative and end of life care needs of patients and families on the basis of clinical need rather than diagnosis or prognosis, and to address the need for effective communication at times of transfer and transition of care.
Continued funding has been agreed for the year(s) 2010-2012, and reporting systems were reviewed between April and June 2010 by representatives of the GP community across Scotland to take account of feedback received. Alignment with the ePCS has also been assured. Revised guidance will be issued shortly to reflect developments arising from the implementation of Living and Dying Well and to support practices in:

- ensuring that they identify appropriate patients for the palliative care register
- sharing assessed needs through anticipatory care plans with patients, those close to them and with health professionals who provide care both on hours and out of hours – especially when needs change
- determining a patient’s preferred place of end of life care and seeking to meet this wish where possible
- taking a systematic approach to end of life care.

Initial analysis of uptake to the DES for the year 2009/10 indicates that 56% of practices across Scotland are participating.

The Work of the Palliative Care ehealth Advisory Group on Collating National Data

A number of the key development areas outlined in the Scottish Government response to the Committee in January 2009 are now being implemented or will be published within the Living and Dying Well: Building on Progress document. The finalisation of this work will provide NHS Boards and the supporting organisations with a firm foundation to further support improvement of palliative and end of life care.

Whilst it is important that national data is collected, through the examples provided, a wider, more encompassing approach to improvement will be developed, (paragraphs 8-11) and through the development of the Quality Outcome Measures of the Healthcare Quality Strategy (paragraph 20).

There are a number of areas where national data is currently being collected and used to improve planning of care for patients with palliative and end of life care, including:

- Scottish Morbidity Register (SMR)
- Quality and Outcome Framework data (QOF)
- General Registrar Office for Scotland (GROS) reports
- Scottish Patients at Risk of Readmission and Admission (SPARRA)
• Single Shared Assessments and Indicators of relative Need (IoRN).

Since the publication of *Living and Dying Well* in October 2008 additional data is now available to NHS Boards, for example:

• data relating to the uptake of the Directed Enhanced Service for Palliative Care; and

• the ongoing roll out of the electronic palliative care summary.

In addition, the completion of many of the *Living and Dying Well* short life working group recommendations will provide future priorities to the development of improvement methodologies that will, for example, provide a national approach to identification, assessment and planning of palliative and end of life care needs. (See paragraphs 22-38).

As previously mentioned a key driver for improvement across Scotland will be the implementation of the Healthcare Quality Strategy. A quality measure is currently being developed, that will contribute to the improvement in palliative and end of life care across Scotland. The indicator proposes evidence that will represent the wishes and choices for patients and their carers and should also demonstrate the effectiveness of having a planned approach to end of life care – in essence the aims of *Living and Dying Well*. Whilst we are still developing the methodology for this measure the data sources for information could include GROS data, Information Services Division (ISD) data that can link hospital admissions with death data.

The focus of the data collection is on existing sources as other data collection could have significant resource implications.

**Progress made by the Living and Dying Well Working Groups**

One of the key actions arising from *Living and Dying Well* was the establishment of a series of short life working groups (SLWGs) to undertake collaborative and development work and make recommendations to the National Advisory Group on a number of areas identified as requiring further detailed consideration.

Six SLWGs (numbers 2-7 below) were formed, drawing their membership from across relevant areas of health and social care and beyond. Their progress may be summarised as follows and will be reflected within *Living and Dying Well: Building on Progress*:

**Development of Standards for Palliative and End of Life Care in Scotland**

The establishment of this group (SLWG 1) was deferred pending the outcomes of some of the other working groups, and will now be subsumed within the plans for continuous quality improvement outlined in the section above (paragraphs 8-11).
Development of palliative and end of life guidelines and referral criteria to specialist palliative care

25 National palliative and end of life care guidelines were considered by SLWG (2), which recognised that the relative absence of good quality evidence in this area made it difficult to create national guidelines using a process such as the Scottish Intercollegiate Guidelines Network (SIGN). Instead, the group mapped the availability of existing palliative and end of life care guidelines within NHS Boards and found that while several Board areas had developed and maintained their own set of guidelines, the availability of such guidance across Scotland was variable. The group decided that rather than set up and maintain a process for agreeing national guidance, there should be an agreed list of topics for which NHS Boards should provide guidelines. In consultation with NHS Boards, SLWG (2) has therefore developed a list of 30 core topics for which guidelines should be available in all NHS Board areas. NHS Boards will be asked through Living and Dying Well: Building on Progress to ensure that the core topic areas are available throughout the Board, and where gaps exist NHS Lothian have agreed to share their extensive guideline resource. In addition through the improvement cycle, outlined above, NHS QIS will work with NHS Boards and the SPPC to agree a national guideline and a mechanism for reviewing and updating its content.

26 SLWG (2) also developed a set of criteria that NHS Boards should review their referral to specialist palliative care against. The referral criteria has been set up to reflect that referrals should be made on the basis of need rather than diagnosis, in situations where generalist practitioners require specialist advice on the patient’s complex needs.

Development of Recommendations for Assessment Tools and Advance Care Plans

27 Living and Dying Well recognised that the key to providing appropriate palliative and end of life care is first of all to identify those likely to benefit from it, and then to initiate a cyclical process of assessment and review to determine the ongoing palliative care needs of patients and their families. This may be at any time from the point of diagnosis, at the point of actual or anticipated deterioration, or on presentation of difficult or complex symptoms. In each of these cases, the consistent use of appropriate assessment tools is essential. To ensure a coherent national approach to this issue, SLWG (3) has established a number of recommendations regarding:

- assessment tools for early identification of patients who may need palliative care
- assessment tools to identify patients with increasing palliative care needs
- assessment tools for symptoms
28 In their exploration of each of these areas, the group undertook extensive literature reviews and consultation with NHS Boards. Their final report presents detailed recommendations on particular tools and their use and will be reflected in *Living and Dying Well: Building on Progress*.

29 In addition this group examined the concept of advance care planning. Working with the Long Term Conditions Collaborative on guidance and recommendations on the development and sharing of anticipatory care plans.

30 The group’s final report distinguishes between the philosophy of advance care planning and the process / practicality of completion of an anticipatory care plan. The group concludes in its final report that the philosophy of advance care planning needs to be accepted as an overall concept, covering an umbrella of terms and processes, and including anticipatory care planning for patients with long term conditions. This aim is echoed in the *Healthcare Quality Strategy* and in the key Quality Ambition of mutually beneficial partnerships between patients and families and those delivering services which respect individual needs and values and demonstrate compassion, continuity, clear communication and shared decision-making.

**Development of Recommendations on Palliative and End of Life Information to Patients and Carers**

31 If patients and carers are to become full partners in decision-making and the planning of care, it is essential that appropriate, timely and easily accessible information is available to them. SLWG (4) was therefore set up as a National Palliative Care Patient and Carer Information Project. Following a successful bid by NHS Forth Valley for Scottish Government *Living and Dying Well* funding, a project manager was appointed from July 2009 to September 2010 to take the work forward. Core and reference groups were established with key representation from Scottish Government, NHS and national voluntary organisations, and project phases and objectives were agreed as follows:

- obtaining patient, carer and healthcare professional’s perspectives in terms of types of information required
- scoping of existing information resources and similar projects
- design and pilot of patient and carer information
- final production, launch and public awareness-raising
- exit strategy

32 Considerable progress has now been made, and following feedback on pilot materials the project will go live in the Autumn of 2010. An integrated approach to patient and carer information has been assured through the links established with a...
number of key organisations and initiatives and the list of topics to be included in the final resource has been agreed. It is established that the final outcome will be a web-based resource, hosted by NHS Inform. The content will be reviewed and updated as appropriate by the Scottish Partnership for Palliative Care, in consultation with key stakeholders.

**Development of Recommendations on the Delivery of Palliative and End of Life Care in Acute Settings.**

33 The Scottish Government aims to provide consistently high quality palliative and end of life care to everyone in Scotland who needs it in every care setting. The particular significance of hospital care during the last 5 years of life has been noted previously. Part of that implementation was the setting up of SLWG (5) to develop recommendations on the delivery of palliative and end of life care in acute care settings.

34 Following extensive consultation, this group has made a series of recommendations, including that a Hospital Palliative Care Service, supported by an appropriate management and clinical governance framework, should be developed and implemented in all acute hospitals. This service will:

- support hospital staff to deliver palliative care
- provide a specialist palliative care service for those with complex needs
- provide advice, guidance and standards for palliative care in acute hospitals should be developed and implemented in conjunction with NHS QIS.

35 The group’s recommendations will be reflected in *Living and Dying Well: Building on Progress* and should be implemented through the NHS Boards reviewed and updated Delivery Plans.

**Development of Recommendations on Appropriate Service Configurations to meet needs of Adolescents and Young Adults with Palliative and End of Life Care Needs**

36 *Living and Dying Well* aims to ensure a cohesive and consistent approach to palliative and end of life care based on clinical need regardless of diagnosis or of age. SLWG (6) developed recommendations to address the needs of adolescents and young adults in the following areas:

- examining and making recommendations on the service configurations necessary to meet the palliative care needs of adolescents and young adults
- ensuring continuity as young people move into adult services, including adult palliative care services
• providing guidance to improve the quality care at the end of life to this same group of individuals.

37 The group has noted in its final report that effective provision of care for this age group demands adaptation and preparation from professionals working in both children’s and adult services, and that integration with other Scottish Government national policies such as Delivering a Healthy Future and Getting it Right for Every Child will facilitate and enhance such collaboration. The group’s recommendations will be reflected in Living and Dying Well: Building on Progress and should be implemented through NHS Boards’ reviewed and updated Delivery Plans.

Exploration of Ideas and Issues Addressing Palliative and End of Life Care from a Public Health and Health Promotion Perspective

38 Living and Dying Well recognised that the provision of palliative and end of life care is influenced by the social and cultural context in which it takes place. It also noted that cultural resistance in modern western societies to acknowledging the reality of death and dying as inevitable and integral parts of life, and reluctance to discuss these, can contribute to poor communication and planning of end of life care. SLWG (7) was therefore established to explore public attitudes to care, loss, dying, death and bereavement and to consider what approaches might be taken in this area to underpin improvements in palliative and end of life care.

39 Many people are denied the opportunity they may wish for to discuss and plan for their death and dying. There is limited general understanding of the long term effects of bereavement and loss, together with a lack of opportunity to share common experiences. The group believes that there are potential benefits to be derived from a more open approach to these issues – for society, its public services and communities, and for individuals. SLWG (7) developed its vision of a Scottish society in which:

• people are able to talk about death and deal with related issues in a constructive way
• children grow up treating dying as an inevitable part of ordinary life
• people are comfortable using words such as “death”, “dead”, and “dying” and are able to make choices relating to their own dying and death
• health and social care professionals and volunteers in all care settings feel able to have discussions relating to death, dying and bereavement with patients and families, and with colleagues
• communities of all kinds are empowered to provide effective support to those dealing with death, dying, bereavement and loss
40 SLWG (7) explored the potential of public health and health promoting approaches to these issues and consulted widely on its vision and on suggested approaches to bringing it about. The group’s final report notes the Healthcare Quality Strategy ambition to improve person-centredness by delivering care based on mutually empathic relationships between staff, patients, carers and families. It points out that for such developments to occur in the context of palliative and end of life care, and for appropriate advance/anticipatory care planning and effective person-centred care and support to be in place for everyone, there needs to be a culture of open discussion about death, dying and bereavement. Staff must be comfortable addressing ‘difficult’ issues and patients must feel comfortable in expressing choices and feelings in the context of such discussions.

41 The report makes ten recommendations towards achieving these aims, including the recommendation that a broad-based coalition be established to lead and co-ordinate further work in this area, and tasked in particular with raising public awareness and promoting community involvement in the issues of death, dying and bereavement across central and local government and appropriate agencies and organisations in all sectors of Scotland’s multi-cultural and multi-faith society. The Scottish Partnership for Palliative Care will be setting up the coalition to take forward this work.

Recommendations Arising from the Auditor General for Scotland and the Public Audit Committee Reports / Scottish Government’s Response (January 2009) Commissioning Arrangements

42 Historically, specialist palliative care services have in some areas been provided through independent adult hospices partly funded by their NHS Boards. Scottish Executive HDL (2003) 18 set out a commitment to build a partnership between NHS Boards and adult voluntary hospices that would ensure 50% funding of agreed annual running costs. However, the Audit Scotland 2008 Review of Palliative Care Services noted a lack of consistency in these arrangements, and recommended that 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 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.

43 The Scottish Government accepted these recommendations and a short life working group was established with representation from the Scottish Hospices Forum and the six NHS Boards with voluntary 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 has explored approaches, within the context of today’s challenging financial environment and increasing expertise in quality assurance issues, to building a viable and enduring partnership and commissioning framework between NHS Boards and voluntary hospices in Scotland. The group has now submitted its final
report and recommendations, *A Partnership for Better Palliative and End of Life Care: Creating a New Relationship between Independent Adult Hospices and NHS Boards in Scotland* to the Scottish Government. The report will shortly be circulated (through NHS Board Chief Executives and Hospices) for comment prior to the development of revised guidance.

**Do Not Attempt Cardiopulmonary Resuscitation**

44 The NHSScotland Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Integrated Adult Policy was launched in May 2010 and should be implemented in all NHS Board areas by 1 October 2010. This has become a crucial part of addressing the increasing movement of patients and staff between different care settings across Scotland. The policy has been developed as part of the implementation of *Living and Dying Well* following both the recommendations regarding consistent DNAR policy in the 2008 Audit Scotland Review of Palliative Care Services and in the *End of Life Care Plan* published jointly by the Scottish Ambulance Service and the Scottish Partnership for Palliative Care in the same year, and the subsequent emphasis by the Public Audit Committee on the need for a single consistent Scotland-wide policy. The term DNACPR is used in favour of DNAR to clarify the emphasis of the policy and reflect current evidence.

45 The development of this national policy has been led by the Scottish Government’s National eHealth Clinical Lead, with additional clinical expertise from NHS Lothian, and brought to fruition through the extensive involvement of NHS Board Resuscitation Leads and a DNACPR Steering Group established for the purpose. The policy, based on the integrated DNAR policy of NHS Lothian, reflects the current evidence base and UK best practice guidance on decisions relating to CPR such as the 2007 revised *Joint Statement* produced by the British Medical Association, Royal College of Nursing and Resuscitation Council (UK) and the General Medical Council’s 2010 guidance *Treatment and Care Towards the End of Life: Good Practice in Decision Making*. It aims to support patients in achieving personal goals for their end of life care in any care setting, but its use does not preclude other active interventions or care. It does not apply to children, for whom a separate and more tailored policy is currently being developed and will be launched in the Autumn of 2010. Implementation of the DNACPR Integrated Adult Policy has been supported by NES through the production of a training resource DVD for healthcare professionals and the provision of training the trainer sessions across Scotland.

**Additional Areas of Development**

46 In addition to the work carried out by the short life working groups outlined above, key developments have been undertaken in the areas of relevance to the implementation of *Living and Dying Well*. These include the standards of palliative care in care homes, the provision of palliative care for children and young people and bereavement care.
Care Homes

47 Care homes in Scotland are playing an increasingly important role in the provision of palliative and end of life care. Considerable progress has been made in recent years to raise standards of care, in particular through Making good care better: National practice statements for general palliative care in adult care homes in Scotland, published by the Scottish Partnership for Palliative Care and the then Scottish Executive in May 2006 and used as an inspection focus by the Care Commission between March 2007 and March 2008. The Care Commission’s subsequent report, Better Care Every Step of the Way, highlights both the good practice achieved and what has still to be done to achieve a uniformly high standard of palliative and end of life care in care homes throughout Scotland. The report makes a series of recommendations for bringing this about.

48 Living and Dying Well also highlighted the increasing importance of care homes in meeting the palliative and end of life care needs of older people and tasked the National Clinical Lead for Palliative and End of Life Care with initiating discussions leading to liaison between the Scottish Government and the Care Commission regarding appropriate quality mechanisms in this area. A meeting of stakeholders, led by Scottish Care, the umbrella body of the independent care sector in Scotland, took place in October 2009 leading to the establishment of a new national Palliative Care in Care Homes Steering Group. This group includes representation from the NHS, care home providers in the private and public sectors, NHS Education for Scotland, COSLA, the Care Commission and the Scottish Partnership for Palliative Care.

49 In a significant linking of cross-sector policy initiatives, this Steering Group will support the implementation of the recommendations in Better Care Every Step of the Way, work which will inform the potential review of the National Care Standards proposed in Living and Dying Well. A national stakeholder conference for care home providers on sharing good practice will take place in the autumn of 2010. To further support a cohesive approach to the provision of palliative and end of life care in care homes, the Palliative Care in Care Homes Steering Group will in future be represented on the Living and Dying Well National Advisory Group. To address the need for consistent and accessible opportunities for education and training in care homes, NHS Education for Scotland has made its training materials available to all care home staff.

Children and Young People

50 Living and Dying Well Short Life Working Group (6), in making recommendations for meeting the palliative and end of life care needs of adolescents and young people, noted that many of its recommendations were also applicable to children. A Scottish Children’s and Young People’s Palliative Care Executive (SCYPPEx) has now been formed to address the specific palliative care needs of children and young people. This group brings together formal and informal networks concerned with the palliative care of children and young people across Scotland in a single unified voice to provide:
- clinical leadership to influence and develop the delivery of palliative care services to children and young people with all types of long term and life limiting illness and their families across Scotland and

- strategic leadership to influence the wider health, social care and education policy agendas to achieve the best outcomes for children and young people with palliative care needs and their families in Scotland.

51 SCYPPEx has suggested extending the recommendations of SLWG (6) to embrace the needs of children and young people, and has a number of suggestions regarding the implementation of Living and Dying Well as it applies to the specific palliative and end of life care needs of children and young people and their families. SCYPPEx is represented on the Living and Dying Well National Advisory Group, and is involved in the development of a national resuscitation planning policy for children and young adults.

Bereavement

52 The Audit Scotland Review of Palliative Care Services in August 2008 noted the inconsistency of bereavement support across Scotland. Living and Dying Well Short Life Working Group (7) also recognised the importance of bereavement care when it included within its remit and examination of attitudes to death and dying the issues of bereavement and loss.

53 In a speech in September 2008, the Minister for Public Health and Sport referred to the long overdue introduction of bereavement guidance in Scotland. That guidance is now in draft form and available for consultation in the discussion document Shaping Bereavement Care A Framework for Action for Bereavement Care in NHSScotland. This document builds on work commissioned in 2005 by the then Scottish Executive, NHS QIS and NES and carried out by Robert Gordon University, and is the culmination of an extensive process of debate and collaboration across professions and sectors. Shaping Bereavement Care is addressed to NHS Boards in Scotland to guide them in the development of good quality bereavement care. Its key messages include the following:

- there is a need to recognise that good care of the dying, the person who has died and of relatives and carers at the time of death leads to better outcomes in grief for those who are bereaved

- quality bereavement care starts, where possible, before death and certainly at the time of death

- quality bereavement care, at least in the period around death, is the responsibility of the health services
• all healthcare staff require education and training in grief and loss at a level appropriate to their degree of involvement with the bereaved

• health boards have a responsibility for the care and support of staff working with the dying and bereaved

• the delivery of quality bereavement care within health boards requires to be coordinated

• healthcare services should work in partnership with other stakeholders in the planning and delivery of care for the bereaved

54 *Shaping Bereavement Care* contains recommendations for NHS Boards, as well as for NHS QIS and NES and advocates a co-ordinated approach both within NHS Boards and nationally. In support of this, it is hoped to establish a national networking hub for those working in the field of grief and bereavement. *Shaping Bereavement Care* also seeks to interface with *Living and Dying Well* and supports the need highlighted by SLWG (7) for greater public acceptance of death and dying as part of the ordinary cycle of life and of bereavement as a normal human experience.