

# Short Life Working Group 7

## Final Report

March 2010



## Addressing palliative and end of life care from a public health and health promotion perspective: facilitating wider discussion of death, dying and bereavement across society

*“Moving palliative and end of life care beyond the professional world and making it everyone’s business is essential...”*

Respondee to SLWG7 consultation

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# EXECUTIVE SUMMARY

## ***Introduction***

*Living and Dying Well*, the Scottish Government's action plan on palliative and end of life care, was published in 2008. Amongst other initiatives the action plan recommended the establishment of a number of short life working groups (SLWGs) to take forward further developmental work on specific issues.

This report sets out the analysis and recommendations of Short Life Working Group 7 (SLWG7), which was set up to address: "the exploration of ideas and issues for addressing palliative and end of life care from a public health and health promotion perspective"<sup>i</sup>.

## ***Remit***

The remit of SLWG 7 was:

"to assist, within the context of *Living and Dying Well* a national action plan for palliative and end of life care in Scotland, in the development of a truly accessible and cohesive approach to palliative and end of life care across Scotland by:

- exploring ideas and issues for addressing palliative and end of life care from a public health and health promotion perspective, including public and professional awareness of and attitudes towards death, dying and bereavement;
- developing recommendations regarding appropriate initiatives to:
  - address current low levels of awareness of palliative and end of life care
  - address existing societal taboos around discussion of death and dying and
  - enable people (patients, families, professionals and the general public) to feel more comfortable in speaking about such issues."

## ***Rationale***

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. There are potential benefits to be derived from a more open approach to these issues, for society, public services, communities and individuals.

## ***Vision***

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.

## ***Approach***

Solutions to the issues identified in this report will not occur overnight. Such changes as are envisioned in this report can only come about gradually within society as a whole. However:

- available evidence and current policy point to the need for the development of a coherent national approach to address existing societal taboos around discussion of death and dying and to enable people to feel more comfortable speaking about such issues
- a public health/health promotion approach would be helpful in doing so
- there are steps which could be taken now which would establish an appropriate direction for future and wider developments within the general community
- some of these steps may also have the potential to bring about gains for patients, families, staff and volunteers within the current context of health and social care
- the overall aim of increasing public awareness and debate of death, dying and bereavement will require leadership, direction and a broad-based collaborative approach engaging all sectors of Scottish society and its diverse communities.

## ***Consultation undertaken***

SLWG 7 produced a document summarising the core elements of its discussions and approach, and consulted on this document between 30 November 2009 and 22 January 2010. 79 consultation responses were received, from individuals, organisations and groups from a range of backgrounds including local authorities, the NHS, social work, public health, religious/spiritual care, education and specialist palliative care. There was overwhelming support for the group's analysis of the issues involved, their significance in the area of death, dying and bereavement, and the approach suggested by the group to address these issues.

## **Recommendations**

### ***Recommendation One***

A broad-based coalition be established to lead and co-ordinate further work in this area. The coalition should be tasked specifically 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.

More specifically the coalition should explore approaches and develop more detailed plans to take forward the following recommendations:-

### ***Recommendation Two***

Facilitate the development of appropriate research to explore ways of fostering more open, healthy and constructive approaches to death, dying and bereavement within society.

### ***Recommendation Three***

Develop a communications strategy, including the identification of appropriate and consistent key messages and themes, to address low levels of awareness of palliative and end of life care, and to enable patients, families, professionals and the public to feel more comfortable talking about death and dying.

### ***Recommendation Four***

Identify and pursue opportunities to facilitate and encourage increased public awareness and wider discussion of death, dying and bereavement within existing Scottish Government policies and work streams. (see also recommendations 6 - 10)

### ***Recommendation Five***

Engage with legal, financial, funeral services and citizens' advice organisations and professions to maximise opportunities and appropriate support for people to engage in forward planning or deal with actual experiences of dying and bereavement, including emphasis on the importance of planning ahead in the context of declining cognitive ability.

### ***Recommendation Six***

Engage with employers and businesses through agencies and initiatives such as Investors in People and Healthy Working Lives to develop workplace approaches to raising awareness and providing support to employees dealing with experiences relating to death, dying and bereavement.

### ***Recommendation Seven***

Influence and support educational commissioners and providers to ensure that health and social care staff and volunteers in all care settings, and those in further education, undergraduate and postgraduate training, feel able to initiate and take part in discussions on death, dying and bereavement, through the inclusion of death awareness in education programmes.

### ***Recommendation Eight***

Promote the provision of an appropriate culture as well as adequate time and support for reflective debriefing sessions for staff and volunteers dealing with death and dying in all health and social care settings, ensuring that staff and volunteers can express their feelings and discuss their attitudes towards death and dying in a safe place and as part of their practice.

### ***Recommendation Nine***

Link to the work of the Bereavement Framework Project, which is aiming to ensure appropriate support and training to enable health and social care professionals to provide support and signposting, as appropriate, to bereaved families and individuals, including colleagues.

### ***Recommendation Ten***

Engage with educational establishments, planners and practitioners to ensure that children and young people develop the attributes, capabilities and capacities which will enable them to be comfortable and confident in talking about and dealing with death, dying and bereavement, and to ensure that appropriate educational resources and support to facilitate this are available.

# 1. Introduction

## 1.1 Background

*Living and Dying Well, a national action plan for palliative and end of life care in Scotland*<sup>ii</sup> was published by the Scottish Government in October 2008. It recognised that further collaborative and developmental work was necessary in order to achieve a truly cohesive, consistent and equitable approach to the provision of palliative care services across Scotland. The Action Plan set out several action points, including the establishment of several short life working groups (SLWGs) to take forward key areas of work identified within the action plan.

This report sets out the thoughts and recommendations of Short Life Working Group 7 (SLWG7), which was set up to address:

“the exploration of ideas and issues for addressing palliative and end of life care from a public health and health promotion perspective”<sup>iii</sup>.

## 1.2 Remit

SLWG7 subsequently agreed and clarified its remit as follows:

“to assist, within the context of *Living and Dying Well a national action plan for palliative and end of life care in Scotland*, in the development of a truly accessible and cohesive approach to palliative and end of life care across Scotland by:

- **exploring ideas and issues for addressing palliative and end of life care from a public health and health promotion perspective, including public and professional awareness of and attitudes towards death, dying and bereavement**
- **developing recommendations regarding appropriate initiatives to:**
- **address current low levels of awareness of palliative and end of life care**
- **address existing societal taboos around discussion of death and dying and**
- **enable people (patients, families, professionals and the general public) to feel more comfortable in speaking about such issues.”**

Although this work was undertaken within the context of the palliative and end of life care action plan, throughout its discussions the group remained aware that these issues are wide and far-reaching and the scope of this work should not be limited to a palliative care context. Death, dying and bereavement is associated with a range of circumstances unrelated to palliative care, such as trauma, accidents, murder, suicide and military service. Illness and death affect those of all ages, cultures and socio-economic backgrounds. The circumstances of death can have profound effects on the practical, emotional and spiritual needs of all involved.

### 1.3 Process

The short life working group was set up comprising representatives from a range of backgrounds. Given the context of this group as part of the *Living and Dying Well* action plan, most members had expertise relating to palliative and end of life care, but the group also included members with public health, health promotion or other relevant experience. (See appendix 2 for a full membership list.)

The group met for the first time on the 27<sup>th</sup> January 2009, and held subsequent meetings in March, May, June, August and October 2009, and February 2010. Some additional sub-group meetings were held in between main meetings, and these drew on additional expertise as listed in appendix 2.

Having considered these issues at length, the SLWG was keen to be informed by the thoughts and ideas of others. The group therefore produced a document summarising the core elements of its discussions and approach, and consulted on this document between 30 November 2009 and 22 January 2010.

79 consultation responses were received, from individuals, organisations and groups from a range of backgrounds including local authorities, the NHS, social work, public health, religious/spiritual care, education and specialist palliative care. A full record of all these responses is available from the Scottish Partnership for Palliative Care on request. Where appropriate, comments have been taken into account during the writing of this final report.

Many responses provided detailed thoughts or suggestions that warrant more detailed exploration than the group could achieve within its given timescale. It is recommended that these consultation comments should be considered in detail as part of future work in this area.

## ***2. Rationale: why do we need wider discussion of death, dying and bereavement across society?***

Many people will have been surprised to see that the exploration of palliative and end of life care from a “public health and health promotion perspective” was included within the scope of *Living and Dying Well*. However, it is included because of a growing recognition, in the UK and beyond, that society’s attitudes towards the discussion of death, dying and bereavement play an important role in:

- the successful planning and delivery of person-centred palliative and end of life care and services
- the general availability of understanding and support for the bereaved
- the long-term health and well-being of individuals and communities.

This section explains the importance of addressing existing societal taboos around discussion of death and dying and why it is important that people feel more comfortable speaking about such issues.

## 2.1 Indications of current attitudes

A UK-wide survey commissioned by Marie Curie Cancer Care in 2004 indicated that 79% of respondents felt that death was a taboo subject for the majority of people.<sup>iv</sup> In 2009, a further survey across the UK conducted by the social research institute NatCen found that while 68% of respondents indicated that they are comfortable talking about death, only 29% had discussed their wishes around dying and only 4% had written advance care plans.<sup>v</sup>

This might be taken as an indication that there is little willingness among the general public to engage with such issues. However, in its 2003 report *Public awareness of palliative care*, the Scottish Partnership for Palliative Care found that 70% of respondents thought that Scottish society does not discuss death and dying enough.<sup>vi</sup> An English survey during 2009<sup>vii</sup> indicated similar findings, with 67% of respondents feeling that society does not discuss death enough. These findings indicate that many people would in fact welcome the opportunity to talk about such matters.

Recently issues relating to death and dying have achieved a high profile in the media. The death of Jade Goody and other celebrities, the Director of Public Prosecution's consultation on guidelines for assisted suicide, Terry Pratchett's Reith Lecture and the introduction into the Scottish Parliament of a bill to legalise euthanasia and assisted suicide have all received blanket coverage. However, whilst certainly indicative of a public appetite to consider issues relating to death and dying, the terms of this public discourse have tended to be narrow and sensationalist. The realities of the everyday lived experience of the Scottish public of death, dying and bereavement have been largely absent.

There are many reasons why people may feel uncomfortable or lack opportunities to discuss these issues. Both *Living and Dying Well* and the Department of Health *End of Life Care Strategy*<sup>viii</sup> recognise that a range of cultural factors present in our modern society contribute to people being less familiar than previously with the concepts and processes of dying and death. Improving health care and developments such as the eradication or control of many serious infectious diseases mean that people live longer, with most deaths in Scotland occurring beyond the age of 65 years.<sup>ix</sup> In addition, different generations are less likely to live together and people are more likely to die in hospitals or care homes rather than in family homes as in the past.<sup>x</sup>

## 2.2 What is the problem?

Clearly much of this progress is good and there are overwhelmingly positive aspects to living in a society where medical care is so good and premature death so rare. However, where once death was seen as a natural and inevitable occurrence, it is now often seen as something avoidable or



extraordinary. There may be an unwillingness within mainstream society to recognise and think about death and dying as inevitable and integral parts of life, and a reluctance to discuss these, particularly in the context of a health service focused on 'cure' rather than 'care'.<sup>xi</sup> Scotland, together with the rest of the Western world, currently has a somewhat "death-denying" culture<sup>xii</sup>. This attitude to death and dying causes several problems for society as a whole:

- 2.2.1 People are unprepared for the experiences of death, dying and bereavement. Many people are so removed from death that they are unprepared for their own death and the deaths of loved ones. Most people don't make plans for the kind of health care they would want as they approach the end of life, meaning that they are less likely to have the kind of death they would choose. In a practical sense people don't often think about the financial and legal implications of their illness or death for their loved ones and don't make straightforward legal preparations to minimise distress for their families when they are gone.<sup>xiii</sup> Emotionally, many people are less prepared than they could be for the impact of the deaths of loved ones and for the needs of grieving friends and family.
- 2.2.2 Communities are disempowered from providing support to the dying and the bereaved. The days leading up to death have gradually become more "specialised" - the province of different health and care specialists rather than part of routine and personal care and support within the community. Over 50% of people die in hospital, though there are indications that a majority would prefer to die at home.<sup>xiv</sup>

A whole generation of people have grown up largely with the expectation that every aspect of dying will be taken care of by professionals and institutions and have never had to acquire the kind of emotional and practical skills for supporting the dying that their grandparents took for granted. There is little general understanding of bereavement issues, or about the wider issues surrounding loss. For example, feelings of loss are often a substantial element of experiences of declining health and function and anticipated bereavement can be as real and disturbing an experience as actual bereavement.

Contemporary society often emphasises individual gratification rather than the importance of caring within the community. We now live in a disparate society where people increasingly live significant distances from their families. This can make it more difficult to provide support as family members become frail or unwell. As a society we have lost many of the community-enhancing and therapeutic rituals formerly associated with death. Community-based and religious frameworks for dealing with death, dying and bereavement are largely absent for many people.

All of this can mean that communities often do not know how to provide support to their own members. This can mean that those who are living with thoughts of their impending death may not get the help and support from friends, neighbours and loved ones that they may need to help them cope with their situation. It can mean that people do not receive the

bereavement support they need to help them cope with their loss, leading to unresolved grief and the psychosomatic symptoms associated with this.

Lack of informal support puts more pressure on the limited professional services that are available. Scotland's ageing population means that institutions will find it harder to care effectively for the number of people approaching death. Professional bereavement services are overtaxed and cannot meet the high demand for their services. In the near future it is likely that communities will need to take more responsibility for caring for their own - currently communities are under prepared for this.

### 2.2.3 Health and social care professionals are unprepared for death-related discussions

As a society we have generally come to expect every aspect of our health to be looked after by professionals, including support through dying, death and loss. However, many health and social care professionals are not as prepared as they need to be in order to meet this expectation.<sup>xv</sup> Living within a society that is uncomfortable talking about death and dying, most health and social care professionals find it difficult to engage in open and sensitive conversations with patients and carers on this subject.<sup>xvi</sup> Many people are denied the opportunity they may wish for to discuss and plan for their death and dying. This can mean that patients and their families are unprepared for death, leading to all the practical and emotional problems outlined earlier. This is even more likely to be the case for younger patients and those affected by non-malignant conditions that have not traditionally been associated with death, dying or palliative and end of life care.

Individual health and social care professionals need to have thought about these issues themselves before they can constructively discuss them with others. However, though many health and social care professionals come across death frequently in their professional lives, few have the time and space to reflect on how this makes them feel. Lack of time and space to come to terms with the deaths of patients means that professionals may have to become gradually de-sensitised to death<sup>xvii</sup>. It has been argued that there has been a gradual erosion of the "compassion" of staff<sup>xviii</sup>. This is at least partly attributable to a healthcare culture where expression of grief is seen as "failure" and there is an unspoken expectation that staff do not need to take time to deal with the deaths they may witness on a daily basis. Services are task-driven and it is generally perceived that staff do not have the time to provide more "soft" elements of care such as "being with" the dying and the bereaved, even though these elements are central to delivering dignified, compassionate and person-centred care.

### 2.2.4 Department of Health End of Life Care Strategy (July 2008)

Outlined above are some of the problems associated with existing taboos on talking about death, dying and bereavement. Many of these are supported within the Department of Health *End of Life Care Strategy* which identifies a

range of possible consequences of a lack of openness and discussion about death and dying, including the following:

- people may be unnecessarily frightened about the process of dying
- close relatives of people who are approaching the end of life may be unaware of their wishes and therefore how best to help and support them
- inappropriate interventions may be tried if those caring for someone are not aware of the person's treatment preferences, including advance decisions to refuse treatment
- people who would have wished their organs to be used for transplantation may not have discussed this with relatives who have to make decisions after their death
- people may die without writing a will and may not have discussed funeral wishes with their relatives
- same sex partners may not have declared their status, with the consequence that professionals may exclude them from involvement in their partner's care
- fear of the unknown means that people sometimes tend to avoid those who are ill for fear of "upsetting them" or "making them worse"
- people, including clinical staff, are ignorant of the possible options that could improve quality of life and restore independence
- lack of knowledge of the financial implications for the bereaved following a death and what needs to be put in place ahead of the event
- lack of public and professional discussion about grief and loss, which results in the isolation of the bereaved.<sup>xix</sup>

The Department of Health sees promoting a better understanding of death and dying as an important part of achieving its strategy of ensuring that appropriate end of life care is available to everyone in England in the place of their choice. To help achieve this it has commissioned the establishment of the Dying Matters Coalition, led by the National Council for Palliative Care. With access to significant resources this Dying Matters Coalition is now leading and supporting a busy programme of action to promote public awareness and debate on issues of death, dying and bereavement.<sup>xx</sup>

### 2.2.5 A real-life example

The following extract from an article in *The Times* newspaper captures the potential impact of a failure to discuss issues and preferences around death and dying openly, not only on those living through a final illness but also on bereaved families and carers:

*“Neil Bonsor was only 35 when he died of cancer in March. His father, Tony, 64, is struggling with regrets about the way his son died. Neil was discharged from hospital to his parents’ home in Preston when doctors said they were unable to cure him. But they never told the family how long he might live and the family never directly addressed it together.*

*‘We were all in denial,’ Tony says. ‘Neil had suggested he had some thoughts about the way he wanted to die several months before he actually did die, but as a family we kept on having to believe there was a chance of survival.’ The family, feeling angered about the cancer, and Neil, who wanted to be in his own flat rather than dependent on his family, spent much of their last months together arguing - mostly about stupid things, Tony says. Neil had to be rushed to his flat in his final hours so that he could be where he wanted to be, with his own friends in his own home.”*

## 2.3 Policy Context

Living and Dying Well highlights the importance of a person-centred planning process in the development of care plans that take account of people’s needs, wishes and preferences at every stage of the patient journey<sup>xxi</sup>. Better Health Better Care<sup>xxii</sup> and Better Together<sup>xxiii</sup> emphasise the development of a mutual NHS and the importance of viewing patients not as service users, but as partners in care. The Healthcare Quality Strategy for Scotland proposes to improve person-centredness “by delivering care based on mutually empathic relationships between staff, patients, carers and families”<sup>xxiv</sup>.

For such developments to occur in the context of palliative and end of life care, and for appropriate advance care planning/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.

The recommendations of this report are therefore supportive of, and instrumental to, the delivery of the aims of Living and Dying Well and the Healthcare Quality Strategy.

## 2.4 Support for this view

The consultation undertaken by SLWG indicated overwhelming support for the analysis presented above of the issues involved and their significance in the area of death, dying and bereavement.

*“I agree strongly with the analysis that heightened awareness of issues around death and dying; and the subsequent increasing confidence to face these issues not only by healthcare staff but by the whole community will have positive benefits for our society”. Respondee to SLWG consultation.*

Many respondents additionally highlighted their agreement with, or experience of, particular issues mentioned in the consultation document such as the impact of bereavement, the importance of involving children, the need for awareness of people’s spiritual needs, the need for a public awareness campaign, the importance of support, education and training for health and social care staff, and the need to raise awareness of palliative care. This reinforces the importance of the issues outlined within sections 1 and 2 of this report and supports the vision of change now outlined in section 3 below.

## 3. ***The vision***

Scotland should be a society in which dealing with death, dying, bereavement and loss in a healthy and constructive way is seen as part of ordinary life and where members of the public and health & social care professionals and volunteers have awareness of these issues and the many ways in which communities and individuals can support each other. More specifically, we want to see a society where:

- People are able to deal with death in a constructive way
- Communities are empowered to provide support of their members
- Health and social care professionals and volunteers are empowered to undertake discussions relating to death, dying and bereavement

The three elements of this vision are expanded below.

### 3.1 People are able to deal with death in a constructive way

Death and dying are unique experiences for each individual and it is normal to have negative responses to these experiences and to fear the unknown. Many people will have had difficult and upsetting experiences relating to loss in their lives and people cope with death, dying and bereavement in different ways, with some preferring not to talk about these issues.

However, without thinking or talking about death all the time, people should know that it is okay to talk about death and dying and be supported to deal with death in a constructive way. For example, there are certain practical

preparations it is sensible to make for one's own death: who will look after your child if you die? Have you made a will? Do you want your partner to have power of attorney if something should happen to you? Do you want an advance healthcare directive? Do you want to be on the organ donors register?

Death should be seen as normal and children should grow up treating dying as an inevitable part of life. People should have thought about death enough to enable them to be comfortable using the words “death”, “dead” and “dying”, and to make choices which will help them to have as good a death as possible.

*“The need to place emphasis on a person-centred planning process is crucial as is the need to create a culture in which dying and death can be addressed in a caring, open and constructive way. It is important that families, friends and health care providers are comfortable with discussing these issues”.*

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### 3.2 Communities are empowered to provide support for their members

People facing the knowledge of their own impending death should get practical and emotional support from their communities and loved ones. People also need to be empowered and motivated to provide help and support to those dying within their communities. The general public need to have an understanding of loss and bereavement, so that people can communicate with each other about them, and so that communities can provide support to those who are bereaved or anticipating bereavement. It is also important that people have culturally and socially acceptable ways of expressing their grief.

For this to happen, communities of people, whether in geographical localities, organisations or workplaces, or in faith, interest or culture based groups, need to develop the resilience to support their members through difficult times. Communities need to be strong, and people need to be in touch with their own “human-ness”, and educated and empowered to be able to support each other through care, loss, death and dying. Communities need to find their own ways of fostering constructive and healthy approaches to death, dying, bereavement and loss, and build up social capital to support their members through death, dying and bereavement. This should include recognising, valuing and encouraging the potential of volunteers.

### 3.3 Health and social care professionals and volunteers are empowered to undertake discussions relating to death, dying and bereavement

Health and social care professionals should be able to build up appropriate relationships with patients, providing care that is based on compassion and empathy, without this care being limited by taboos surrounding the discussion of death, dying and bereavement. Staff and volunteers should therefore be supported and empowered to initiate and engage in open and sensitive conversations with people around death, dying and loss and around palliative and end of life care.

Health and social care professionals and volunteers must have the time and space to come to terms with the deaths of patients. They must have opportunities to reflect and explore issues relating to their own mortality and the mortality of others, building up self-awareness and a concept of themselves “as a human being”. Much of this will involve a change in culture within health and social care organisations, so that staff and volunteers have the expectation that they will have organisational support and support from colleagues in coming to terms with these issues.

Healthcare should be “compassionate” and each family given individual attention and treated with sensitivity and empathy. Appropriate education and training, including bereavement support training, should be available to all those who are likely to come into contact with patients, including volunteers, since all staff groups have an important role to play in the experience of patients<sup>xxv</sup>. Adequate bereavement services and follow-up services must be available, for staff and volunteers as well as for patients and carers.

## 4. *Achieving the vision: finding the solutions*

Solutions to the issues identified in this report will not occur overnight. The changes envisioned can only come about gradually within society as a whole. The SLWG explored what kind of general approach and specific steps might be taken now in order to:-

- establish an appropriate direction for future and wider developments within the general community
- bring about gains for patients, families, staff and volunteers within the current context of health and social care.

The exploration of these challenges formed a major part of the SLWG’s consultation exercise, in which a number of areas for targeted future activity were proposed.

The SLWG’s consultation identified strong support for the general approach suggested by the group, especially its holistic and collaborative nature, involving all sectors and communities. Those respondents who commented on the “health promotion/public health” element of the approach reacted to this notion positively.

Those respondents who were directly involved in public health seemed open to this idea, though they accepted that there would be challenges to achieving this.

There was clear general support for the areas for targeted activity set out within the consultation document, and several respondents took the opportunity to highlight the areas of activity that they saw as being of particular importance or effectiveness, including:

- staff training, supervision, education and support
- engaging community groups and using a bottom-up approach
- public education/ information / communications strategy
- utilising opportunities within existing Scottish Government policies
- engagement with schools and young people
- future research and scoping current activity
- raising awareness of palliative care
- collaborative working and looking beyond organisational barriers
- engaging with employers through mechanisms such as Investors in People

These aspects are all reflected to a greater or lesser extent within the “key principles” section below.

#### 4.1 The health promoting palliative care approach

The SLWG spent some time exploring the public health and health promoting approach put forward by Professor Allan Kellehear, Professor of Sociology at the Centre for Death and Society, University of Bath. Professor Kellehear has been instrumental in introducing the concept of health promoting palliative care to the UK at an academic level. He argues that death and loss should be more clearly recognised as an important public health issue in its own right<sup>xxvi</sup>. He emphasises the need for community support and for ‘death education’ to combat the prevailing ignorance and misconceptions around death, dying and bereavement. Professor Kellehear draws on his practical experiences as Professor of Palliative Care and Director, Palliative Care Unit, School of Public Health, La Trobe University in Melbourne, Australia, to demonstrate in his publications and presentations the value of partnerships between palliative care and the wider community, showing how a practical health promoting palliative care approach can enhance the resilience of communities.<sup>xxvii</sup>

There is currently limited evidence regarding the effectiveness of a health promotion approach to palliative care. However this approach appears particularly relevant to Scotland, where a rapidly ageing population and shrinking workforce will challenge the capacity of institutions to care effectively for the number of people approaching death, and where both personal preference<sup>xxviii</sup> and ‘shifting the balance of care’ policy<sup>xxix</sup> tend toward the provision of more care at home. If we are all to find the support we need at the end of our lives then individuals and communities of all kinds will need the knowledge, support and confidence to enable them to take more responsibility in providing care and support. Similar conclusions are expressed in the 2003 NHS Scotland and Scottish Health Council report *The Fifth Wave*:



“Wellbeing in Scotland will be improved significantly when we can find ways to enable the care, compassion and energy of citizens to be expressed in, rather than excluded from, our civic life.”<sup>xxx</sup>

A wide range of individual initiatives are already underway in a variety of contexts to encourage discussion and awareness of death and dying. Many of these are consistent with the health promoting approach put forward by Allan Kellehear and a sample of these appears in section 4.3. Local activities such as these will be an important way of helping to bring about a more open approach to these issues across society. Evaluation of some of these or similar initiatives would be helpful.

## 4.2 Key principles for future work

A small number of key principles should underpin future work in this area:-

### 4.2.1 a broad-based collaborative approach

There is a risk that imposing public health initiatives on a community may be counter-productive, since without community involvement in the development of initiatives, they are likely to lack local support, be misguided and therefore be unsustainable. Any approach taken to this issue should therefore include both “top-down” and “bottom-up” elements. There should be a clear focus on engaging, encouraging and assisting communities to find ways of developing constructive and healthy approaches to death, dying and loss. Work should engage society at all levels, including the Scottish Government, local authorities, community planning partnerships, communities, health and social care environments and the media.

### 4.2.2 encouragement of community resilience

“Community resilience” is about the ability of communities to cope well with the adversity or difficult experiences of individuals or groups of individuals within their community. Social networks, support and understanding are important elements of community resilience within the context of death, dying and loss.

Many different and varied communities are present within Scotland. Within these communities there exist many different cultures, religions, values, attitudes, experiences, beliefs, practices, rituals and traditions relating to death, dying and loss. As described more fully within the glossary, this report uses the term “community” in a wide sense to refer to “any social, religious, occupational, or other group sharing common characteristics or interests and perceived or perceiving itself as distinct in some respect from the larger society within which it exists”<sup>xxxi</sup>.

Any approach taken to addressing the discussion of death, dying and bereavement in Scotland should encourage community resilience, while maintaining a keen awareness that different communities will

have different strengths, weaknesses, problems and priorities relating to death, dying and bereavement; what might work for one community may be completely inappropriate in another.

#### 4.2.3 communications and engagement

Initiation of culture change of the nature described within this report will clearly require engagement with the population through many and various communications routes. In England the Dying Matters Coalition has developed a sensitive, sophisticated and evidence-based approach to communication. There are many ways in which media and communications can be used to engage with communities. As well as official “media channels” many other groups in society have the ability to bring people together and influence behavior. For example, many professional groups such Financial Advisors, Solicitors, Lenders, Insurance Brokers, and Insurance Companies have opportunities to discuss with their clientele the potential effects of the client’s death or the death of family members when those clients are well and perhaps only contemplating their own death in an abstract fashion. Pensioners Associations, community groups, Rotary organisations also discuss and disseminate information of common interest to their members.

It is therefore likely that any approach taken to addressing the discussion of death, dying and bereavement in Scotland will require a communications strategy and informed and sensitive engagement with media in its various forms.

#### 4.2.4 engagement with children and young people

Engagement with children and young people are vitally important in helping to foster healthy and constructive approaches to death, dying and loss among young people in Scotland. The formal school education system can play a main role in this. Opportunities already exist within Curriculum for Excellence for bringing discussion and activities related to these issues into schools. Any approach to encouraging wider discussion of death, dying and bereavement in Scotland should aim to work with education services to find ways to bring these issues into schools in sensitive and supportive ways.

#### 4.2.5 education, training and support for health and social care staff and volunteers

Encouraging healthy and constructive approaches to death, dying and loss is something with which all sections of society need to engage and be educated. However, certain groups within society come across death, dying and loss more than others, for example the armed forces, health and social care professionals and teachers. Health and social care professionals are expected to provide support to patients and families in the face of illness and bereavement.

Education, training and support for health and social care staff and volunteers are an integral part of any future work in this area.

#### 4.2.6 research

There is not a high volume of research evidence relating to the impact of “health promoting palliative care”. However, as outlined above, there are indications from work in Australia and the UK that this has the potential to be an effective approach. Consultation feedback indicates the general feeling that time is right for such an approach to be trialled in Scotland. It is important that the introduction of such an approach in Scotland includes a combination of pilot initiatives and action research with the aim of actively achieving culture change while contributing to the current evidence base. Work should also take into account the results of the recently completed systematic literature review commissioned by the Dying Matters coalition in England<sup>xxxii</sup>.

#### 4.3 Getting started: examples of existing initiatives to encourage increased awareness and open discussion of death, dying and bereavement

As outlined above, wider discussion across society and a more open approach to death, dying and bereavement will only come about through the widespread engagement of individuals and groups of all kinds – at work, in education, at leisure, in organisations and businesses, in geographical, social and ethnic communities, in faith and interest groups and many more.

Many respondents to the preliminary consultation on this work voiced their particular enthusiasm for this approach and eleven respondents expressed an interest in being involved in the development of this work in the future. A significant number of respondents, from various backgrounds, suggested ways of opening up discussion on death, dying and bereavement in their own areas of work. This is particularly encouraging since it indicates that respondents have a degree of enthusiasm for and understanding of this work, and are already willing to engage to some extent with the ideas proposed in this report.

Indeed, some respondents outlined areas where they are already addressing some of the relevant issues and it is clear that many individuals and groups are already involved in work to open up discussion of death, dying and bereavement. In the course of its explorations the SLWG identified many examples of existing initiatives which might be considered as useful models in taking the work forward. A complete list is available from the Scottish Partnership for Palliative Care. These might help to suggest ways for individuals and groups to help ‘kickstart’ appropriately in their own local community or group the process of opening up discussion. A sample of these is provided below.

**Example box 1: Some suggestions from Allan Kellehear**

Within Chapter 8 of his book *Compassionate Cities*<sup>xxxiii</sup> Allan Kellehear describes a number of initiatives that might support health promoting palliative care. He writes:

“These activities are offered as a guide and illustration of what some communities or activists might consider by way of public health actions that encourage communities to take a greater role in the care of their people living with life-threatening illness and loss... to stimulate readers to thinking of their own possibilities, or indeed even to experiment with some of the suggestions in their own communities.”

He then goes on to make several suggestions including the following:

- Poster campaign, for example posters giving advice on how to comfort a grieving person.
- Annual emergency services round table for paramedics, police, fire fighters and other emergency workers who deal with sudden death on an everyday basis in the community. An annual “round table” could be an opportunity for them to discuss organisational ways that recognise and support the special stresses and satisfactions of their work.
- Neighbourhood watch programmes: building on existing crime-watch programmes, neighbours can be encouraged to observe and reflect on the health, age-frailty or sudden death of their neighbours. Offers to feed pets while neighbours are away, or in respite care, are examples. A simple but regular offer of help after bereavement can be helpful.
- Short story competition covering issues related to death, dying and loss: the winners and runners-up can be published in the local newspaper, helping readers to gain an insight into some of these issues, providing a substantial basis for community empathy and support, and providing a normalising and comforting way for people to express themselves.
- School and workplace plans for death and loss: many schools but few workplaces have plans to deal with the sudden death of staff, students and workers. Where such plans do not exist they should be developed.
- Building/architecture prize for carers: seldom are affordable homes designed so that certain rooms can convert easily into “granny flats”; or bathrooms and kitchens designed for disabled as well as able-bodied use. An annual building and architecture prize may well encourage those members of the community for whom building and designing is a life passion to rethink the problem of living design in the face of ageing and serious illness for public, private and domestic use.

### **Example box 2: Initiatives within schools**

#### *St Christopher's Hospice Schools Project*

The St Christopher's Hospice Schools Project aimed to bring diverse groups of people together in order to learn from each other and dispel myths. 10 and 11 year old children were brought into the hospice, and worked with patients to write songs, create theatre based on patients' life stories, and produce large mosaics and other artworks. Feedback from participants was very positive, and indicated that children and patients enjoyed the project and that it dispelled some myths about hospices. More recent experience has indicated that this model is easily transferrable to community groups other than children, such as care homes and faith groups. A guidance and information pack is available from [d.brady@stchristophers.org.uk](mailto:d.brady@stchristophers.org.uk) for a £5 donation. This pack is a 'how to do it' manual, highlighting the four week model and key considerations. <sup>xxxiv</sup>

#### *Perth & Kinross Schools Bereavement Project*

The Perth & Kinross Schools Bereavement Project, funded by *Choose Life*, involved providing each school in the area with a bereavement resource, providing support to teachers, and employing a teacher to go into schools and undertake projects with the children (eg artwork) relating to bereavement.

#### *Bounce Back*

Bounce Back is an Australian classroom resiliency programme. In February 2007 the Centre for Confidence and Wellbeing ran a two day course based on Bounce Back in Glasgow presented by Dr Toni Noble, one of the creators of the programme. The course attracted around 65 participants, many from education. The Centre believes that the response to this course was extremely positive, and held three more courses in August 2008, featuring Midlothian and Glasgow City Councils.

Within its Activities Report for 2007, the Centre recognises that

"... Bounce Back is a very specific programme on resilience... and is not directed in general towards the education of feelings. It specifically looks at resilience – particularly coping with set-backs and failures. We recognise that there is a growing problem with young people's resilience partly because parents are trying to ensure that their children experience no bad feelings. We think that Bounce Back is a useful anti-dote to this and recommend that schools implementing it should use the ideas to educate parents." <sup>xxxv</sup>

### **Example box 3: Making legal preparations for death and dying**

#### *Caesar & Howie Solicitors*

Caesar & Howie Solicitors, having become aware of the importance of these issues, has helped many of its clients write advance healthcare directives. So far, the firm has found most people quite willing to engage in these discussions, as people are keen to make preparations which will prevent their children having to deal with difficult issues in the future. Having dealt with Power of Attorney and Wills for years, the firm has found it relatively straightforward to incorporate advance healthcare directive discussions by adding on a script on AHDs. People are generally happy to have these discussions, at least partly because they feel that ill health and death are not imminent. As part of this, the firm has created two internet sites [www.seniorissues.co.uk](http://www.seniorissues.co.uk) and [www.bereavementlegalservices.co.uk](http://www.bereavementlegalservices.co.uk) and are constructing [www.positiveforwardplanning.co.uk](http://www.positiveforwardplanning.co.uk). The thinking behind these is to educate the public regarding future life issues including incapacity and death and to encourage the public to prepare positively to deal with the resulting legal and practical issues. The firm has also received considerable interest from Financial Advisers looking for training in these issues, who see it as a possible way of opening up financial discussions with clients.

#### *VOCAL: free advice on Power of Attorney*

The Adults with Incapacity (Scotland) Act 2000 changes the system for safeguarding the welfare, and managing the finances and property, of adults (aged 16 or over) who lack the capacity to take some or all decisions for themselves because of mental disorder or inability to communicate by any means. It allows other people to make decisions on behalf of these adults, subject to safeguards. Individuals can arrange for their welfare to be safeguarded and their affairs to be properly managed in future, should their capacity deteriorate. They can do this by giving another person (who could be a relative, carer, professional person or trusted friend) power of attorney to look after some or all of their property and financial affairs and/or to make specified decisions about their personal welfare, including medical treatment. However, the cost of obtaining legal advice is a major barrier for many people who might otherwise want to nominate a health or financial attorney. In order to address this problem the Lothian carers' charity VOCAL offers free advice to carers about how to set up a Power of Attorney.

#### **Example box 4: More examples**

##### Light up a Life

'Light up a Life' is a series of community events that are open to all and take place around the UK during the Christmas period. The events are organised by independent hospices to help families and friends to come together to remember and celebrate the lives of loved ones. Every Light up a Life event is different, but for most a vital part is the opportunity to dedicate a message in memory of a loved one, either by lighting a candle, hanging a message on a tree, recording the name of someone special in a book of remembrance or reading it aloud. For most hospices, Light up a Life is one of their best-loved and most meaningful events, attracting hundreds of local people year after year. It represents a time to be comforted and to share hope with others.<sup>xxxvi</sup>

##### Charter for a Good Death in North East England

In England, Public Health North East has established a Regional Advisory Group on a Good Death comprising individuals from a variety of interests. This group advised on the development and communication of a Charter for a Good Death in the North East. The Charter was launched in October 2009, and was produced by a range of partners across the health, social care and voluntary sectors, as well as patients and carers, as guidance for anyone planning and providing end of life care or support. It aims to ensure the right services and support are available at the right time for anyone who needs them. A consultation on the Charter is being run, with the aim of getting people thinking and talking about these important issues, and raise awareness of the fact that if we aren't thinking or talking about the care and support we would like to receive when the time comes, then we may not have our wishes met.

##### Volunteers as ambassadors, Children's Hospice Association, Scotland (CHAS)

In order to increase the public awareness of the role of their hospice, CHAS has developed a volunteers' speaker network consisting of 125 enthusiasts. The volunteers have a direct link with clinical services, and meeting patients and families, they are able to bring real life stories into their public talks. A vibrant team of young volunteers has also been developed with the aim of supporting young people who are dying. The aim is to develop and sustain a network that is locally based to offer support in the neighbourhood. The young volunteers stay for a long time as supporters of the hospice and/or may come back later in life to volunteer for the hospice.

##### Beyond Barriers Project

The Alzheimer Scotland Beyond Barriers Project set out to develop current care practice in care homes by supporting both staff and relatives to meet the palliative care needs of people in the later stages of dementia.<sup>xxxvii</sup> Beyond Barriers took an innovative approach, involving care home staff and relatives together in a training programme which put communication with the person with dementia at the core, and supporting staff to improve practice through action learning.

For more information see: Beyond Barriers Developing a palliative care approach for people in the later stages of dementia An Alzheimer Scotland Partnership Project Summary Report Alzheimer Scotland Action on Dementia, Care Commission, The Dementia Services Development Centre. 2009.

## **5. Recommendations**

The broad-based consultation was overwhelmingly supportive with a number of areas suggested for exploration, development and collaboration. The Group's recommendations reflect these areas. Many of these recommendations can be addressed by building upon, supporting and influencing existing and complementary work streams.

### ***Recommendation One***

A broad-based coalition be established to lead and co-ordinate further work in this area. The coalition should be tasked specifically 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.

More specifically the coalition should explore approaches and develop more detailed plans to take forward the following recommendations:-

### ***Recommendation Two***

Facilitate the development of appropriate research to explore ways of fostering more open, healthy and constructive approaches to death, dying and bereavement within society.

### ***Recommendation Three***

Develop a communications strategy, including the identification of appropriate and consistent key messages and themes, to address low levels of awareness of palliative and end of life care, and to enable patients, families, professionals and the public to feel more comfortable talking about death and dying.

### ***Recommendation Four***

Identify and pursue opportunities to facilitate and encourage increased public awareness and wider discussion of death, dying and bereavement within existing Scottish Government policies and work streams. (see also recommendations 6 - 10)

### ***Recommendation Five***

Engage with legal, financial, funeral services and citizens' advice organisations and professions to maximise opportunities and appropriate support for people to engage in forward planning or deal with actual experiences of dying and bereavement, including emphasis on the importance of planning ahead in the context of declining cognitive ability.

### ***Recommendation Six***

Engage with employers and businesses through agencies and initiatives such as Investors in People and Healthy Working Lives to develop workplace approaches to raising awareness and providing support to employees dealing with experiences relating to death, dying and bereavement.

### ***Recommendation Seven***

Influence and support educational commissioners and providers to ensure that health and social care staff and volunteers in all care settings, and those in further education, undergraduate and postgraduate training, feel able to initiate and take part in discussions on death, dying and bereavement, through the inclusion of death awareness in education programmes.



### ***Recommendation Eight***

Promote the provision of an appropriate culture as well as adequate time and support for reflective debriefing sessions for staff and volunteers dealing with death and dying in all health and social care settings, ensuring that staff and volunteers can express their feelings and discuss their attitudes towards death and dying in a safe place and as part of their practice.

### ***Recommendation Nine***

Link to the work of the Bereavement Framework Project, which is aiming to ensure appropriate support and training to enable health and social care professionals to provide support and signposting, as appropriate, to bereaved families and individuals, including colleagues.

### ***Recommendation Ten***

Engage with educational establishments, planners and practitioners to ensure that children and young people develop the attributes, capabilities and capacities which will enable them to be comfortable and confident in talking about and dealing with death, dying and bereavement, and to ensure that appropriate educational resources and support to facilitate this are available.

## ***Appendix 1: Glossary***

### **Community**

“any social, religious, occupational, or other group sharing common characteristics or interests and perceived or perceiving itself as distinct in some respect from the larger society within which it exists”<sup>xxxviii</sup>

This includes:

- black and minority ethnic communities (including gypsy/travellers, refugees and asylum seekers)
- children and young people
- disabled people
- older people
- religious/faith Groups
- the lesbian, gay, bisexual and transgender community
- women and men

The following issues are also of relevance:

- homelessness
- involvement in the criminal justice system
- language or social origin
- marital status
- mental health
- poverty<sup>xxxix</sup>

### **Health Promoting Palliative Care**

In his book *Compassionate Cities*<sup>xi</sup> Kellehear writes:

“The idea of health-promoting palliative care, however, is one that continues to recognize the social character of living with life-threatening illness. Health-promoting palliative care recognizes issues about quality of life and the need for health maintenance even in the context of advanced disease. Being ‘healthy’ and experiencing ‘disease’, even ‘terminal’ disease, is not necessarily contradictory (Fryback 1993). The spiritual and social issues which strike at the heart of life-threatening illness can be addressed by health-promotion strategies – prevention, harm-reduction or early intervention – just as many of the physical and psychological issues can be addressed for these populations as they were in the early or middle years of their life and health...

...The task of ‘making sense’ of life at the end of life is an important task for those whose experience and expertise lies in health promotion and palliative care. The social and spiritual task and challenge of living life in the face of death should be a shared health-promotion task because its social significance applies to all of us, and because its successful management may be important to alleviating personal and physical pain.” (p.27)

In his book *Health Promoting Palliative Care*<sup>xii</sup> Kellehear writes:

“The goals of health promoting palliative care are to facilitate education and information for health, dying, death and loss; to facilitate social supports both personal and community; to encourage interpersonal reorientation that adds value to people’s ability to cope and develop alongside their experiences of dying, death, and loss; to encourage palliative care services to reorient towards health promotion rather than simply confine themselves to clinical service offerings; and to combat death-denying health policies and attitudes in the general community, media, and community health colleagues and services.”

Within Resilience in Palliative Care: Achievement in Adversity<sup>xiii</sup>, Allan Kellehear and Barbara Young write:

“People who live with life threatening illness are subject to social and emotional difficulties such as depression or social rejection and stigma whether they are living with HIV or cancer. Health promoting palliative care programmes recognize the social character of these difficulties, recognize their impact on the quality and even longevity of patients and their families, and attempt to strengthen a community’s resilience against these through community development initiatives<sup>1</sup>... A broad public health approach to death and loss is crucial to the resilience of every community in their ongoing attempts to make sense of mortality, and in helping each other to enhance the quality of their lives in its shadow.”

### **Health Promotion**

“Health promotion represents a comprehensive social and political process, it not only embraces actions directed at strengthening the skills and capabilities of individuals, but also action directed towards changing social, environmental and economic conditions so as to alleviate their impact on public and individual health. Health promotion is the process of enabling people to increase control over the determinants of health and thereby improve their health.

Participation is essential to sustain health promotion action. ”

*World Health Organisation Health Promotion Glossary* (WHO, 1998)<sup>xliii</sup> (See also appendix 3.)

### **Palliative care**

"Palliative care is 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. Palliative care: provides relief from pain and other distressing symptoms;

- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."<sup>xliv</sup>

*World Health Organisation*

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<sup>1</sup> They explain “community development” as being “any set of initiatives designed to develop the social resources of the community in order to enhance its quality of life. Definition taken from *Compassionate Cities*, p.118

## ***Appendix 2: Short life working group membership***

John Birrell	Bereavement Project Lead, Scottish Government Patient Focus
David Borrowman	Managing Partner, Caesar & Howie, Solicitors
Dr Rosalie Dunn	Macmillan GP Palliative Care Facilitator
Adam Gillespie	Patient /carer representative, West of Scotland Managed Clinical Network for Palliative Care
Dr Erna Haraldsdottir	Head of Education, Strathcarron Hospice
Mark Hazelwood	Director, Scottish Partnership for Palliative Care (from Dec 09)
Ewan Kelly	NES Programme Director of Healthcare Chaplaincy and Spiritual Care, NHS Education Scotland
Dr Fiona Kelly	Lecturer in Dementia Studies, Dementia Services Development Centre, University of Stirling
Linda Kerr	CNS in Palliative Care, NHS Ayrshire & Arran
Kate Lennon (Chair)	Macmillan Nurse Consultant in Palliative Care, NHS Greater Glasgow & Clyde and Deputy Chairman, Scottish Partnership for Palliative Care
Dr Gordon McLaren	Consultant in Public Health Medicine, NHS Fife
Maria McGill	Chief Executive, Highland Hospice
Monica Merson	Head of Health and Wellbeing Team, NHS Health Scotland
Professor Scott Murray	St Columba's Hospice Chair of Primary Palliative Care, University of Edinburgh
Dr Euan Paterson	GP, NHS Greater Glasgow & Clyde
Rebecca Patterson	Policy Manager, Scottish Partnership for Palliative Care
Dr Juliet Spiller	Palliative Care Consultant, NHS Lothian
Patricia Wallace	Director, Scottish Partnership for Palliative Care (until Dec 09)
Maggie White	Associate Director Hospices, Marie Curie Cancer Care

### ***In attendance:***

Mark Aggleton	Scottish Government Health Directorates
Eric Chen (until May 09)	Scottish Partnership for Palliative Care
Dr Peter Kiehlmann	Clinical Lead Palliative Care eHealth SGHD

### **The following individuals have also contributed to this report through sub-group discussions:**

Sandra Campbell, Macmillan Nurse Consultant - Cancer & Palliative Care, NHS Forth Valley  
Dr Anne Hendry, National Clinical Lead, Long-term conditions collaborative  
Liz Travers, Education Projects Manager (Palliative Care) NHS Education for Scotland  
Una Smale, Association of Bereavement Services Co-ordinators

### ***Appendix 3: Extract from the World Health Organisation Health Promotion Glossary***

Health Promotion is the process of enabling people to increase control over, and to improve their health.

Reference: Ottawa Charter for Health Promotion. WHO, Geneva, 1986

Health promotion represents a comprehensive social and political process, it not only embraces actions directed at strengthening the skills and capabilities of individuals, but also action directed towards changing social, environmental and economic conditions so as to alleviate their impact on public and individual health. Health promotion is the process of enabling people to increase control over the determinants of health and thereby improve their health.

Participation is essential to sustain health promotion action.

The **Ottawa Charter** identifies three basic strategies for health promotion. These are advocacy for health to create the essential conditions for health indicated above; enabling all people to achieve their full health potential; and mediating between the different interests in society in the pursuit of health.

These strategies are supported by five priority action areas as outlined in the **Ottawa Charter** for health promotion:

- Build healthy public policy
- Create supportive environments for health
- Strengthen community action for health
- Develop personal skills, and
- Re-orient health services

Each of these strategies and action areas is further defined in the glossary.

The **Jakarta Declaration** on Leading Health Promotion into the 21st Century from July 1997 confirmed that these strategies and action areas are relevant for all countries. Furthermore, there is clear evidence that:

Comprehensive approaches to health development are the most effective. Those that use combinations of the five strategies are more effective than single-track approaches; Settings for health offer practical opportunities for the implementation of comprehensive strategies;

Participation is essential to sustain efforts. People have to be at the centre of health promotion action and decision-making processes for them to be effective; Health literacy/ health learning fosters participation. Access to education and information is essential to achieving effective participation and the empowerment of people and communities.

For health promotion in the 21st century the **Jakarta Declaration** identifies five priorities:

- Promote social responsibility for health
- Increase investments for health development
- Expand partnerships for health promotion
- Increase community capacity and empower the individual
- Secure an infrastructure for health promotion

- Each of these priorities is further defined in the glossary. Increasing community capacity is addressed in the definition

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<sup>i</sup> *Living and Dying Well a national action plan for palliative and end of life care in Scotland* Scottish Government, 2008. P.24, no.45.

<sup>ii</sup> *Living and Dying Well a national action plan for palliative and end of life care in Scotland* Scottish Government, 2008.

<sup>iii</sup> *Living and Dying Well a national action plan for palliative and end of life care in Scotland* Scottish Government, 2008. P.24, no.45.

<sup>iv</sup> *Views about dying at home: Survey of the UK general public* Marie Curie Cancer Care/KRC research/YouGov, February 2004

<sup>v</sup> NatCen survey, commissioned by the Dying Matters Coalition. NatCen included the questions in an Omnibus survey between July and September 2009.

<sup>vi</sup> *Public awareness of palliative care Report of the findings of the first national survey in Scotland into public knowledge and understanding of palliative care* Scottish Partnership for Palliative Care, December 2003

<sup>vii</sup> *How we manage death and dying in Norfolk County and Waveney.* Report of the Norfolk Health Overview and Scrutiny Committee in partnership with Norfolk and Waveney Cancer Network (2005)

<sup>viii</sup> *End of Life Care Strategy Promoting high quality care for all adults at the end of life.* Department of Health, July 2008

<sup>ix</sup> General Register Office for Scotland. *Scotland's Population 2006 – The Registrar General's Annual Review of Demographic Trends.* Edinburgh: 2007

<sup>x</sup> *End of Life Care Strategy Promoting high quality care for all adults at the end of life.* Department of Health, July 2008, p.37

<sup>xi</sup> *Living and Dying Well*, p.4, no.11, Scottish Government, 2008.

<sup>xii</sup> *The denial of death thesis: sociological critique and implications for palliative care.* Zimmermann C and Rodin G 2004 *Palliative Medicine*, 16, 121-128

<sup>xiii</sup> *How to have a good death – General Public* poll of 1027 people by ICM Research for Endemol UK, 2005

<sup>xiv</sup> *How to have a good death – General Public* poll of 1027 people by ICM Research for Endemol UK, 2005. (1027 participants)

<sup>xv</sup> *Better care every step of the way Report on the quality of palliative and end of life care in care homes for adults and older people*, Care Commission, April 2009.

<sup>xvi</sup> *Evidence Based Communication Skills Training: Guidance* published by West of Scotland Cancer Network, 2009.

<sup>xvii</sup> *A case study in the function of social system as a defence mechanism against anxiety.* Menzies I.(1960) *Human Relations*, **13**, 95-121

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- <sup>xviii</sup> *Can you measure compassion?* Article by Helen Mooney. NursingTimes.net 21 April 09
- <sup>xix</sup> *End of life care strategy* Department of Health, July 2008
- <sup>xx</sup> The Dying Matters Coalition <http://www.dyingmatters.org.uk>
- <sup>xxi</sup> *Living and Dying Well a national action plan for palliative and end of life care in Scotland* Scottish Government, 2008. Section 3.2
- <sup>xxii</sup> *Better Health, Better Care: Action Plan*, Scottish Government, Edinburgh, 2007
- <sup>xxiii</sup> *Better Together, Scotland's Patient Experience Programme* [www.bettertogetherscotland.com](http://www.bettertogetherscotland.com)
- <sup>xxiv</sup> *The Healthcare Quality Strategy for Scotland Draft Strategy Document For Discussion and Feedback by 27 November 2009*. The Scottish Government, October 2009
- <sup>xxv</sup> *Evidence Based Communication Skills Training: Guidance* published by West of Scotland Cancer Network, 2009.
- <sup>xxvi</sup> Kellehear, Allan *Compassionate Cities. Public Health and end of life care*. Routledge Oxford 2005
- <sup>xxvii</sup> Chapter 12 of Monroe B and Olivier D (Eds) *Resilience in Palliative Care – Achievement in Adversity* Oxford University Press, 2007
- <sup>xxviii</sup> *How to have a good death – General Public poll of 1027 people by ICM Research for Endemol UK, 2005*
- <sup>xxix</sup> *Better Health, Better Care: Action Plan*, Scottish Government, Edinburgh, 2007
- <sup>xxx</sup> *The Fifth Wave* Compiled by Andrew Lyon. Scottish Council Foundation, 2003
- <sup>xxxi</sup> Definition taken from: <http://dictionary.reference.com/browse/community>
- <sup>xxxii</sup> *Public attitudes to death, dying and bereavement: a systematic synthesis*. Seymour, Kennedy et al. University of Nottingham 2009.
- <sup>xxxiii</sup> *Compassionate Cities Public health and end-of-life care* Allan Kellehear Routledge 2005
- <sup>xxxiv</sup> *Creating healthier attitudes to death and dying The St Christopher's Hospice Schools Project* by Nigel Hartley. NCPIC *Inside Palliative Care* magazine, vol 7, March 09
- <sup>xxxv</sup> The Centre for Confidence. Review of Activities. Bounce Back [www.centreforconfidence.co.uk](http://www.centreforconfidence.co.uk)
- <sup>xxxvi</sup> Help the Hospices. <http://www.helpthehospices.org.uk/getinvolved/campaigns/light-up-a-life/>
- <sup>xxxvii</sup> Brought to the group's attention through: "What are we doing in Scotland to engage people in talking about care, loss, death and dying?" survey undertaken by the Scottish Partnership for Palliative Care in April 2009.
- <sup>xxxviii</sup> Definition taken from: <http://dictionary.reference.com/browse/community>

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<sup>xxxix</sup> List taken from: *Helping you get a handle on the equality and diversity impact assessment toolkit*, Scottish Government. Web publication date, February 22, 2005

<sup>xi</sup> Kellehear, Allan *Compassionate Cities. Public Health and end of life care*. Routledge Oxford 2005

<sup>xii</sup> Kellehear A (1999) *Health Promoting Palliative Care*. Melbourne: Oxford University Press. p.20  
Obtained from a reference made within Monroe B and Olivier D (Eds) *Resilience in Palliative Care – Achievement in Adversity* Oxford University Press, 2007 – from chapter 12: *Resilient communities* by Allan Kellehear and Barbara Young.

<sup>xiii</sup> Chapter 12 of Monroe B and Olivier D (Eds) *Resilience in Palliative Care – Achievement in Adversity* Oxford University Press, 2007

<sup>xiii</sup> Health Promotion Glossary, World Health Organisation, 1998

[http://www.who.int/hpr/NPH/docs/hp\\_glossary\\_en.pdf](http://www.who.int/hpr/NPH/docs/hp_glossary_en.pdf)

<sup>xiv</sup> WHO definition of palliative care <http://www.who.int/cancer/palliative/definition/en/>