Are We Living and Dying Well Yet?

A report by

Marie Curie Cancer Care
Scottish Partnership for Palliative Care (SPPC)

May 2014

Foreword

On the 5th February 2014, Marie Curie Cancer Care and the Scottish Partnership for Palliative Care (SPPC) organised a seminar to discuss the future of palliative care, end of life care and all related issues. Professionals involved in palliative and end of life care from across the health, social care and voluntary sectors came together with MSPs. The aim was to discuss successes to date, challenges for the future, and to work together to find a consensus on how we move forward. In this short publication Marie Curie Cancer Care and the SPPC have reported on the key themes and issues raised in the discussions and set out recommendations which emerged from the event.

Aileen McLeod MSP (as sponsoring MSP for the seminar)

I was pleased to host the discussion at the MacDonald Hotel in Edinburgh around the question of “Are We Living and Dying Well Yet?” with Marie Curie Cancer Care and the Scottish Partnership for Palliative Care. The event brought together a wide range of experts and healthcare professionals from across the NHS, the third sector, the Scottish Government, Parliament and academia.

It provided a very timely opportunity to discuss the future of palliative and end of life care in Scotland. The successes of the Scottish Government’s 2008 national action plan on palliative and end of life care *Living and Dying Well* provided an appropriate starting point as we discussed how together we can build on the excellent work over the last six years and better understand and address the very real challenges that surround the kind of end of life and palliative care Scotland should have. In other words, we asked ourselves the question: “what comes next?”

It was clear from the discussion that how we, as a society, care for people at their end of life is an issue of growing importance and concern. As the demand for end of life and palliative care in Scotland is set to increase significantly in the coming years, it will fall to individual experts, institutions and agencies to bring forward a clear vision for the future provision of this care. This report, which reflects and builds upon the themes discussed on the 5th February, provides an insightful, and informed review of the challenges we face if we are to ensure high quality palliative and end of life care for all, and a guide to the actions that will be necessary if we are to meet these challenges. In recommending the need for a new Strategic Framework for Action this report is a very welcome step forward.

Kenny Steele, Chair, SPPC (as Chair of the seminar)

I would like to thank the team at Marie Curie Cancer Care and SPPC, my panel members and everyone who took part in the discussions that have led to the publication of this report.

Good care towards the end of life must be a priority for any healthy, caring society. There are many factors in our modern world, which are highlighted in this report, which mean we must refocus our efforts if we are to meet the challenges ahead. This is a topic which is not just a “health” issue but is a wider societal issue and so broad engagement is needed in order to succeed.

Every one of us will experience end of life care through our family and friends and eventually personally. It is not a minority issue but one that touches everyone in society. Delivering on the recommendations in this report will therefore be of benefit to us all and for that reason I commend this report to you.

Introduction

You only die once. That means there is only one chance to get a person's care at the end of life right.

Everyone deserves to live as well as possible until they die. Whether rich or poor, old or young, living in Glasgow or Benbecula, experiencing cancer or dementia, everyone in Scotland should experience excellent care, life enriching experiences and dignity right until the end of their life.

Excellent care means receiving relief for pain and other symptoms. It means having as much control as possible over how and where you are cared for.   Excellent care means having access to spiritual, psychological, emotional and family/carer support. It means being able to have open and honest discussions with professionals so that you can make plans and have important conversations with loved ones before it is too late.

In 2008 the Scottish Government published *Living and Dying Well: a national action plan for palliative and end of life care in Scotland*, which set out a framework to support a person-centred approach to delivering consistently good palliative and end of life care on the basis of need not diagnosis. *Living and Dying Well* has achieved a great deal, but there are still challenges remaining.

The Scottish Government has set out a 2020 Vision and Route Map outlining a plan for achieving quality healthcare delivered in a person-centred fashion. There is no mention of death and dying in these documents and this creates a risk that these issues are overlooked, particularly in a society where we find death and dying difficult to talk about even at a policy level. The relevance and importance of palliative care issues within many areas of healthcare strategy and policy is often obscured by the understandable pressure to prioritise treatment and technology which cures acute illness and prolongs life. The 2020 Vision and Route Map are of necessity high level and need to be complemented by a more detailed strategy for palliative and end of life care.

Death, dying and bereavement affect us all. They are not simply health issues – they are issues that impact on every aspect of our society, and many diverse policy areas. For example death is an issue for education because we need to equip our young people to deal with bereavement. Death is an issue for poverty agendas because growing numbers of people cannot afford to bury their dead.

Everyone has a stake in good care towards the end of life, and it is important that all stakeholders work together to build on the work done so far and develop a plan for the work to ensure that everyone experiences excellent care towards the end of life.

1. Location of care

Where people receive their care when they are terminally ill and approaching the end of their lives is extremely important to them. Health and social care services must be geared up to quickly undertake needs assessment and implement the right care packages so that, where feasible, people can be cared for in the place of their choice as soon as possible and for as long as possible.

The vast majority of people do not want to be cared for in hospital for any significant length of time, especially if it is not the best place for them to receive the care they need. They mostly want to be at home surrounded by their family and loved ones, with adequate support from community health and social care services. Home is also where most people would prefer to die.

Currently more than 50% of people die in hospital. This level of hospital care is simply not sustainable with growing numbers of very old people and a broadly static level of public resource available. Marie Curie Cancer Care has carried out research which suggests that caring for people at home is significantly more cost effective than caring for someone in an acute setting[1]. This is a potential win-win situation. The Scottish Government *2020 Vision* and *Quality Strategy* are clear that health and social care should be provided in a homely setting where possible. However, despite the very welcome intention of this policy it is widely recognised that progress to date has been limited. Recently the Scottish Parliament has passed the new health and social care integration legislation, which places a new statutory emphasis on person-centred planning and delivery. It is to be hoped that over time the envisaged bringing together of health and social care resources will deliver joined up, effective and efficient services that meet the increasing number of people with longer term and often complex needs.

Over 54,000 people die in Scotland every year. More people are living longer than ever before, but the flip side of this positive trend is that over the next 20 years, the numbers of people dying will rise by 17%. More and more people will be living with co-morbidities and terminal illness requiring a greater amount of care.

There is a pressing need to consider new models of care that can address the reality of a society that needs to support growing numbers of people who will die in advanced old age, whose carers may also be very old and frail (or may have died previously) and whose wider network of support is either geographically dispersed or non-existent. There is also a need to consider new models of care for younger people living with a life shortening conditions and complex needs where current access to quality respite and continuing care is at best inconsistent and at worst absent altogether.

2. Public awareness and talking about death, dying and bereavement

In Scotland, in common with other parts of the UK, there is a societal, institutional and individual reluctance to talk about death and dying. This can cause some difficulties that could be avoided:

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[1] http://www.mariecurie.org.uk/Documents/HEALTHCARE-PROFESSIONALS/commissioning-services/understanding-cost-end-life-care-different-settings.pdf

- People who are dying or bereaved can experience isolation because people don't know what to say or how to act towards them.
- People aren’t knowledgeable about the various practical, financial, legal, emotional and medical issues that may affect them towards the end of life, and so are unprepared and can leave complicated situations for their families and friends to cope with.
- Public policies have a tendency to skirt round “death” and “dying” and talk in euphemistic terms. Without explicit and open engagement at policy level about decline, end of life and death, there is a limit to the improvements that can be made in care for people at the end of life.
- Healthcare professionals struggle to have open and realistic conversations with their patients about what care or treatments they want as they approach death. This makes it hard to plan the care that a person really wants.

An example of the last point is that often even towards the end of life the possibility of dying may not be explicitly acknowledged within conversations between healthcare staff and patient and their family. This can prevent a person from expressing their wishes regarding what they would like to do in the time they have left, where and how they would like to receive their care, and their preferred place of death. A failure to acknowledge that death is imminent has implications for the care provided, for example inhibiting the discontinuation of inappropriate intrusive medical interventions and focussing on keeping a person comfortable.

More needs to be done to support practitioners to have meaningful conversations relating to decline, death and dying, including adequate provision of time. Additional training and support for practitioners should be considered as well as reviewing existing training programmes.

Death and dying are distressing emotional experiences, and this is only made worse if as a society we lack understanding of the process of dying, or the complexities of caring for someone approaching the end of their life. Recent media and public concerns relating to the Liverpool Care Pathway (LCP) cannot have been helped by our cultural reluctance to address these issues openly. As the LCP is being phased out, any national work to develop revised approaches to care in the last days and hours of life must embrace a culture of openness by consulting the public about their experiences, hopes and expectations of end of life care.

The significant impact and role of the media in raising public awareness about such issues must be acknowledged and consideration given to new ways of engaging with the media in a positive and proactive way to enhance genuine public knowledge that empowers the public rather than causing avoidable harm and distress.

In encouraging public discussion we must consider the language we use. Overly medicalised language and jargon needs to be avoided. We should recognise that terms such as “palliative care” and “hospice” are not always well understood. A clear and unhelpful tension exists between the public desire for control over a natural, unmedicalised death and unrealistic expectations of what modern healthcare technology can achieve in the context of chronic and life limiting or terminal illness.

It is clear that Scotland needs to become a place where people can be more open about death, dying and bereavement. As a proposed outcome, “culture change” sounds vague - hard to quantify or plan for. However, in recent years much concrete work has been done towards setting into motion the kind of culture change that MSPs and palliative care specialists have outlined the need for. Using an assets-based approach, *Good Life, Good Death, Good Grief (GLGDGG)* has ably led and supported engagement on these topics, operating on a shoe-string budget. However this work needs to be scaled up if it is to achieve the requisite impact.

For example, opportunities exist within a *“Curriculum for Excellence”* for teachers and pupils to explore death and bereavement within a classroom environment. This could be highlighted and promoted by Education Scotland. Given that 70% of schools will have at least one bereaved pupil on their role at any one time[2] engaging with the education system is an important area. With additional capacity GLGDGG could expand its work to effectively target specific areas such as these.

The importance of changing Scotland’s culture of reticence relating to death, dying and bereavement is a recurring theme in parliamentary and clinical discussions relating to palliative care and end of life care. The Scottish Government, in developing a new way forward following *Living and Dying Well,* must put a public discourse on death and dying at the heart of its future framework for action. A lack of openness is a major limiting factor on the improvement of formal services and a major barrier to strengthening the resilience of individuals and communities to deal with the hard times which can come with death, dying and bereavement. The adoption of a public health/health promoting approach[3] which encompasses individual and community resilience is essential.

3. Quality, outcomes, data and measurement

There is a need for data and analysis to accurately characterise and quantify the challenges of future planning and provision of palliative and end of life care. At present we lack even basic data to support a true understanding of care at the end of life in Scotland. Scotland has a deserved international reputation for its innovative and robust use of health data, and it is now time to align this expertise in support of understanding and improving end of life care. A strategic framework for action should encompass the need for research and development and academic collaboration, including the development of key data. There is also potential to make better use of data which is already gathered - a recent example of what can be done is the study showing that nearly 30% of people in hospital on a given day are within the last 12 months of their life[4].

There is a need to develop a comprehensive measurement framework which sets out what needs to be measured, to what end and how it will be measured.
The measurement framework of the Scottish Government’s Quality Strategy currently includes the quality outcome “Percentage of the last six months of life spent

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[2] Child Bereavement UK http://www.childbereavement.org.uk/Support/Schools

[3] http://www.scotland.gov.uk/Resource/Doc/924/0105610.pdf

[4] Clark, D Armstrong, M Allan, A, Graham, F Carnon, A Isles, C. Imminence of death among hospital inpatients: a prevalent cohort study. *Palliative Medicine*, March 2014, online first - http://pmj.sagepub.com/content/early/2014/03/17/0269216314526443.full

at home or in a community setting". Whilst this is welcome there is a need for measures of broader scope and greater sophistication. Healthcare Improvement Scotland produced and published National Palliative Care Quality Indicators in 2013. In time these may usefully prompt local review of how end of life care is being delivered. However, these indicators have some significant limitations; they do not give a direct indication of the quality of end of life care experienced by patients and families, and as yet the relevant data has not been collated and published.

The experiences of patients and of bereaved relatives should be central to our thinking about improving end of life care. In England, the national survey of bereaved people, VOICES, which is about to be carried out for the third time, has produced a number of significant key findings, which is helping shape the debate about end of life care. There is currently no such survey carried out in Scotland. A survey similar to VOICES should inform future service planning, identify gaps and deficiencies in service delivery, as well as help policy-makers understand to what extent care delivered is truly person-centred.

Future approaches to improving data for planning and service improvement must avoid increasing measurement burdens on frontline staff. There is also a need to recognise that many aspects of what makes high quality palliative care (compassion, relationship, healing, the spiritual domain) will be hard to define and measure.

4. Equity of access

For some people with complex needs accessing palliative care may mean being referred to specialist services, such as those provided by a hospice or specialist unit. However, the vast majority of palliative care is provided by GPs and generalists, in homes, care homes and on hospital wards. Good care towards the end of life is care which:-

- openly explores uncertainties in treatment outcome and acknowledges the possibility of dying so that it can inform choices and planning
- provides good symptom management
- is holistic
- takes account of carer and family issues

A recent study suggested that 80% of non-cancer patients are not being identified in primary care for palliative care, which would benefit them[5]. This compared to 75% of those with a cancer diagnosis who were accessing palliative care.

Most people living in the community will only receive palliative care if their GP or District Nurse recognise that they have a need for it. However, primary care teams are not always good at identifying people who could benefit from palliative care, especially if they do not have cancer. This reflects the lack of openness on the part of public and professionals, a belief that palliative care is only for people who are near to death and the difficulty in predicting how long someone may live with non-malignant disease.

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[5] Zheng L, Finucane AM, Oxenham D, McLoughlin P, McCutcheon H, Murray SA. *How good is primary care at identifying patients who need palliative care? A mixed-methods study*. European Journal of Palliative Care 2013; 20: 216–222

A palliative care approach should be used as appropriate alongside active disease management from an early stage in the disease process. However, the above study indicated that most people receiving palliative care are getting it far too late in the terminal phase of their disease, typically in the last 8 weeks of life. This study also highlighted the difficulties that primary care staff have in approaching these issues with patients.

We should be ambitious enough to strive for 100% of all patients who would benefit from palliative care having the opportunity to access it in a timely manner. The gap between this ambition and the current position needs to be addressed:

- More support should be given to primary and secondary care staff, to identify patients with palliative care needs and then to initiate sensitive discussions which can inform the creation of Anticipatory Care Plans (ACP). ACPs can help ensure that the patient's care is person-centred, and planning can help reduce inappropriate hospital admissions and give patients a greater chance of being cared for and dying in their preferred place.
- Generalists should be equipped and supported to understand and deliver their role in supporting all those with palliative care needs regardless of diagnosis.

5. Carers, volunteers and the Third Sector

Caring for those coming to the end of life becomes all-encompassing as the condition of the person they care for deteriorates and carers inevitably face increasing demands and challenges on their time. These carers often have specific needs and requirements, which must be reflected in the care and support made available to them. Increasingly, as the average age at death rises, many carers are themselves likely to be older and will be looking after people with multiple chronic conditions for extended periods towards the end of life. These are difficult and challenging circumstances in which to provide care.

Many carers remain unidentified and are not getting the support they need. Carers need to be part of the decision-making processes and involved with the patient in the design of care packages and support. By ensuring that the wellbeing of the carer is at the heart of the patient's care package it greatly increases the chance of them remaining at home for as long as possible. Where care at home is or becomes impossible for whatever reason carers' needs for speedy access to high quality 24hr care (respite and continuing care) for their loved one should be prioritised. Such services must be as easily accessible for patients under 65yrs as for those over 65yrs.

Any future strategy or framework for action to take forward the work of *Living and Dying Well* must put the needs of carers at its heart. The Scottish Government's proposed legislation on carers should also reflect the needs of carers for those with a terminal illness or at the end of life.

The Third Sector already makes a huge contribution to the provision of specialist palliative care, through the work of the independent hospices and organisations like Marie Curie Cancer Care. Hospices are also the major provider of education and training on palliative care to care homes. This Third Sector contribution is unparalleled in other areas of healthcare. The Third Sector has acknowledged strengths and expertise in recruiting, training and supporting volunteers. This will be key in supporting and supplementing the role of statutory services in future with anticipated pressures on public finances.

As a society there is a need for a discussion about volunteering and the role that it plays and if and what communities should be doing to support others, in the context of wider public service reform. The ageing population and corresponding increasing demand on health and social care services will make it difficult for statutory bodies to meet demands. There is a need to make better use of individual and community strengths, including the development of volunteers.

All of this reinforces the need to build on the strengths of individuals and communities by fostering a culture of greater openness, as is already being advocated by organisations such as the Scottish Partnership for Palliative Care, Marie Curie Cancer Care, hospices, other charities and statutory organisations through *Good Life, Good Death, Good Grief.*

The Scottish Government must recognise the wide-ranging and significant value of Third Sector organisations to the provision and improvement of palliative and end of life care in Scotland, and encourage and support organisations in these vital activities.

6. Care in the last days and hours of life

In response to the publication of *More Care, Less Pathway* in England, the National Advisory Group to the Scottish Government on Living and Dying Well made a series of recommendations to the Scottish Government concerning how to further improve care in the last days and hours of life. In December 2013, the Scottish Government took the decision to phase out the Liverpool Care Pathway by the end of 2014. There is now a need to consider how to improve care in the last days and hours of life, whilst maintaining the progress achieved over recent years and building on existing good practice, of which there is much.

Reliable and consistent provision of good care in the last days and hours of life requires appropriately trained and educated staff, working within environments which support and enable them to use their skills and knowledge. It requires the alignment of regulatory and scrutiny systems, and the harnessing of knowledge and experience about ways to reliably implement change.

The NHS and Scottish Government should undertake public engagement to ensure care in the last days and hours of life is aligned to the needs, wishes and expectations of the Scottish public. This will help to address some of the damage to public trust and confidence caused by instances of poor care and associated media reports.

Improving care in the last days and hours is also dependent on the greater public and professional openness, communication and planning referenced in earlier sections.

7. Children, young people and life-limiting illness

Much attention is given to the palliative care needs of a population with growing numbers of old people. It should not be forgotten however that up to 200 babies, children or young people die each year in Scotland with a recognised life limiting or life threatening condition. Whilst this number is small the impact on individuals and families is enormous and the challenges for services are complex. Advances in medical science have seen more neonates with complex conditions surviving into childhood and additionally more children surviving into adulthood. A study is commencing in 2014 to investigate the number of babies, children and young people who have palliative needs, and what their needs are.

For any young person the transition into adulthood is a significant stage in their life experience, however for a young person with a life shortening condition it can be an incredibly difficult and stressful time. The services they require may not be available or appropriate for their particular needs.

A focus on implementation of the Scottish Government's *Framework for the Delivery of Palliative Care for Children and Young Adults* is necessary to address inadequacies and inconsistencies in provision.

8. Conclusions and Recommendations

This event posed the question "Are we living and dying well yet?". The answer to that question must currently be "no".

Despite progress and much good practice there remains huge scope for improving the Scottish public's experience of death, dying and bereavement.

The discussions which took place highlighted the major scale and importance of palliative and end of life care within the health and social care system, and the importance to the people of Scotland of getting that care right, for everyone.

They also highlighted that further improvement in palliative and end of life care requires a co-ordinated, systematic and sustained approach to tackling issues which are complex in nature and diverse in scope.

Therefore we welcome the Scottish Government's recent commitment to the development of a Strategic Framework for Action, and present this report illustrating why such a Strategic Framework Action must be broad in scope and bold in intent and delivered with urgency.

We recommend that the new Strategic Framework for Action should:-

1. Be based on engagement with the Scottish public, patients and families, and on their needs, wishes, experiences and expectations.

2. Encompass the needs of all age groups, diagnoses and individual circumstances.

3. Address palliative and end of life care as a society-wide issue, adopting a public health/health promoting approach.

4. Encompass not only the immediately obvious domains of health and social care but also other relevant fields such as Education and Communities.

5. Be underpinned by the development of data, meaningful measures and relevant research activity.

6. Encompass statutory, voluntary and independent sectors.

7. Apply knowledge of approaches proven to achieve and sustain change.

8. Set out coherent and compelling approaches, including investment where necessary, to improve the areas of concern highlighted in preceding sections:-
    a. Delivering care which is better aligned to what people want – for example location of care and death.
    b. Raising public and professional knowledge and awareness of palliative and end of life care.
    c. Increasing openness about death dying and bereavement and building individual and community resilience to deal with the hard times which can come with these experiences.
    d. Improving the identification of people who could benefit from palliative care, and their carers, and ensuring that they get the care and support they need.
    e. Ensuring consistently good care in the last days and hours of life in all settings.

Members of the panel for the Are We Living and Dying Well Yet Seminar

- Kenny Steele, Chair –Chair SPPC
- Aileen McLeod MSP
- Nanette Milne MSP
- Jim Hume MSP
- Rhoda Grant MSP
- Craig White – Divisional Clinical Lead in the Quality Unit, Health and Social Care Directorates
- Juliet Spiller – Consultant in Palliative Medicine at the Marie Curie Hospice, Edinburgh
- David Clark – Director of the University of Glasgow, Dumfries Campus
- Maria McGill – Chief Executive of the Children's Hospice Association Scotland (CHAS)
- Elizabeth Ireland – GP at the Kintyre Medical Group, Chair, NHS National Services Scotland

Marie Curie Cancer Care

Marie Curie is the leading charity providing care to people with any terminal illness in their own homes or in one of its nine hospices, including Edinburgh and Glasgow. The charity is also a leader in research into the best ways of caring for people with a terminal illness. In addition to this the charity designs and advises on end of life services and works to ensure that the best possible care and patient choice is at the heart of commissioning end of life care across the UK. All Marie Curie services are completely free of charge. Around 70% of the charity's income comes from donations with the balance of funds coming from the NHS.

For more information visit www.mariecurie.org.uk; Like us at www.facebook.com/mariecuriescotland ; Follow us on www.twitter.com/mariecuriePA;

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Scottish Partnership for Palliative Care

The Scottish Partnership for Palliative Care is an umbrella and representative organisation which, through a collaborative approach, supports and contributes to the development and strategic direction of palliative care in Scotland. Our objective is to promote equitable access throughout Scotland to high quality palliative care for all patients and families on the basis of need not diagnosis. With our member organisations, we contribute to national thinking and policy in relation to palliative care and promote improvements in service delivery at local level.

For more information visit: www.palliativecarescotland.org.uk

Scottish charity number SC017979.