Strategic Framework for Action on Palliative and End of Life Care

2016-2021

Supporting Evidence Summary



The Scottish Government

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1. INTRODUCTION

A society which shuns the dying must have an incomplete philosophy **(Cicely Saunders)**[1]

1.1 The context

Death is a universal experience. But recently, increased life expectancy as well as changing beliefs, values and expectations have served to increase awareness of end of life care in the public mind. There is a growing recognition that every person's death is unique and something the caring services must acknowledge and respect. The Scottish Government has asked experts and people with lived experience of the issues to develop a Strategic Framework for Action to respond to the changing needs of the population. Its goal is a more compassionate Scotland where there is continuous improvement in access to high quality palliative and end of life care.

This document is intended to inform the process of delivering the commitments within the Strategic Framework. It is a resource for further context and information. It suggests various approaches and reflects on their effectiveness. It identifies gaps in provision and problems to be tackled. It points the way to a wide body of evidence, clinical experience and conceptual discussion – all of which have the potential to enrich the process of implementing the Framework.

Palliative care aims to prevent and alleviate suffering associated with life limiting and life shortening illness. It is particularly associated with care at the end of life. It focusses on physical, social, psychological, spiritual and family concerns and to be effective it requires teamwork.

Palliative care involves understanding and managing pain and suffering associated with advanced disease and it provides expertise in relation to complex symptoms that may occur across the trajectory of illness. It engages the skills of medicine, nursing, pharmacy, social work, psychology, allied health professions, family members, and often volunteers and wider communities.

The need for palliative and end of life care is growing. Meeting that need is going to require new approaches, fresh ideas and a broad-based commitment across Scottish society.

Improving outcomes for patients and families when time is short, overcoming inequalities and promoting equal access to integrated care must all be among the goals of palliative care.[2]

1.2 Building on our achievements

Scotland has benefitted from the action plan known as *Living and Dying Well*, published in 2008. It aimed to 'enable all NHS Boards to plan and develop services which will embed a cohesive and equitable approach to the delivery of palliative and end of life care for patients and families living with and dying from any advanced, progressive or incurable condition across all care settings in Scotland'.[3]

In 2012 a review of *Living and Dying Well* was positive about the progress that had been made, referring to 'an enormous amount of work taking place across settings,

across sectors and across Scotland'. It spoke of 'compelling evidence of a high level of energy and commitment on the part of individuals and organisations' and it suggested that 'a focus on improving palliative and end of life care is being sustained'.[4] The Strategic Framework for action builds on those achievements.

Scotland has a wide array of specialist palliative care services, across community and hospital settings. The United Kingdom consistently ranks at the top of European and global league tables for the development and delivery of palliative care.[5]

In November 2014 a full set of Palliative Care Guidelines was issued for Scotland. In December 2014 Scottish Government published guidance on Caring for People in the last Days and Hours of Life. The guidance is based on four principles:

> Principle 1: Informative, timely and sensitive communication is an essential component of each individual person's care
>
> Principle 2: Significant decisions about a person's care, including diagnosing dying, are made on the basis of multi-disciplinary discussion
>
> Principle 3: Each individual person's physical, psychological, social and spiritual needs are recognised and addressed as far as is possible
>
> Principle 4: Consideration is given to the wellbeing of relatives or carers attending the person.

In support of these principles, Scotland has a rich 'community of practice' around palliative care. NHS, social services and care home workers deliver care to people with advanced illness and to their families, using well developed palliative care approaches. Important work is undertaken by the Scottish Partnership for Palliative Care and its public engagement arm *Good Life, Good Death, Good Grief*. Independent hospices make major contributions to their local communities. National charities provide services, leadership and support for innovation. Academic palliative care expertise exists in Universities and Colleges and there are established training and accreditation programmes. But we know there are gaps in our knowledge and inadequacies in coverage. The Strategic Framework points the way to addressing these by promoting local implementation plans against a broad national vision.

In 2014 the World Health Assembly – the governing body of the World Health Organisation - passed a resolution requiring all governments to recognise palliative care and to make provision for it in their national health policies. The Strategic Framework for Action is a response to that call. It builds on many actions and policies already in place and sets out the goals, challenges and direction for future improvement[6]. It is also informed by the detailed recommendations, suggestions and guidance to be found in the report of the Scottish Parliament's Health and Sport Committee, following its inquiry into palliative care in 2015.[7]

These are inspiring times for palliative and end of life care in Scotland. The Strategic Framework for Action is published in a year of unprecedented public discussion about end of life issues – in the Scottish Parliament, in the national media, in expert reports, briefing documents, consultation submissions and in the work of leading researchers.

As a society we are facing a growing need for appropriate care in the face of ageing, life limiting illness and death. We are challenged by the scale and complexity of this. But we have substantial assets and expertise with which to respond. The Framework builds on these, to map out a vision where everyone who can benefit from palliative care in Scotland will receive it – no matter what their circumstances.

To achieve this vision, many people, organisations and agencies will have to work together in a culture of collaboration and with a passion for improvement.

Palliative and end of life care are now issues of major public interest. The Strategic Framework for Action lays out the elements in the work that must now be done to create a more compassionate Scotland - and to give people the best care possible at the end of their lives.

1.3 Public Health

There is a view that palliative care has a starting place that begins not with services and deficits but with people, communities and capacity. [8] This view recognises that in the last period of life for most people in Scotland, 90% of time is spent at home or in community settings, where most of the care is delivered by family members and informal carers. [9]

This perspective sees illness, loss, and death as social experiences that are shaped primarily by culture, communities and relationships. Within this, medicine and medical care can be quite small elements. The goal from this point of view is to achieve a greater measure of compassion and dignity in all aspects of serious illness, dying and death, wherever they occur and not within the healthcare system alone.

Palliative care is not always well understood. It requires integration within health and social care systems. This means clear assessment of need, appropriate service and community responses, measurable outcomes and robust indicators of improvement over time. It has to become 'everybody's business'.

Work by the Scottish Public Health Network has been important in highlighting some of these issues and has examined the rationale for applying a public health approach to palliative and end of life care, exploring where and how public health approaches could be applied to support local service planning and delivery. It takes the view that palliative care is a safe and effective way to reduce morbidity, but that in the face of growing demand palliative care in Scotland – as currently designed - is neither equitable nor sustainable[10].

Taking this wider perspective, many opportunities open up for the re-framing of palliative and end of life care as an aspect of a more compassionate Scotland. This could build on wider concepts about compassionate communities and cities and can resonate with work already developed in Scotland by *Good Life Good Death, Good Grief*. There is a role for a wide range of government and non-government organisations to explore this concept and assess its usefulness, within the broad umbrella of the Strategic Framework for Action and its commitments.

1.4 Human Rights

Recognition of palliative care as a human right has been developing for some time.[11] The United Nations Committee on Economic, Social and Cultural Rights has stated that it is critical to provide attention and care for chronically and terminally ill persons, sparing avoidable pain, and enabling death with dignity. Under article 12 of the International Covenant on Economic, Social, and Cultural Rights, and article 7 of the International Covenant on Civil and Political Rights, countries are obliged to take steps to ensure that patients have access to palliative care and pain treatment.

Likewise, according to the United Nations Committee on Economic, Social, and Cultural Rights, states are under the obligation to respect the right to health by refraining from denying or limiting equal access for all persons to preventive, curative, and palliative health services. Access to palliative care is a legal obligation, as acknowledged by UN conventions, and has been advocated as a human right by international associations, based on the right to the highest attainable standard of physical and mental health.

1.5 Changing aspects of illness and dying

Modern palliative care began in the 1960s with a focus on patients and families affected by cancer. Over time its benefits were extended to those dying from - and living with - other conditions. Initially, this involved people with multiple sclerosis and motor neurone disease, but in time it included those with heart failure, stroke and dementias, as well as those affected by HIV/AIDS. Services for children, many with complex and rare conditions, also developed.

Diagnosis or disease severity can no longer be the determinants of whether a person gets access to palliative care. There is growing interest in palliative care for prisoners and for homeless people. Palliative care for those identifying as lesbian, gay, bisexual or transgender has also gained attention. Palliative care has much to offer in under-served communities, in rural areas and in relation to those who are marginalised in society.

There is growing recognition that people with advanced age or terminal disease can experience multiple difficulties, symptoms and challenges. Palliative care now has to focus on patients with complex problems, which might endure for potentially long periods. Attempts have been made to characterise these into specific trajectories of dying: rapid, intermittent or dwindling decline.

This shift is also associated with population ageing. Over 50,000 people die in Scotland every year. The population of Scotland in 2012 was 5.3 million. It is projected to reach 6.3 million by 2087 – when the number of deaths could be 60,000 annually. Scotland's population increase will not be spread evenly across all age groups however. The number of people age over 75 will increase most - by 86% between 2012 and 2037.[12]

Modern palliative care can sit alongside curative treatments. Closely tied to the needs of older people, it is no longer delivered by specialists alone. The landscape in which palliative care is now required to operate has become much more complex than it was fifty years ago, when the early pioneers of the field began their work.

1.6 Definitions

The World Health Organisation has produced two definitions of palliative care, in 1990[13] and in 2002[14], but many more can be found in the literature. There is also a WHO definition of children's palliative care.[15] These can be found in Appendix 1.

In 2015 the WHO stated:

> Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.
>
> Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death.
>
> Palliative care is explicitly recognised under the human right to health. It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals.[16]

The Scottish Government endorses this description of palliative care.

There is also a need to settle on an appropriate definition of end of life care, a term which is so often linked to palliative care. Here there is no authoritative wording which can be adopted. The following definition is recommended for use as part of the implementation of commitments within the Strategic Framework for Action.

> End of life care addresses the medical, social, emotional, spiritual and accommodation needs of people thought to have less than one year to live. It includes a range of health and social services and disease specific interventions as well as palliative and hospice care for those with advanced conditions who are nearing the end of life.[17]

1.7 The vision

The Strategic Framework for Action is under-pinned by a vision that takes these factors and changes into account.

It recognises that palliative care is a developing field of interest and has undergone rapid change since the specialty of palliative medicine was first recognised in 1987. It acknowledges the changes in population structure, as well as that patterns of disease and treatment in which palliative care operates create greater and more complex demand. It understands that personal and family perspectives and priorities are central to the palliative care approach.

The approach of the Framework seeks to ensure that a person's wellbeing – and that of their family - is supported, even as their health declines. It should enable people to die well and support those who are bereaved.

The Strategic Framework for Action sets out the approach and a shared vision for people in Scotland where by 2021 everyone who needs palliative care will have access to it. This will mean:

- access to palliative and end of life care is available to all who can benefit from it, regardless of age, gender, diagnosis, social group or location
- people, their families and carers have timely and focussed conversations with appropriately skilled professionals to plan their care and support towards the end of life, and to ensure this accords with their needs and preferences
- communities, groups and organisations of many kinds identify palliative and end of life care as important to the well-being of society.

2. REALISING THE VISION

The vision … to integrate palliative care into all levels of society from the community level upward **(Jan Stjernsward and colleagues)**[18]

Bringing about the vision for the Strategic Framework for Action involves several crucial components for action. Some of these focus on patients, families and the recipients of care. Others relate to those who provide support, resources and services. But ultimately, all of the components make up a set of aims through which the vision can be achieved – and are therefore everyone's business.

2.1 Components for Action

To achieve this, those involved in the provision of palliative care in Scotland must be supported with how to:

IDENTIFY
everyone who might benefit from palliative care

INVOLVE
people in discussions about palliative care - what it is and how it can be made more widely available

INCLUDE
all diagnoses, ages and groups within the commissioning and delivery of care

INVESTIGATE
how well palliative and end of life care is being delivered

INDIVIDUALISE
every person's care to their needs

INTEGRATE
relevant services and resources

IMPROVE
and develop services continually

INNOVATE
to respond to emerging needs

Each of these components has local and national relevance. Each one presents opportunities to think, act and practice differently. The components call on us to be more reflective, to build on best evidence, to be flexible and imaginative. Working on each of them is key to making a high level vision into an achievable goal.

Identify **those who can benefit from palliative care**

Reliable systems and methods are required to ensure that everyone who can benefit from specialist palliative care or the palliative care approach gets access to appropriate help. Identifying the need for palliative care should become as routine as recording a person's allergies. The emphasis should be on early and comprehensive identification and smart sharing of information.

Include all diagnoses, ages and groups

Palliative care can benefit people with many medical conditions in a wide range of social circumstances. Some people with cancer do not receive the palliative care that would help them. Many people with other conditions, such as dementia, stroke, heart failure and a variety of neurological conditions slip though the palliative care net. Some of these need specialist palliative care, many more can benefit from a palliative care approach delivered across health, social care and community settings.

Individualise each person's care

Every person should be treated with respect and dignity. Personalising care has to take place across all settings. It should include pain and symptom management, social and psychological support, spiritual care focussed on the 'whole person' and those close to them. Receiving individualised care should not be a lottery. It can be achieved by working in partnership with patients and carers using the principle 'you matter because you are you'.

Improve on a continuing basis

Sound principles can support localised initiatives to do things better. There are opportunities to learn from experience, to reflect and build on good practice and to benefit from others. World class palliative care should be everyone's right and everyone's goal.

Involve people in discussions about palliative care - what it is and how it can be made more widely available

Greater clarity and more simple language are needed to describe palliative care and what it can offer. People who could benefit from it should feel confident to ask for palliative care and expect an informed response. Palliative care is support for adults, children and families to prevent and relieve the pain and suffering of serious or chronic illness, it applies throughout illness as well as where death is impending, and in bereavement.

Investigate how well it is being delivered

More knowledge is needed about who gets palliative and appropriate end of life care, how well it is delivered and how gaps and inadequacies can be overcome. It is time to invest in research endeavours and collaborations that can produce high quality evidence to support the improvement of palliative care, locally and nationally.

Integrate relevant services and resources

The delivery of health and social care is becoming integrated. Much can be done to break down the barriers in how care is paid for, delivered and experienced. Partnerships are key to this and these can be widened and strengthened across voluntary and statutory agencies, and can include community groups and associations of many types – working in a culture of collaboration.

Innovate to respond to emerging needs

Everyone dies. Most people would benefit from palliative care at some point. But we know that how needs are expressed can change over time and in different circumstances. It is important to develop foresight about palliative care and to be ready to develop new approaches in relation to changing circumstances. Now is an important moment to re-think our past assumptions and practices – and to tailor care to the needs of a changing society.

3. WHAT MATTERS TO ME?

When we are suffering, we have a heightened awareness of small acts of kindness. **(Eduardo Bruera)[19]**

In the face of serious illness, uncertain prognosis, the imminence of death itself, and in bereavement, human beings respond in very personal ways. This is a time when we may need several things from the health and social care services, as well as from friends, families and other sources of support across our communities.

These needs will depend on individual circumstances, what is important, and what can be hoped for and achieved. They may include:

- Relief from distressing symptoms.
- Reliable and consistent access to support and advice from health care and social care professionals who are compassionate, knowledgeable and competent.
- Information about what is happening now, what is likely to happen next, the uncertainties that might be involved, and ideas of what to do.
- Empathy and support in adjusting to coping with uncertainty and deteriorating health.
- Support to get the most out of limited time left with the people that matter most.
- Assistance with financial, legal and other practical issues.
- Understanding and support from family, friends, colleagues and communities when dealing with loss and bereavement, and access to more specialised support if required.

In this context, human rights-based approaches increase public awareness and understanding of what can be expected from caring services. Policies and systems can be framed in terms of people's needs and goals, as shown in the *Charter of Rights for People with Dementia and their Carers in Scotland* and the *Children and Young People (Scotland) Act 2014.*

3.1 Principles

Atul Gawande's BBC Reith Lecture, delivered in Edinburgh in November 2014 and his accompanying book[20], urged clinicians, patients and families to engage actively in conversations about end of life issues. He highlighted the key questions that might be explored:

- What is your understanding of your situation?
- What are your fears and hopes if time is short?
- What are the trade-offs you are willing to make and not make?
- And what is the course of action that best serves this understanding?

Compassion, practical support, human connections and thoughtful medical intervention can go a long way to giving people quality and meaning at challenging moments in their lives.

Three areas are key:

- Autonomy – having a sense of control even when options might be limited by illness
- Personal preferences – supported by opportunities to plan ahead and be understood
- Honesty and openness – from the health care and social care professionals involved

These principles should apply across all care settings and groups.

3.2 Communication

Communication is one of the most important aspects of ensuring people receive good palliative care and end of life care. Good communication is needed between professionals and service users, but also between professionals and between the agencies involved.

There is a wide commitment among providers of palliative and end of life care to high level communication skills and practices. That commitment is also shared across the caring services, though pressures of work and demand sometimes lead to short-comings. Poor communication however can be costly in many ways – in the hurt it causes, the time it wastes and the resources it squanders.

Getting it 'right first time' means impeccable communication - and that should be a goal of everyone involved in caring for people with serious illness, at the end of life and in bereavement.

- This can be enhanced by wider understanding and more effective use of existing electronic communication systems, such as the Key Information Summaries (KIS). Consideration should be given to wider access to these systems on the part of professionals outside of primary care and across public and third sector care organisations, and particularly to the role of specialist palliative care staff.

- It can also be supported by better system compatibility surrounding the use of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR). This would promote shared understanding of preferences and wishes in cases of considerable complexity, as well as a more person-centred orientation.

- Plus it can be promoted by greater agreement and clarity on the definitions and practical descriptions that are used to describe the work of palliative care and end of life care.

3.3 Dignity

Palliative and end of life care should both contain and promote dignity. Such care can dignify everyone involved. The literature of palliative care abounds with examples where this has been achieved – by careful listening, by attention to detail, by skilled intervention, by timely action and by effective teamwork.

Scottish Care the representative body for independent social care services in Scotland, states: '…everyone has the right to die with dignity and respect with the wishes of the individual at the heart of their care and support and where their voice is heard and known by all around them. We believe it is important that such a person-centred, rights based approach is enshrined in all the services that support someone at the end of their life'.[21]

A major proponent of dignity-enhancing approaches in end of life care, has observed:

> '.. the more that healthcare providers are able to affirm the patient's value - that is, seeing the person they are or were, rather than just the illness they have - the more likely that the patient's sense of dignity will be upheld'.[22]

This view applies to care in all settings.

> **The Patient Dignity Question** asks: 'What do I need to know about you as a person to take the best care of you that I can?' It has been piloted in Ninewells Hospital, Dundee, with encouraging results.[23]
>
> **The Patient Dignity Inventory (PDI)**[24] is designed to give clinicians a broad overview or 'snapshot' of how someone in their care is doing at any point in time. The questionnaire is designed to be used by physicians, nurses, social workers, pastoral care providers – anyone attempting to evaluate how a person in their care is coping.
>
> **Dignity Therapy for dying patients**[25] is a brief intervention that gives patients a chance to place on record and share with others the meaningful aspects of their lives and to leave something behind that can benefit their loved ones in the future. The approach has been trialled in Scotland with people in early stage dementia and can make a valuable contribution to their support and care.[26]

3.4 Children's palliative care

In the case of children with life-shortening illness, *what matters to me* has certain specific dimensions.

Holistic children's palliative care spans health, social care, education and other services.[27] It is a 'whole-family' that is flexible and focussed on children, their parents and their siblings. It spans the three stages of life-limiting and life-threatening conditions in children and young people: diagnosis or recognition; ongoing care; and end of life. It supports and enables children and families to choose the type, location and the provider of the care they receive and allows them to change their mind. It is not age, time or diagnosis specific – 15% of children who need children's palliative

care have no definitive underlying diagnosis. It is multi-disciplinary and multi-agency and accessible to people of different faiths, culture, ethnicity and locations. It includes pre and post-bereavement support for families. It supports and enables smooth transitions for young people with life-limiting and life-threatening conditions who move from children's to adults' services.

These children and families require access to a range of children's palliative care services, 24 hours a day, seven days a week, when and where they want and need it. This must be provided by professionals with the appropriate skills, knowledge and competencies. It is common for the condition of children and young people with life-limiting conditions to fluctuate, deteriorate, then recover. It can be difficult to identify when they are moving into the last phase of life. Often children are described as 'dying many times' as they decline, then improve before deteriorating further. This uncertainty challenges both families and professionals. Because of the variety and complexity of individual conditions, each child's prognosis, treatment and support needs will be unique.

Care is delivered in hospitals, family homes, community settings, schools, nurseries and children's hospices, or another chosen place. But some children are unable to access the 24/7 palliative care they require. Parents and families also struggle to access the bereavement support they need.

The prevalence of children and young people in Scotland with a life limiting condition rose markedly in the decade to 2013/14 from 12,039 to 15,404.[28] At any one time, over 2,000 children and young people may be in an unstable condition, deteriorating or dying in Scotland. The potential demand for palliative care in this context clearly outstrips current provision.

3.5 Loss

It is important to recognise that *what matters* includes the perspectives and experiences of those who are left behind when a person dies.

Quality bereavement care in Scotland starts with the care of the dying person, and is dependent on the provision of evidence based training for staff to enable them to provide the appropriate support for bereaved relatives and carers.[29] It acknowledges that experience around the time of death will influence the trajectory of grief. Where health services show empathy and provide good quality care, bereaved people are supported through the process of grief. When health services get it wrong, then bereaved people can experience additional distress and problems as they grieve.

The Scottish Grief and Bereavement Hub developed an internet-based resource for improving the quality of bereavement care throughout the NHS and its partner agencies by linking those professionally involved in planning and delivering bereavement care, disseminating news and information, promoting high quality education and training, affording opportunities for discussion, sharing best practice and hosting shared resources. New content matched to similar objectives, developed by NHS Education for Scotland, is now available. [30]

NHS Education for Scotland has also undertaken work to support medical staff with the Medical Certification of Cause of Death (MCCD) procedures introduced in 2015.[31]

The hidden socio-economic impact of spousal bereavement costs NHS Scotland £20 million each year. Losing a spouse is not only associated with a decrease in life expectancy, but also with an increase in the likelihood of being admitted to hospital and with a longer stay resulting. The total cost of visits to GPs or practice nurses for bereavement issues is around £2.2 million each year, but this is likely to be only the tip of the iceberg of associated support costs.

More than 200,000 people in Scotland are affected each year by the loss of someone close. Bereavement has personal, social and economic implications for families, businesses, and public organisations. These are important, but sometimes overlooked components of palliative and end of life care, and merit more attention.

4. CHALLENGES, CHANGE AND IMPROVEMENT

Each of us must ask what shortcomings in end of life care affect the places where we practice, how they can be addressed, and how improvements can be accomplished **(Joanne Lynne and colleagues)**[32]

Scotland has a good record of delivering high quality palliative and end of life care and has produced some of the global leaders in the palliative care field. It is a country rich in the necessary resources. There are strong primary and secondary care systems, supportive communities, a vibrant third sector and access to a wide range of information and help through print and electronic media.

But we know there are gaps in provision. Some people do not get access to the palliative care they require. There are barriers to be overcome. There can be experiences of poor care and unrelieved suffering. Palliative and end of life care should not be seen solely as the responsibility of specialists. It should be the business of everyone. Its principles – of person centred-ness, attention to detail, excellent communication, justice and fairness - should suffuse the entire care system.

Palliative and end of life care in Scotland must change and improve. Now it is time to identify changing needs, overcome inequalities, increase foresight and planning – and deliver better outcomes for everyone involved. This will require an increasingly 'collaborative culture' across the various agencies and service providers.

4.1 Identifying need and responding appropriately

The need for palliative care is increasing and becoming more complex. Reliable studies estimate that in rich countries up to 82% of all people who die can benefit from palliative care.[33] This would equate to c40,000 people dying in Scotland each year. So it is important to identify systematically and at an early stage those people likely to benefit from palliative care, based on open and honest conversations about their priorities and preferences as their health deteriorates.

Scotland, in common with the rest of the United Kingdom, has a primary-care based system for identifying patients with palliative care needs.[34] About 1% of general practice patients will die each year. It is important to find ways of identifying these patients so that their needs and preferences can be assessed in order to plan for them and to provide the right services at the appropriate time. On average, each GP has experience of 20 deaths per year: about one-quarter from cancer; these are the patients that have generally been thought of when initially discussing palliative care. In addition about one-third will die from organ failure, e.g. heart failure and COPD; about one-third will die from multiple organ failure, frailty or dementia; about one-twelfth will die suddenly with little or no warning.

In a study in nine Scottish general practices of 684 patients who were on the palliative care register, around 75% of patients with cancer were formally identified for palliative care, for those with non-malignant disease, only 20% were formally identified. In both cases identification was in the last weeks of life, and relatively much later in the progression of their disease for the non-cancer group. Formal

identification was closely associated with and triggered by referral to specialist palliative care.[35]

4.2 Tools

Key Information Summaries (KIS) were introduced throughout Scotland in 2013 so that anticipatory care plans written by GPs could be routinely shared electronically and up-dated in real time, between GPs and providers of unscheduled and secondary care.

The Supportive and Palliative Care Indicators Tool (SPICT) has been in development since 2010 as a collaborative project between NHS Lothian and The University of Edinburgh Primary Palliative Care Research Group and has become widely known, with international collaborators in Australia, North and South America and Europe.[36] SPICT is a guide to 'identifying people with one or more advanced conditions, deteriorating health and a risk of dying'. Those identified can then be offered assessment and care planning to review their health care and wider needs and those of their family carers. By these means it is possible to find out about 'what matters' to them, introduce earlier supportive and palliative care integrated with their current care, and begin planning future treatment and care with them. Individual clinicians are advised to look for the following indicators of deteriorating health in their patients and consider applying the SPICT:

- Poor or deteriorating performance status
- Increasing need for personal care
- Recurrent hospital admissions
- Poor control of symptoms despite optimal treatment of underlying condition

Although it is mainly used in primary care, in a study in one Scottish hospital SPICT has been shown to aid clinical decision making and to prompt review of patients' unmet needs for supportive and palliative care.[37] It is sometimes used in combination with the 'surprise question' – would you be surprised if this patient died within 12 months? The SPICT is not designed to identify patients for specialist palliative care referral, but primarily to support improved care by those providing general supportive and palliative care for their patients.

4.3 Who can benefit?

Palliative care started with a focus on patients and families affected by cancer. It has built up considerable expertise in the challenges associated with specific pain syndromes, as well as breathlessness, anorexia and cachexia, anxiety, and depression—all of which are key clinical determinants of quality of life in patients with advanced cancer. This remains the core of much palliative care activity – though not all people with cancer get access to it and that must remain a focus of attention.

Now there is a drive to also bring the benefits of palliative care to those dying from - and living with - other conditions. Initially, this involved people with neurological conditions, such as multiple sclerosis and motor neurone disease, but in time it has extended to those with heart failure, stroke, dementias, as well as those affected by HIV/AIDS. People with multi-morbidity can also benefit from a palliative care approach especially relating to co-ordination of their care, but such patients are

rarely identified in this context[38]. There are also complex and rare conditions affecting some children, where palliative care has much to offer. Like cancer, these conditions also present their own social, psychological and practical challenges, to which palliative care can respond. Palliative care is therefore 'total care' – holistic and multi-dimensional.

There is a growing will to make palliative care available to all who can benefit from it, regardless of diagnosis, prognosis, social circumstances, geography or care setting. This is linked to an interest in earlier intervention, to deliver the benefits of palliative care over longer periods. It is widely accepted that those with malignant conditions may have different needs from those with other conditions and that the needs of babies, children and young people are quite different from those of adults and people in old age.

4.4 Everyone's business

For all these reasons, palliative care is becoming not just the business of palliative care specialists, but of professionals and carers of many kinds who encounter people with serious and life-limiting illness – some of them specialists in their own right in other fields. Meanwhile, ageing populations, the likelihood of experiencing several significant health problems at the end of life and a growing emphasis on person-centred care and individual choice, all create new demands in the delivery of palliative care.

There is much debate about where palliative care should begin. Is there a trigger point, a transition or a shift that signals it is right to take a palliative approach? One idea is to introduce palliative care 'at the point of need' – recognising that this may vary from one individual to another, but highlighting its person-centred and individual approach.

For planning purposes it is important to have estimates of the population need for palliative care. Local needs assessments can therefore inform service design and configuration. Some good examples have been developed by Marie Curie Scotland, working with NHS and other partners – for example, in Argyll and Bute, Scottish Borders, and Lothian.[39]

The Health and Social Care Partnerships will be especially well placed to undertake local needs assessments involving relevant stakeholders and to establish current and future needs for palliative and end of life care. Planning for delivery can include reviews of the current workforce and skill base across agencies as well as putting in place the necessary leadership arrangements. Such planning is best supported by good quality, accurate local data collection and analysis which can also be shared more widely. This way palliative and end of life care services can form a key element of strategic needs assessment and strategic commissioning plans.

4.5 Co-ordination

Co-ordinating services across organisational boundaries 24 hours per day and 7 days per week can ensure that people have timely access to high quality, person-centred, safe and effective palliative care whenever they need it. People identified as having palliative care needs may benefit from access to a priority response 'out of

hours' phone number, linking to local services. This could be via NHS 24, enhanced by streamlined algorithms and protocols to speed up the process. Working like this means focusing on community as well as hospital services and exploiting multi-professional models of care that maximise the potential to meet needs and improve outcomes. There is also scope to further explore and utilise the involvement of trained and well supported volunteers.

Telephone advice from a palliative care specialist nurse supported by a consultant available 24/7 throughout Scotland could be supported by access to patient electronic records across Health Boards, making care provision sustainable for the professionals involved, cost-effective and safe.

For professionals (for example a General Practitioner) seeking to assemble a package of care or additional help to support people at home should be as easy to access as an unscheduled admission to hospital. This requires a single point of entry to a range of community services, for example community nurses, pharmacists, allied health professionals, community psychiatric nurses, Scottish Ambulance Service, social work and care providers.

4.6 Hospitals and care homes

National data can help shape wider strategic and investment decisions. An innovative study demonstrated that in Scotland on a given day, almost a third of the hospital population is in the last year of life.[40] The likelihood of dying rose steeply with age and was three times higher at one year for patients aged 85 and over, compared to those who were under 60. Men were more likely to die than women. A striking finding was that almost one in ten patients of patients in hospital on any given day will die before they leave.

The study findings support initiatives to raise the profile of end of life care in hospitals, where it is known there are still difficulties in making the transition to palliative care and in implementing interventions for the imminently dying. A new organisation has come into being – PATCH – specifically to support specialist palliative care in Scottish hospitals, 24 hours a day, 7 days a week.[41] There are also other models to draw from, such as the Hospice Friendly Hospitals initiative in Ireland, which seeks to improve end of life care by attending to the hospital environment, staff training, policies and procedures.[42]

People in care homes also have high levels of palliative care need and frequently have reduced capacity, but have variable access to appropriate care. Levels of care home staff knowledge, skills and confidence in palliative care also vary. Strong links to general practice make a big difference but are not uniform across regions. Nearly all people in care homes need an anticipatory care plan and Key Information Summary, but around 40% do not have these.

Because NHS information systems do not extend into care homes, timely hospital/hospice discharge information is not available when it is needed. There is much that Health and Social Care Partnerships can do to support change in these areas by fostering partnerships between care homes, general practice/primary care and hospices. Examples of effective interventions to promote quality end of life care in care homes in Scotland have been published in the international literature, leading

to increased use of Do Not Attempt Resuscitation documentation, advanced care planning, and reductions in hospital deaths.[43] There is increasing evidence that caring for people in the last phase of life in care homes is more cost effective than in hospital[44].

4.7 Overcoming inequalities

Ensuring equity of access to palliative care on the basis of need is a public health issue. Identifying individual patients and families who could benefit from palliative care and whether and when they should be referred to specialist services, is an individual and clinical matter. The two are closely related. Both involve matters of equity.

A person's medical condition can influence where they are cared for, their referral pathways, who funds their support and accommodation, and what is available to them. In some instances access to appropriate care is not available equitably across conditions and settings. There are also inequalities rooted in wider socioeconomic and educational disadvantage, as well as ethnicity or sexual orientation. Likewise, particular groups in society such as prisoners, travellers, and migrants can have serious difficulties in accessing palliative care.

People who have received a diagnosis of cancer are more likely – though not guaranteed - to get the palliative care they need. But those with organ failure, frailty or dementia are much less likely to access palliative care.[45] There is a reluctance among professionals and the public to have open discussions about deteriorating health, the uncertainties it involves and the possibilities of death. Public and professional perceptions are largely of palliative care as a specialist service for people imminently dying with cancer. There should be a greater and more widespread focus on quality of life when a person's health is clearly deteriorating and life expectancy is limited. Greater awareness should be promoted that palliative care can, where appropriate, be delivered alongside active treatment. Likewise, it is clear that health and social care services of many kinds can continue to make a significant difference to a person's wellbeing, even when 'cure' is impossible or unlikely.

4.8 Planning ahead

There is much that can be achieved by fully exploiting and improving the IT infrastructure that supports palliative and end of life care. Using the Key Information Summary (KIS) to share anticipatory care planning notes created by 'in-hours' GPs across care settings and 'out of hours' has great potential to improve care, but much remains to be done to complete and consolidate implementation. There is a need to address technical issues so that the KIS can be readily accessed in all settings and extended to social care as well as specialist palliative care services in the voluntary sector.

There are several human dimensions to this IT issue. More awareness of KIS and its potential is required – by professionals and the wider public alike. General practitioners should be confident the data they enter will be accessed and used. Those accessing the KIS in other settings should find information and insights which enables them to improve care. The KIS should be updated when admission and discharge processes occur. Members of the public should be aware of the existence

of the KIS and the potential benefits of discussing care preferences with their GP. In the longer term a single shared record which is updatable from within different settings could be prototyped and tested.

Anticipatory care planning is an essential part of most aspects of healthcare and is not restricted to the context of palliative and end of life care. It may well start before a person has palliative care needs and can change as a person's prognosis, understanding and priorities evolve. It should reflect what matters to the person, and is therefore likely to go beyond specifically clinical issues.

Anticipatory care planning which encompasses palliative and end of life issues can improve the outcomes experienced by an individual and their family.[46] Sensitive, open and honest conversations about what matters to the person are the heart of anticipatory care planning. Documenting, reviewing, updating and sharing decisions and preferences identified during these discussions makes it more likely that care provided will reflect what the person wants. *My Thinking Ahead and Making Plans* [47] is a useful tool that can facilitate forward planning.

These processes may take place in any setting. For example, it is important that care home staff are engaged in anticipatory care planning and are empowered to respect the preferences recorded in a plan, for example by not initiating an unwanted hospital admission. Transitions between settings can also provide useful triggers for initiating or updating plans, for example on discharge from hospital.

4.9 Escalation and deterioration

Anticipatory care planning may include the development of personal emergency care plans which record what treatments will be of benefit and in line with a person's preferences in the event of a sudden deterioration. Such plans should also include actions for informal carers. To maximise their benefit, anticipatory care plans should be widely accessible and recognisable, with a consistent approach in use across Scotland, engaging with eHealth systems, 'out of hours' and emergency healthcare services.

There is good legislation to support best practice in making decisions with people whose capacity is reduced by advanced illness. It is important to acknowledge too that capacity fluctuates and an approach that involves those who are close to the patient can assist with this.

4.10 National and local contexts

The Scottish Partnership for Palliative Care emphasises the relationship between local and national interventions to bring about improvement. [48]

System-wide change can create the conditions for improvement, for example through greater leadership and accountability. System-wide action can transcend the geographic boundaries of NHS Boards, Local Councils or Health and Social Care Partnerships. Working across the system can lead to diverse improvements – in ICT infrastructure or the development of a common and consistent approach to language and terminology. It can also avoid duplication of effort at the local level, for example by building on the Scottish Palliative Care Guidelines published in December 2014.[49]

It can inform local needs assessments and planning for palliative and end of life care by Health and Social Care Partnerships.

Local improvement activities can be supported by ensuring the alignment of existing infrastructures (such as Healthcare Improvement Scotland, the Joint Improvement Team and the Quality Improvement Support Team) to bolster activity focussed on palliative and end of life care.

Small scale, locally led improvement work has an important role to play and the Institute of Health Improvement model is a tried and tested process for achieving results. The Scottish Partnership for Palliative Care has identified a number of priorities for this, including:

- Co-ordinating services across organisational boundaries and out of hours
- Increasing the capacity of palliative care specialist to better support generalist services
- Developing best practice in making decisions for people with reduced capacity

4.11 Competencies and learning

The EAPC defines 'specialist' services in this context as those where the main activity is the provision of palliative care. [50] These services generally care for patients with complex and difficult clinical problems. Specialist palliative care therefore requires a high level of education, appropriate staff and other resources. In addition many other specialist fields of medicine have a part to play in the delivery of palliative care – a point recognised in many countries where there are opportunities for specialists in, for example, oncology, geriatrics, paediatrics, cardiology or intensive care to 'sub-specialise' in palliative care. Beyond this there is the role of general physicians and surgeons, general practitioners and non-specialist nurses, allied health professionals, social workers and carers of many kinds to contribute to palliative care.

There is a need to map existing educational resources that support these core competencies, including modes of delivery and access. More can be done to include relevant palliative and end of life content in undergraduate, postgraduate and pre-qualification curricula for the caring professions.

Palliative and end of life care are the business of a wide range of professionals, carers, agencies, organisations and communities. There is a huge requirement to provide appropriate education and training to ensure that this 'workforce' is well equipped to deal with the many demands that are being placed upon it – across a spectrum of care settings and levels of specialisation. More generally, people working in health and social care should feel empowered to exercise their skills in caring *for* and caring *about* those who require palliative and end of life care.

A high order assessment and mapping of palliative and end of life care education and training opportunities would provide a roadmap for those seeking to learn and enhance their skills. Such an overview could cover many education providers – schools, colleges, universities, specialist organisations and professional groups, as

well as community based associations of many kinds. Huge opportunities are afforded through new e-learning platforms, blended learning and the rich educational resources of hospice and specialist palliative care services. Scotland must ensure that it has a trained workforce to deliver palliative and end of life care and that informal carers, family members and volunteers also have access to support and training that can enhance their contribution.

In addition it is important to determine the size of the specialist palliative care workforce that Scotland requires and then to plan for its further formation, ongoing development and sustainability. Specialist practitioners and services, including hospices and national charities, have a continuing importance in identifying new models of care, evidence based interventions and educational strategies to match these.

5. EVIDENCE AND OUTCOME

Palliative practice has a surprisingly strong evidence base … This evidence base can be strengthened further not only by the growing numbers of researchers … but by every clinician complementing these studies with high quality effectiveness studies in the real world **(David Currow)** [51]

Work is needed to improve the range and quality of information we have about the provision of palliative care in Scotland.[52] This has three dimensions:

1. Indicators of specific resources (or inputs) that support the delivery of palliative care – services, beds, staff, drug availability, training, policies, research infrastructure, guidelines, funding mechanisms, professional accreditation
2. Indicators of need or process that tell us something about the requirement for palliative care or the ways in which it is being organised and delivered
3. Indicators of quality (or outcomes) that tell us something about how well palliative care is being delivered – audits, evaluation studies, quality markers, service user feedback and results from randomised trials.

The European Association for Palliative Care white paper on outcome measurement notes that outcome measures play an increasing role in improving the quality, effectiveness, efficiency and availability of palliative care.[53] But until recently, much assessment of the quality of palliative care has focused on care structures and processes rather than on outcomes. Outcome measures are often used in palliative care research to describe patient populations or to assess the effectiveness of interventions, but they are not widely incorporated into routine clinical practice. In Australia, they have been introduced routinely into practice with timely feedback loops, producing evidence of improved patient outcomes at a systems level.[54] This patient-centred approach to outcome measurement requires the systematic collection of outcome measures at 'point of care' in order to inform areas where improvements need to occur.

At the same time, more work needs to be done to establish the *coverage*[55] of specialist services in Scotland – defined as the relationship between the known level of provision and the actual level of need – as set out in guidelines produced by the European Association for Palliative Care (EAPC).[56]

5.1 Indicators

In 2013 Healthcare Improvement Scotland addressed the issue of palliative care indicators. It defined an indicator as 'a measure of outcome which demonstrates delivery of person-centered, safe and effective healthcare, and promotes understanding, comparison and improvement of that care'.[57] Four palliative and end of life care indicators were presented.

> Indicator 1: Increase in the number of people with palliative and end of life care needs who are identified – that is, the proportion of people with cancer who are on a palliative care register and the proportion of people with a long-term condition other than cancer who are on a palliative care register.

Indicator 2: Increase in the number of people with palliative and end of life care needs who are assessed and have a care plan.

Indicator 3: Increase in the number of electronic palliative care summaries accessed.

Indicator 4: Place of death. This consists of two sub-indicators: proportion of people who die in hospital; proportion of people who die in their usual place of residence.

There are several challenges in generating these indicators, which cannot easily be derived from available data. The indicators need refinement and must also take account of changing debates about place of death as a marker of quality – and in particular the perception that home death is preferable.[58] They should also be enhanced by data from reported patient or carer experience.

The National Health and Wellbeing Outcomes provide a strategic framework for Integrated Authorities for the planning and delivery of health and social care services. A related suite of core indicators[59] has been developed that draws together measures that are appropriate for the whole system under integration. These have been developed in partnership with NHSScotland, COSLA and the third and independent sectors. They include a specific indicator about expenditure on end of life care.[60]

Indicator 23, 'Expenditure on end of life care', relates to an indicator already published by ISD that measures the percentage of time in the last six months of life spent at home or in a community setting. Although this is not a direct measure of compliance with people's preferred place of death, it is considered to be a measure of quality, with a planned approach to end of life care resulting in less time in an acute setting. The measure is published annually at health board and local authority level'.[61] It shows that for the approximately 50,000 Scottish residents who died in 2013/14, and with some variation between Health Boards and urban/rural areas, 91% of the last six months of life was spent at home or in the community, and the remaining 9% of time was spent in an acute hospital. [62]

In the Marie Curie Hospice Edinburgh a baseline audit conducted in 2006 showed that only a small proportion (18%) of patients referred to hospice services died at home. The audit also revealed that only 31% of those who expressed a preference to die at home were able to do so, whereas 91% of those who chose a setting other than home achieved their preference. Overall achievement of preferred place of death was 56%, with a significant number of patients (29%) having no recorded preference. A programme of quality improvement continued over the next 7 years to improve identification, communication and achievement of preferred place of death for all patients. A follow up audit, reported in 2013, showed that all patients had a recorded preference or a documented reason why their preference was unclarified. One third of patients died at home – nearly double the proportion that died at home in the baseline audit. Seventy one per cent of patients who wished to die at home did so - a substantial increase from 31% at baseline. Achievement of preferred place of death for patients wishing to die in the hospice remained high at 88%.[63]

An *Audit Scotland* report in 2007 conducted a sample survey of bereaved relatives, making use of the well-developed survey instrument - VOICES (Views of Informal Carers – Evaluation of Services).[64] The 2007 study covered four health board regions, and results were reported from 997 respondents.[65] In the interim there has been some modest use of VOICES at a local level in Scotland, but the year on year monitoring of the quality of end of life care that VOICES affords, is not available for the Scottish population. Discussions are underway about new piloting of VOICES in specific local settings and consideration is being given to the merits of a periodic national survey.

The aims of the survey are to assess the quality of care delivered in the last 3 months of life for adults and to use this to assess variations in the quality of care delivered in different parts of the country and to different groups of patients. VOICES can show levels of overall satisfaction with care at the end of life; satisfaction with end of life care in hospitals, care home, hospice or home; and the extent to which care is co-ordinated between providers. [66]

5.2 Improving the evidence base

A 2015 report prepared for the Scottish Parliament Health and Sport Committee[67] poses a number of key questions about the evidence base for palliative care in Scotland. These, and related questions should be addressed through a collaborative approach to research and data collation, informed by University researchers, clinicians, NHS data analysts and other interested stakeholders.

- *How does Scotland compare against the categories of development and the rankings for palliative care published in the international literature?* We would expect Scotland to appear in the highest category of development, but the literature does not differentiate Scotland from the rest of the United Kingdom. We lack a great deal of data on the inputs and resources available for specialist palliative care in Scotland and that information deficit needs to be filled.
- *What level of palliative care coverage exists in Scotland for inpatient services, hospital support and home care teams?* This question will be answered when reliable data is available on the number and character of inpatient palliative care services/hospices (with beds), hospital support teams and home care teams that exist in Scotland.
- *What do we know about the vitality of palliative care research in Scotland?* Primary data collection is needed to ascertain this. A good starting point would be a systematic review, such as that produced in 2013 for the island of Ireland.[68]
- *Which is the best measure of whether primary care is identifying the people in need of palliative and end of life care in Scotland - the KIS or the Palliative Care Register?* There is no clear answer to this. Some studies have been completed and are underway which will shed light on the question.
- *How can we identify the 29 % of the acute hospital inpatient population in Scotland that are in the last year of life?* Further investment in the SPICT for this purpose seems likely to yield results, but it needs further robust testing of its efficacy and then wide adoption across the hospitals of Scotland. Other screening approaches should also be considered.

- *How much progress has been made with the identification of palliative care indicators in Scotland?* The progress is limited. The only robust measure available at present is the ISD analysis of proportion of time in the last six months of life that is spent at home or in a community setting.
- *Does Scotland require a National Bereavement Survey?* A National Bereavement Survey [gathering views on the experiences of bereaved persons and their perceptions of the care given to a deceased person close to them] would be the fastest way to gather some data on the quality of end of life care in Scotland that could be monitored over time. It would have the benefit of not being restricted to those accessing any particular kind of service. It could also be used to foster local improvement and change. It would be a source of insight into overall change in the period from the adoption of *Living and Dying Well* and would in turn form a baseline against which to plot the impact of the Strategic Framework for Action. Ideally, such a survey should be conducted across all health boards, affording opportunities for regional comparison but also for local improvement strategies.[69].
- *In what ways can the four principles of care at the end of life, adopted in 2014, be used to measure the outcomes of individual care or as quality indicators for services?* Whilst these are not readily measureable, work could be done in order to achieve this by breaking down the component principles into measureable indicators. These should be few in number and directly meaningful to the providers and users of services.

6. LEADERSHIP AND DELIVERY OF THE FRAMEWORK

It was amazing to see the leaders' presentations of achievements, ongoing work and future projects, to realise what they have achieved … and how their work has made an impact on their own services and beyond (Lukas Radbruch)[70]

Achieving the vision of this Strategic Framework will require building on assets and enthusiasms across many sectors of Scottish life. It will be necessary to stop framing end of life issues as the sole responsibility of the health and social care system and of palliative care in particular. It will be necessary to look at the public and professional education needs and opportunities; the potential to engage with business; the role of community organisations and leaders; as well as the contributions to be made from the arts, culture and wider media.

Leadership will be key to this. Leadership is about creating the conditions necessary to empower and engage people and organisations in exercising their influence to achieve a vision to which they can relate. Leadership encompasses much more than deciding what needs to be done, setting out targets, and delegating tasks. To be effective, leaders need to listen to find out what support they can provide to empower others to make meaningful contributions towards achieving a shared vision. The Strategic Framework for Action is an opportunity to foster this kind of leadership in palliative and end of life care.

The Scottish Government will play a key role in shaping on-going policy in this area, ensuring accountability, and exemplifying openness and honesty about deteriorating health, end of life care and death.

The Scottish Partnership for Palliative Care is a collaboration of all the major organisations involved in delivering palliative care and end of life care in Scotland. It brings together the views and expertise of provider organisations, and of practitioners from across sectors and professions. It can lead information sharing and collaboration across Scotland and develop stretching ambitions for its future strategic direction.

The establishment of Health and Social Care Partnership Boards and the inclusion of palliative care in their responsibilities bring an opportunities for strong leadership to improve the co-ordination and effectiveness of services across organisational and institutional boundaries.

Experiences of declining health, death and bereavement are only partially determined by formal and public services. The social and cultural environment is a key influence on people's experiences as well as being a limiting factor in service improvement.

Public health approaches to palliative care can address this and are set out in the report from the Scottish Public Health Network.[71] *Good Life, Good Death, Good Grief* is an approach to supporting and engaging with communities to empower and educate in ways that are respectful to cultural and individual needs and preferences.

Its membership includes all NHS Boards, many local and national voluntary organisations, universities, schools, faith-based organisations, local authorities, arts organisations, and interested individuals.

The Strategic Framework for Action and this document provide a vision for palliative and end of life care in Scotland. They lay out ideas and approaches that can be implemented to achieve the desired outcomes. The Strategic Framework for Action seeks to improve palliative and end of life care for all who need and can benefit, regardless of circumstances. It highlights the key issues and challenges to be addressed and suggests approaches to be taken.

The Framework is clear about the definitions and terminology that should be adopted for palliative and end of life care. These can assist in the task of engaging the many professionals and organisations, as well as the wider public, in the vison and aims of the Framework.

High level leadership can also support the alignment and shared actions of these multiple groups, promoting and guiding organisational change relating to palliative and end of life care. National and local actions should be prioritised in relation to the overall aims of the Framework, and the availability of resources.

- Nationally, improving palliative and end of life care is important and relevant to wider change programmes within health and social care - and can therefore benefit from the systems of accountability that go with these.
- Locally, there is much that can be done to promote improvement activity that is sustainable and clearly focussed on need, care and services

Many people, organisations, groups and professions must play their part in delivering the Strategic Framework for Action. There can be no single blue print for change. Overall policy, set by Scottish Government provides a context in which others can then work towards a shared vision.

APPENDIX – DEFINITIONS[72]

World Health Organisation Definition of 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.

World Health Organisation Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. The WHO definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.

- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.

- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

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