EVERY STORY'S

Scottish
Partnership
for Palliative Care

good life
good death
good grief

Member Organisations of Scottish Partnership for Palliative Care (SPPC)

St Margaret of Scotland Hospice
open to all in need of care
Bethesda Care Home & Hospice
Association of Palliative Care Social Workers
MSA Trust
St. Vincent's Hospice
MS Multiple Sclerosis Society
Highland Hospice
International Association of Nurses in Palliative Care
IANPC
Charlie house
MND Scotland
Marie Curie
Care and support through terminal illness
together for short lives
Ayrshire Hospice
Making today matter
PSPA
British Heart Foundation
Cruse Bereavement Care Scotland
The Prince & Princess of Wales Hospice
Association of Hospice & Palliative Care Chaplains
Royal College of Nursing
Parkinson's UK
Change attitudes. Find a cure. Join us.
Alzheimer Scotland
Action on Dementia
apm
Association for Palliative Medicine of Great Britain and Ireland
Faith in Older People
CHAS
Children's Hospices Across Scotland
St Columba's Hospice
Care and compassion
ACCORD Hospice
We are Macmillan. Cancer Support
Strathcarron Hospice
Making every moment count
Sue Ryder
Incredible hospice and neurological care
kilbryde hospice
St. Andrew's Hospice
Caring for the people of Lanarkshire
Scottish Palliative Care Pharmacists Association
association of bereavement service coordinators

NHS Eileanan Siar Western Isles
NHS Lothian
NHS Grampian
NHS Highland
OHAC orkney health and care
NHS Tayside
Clackmannanshire & Stirling Health & Social Care Partnership
Fife Health & Social Care Partnership
Supporting the people of Fife together
Western Isles Community Health and Social Care Partnership
Aberdeen City Health & Social Care Partnership
A caring partnership
NHS Shetland
Dundee Health & Social Care Partnership
Angus Health & Social Care Partnership
NHS Lanarkshire
Renfrewshire Health & Social Care Partnership
Argyll and Bute. Health and Social Care Integration.
NHS Lothian · Edinburgh · The City of Edinburgh Council
Working together for a caring, healthier, safer Edinburgh
NHS Fife
NHS Greater Glasgow and Clyde
East Lothian Health & Social Care Partnership
East Ayrshire Health & Social Care Partnership
East Dunbartonshire Health and Social Care Partnership
West Dunbartonshire Health & Social Care Partnership
East Renfrewshire Health and Social Care Partnership
NHS Ayrshire & Arran
Shetland Health and Social Care Partnership
Shetland Islands Council
NHS Shetland
Health & Social Care Moray
NHS Borders
NHS Dumfries & Galloway
Scottish Borders Health and Social Care Partnership
south ayrshire health & social care partnership
South Lanarkshire Health and Social Care Partnership
Working together to improve health and wellbeing in the community – with the community
Health & Social Care North Lanarkshire
Aberdeenshire Health & Social Care Partnership
Glasgow City HSCP
Health and Social Care Partnership
Falkirk Health and Social Care Partnership
NHS Forth Valley
NHS Orkney
Dumfries and Galloway Health and Social Care
North Ayrshire Health and Social Care Partnership
Perth and Kinross Health and Social Care Partnership
Inverclyde HSCP
Health and Social Care Partnership
West Lothian Health & Social Care Partnership
www.westlothianhcp.org.uk
NHS Lothian
West Lothian Council

This paper draws on engagement with SPPC members, practitioners, the public and other stakeholders. More details of this process are in **Appendix 2.**

FOREWORD

The past 15 months have been a tragic and brutal reminder of the impacts of serious illness, dying and bereavement. Whilst individual experiences have varied greatly, COVID-19 has highlighted an eternal truth: we are a community rooted in the shared experience of mortality. We are all vulnerable ultimately to the fears, uncertainties, suffering and losses that come with serious illness, dying and bereavement: this can make it hard to face up to death and dying – whatever our role individually, organisationally or at national level.

This past year has also demonstrated the best of humanity - in the care and support provided by communities, and by health and care services, to those reaching the end of life or who have been bereaved. These compassionate responses demonstrate a deeply rooted conviction that at this most vulnerable stage of life people have a fundamental human right to the care and support they need.

Around 58,000 people die in Scotland each year, and there is much to be proud of in the way that communities and formal services respond to those impacted. However, despite progress over the past decade, there remains a long way to go before Scotland can be sure of its ability to fulfil the rights of its citizens towards the end of life. It is eminently possible to make those rights a consistent reality. To fail to do so is a conscious choice which reflects poorly on a wealthy and technically accomplished society.

Just as 'it takes a village to raise a child', it takes a community of public and professionals to provide care and support for people who are living with serious illness, dying and bereavement. There is no more appropriate time to renew our commitment to this undertaking than now, and no finer expression of our shared humanity. This paper describes approaches and actions which will deliver progress.

Mark Hazelwood, CEO
Scottish Partnership for Palliative Care

May 2021

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EXECUTIVE SUMMARY and PRIORITIES

Serious illness, death and bereavement affect everyone profoundly at some point in their lives. Scotland should be a place where:

- people's wellbeing is supported even as their health declines
- people die feeling well looked after and having had their beliefs and wishes respected
- people feel supported throughout bereavement.

Our health and social care system expends very significant resources caring for people who are approaching the end of their lives:

- 1 in 3 hospital beds is occupied by people in the last year of life.
- The average length of stay in care homes for older people is 15 months.
- Well over 30,000 frail elderly people receive care at home each week.

Though much outstanding care is provided by our health and social care system, some people have experiences that which could have been better, and which leave a legacy of regret and avoidable distress. Stark inequalities exist in the care and support people experience.

Recent events, and anticipated changes over the next decade, will create an even greater imperative for focussing on improving people's experiences of living with serious illness, dying and bereavement:

- The COVID-19 pandemic has left a legacy of loss and highlighted key weaknesses in the way Scotland tackles the challenges of living with serious illness, dying and bereavement.
- The number of people dying each year is set to rise by 16% between 2016 and 2040 and more people will need palliative care. By 2040 66,000 people will die *every* year – as many people as have died during the first 12 months of the COVID-19 pandemic. A sharply increased number of people will die in advanced old age after living with complex multimorbidity. An increasing number of older people will live alone.
- Post-Brexit and post-COVID-19 public finances will tighten further creating a strong imperative to make use of interventions and approaches that can both reduce costs and improve outcomes.

- Workforce shortages will require remodelling of services.

This paper undertakes a thorough exploration of the provision of palliative care and end of life care in Scotland and offers a comprehensive set of proposals to improve people's experiences of living with serious illness, dying and bereavement. **Several priority themes are identified**:

Establishing Leadership, Commitment and Collaboration

Palliative and end of life care is provided in the context of multiple delivery agencies, parallel planning processes and complex lines of accountability. There is therefore a need for a strategic approach, with strong national and local leadership. There is also a need for commitment and collaboration from a wide range of organisations, alongside an infrastructure to support learning, innovation, collaboration and investment.

Planning and Commissioning for Success

At system level there is a need to identify what improved outcomes towards the end of life should look like, and then plan to achieve these explicitly identified outcomes. Processes should support partnership and collaboration between different sectors and should involve local communities.

Empowering Communities

Most care and support is provided informally by family and other community members. This should be recognised and supported with a 'public health approach' that nurtures community-led action and builds everyday knowledge and skills relating to death, dying, loss and care.

Promoting and Enabling Planning Ahead for Ill-health and Death

Thinking ahead and making plans for declining health and dying can improve people's experiences and outcomes. There is therefore the need for a co-ordinated national approach to anticipatory care planning (ACP) which encompasses public awareness/information, staff education, clear triggers, and with clarity on roles and responsibilities. This must be underpinned by a digital ACP to allow updating and sharing across settings.

Improving Bereavement Support

During the pandemic many more people have experienced bereavement, often in difficult and traumatic circumstances. A public health approach to bereavement should be developed which identifies the experiences and levels of need of the population, maps current capacity and which brings together providers and commissioners to collaborate on clear pathways, adequate resourcing of services and building informal community capacity.

Building and Sustaining the Workforce

Improving care towards the end of life requires the success of national workforce planning measures addressing well-documented challenges such as the recruitment and retention of social care staff, the imminent retiral of a high proportion of GPs and district nurses, and trauma/burnout from the COVID-19 pandemic. In addition there must be adequate palliative and end of life care education for generalists. National and local workforce planning must also ensure adequate specialist palliative care capacity to provide direct care, support to generalist colleagues, education and leadership.

Measuring What Matters

Currently no-one can adequately evidence the quality of care and outcomes delivered for people living with serious illness, dying and bereavement in Scotland. Local and national measures of quality of care and experience towards the end of life should be developed. Such measures should inform commissioning decisions, inform the focus of improvement work and provide public assurance at local and national level.

1. INTRODUCTION

Serious illness, dying and bereavement are experiences that will affect everyone at some point in their lives.

This paper explores what can be done in Scotland to improve these experiences.

It is designed to be read by:

- policy and decision makers at national and local level who can help create conditions for change.
- everyone with an interest in leading or contributing to change in this area, whether working at national or local level, within an institution, an organisation, a team, a community or a neighbourhood.

This paper examines a wide range of issues, many of them complex. The scope of necessary activity and change is wide and will require broad and sustained engagement from a range of organisations.

However, for every area explored, this paper sets out practical actions that will move improvements forward.

It has been developed by the Scottish Partnership for Palliative Care (SPPC) in collaboration with those working in hospitals, hospices, communities, policy, with those responsible for planning and managing services, and with professional bodies and academia.

We hope it will support thinking and action which will improve people's experiences of living with serious illness, dying and bereavement.

2. ABOUT THIS PAPER

Aims

This paper aims to:

- explore and clarify the major issues affecting care and support of people living with serious illness, dying and bereavement in Scotland
- propose a practical agenda for progress over the next 3-10 years.

Structure

This paper:

- **sets out an ambition** for what living with serious illness, dying and bereavement in Scotland could and should look like
- **explores what matters to people** when they are seriously ill, dying or bereaved
- **takes stock** of recent progress, work underway and the current situation in Scotland regarding people's experiences of living with serious illness, dying and bereavement
- **explores why and how to make change happen** over the next 3-10 years
- **identifies key challenges, priorities and actions** that will make a positive difference to experiences of living with serious illness, dying and bereavement in Scotland.

Scope

Health and social care services play an essential role supporting people through serious illness, dying and bereavement, and it is important to look at what can be done to improve the ability of formal services to provide support.

However, when going through difficult times, people also need support from their families, friends and communities.

The scope of this document is therefore broad, exploring:

- different settings where formal services are experienced - primary care, hospitals, care homes and hospices
- the role played by wider society, for example education, workplaces, family, the media, information provision and communities.

3. A NATIONAL AMBITION

for what living with serious illness, dying and bereavement in Scotland could and should look like

Death, dying and bereavement are inevitable parts of the natural life course. Together, we can work to ensure people are supported as well as possible through these difficult experiences.

Scotland should be a place where:

- people's wellbeing is supported even as their health declines
- people die feeling well looked after and having had their beliefs and wishes respected
- people feel supported throughout bereavement.

This ambition can only be achieved by individuals, communities and formal services working together.

Everyone, regardless of age, diagnosis, characteristics, beliefs or circumstance should experience kind, compassionate, safe, effective person-centred care wherever it is required from health and care staff who continue to take actions that make a significant difference to a person's wellbeing throughout the last years, months, weeks, days and hours of that person's life.

Yet some roles can only be undertaken by friends, families and communities. Therefore, communities and individuals need to have the knowledge, information, confidence and opportunity to help each other through the hard times which can come with declining health, death, dying and bereavement.

4. WHAT MATTERS

to people who are seriously ill, dying or bereaved?

[This chapter draws on the views and experiences of people living with serious life-shortening illness, their loved ones and people who are bereaved] [i].

When faced with the reality of deteriorating health and death, people need many things from their friends, families and communities, the NHS, social care services and other formal services.

Support, Empathy, Information

What a person needs depends on their personal circumstances and what is important to them. For many of us, our needs will include:

- **relief** from distressing symptoms
- reliable and consistent access to **support and advice** from healthcare and social care professionals who are compassionate, knowledgeable and competent
- **information** about what is happening, what is likely to happen next, the uncertainties that might be involved, and ideas of some ways of responding
- **empathy** and support in adjusting to coping with uncertainty and deteriorating health
- **support to get the most out of whatever time is left** with the people we care about
- time, space and support to discover and maintain **a sense of meaning**, purpose and spiritual wellbeing in new and changing circumstances
- access to **short breaks/ respite** and other support for the people we care about who are caring for us
- **support with financial, legal and other practical issues**, including the 'little' things that can make a big difference, like mowing the lawn, or taking the dog for a walk
- understanding and support from **family, friends, colleagues and communities** when dealing with loss and bereavement, and access to more specialised support if bereavement becomes harder to cope with.

Autonomy, Opportunity, Honesty

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

Three inter-dependent factors are key:

Autonomy

People generally value a sense of being in control, yet ill-health often throws people into situations no-one would choose. The options available to an individual may be limited for various reasons, but it is important that people are supported to retain the autonomy to choose from the options that are available for as long as possible.

Opportunities to explore personal preferences

Planning ahead for deteriorating health increases the likelihood that a person will receive the kind of care they would like. Therefore, efforts to encourage this kind of planning and to promote more cultural openness about death are welcome. Not everyone will *want* to plan ahead or talk about death, but everyone should have *opportunities* to do so, accompanied by the recognition that people's needs and wishes can change over time. It is important that every individual has the opportunity to tell their own story, and that others listen to find out what matters to them and what support they might need.

Honesty and openness

While remaining sensitive to an individual's situation and sensitivities, healthcare and social care professionals need to be honest with the person about their expectations for that person's health. This includes what uncertainties are involved, what support will be reliably available, and any limits there might be to the support provided. The desire to shield people from unwelcome information is understandable. Learning that someone will not get better, or that the ideal support services are not available, or that the end of life is close, will likely always be difficult. Yet, without honest information, individuals and families are ill-equipped to make decisions or plan ahead. Thinking about serious illness and death can be difficult for both professionals and for the public but recognising shared mortality and common humanity is where good palliative and end of life care builds from.

Privacy, Individuality, Relationships

No place like home?

People often express a wish to be cared for and to die at home.

For many people their home is somewhere familiar, where loved ones can be to hand, and where important words and moments can be shared in privacy. Home can be a personal, intimate and individual space steeped in meaning.

However, often people's needs and priorities change as the realities and uncertainties of serious illness become manifest. Someone might wish to avoid feeling as though they are 'burdening' family members; to be sure of quick access to rapid treatment or to feel secure with experienced staff close by.

Sometimes there maybe trade-offs to consider and choices to be made between the place someone would ideally want to be and other things that are important to them.

Care homes, hospitals, hospices and individual homes are all places where people can live and receive good care when they are seriously ill or dying. Each setting has an important role to play as complementary parts of a single system.

It is therefore important that, wherever someone is living, efforts are made to enable them to experience as much of the 'essence of home' as possible. For many of us, that is about having privacy, individuality and space for intimacy and important relationships.

5. WHAT IS PALLIATIVE CARE?

Within this document we use the terms 'palliative care' and 'end of life care'. There are differences of understanding and perspective relating to what these terms mean, so below we set out how these terms are used within this document.

Good care when someone's health is in irreversible decline …

Though more specific definitions can be helpful (see Glossary), one way of thinking about 'palliative care' is to talk in terms of providing 'good care' to people whose health is in irreversible decline or whose lives are coming to an inevitable close.

Perhaps what differentiates 'palliative care' from 'just good care' is the awareness that a person's mortality has started to influence clinical and/or personal decision-making.

… optimising wellbeing during whatever time is left.

However, palliative care is not synonymous with death – it is about life, about the care of someone who is alive, someone who still has hours, days, months, or years remaining in their life, and about optimising wellbeing in those circumstances.

Palliative care interventions are holistic and aim to *modify the impact* of illness/ disease by addressing symptoms and controlling the underlying condition(s). Palliative care can and should be delivered alongside treatment aiming to *cure or remove* the underlying illness/ disease where such treatments exist.

Generalist palliative care by all health and social care professionals

In Scotland much of the care that people receive when their health is deteriorating could be termed **generalist palliative care**, being provided by health and social care professionals to people living in the community, in care homes and in hospitals.

It is palliative care regardless of whether someone has cancer, organ failure (including neurological conditions) or ‘old age’, or whether they are living at home, in a hospice, in a care home, in prison or in a medical ward, in ICU or a homeless shelter, or in a neonatal ward.

Specialist palliative care by multi-professional specialist teams

Specialist palliative care can help people with more complex palliative care needs and is provided by specially trained multi-professional specialist palliative care teams who are generally based in a hospice, an NHS specialist palliative care unit or an acute hospital, but whose expertise should be accessible from any care setting and at any time. Services labelled ‘palliative’ are usually specialist palliative care. Key contributions of specialist palliative care include:

- assessment and management of complex physical, psychological and spiritual symptoms
- supporting complex clinical decision-making, seeking to apply relevant ethical and legal frameworks alongside clinical assessment and respect for personal autonomy and values
- direct provision and management of symptom management interventions
- providing care and support to those important to the person receiving care, including facilitating bereavement care
- providing specialist advice and support to the wider care team which is providing direct care to the person
- liaison with and between different settings
- providing formal and informal education and training for the wider health and social care system
- attending and providing input to multidisciplinary team meetings, including key decision-making contributions

- providing strategic expertise and leadership to support the health and care system to recognise and meet the needs of people approaching the end of their lives.

End of life care

Palliative care includes, but is *not exclusively about,* end of life care.

End of life care is a core part of palliative care which should follow from the diagnosis of someone entering the process of dying, whether or not they are already in receipt of palliative care. This phase could vary between months, weeks, days or hours in the context of different disease trajectories[1]. There can be uncertainty involved in identifying when someone might be expected to die – illness can be unpredictable, and changes can occur suddenly and unexpectedly.

Provision of palliative care

Palliative care is provided by the NHS, the Third Sector, the Independent Sector and local authorities.

Organisations involved in delivering palliative care include primary care; care homes; care at home services; hospices; NHS 24; Scottish Ambulance Service; NHS specialist palliative care units; acute hospitals; community hospitals.

Legal responsibility for the strategic commissioning of palliative care lies with Integration Authorities (IAs).

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[1] 'end of life care' is often used to refer to care in the last year of life. However, this is hard to identify prospectively, so this document uses the term differently - to refer to imminent and identifiable dying.

6. WHERE ARE WE NOW?

Taking stock of progress, work underway and the current situation

The policy environment

Palliative and end of life care policy

Historically, ‘palliative care’ has been associated with hospices and with cancer care. However, *Our National Health: A Plan for Action, a Plan for Change* (SEHD 2000) stated that palliative care was important in cancer but should also be available to all those who need it regardless of diagnosis. *Better Health Better Care (SG 2007)* made a commitment to developing a national action plan for palliative care.

In 2008 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. This was followed by *Living and Dying Well: building on Progress (2011). A Framework for the Delivery of Palliative Care for Children and Young People in Scotland* (SG 2012) described approaches to meeting the specific needs of children and young people. *Shaping Bereavement Care – a framework for action* was published by Scottish Government in 2011 and set out guidance on the development and delivery of quality bereavement care services within NHS Scotland. In 2013 SG published *The Keys to Life: improving quality of life for people with learning disabilities*[ii] which made recommendations about palliative care for these people.

Also in 2013, in the context of adverse media coverage of the Liverpool Care Pathway (LCP), Scottish Government announced that the LCP would be phased out and issued guidance on caring for people in the last days and hours of life.

In 2015 Scottish Government published the *Strategic Framework for Action on Palliative and End of Life Care* (SFA) which noted the importance of palliative care in all settings and interdependence of different parts of the health and care system.

The SFA's vision was that

> *'By 2021, everyone in Scotland who needs palliative care will have access to it.'*

This vision was underpinned by three aims, four outcomes, six objectives and SG itself made 10 Commitments to action.

Integration Authorities were legally delegated responsibility for the strategic commissioning of palliative care from 2016, and an advice note to support this role was published in 2018. The *Health and Social Care Delivery Plan* (SG 2018) committed to *'doubling the palliative and end of life provision in the community'*.

Scotland's *General Standards for Neurological Care and Support* (Healthcare Improvement Scotland, 2019)[iii] and *Neurological Care and Support in Scotland: A Framework for Action 2020 – 2025* (SG, 2019) both reference the provision of palliative care.

Very recent publications by Scottish Government have referred specifically to the importance of improving palliative care. These include *Health and Social Care for Older People: statement of intent* (March 2021)[iv], the *Heart Disease: Action Plan* (March 2021) [v] and the *Respiratory care - action plan: 2021 to 2026*[vi] (March 2021). However, *Recovery and Redesign: An Action Plan for Cancer Services* (SG, Dec 2019) makes no reference to palliative care.

Other relevant policy developments

2016 saw the publication of *Realistic Medicine* and the ensuing workstream has encouraged a focus on shared decision-making and person-centred care encompassing the end of life.

Active and Healthy Ageing: An Action Plan for Scotland 2014 – 2016 recognised the importance of open and honest discussion about end of life and bereavement – 'healthy dying' as part of healthy aging.

The *Carers (Scotland) Act* came into force in April 2018. It gave adult and young carers the right to a support plan. The assessment and preparations of these plans must be completed within a specific time frame where the person being cared for is 'terminally ill'.

The *Social Security (Scotland) Act 2018* provides the legislative framework to change the eligibility criteria for terminally ill people to gain expedited access (at higher rates) to a range of devolved benefits. Under the new system the six-month prognostic criterion will be replaced by a more flexible approach based on individual clinical judgement. Another consequence of the devolution of some UK benefits was the creation of the Funeral Expense Payment. 40% more people on low incomes are eligible for this benefit compared to the UK benefit, and the new Scottish benefit will also be increased in line with inflation (the UK benefit hasn't been uplifted since 2003).

The *Health and Social Care Standards (2017)* set positive expectations about people's right to care which is compassionate, respects dignity, is provided by competent staff, empowers people in decision-making about their lives and is provided in a high-quality environment. The Standards state that people must be *'supported to discuss significant changes in my life, including death or dying, and this is handled sensitively'.*

The vast majority of people living in adult care homes and many receiving care at home have palliative care needs. The reforms proposed by the *Independent Review of Adult Social Care* (Feb 2021)[vii] are crucial to the improvement of palliative care in social care settings. Or to look at it a different way improving palliative care is a key part of delivering the improved outcomes envisioned by the reforms.

Policy and strategy gaps

The organisation and delivery of palliative care services in Scotland is complex. Multiple delivery agencies and parallel planning processes are involved, and the lines of accountability are complex. This can lead to a lack of strategic attention to palliative care as a whole.

This is compounded by an individual and organisational discomfort in contemplating mortality. There can also be a (perhaps unconscious) assumption that because death is inevitable there is nothing which can be done to improve associated experiences.

Despite being a huge part of what the health and social care system delivers each day, palliative and end of life care is often surprisingly invisible in polices, plans, strategies and particularly in the measurement of outcomes.

Work to develop and improve services

A survey recently conducted by SPPC invited stakeholders to suggest areas where in their experience the practice and provision of palliative and end of life care had improved over the past decade.

There was a consensus that much remained to be done, but positive developments (often local) which were commonly identified included:

- increased public and professional awareness of palliative care as an approach relevant to many people in Scotland regardless of diagnosis
- anticipatory prescribing improving access to symptom relief at end of life
- increased numbers of Key Information Summaries (KIS): there are now more than 1.7m KIS records and improved access to and use of these summaries in different settings
- increases in anticipatory care planning conversations (and plans)
- the establishment of the Paediatric End of Life Care Network (PELiCaN)[viii] and development of medical staffing in paediatric palliative care
- work to build confidence and capacity of care home staff to provide palliative and end of life care
- increasing examples of joint and better integrated working between specialist palliative care teams and the wider system
- increased staff capacity in some areas
- education of non-specialist staff
- the development and widespread use of the Scottish Palliative Care Guidelines
- establishment of the Scottish Network for Acute Palliative Care, which links those working to improve hospital palliative across Scotland
- initiatives to start to address the needs of particularly disadvantaged groups, for example prisoners and homeless people.

Developments arising from the SG Commitments in the SFA include:

- the development of a framework for education and training
- improved analysis of routinely collected data and pilot collection to fill gaps in current data
- a programme of quality improvement projects focussed on early identification and care co-ordination
- major development of children's palliative care
- early-stage eHealth development around ACP
- small scale investment in public facing work to promote open and supportive cultures and behaviours around living with serious illness, dying and bereavement
- the initial establishment of a Palliative Care Research Forum

- an advice note for Integration Authorities note on Strategic Commissioning of Palliative and End of Life Care (see above).

Various other work has taken place or is underway to improve palliative and end of life care in Scotland involving different collaborations and many are referenced in this document. For example, the Scottish Patient Safety Programme Deteriorating Patient work stream, in collaboration with the SPPC, has done work to trigger more reliably discussions about goals of care with patients and families in acute hospitals.

Scotland has been an active participant in the UK-wide Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) collaborative. The ReSPECT process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices. These recommendations are created through conversations between a person, their family, and their health and care professionals to understand what matters to them and what is realistic in terms of their care and treatment. The ReSPECT process provides a basis for future development of a digital anticipatory care plan.

There are numerous other examples of local service development and innovation.

Public attitudes and behaviours

70% of people are comfortable thinking and talking about death …

Public attitude surveys consistently find that around 70% of people say that they are comfortable thinking and talking about death and dying[ix].

… BUT this isn't always reflected in people's behaviour.

Planning ahead by taking actions such as anticipatory care planning, making a Power of Attorney, or completing an Advance Directive are actions that individuals can initiate themselves to make it more likely that they will get the care they'd choose. It also makes the financial, legal and practical consequences of illness and death a little easier to cope with.

However, less than half the UK population have had any sort of discussion about end of life wishes with their loved ones. Most commonly people explain that this has not been a priority and/ or that it seems too soon (including a significant percentage of people aged over 75).

Whilst increasing numbers of Powers of Attorney are registered with the Office of the Public Guardian, the statistics are difficult to interpret. A significant proportion of delayed discharges are due to the absence of a Power of Attorney. Around 60% of people in Scotland do not have a will. Use of Advance Directives remains low. Only 5% of UK adults have a living will or advance care plan. Few people have considered, discussed or written down anything in relation to end of life care preferences. 11% have any sort of written preferences for their funeral.

There can be misunderstandings and low awareness

A recent survey found that around a quarter of people in Scotland feel anxious and are unsure of what to say to someone who has been bereaved.

Media coverage and public discourse suggest there are low levels of awareness and understanding of the intent and potential benefit of anticipatory care planning (ACP). Similarly, misunderstandings exist about the purpose of Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR)[2] discussions, decisions and forms. Sometimes misunderstandings can cause fear and mistrust. Misunderstandings and low awareness create a more difficult starting point for healthcare professionals to initiate conversations about forward planning. This can be exacerbated if healthcare professionals attempt to initiate planning conversations, for example about DNACPR, without first exploring people's understanding and individual preferences.

Outcomes for individuals and families – how well are we doing?

There is no simple way to assess the outcomes and experiences of people living with serious illness, dying and bereavement. People's experiences are personal and their circumstances varied. Care often takes place within and across multiple formal and informal settings, over variable and sometimes extended periods of time. In the context of deteriorating health and dying traditional health outcome measures can't easily be applied. Dying and bereavement can be traumatic even when care and support is optimised.

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[2] A DNACPR form documents a decision that in event of someone's heart stopping attempts should not be made to restart it.

In addition to these inherent challenges Scotland has progressed slowly in the development and use of data around this phase of life. This creates a difficulty in evaluating the impact of policy and service development in this area.

Progress on the aims and objectives in Scottish Government Strategic Framework for Action on Palliative and End of Life Care are not easily evaluated using the data available. Unfortunately, the Framework's commitment to 'provide an annual learning and improvement report that would outline the ways in which improved care and outcomes have been delivered' has not been achieved. Similarly, the commitment in the Health and Social Care Delivery Plan (SG 2018)[x] to *'doubling the palliative and end of life provision in the community'* was not further defined and there was no accompanying measurement process.

Care Opinion and NHS feedback websites have captured powerful stories about palliative and end of life care across the health and care system. Many accounts are of very good and compassionate care:

> ***I am currently being looked after by the palliative care team, alongside my local GP Dr McLeod. Since coming under their care I just cannot thank them enough for the wonderful work they have done in improving my quality of life over these last few weeks. Sharon, the palliative care nurse, has been so helpful and has always done exactly what she has promised, and she is an absolute credit to the palliative care service. The communication between Sharon and the GP's seems to work really well and I have been lucky to have had some great quality days over the last month. I just wanted to put on record how much I appreciate the support I am getting.***

Other stories recall poor care:

> ***Recently my Gran passed away and although the family were asked to leave the room, we came back to flowers laid out but with my Gran still in the same soiled nightdress and sheets. I took the time to brush her hair and put her glasses on myself. I understand the pressure the NHS staff are under. Small things that we do every day can make the biggest difference to those saying goodbye to loved ones.***

Some stories have elements of both good and bad. It is not possible to say definitively how representative they maybe of the general experience of care. All the stories convey the profound importance of care at this stage of life.   As Cicely Saunders wrote *'How people die remains in the memory of those who live on'*. These stories highlight the importance of developing more comprehensive and systematic means of measuring the experiences and outcomes of people living with serious illness, dying and bereavement.

Chapter 10 of this paper explores the issue of measurement of quality and experience, making recommendations which will enable better assessment of progress in the future.

7. IMPERATIVES FOR CHANGE

Recent events and anticipated changes within Scottish society over the next decade will create an even greater imperative for focussing on palliative and end of life care and improving people’s experiences of living with serious illness, dying and bereavement:

7 a. The COVID-19 Pandemic

has created a legacy of loss and highlighted key weaknesses

The pandemic has raised public consciousness of dying and emphasised the importance of responding to suffering when recovery may not be possible. It has also created a legacy of grief and bereavement.

The pandemic has also served to highlight pre-existing deficiencies in the way Scotland tackles the challenges of living with serious illness, dying and bereavement:

- Many people who would benefit from an anticipatory care plan were found not to have one.
- Anticipatory care planning and DNACPR are widely unknown, misunderstood and/ or often negatively viewed by the public.
- Clinical decision making intended to avoid burdensome and non-beneficial treatments was sometimes perceived as denying access to life-saving treatment for old people, especially those in care homes.
- Care homes for older people are under-resourced and insufficiently supported by and integrated with health services.

These and other challenges have been met in many instances by unparalleled collaboration, innovation, accelerated adoption of new technologies and rapid progress[xi], which can inform and inspire future work. In Chapter 13 we explore palliative care during the pandemic and make recommendations for future preparedness.

7 b. Demographic Changes

Numbers of people dying will increase …

The next 20 years will see a steady increase in the number of people dying in Scotland each year. By 2040 it is projected that 65,757 people in Scotland will die each year, a 16% increase on 2016. To put this rise in context, by 2040 as many people will die every year as have died during the first 12 months of the COVID-19 pandemic[xii]. It is expected that on average people will die at an older age – including a 59% increase in deaths of people aged 85+, who will account for 45% of all deaths (up from 33% in 2016)[xiii].

… and more people will need palliative care.

Alongside the growth in the numbers of people dying there will be an increase in the numbers of people needing palliative care. By 2040 it is estimated that between 74% and 95% of those who die would benefit from a palliative approach[xiv]. It is projected that 14-20% more people may need palliative care by 2040.

Cancer and dementia will increase as the main underlying causes of death, but even more significant will be an increase in multi-morbidity. The proportion of people dying from multiple chronic progressive diseases spanning difference disease groups will rise by 60%. Such deaths will account for 46% of palliative care deaths by 2040.

More people will live longer with multi-morbidities and uncertain prognosis ...

Since on average people have an extended period of ill health towards the end of life those living with serious illness and multi-morbidity significantly outnumber the number of people who die each year[xv]. There will be uncertainty about how and when their health may deteriorate, and uncertainty as to whether any particular episode of deterioration will lead to death or be followed by an extent of recovery. The numbers of people with multi-morbidity who are in caring roles will also increase.

Making and guiding decisions about clinical care for people with multi-morbidity is difficult because of the uncertainties involved. Medical advances widen the range of possible interventions but without necessarily providing any greater certainty as to outcome. The balancing of possible risks and possible benefits becomes more complicated.

Understanding what matters most to the person should guide decision-making but may be difficult if the person has reduced agency including reduced mental capacity. By 2040 it is estimated that over 115 000 people in Scotland will have dementia – a 74% increase on 2019[xvi].

These changes are already having real effects on how people living with advanced multi-morbidity live their lives.

… affecting people's experiences and requiring changes in the system.

It is important to understand how these demographic changes play out in the experiences of people living with advanced multi-morbidity and how these relate to current service models and practice. A recent study[xvii] found that such people:

> *'…… struggled with multiple changing medications, multiple services better aligned with single conditions such as cancer, and a lack of co-ordination and continuity of care. Family carers spoke of physical, mental and emotional exhaustion and feeling undervalued by professionals. Patients and carers frequently saw deteriorating health as part of 'growing old'. Many used a 'day-to-day' approach to self-management that hindered engagement with advance care planning and open discussions about future care. 'Palliative care' and 'dying soon' were closely related concepts for many patients, carers and professionals, so rarely discussed'.*

There are more babies, children and young people with palliative care needs

The number of children living with a life-shortening condition has increased over time. Complete prevalence[3] has risen from 92 children per 10,000 in 2009/10 to 130 in 2018/19. This equates to 16,742 children across Scotland in 2018/19. Of these 5789 had one or more inpatient stay in hospital during the year. Of those admitted to hospital, approximately

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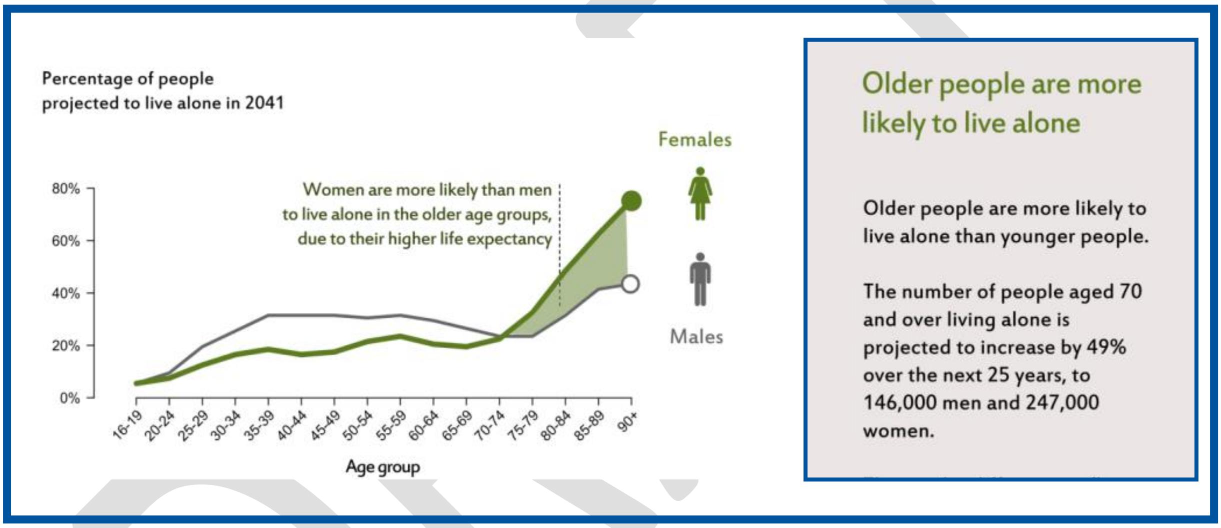
[3] includes any baby, child or young person who has either had an inpatient episode or previously had an inpatient episode relating to a life-shortening condition and have received a community prescribing record within a financial year

40% were unstable, deteriorating or dying. The data shows that 149 children died in 2018/19, 28% of those who died were under 1 year old[xviii].

More people will live alone, with implications for informal care provision and hospital admissions.…

More people will be living alone by 2041[xix]. This is particularly true of older people. This has implications for quality of life and loneliness and also for assumptions made about the availability of informal care. Technology may have a growing role in mitigating the impact of this change. Living alone is a major risk factor for hospital admission towards the end of life.



Older people are more likely to live alone

Older people are more likely to live alone than younger people.

The number of people aged 70 and over living alone is projected to increase by 49% over the next 25 years, to 146,000 men and 247,000 women.

Household Projections for Scotland (2016-based)
National Records of Scotland, July 2018

Data from the most recent census in 2011 shows that 34% of people in the last year of life lived alone[xx] and this is projected to increase. People are more likely to live alone if living in social housing, private rented and/or a deprived neighbourhood[xxi].

7 c. The Economy

Public finances will be under extreme pressure …

Over the next decade the Scottish economy will reflect the legacy of the 2008 global financial crisis[xxii], the net-negative impacts of Brexit and the enormous growing (and uncertain) impacts of the COVID-19 pandemic. Public finances will be under extreme pressure, household budgets will suffer and Independent and Third Sector providers of palliative care will also see pressure on income. In this context there will be a premium on efficient and effective use of resources (in all sectors).

… significant amounts are spent on providing care and support for people approaching the end of life …

A very significant proportion of Scotland's total health and social care expenditure relates to providing care and support for people approaching the end of life. Average costs increase steeply in the last few months of a person's life. For example, 95% of people use unscheduled care services in the last year of life, accounting for £190m of expenditure alone[xxiii]. Based on a recent Scottish study[xxiv] annual secondary care costs for people in the last year of life can be conservatively estimated at £480m.

… creating a strong imperative to make use of interventions that both reduce costs and improve outcomes.

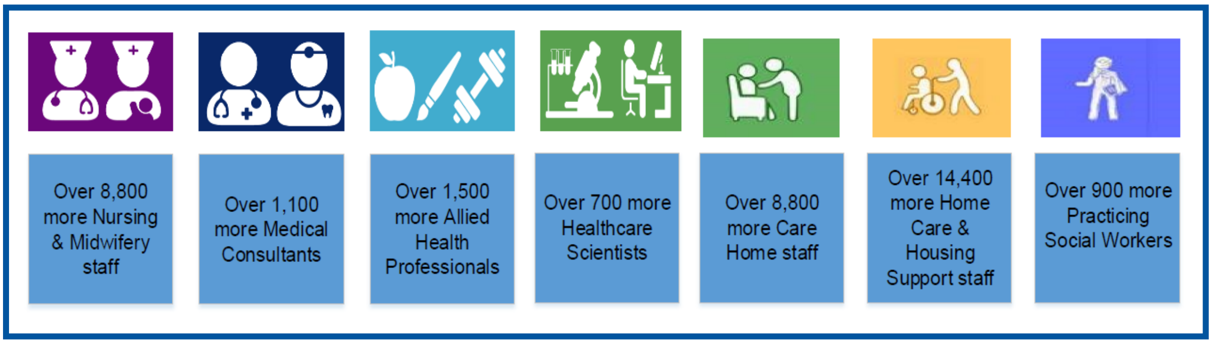
Some interventions in palliative care have potential to both reduce costs and improve outcomes for people. In Chapter 11 this paper explores the health economics of palliative care in more detail.

Workforce

There are difficulties recruiting and retaining an adequate workforce …

A rising need for services, a changing ratio between the working and non-working population, and high levels of imminent retirement amongst key groups such as district nurses, GPs and social care roles are already creating difficulties in recruiting and retaining an adequate workforce in Scotland's health and care workforce. *An Integrated Health and Social Care Workforce Plan for Scotland*[xxv] (Scottish Government/ COSLA 2019) models the increase in numbers of posts in key roles over the next 10 years.

This model assumes a growth of 1.3% per annum more NHS employees and 1.7% per annum more social care staff. These are the increases thought necessary to meet demand for services after mitigating measures such as service redesign, tech enabled care and efficiencies are achieved.



An Integrated Health and Social Care Workforce Plan for Scotland
Scottish Government/ COSLA 2019

This equates to a decade during which workforce limitations may be as important as financial pressures.

In Chapter 12 we look at issues relating to the specialist palliative care workforce and the development of relevant skills amongst the general workforce.

… and a heavy reliance on unpaid carers.

In the context of these workforce pressures further development of community capacity for informal care will become more critical over the next 10 years. Nearly half of adults in Scotland already provide unpaid help (of all kinds) through formal or informal volunteering[xxvi]. Future development will need to encompass better support to carers, a wider involvement of formal volunteers, removing barriers to active citizenry and nurturing community-led action. We explore these approaches in the content of serious illness, dying and bereavement in Chapters 15 and 16.

7 d. Human Rights[4]

Human rights commitments cannot be realised without focused efforts to improve experiences of serious illness, dying and bereavement

Human rights-based approaches have become an increasingly influential and central part of Scotland and Scottish Government’s approach to social justice. Examples include the *Charter of Rights for People with Dementia and their Carers in Scotland,* the *Children and Young People (Scotland) Act 2014* and rights-based *National Health and Care Standards*.

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[4] Sue Ryder and the British Institute for Human Rights have produced a guide explaining the practical application of human rights in palliative and end of life care https://www.sueryder.org/for-healthcare-professionals/education-and-training/human-rights-end of life-care/download

More recently work has taken place to develop a proposal for a second Scottish National Action Plan on Human Rights[xxvii] . The proposal makes explicit reference to palliative care. The First Minister's National Taskforce for Human Rights Leadership has recently proposed a new statutory framework to improve human rights protection for everyone in Scotland[xxviii]. The proposals include incorporating the UN Convention on Economic, Social and Cultural Rights – this convention carries explicit rights to health and implicit rights to palliative care.

It is not credible to commit to realising the fundamental human rights of the people of Scotland without paying further focussed attention to the universal, profound and individual experiences of serious illness, dying and bereavement.

7 e. Potential Changes to the Law on Assisted Suicide

Experiences of deficient care should never influence anyone's decision to shorten their life

Proponents of assisted suicide have committed to the introduction of an enabling Bill to the new Parliament after May 2021.

The Scottish Partnership for Palliative Care's position[5] on the legalisation of assisted suicide, and the reasoning for that position, can be read here[xxix].

Deficient care towards the end of life should never form part of anyone's decision to shorten their life. Palliative and end of life care must therefore be excellent, and evidence must be available to provide public reassurance about the quality of care.

Imperatives for change: End of section conclusion

Taken together the impact of COVID-19, the increased demand for palliative care, economic pressures, the need to remodel workforce, rising expectations of rights to care and the debate around legalisation of assisted suicide highlight the need for a sustained focus on people's

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[5] This position was developed in respect of the draft Bill considered by the Scottish Parliament in 2015.

experiences of living with serious illness, dying and bereavement, including the improvement of palliative and end of life care. Scotland faces and must respond to this major societal challenge.

8. MAKING CHANGE HAPPEN

Horses for courses

To improve people's experiences of living with serious illness, dying and bereavement many different things need to change in different domains. This will require adopting a variety of different approaches.

For example, nurturing neighbourhood networks of informal support may best be achieved through **community development approaches**. Designing and testing improved communication processes between clinical staff might be best approached using **Quality Improvement** methods. Some changes require **innovation** and development of new solutions. In other areas the challenge is to take long-established **well-evidenced solutions** and implement them reliably at greater scale. Policy and practice should underpinned by robust **research** evidence.

Different organisations bring experience and expertise in different approaches, and they also bring other distinctive assets and levers for change.

It takes a nation

As described earlier, the organisation and delivery of palliative care services in Scotland is complex, with multiple delivery agencies, parallel planning processes, and complex lines of accountability.

This means that achieving change will require engagement from a range of stakeholders including: the people of Scotland, community groups, neighbourhoods, faith groups, the funeral industry, Integration Authorities, NHS Boards, Local Authorities, hospices, care homes, care at home, charities, Care Inspectorate, Healthcare Improvement Scotland, NHS 24, Scottish Ambulance Service, NHS Education Scotland, Public Health Scotland, Scottish Social Services Council, Education Scotland, MSPs, local Councillors, local and national media, Audit Scotland, universities, General Medical Council, Nursing and Midwifery Council, medical colleges and others.

Bringing people together

Experience, expertise and energy

We are fortunate in Scotland to have highly skilled and experienced

health and social care professionals with the motivation to work to make improvements in this area. In addition, there are many more people working in communities, in the funeral industry and in other related fields who are also already engaged in attempts to achieve positive change.

Scottish Partnership for Palliative Care

The Scottish Partnership for Palliative Care plays a unique role in Scotland, bringing together a range of organisations, and health and social care professionals from hospitals, social care services, primary care, hospices and other charities, to find ways of improving people's experiences of declining health, death, dying and bereavement.

Its public-facing arm, Good Life, Good Death, Good Grief has made significant progress exploring ways of engaging with wider society and empowering the general public in relation to these issues, for example through the Truacanta Project, To Absent Friends festival and End of Life Aid Skills for Everyone course.

The SPPC and GLGDGG therefore provide valuable vehicles for bringing people together and enabling positive change.

Scottish Government

To achieve change there is a need for the alignment of a complex institutional landscape. Scottish Government is in a unique position to promote such alignment and to convene and support productive collaboration. Government has experience of helping to enable multi-agency working to achieve complex change. Government can mandate leadership at national level and promote protected time for leadership at local level. Where change requires investment Scottish Government has the capacity to help with that too.

CHALLENGES AND OPPORTUNITIES

A range of challenges and opportunities exist in relation to improving people's experiences of living with serious illness, dying and bereavement. The remaining chapters take stock of issues and propose actions for progress. First, we look at cross cutting issues and then look at issues relating to specific settings.

9. LEADERSHIP, PLANNING AND COMMISSIONING

Leadership

The organisation and delivery of palliative care is complex and fragmented. Organisations involved in providing palliative care include general practice, care homes, care at home services, hospices, NHS 24, NHS specialist palliative care units, and both acute and community hospitals. In addition to the NHS substantial parts of palliative care are delivered by the Third Sector, the Independent Sector and local authorities.

Legal responsibility for the strategic commissioning of palliative care lies with Integration Authorities. Within Scottish Government improvement of palliative care is relevant to many different areas of policy and specific workstreams for example: mental health/ dementia, Realistic Medicine, specific clinical priorities (eg heart disease, cancer), carers policy, benefits, What Matters To You, health literacy, public health, social care reform, human rights and older people.

Palliative and end of life care has a key role to play in addressing the quality, safety and resource challenges facing NHS Scotland and Integration Authorities and contributing to national priorities and outcomes. High quality palliative care – delivered in a range of settings - can reduce inappropriate hospital admissions, reduce overtreatment, facilitate discharge, support patients and families in the community, promote person-centred care and shared decision making, and support wellbeing during whatever time remains.

As described earlier this context of multiple delivery agencies, parallel planning processes, and complex lines of accountability can easily lead to a lack of strategic attention on care during this phase of life. Individual and organisational discomfort in contemplating mortality (or an internalised belief that because death is inevitable there is nothing which can be done to improve associated experiences) can sometimes compound this lack of specific focus. Despite being a huge part of what the health and social care system delivers each day palliative and end of life care is often surprisingly invisible in polices, plans, strategies and measurement of outcomes. There is currently no national advisory or oversight group for palliative care. There is no national leadership post for palliative care.

Scottish Government needs to signal more effectively that the care of people approaching the end of life is a national priority. This is a key condition for change and improvement. Government policy and leadership supports culture change.

Planning and Commissioning

Translating strategic aspiration into practical reality requires effective planning and commissioning. At system level there is a need to identify what improved outcomes towards the end of life should look like, and then plan to achieve these explicitly identified outcomes.

Challenges

It should be acknowledged that improved palliative and end of life care presents big challenges to planners and commissioners – in addition to the complex institutional landscape described above palliative care spans all demographics, transcends specific conditions and settings, has outcomes which are difficult to measure and requires effective community engagement. In addition, since most palliative care takes place in general settings, it can be hard to identify a baseline for a significant proportion of the resource use.

Learning from others

There are an increasing number of examples[xxx] of whole-system population-based approaches and guidance[xxxi] whose key features are:

- identification of a defined population and its needs
- identification of current resource use
- development of a 'value framework' which describes important outcomes and how to measure them
- development of trans-organisational networks/partnerships which are responsible and accountable for resource use, and which have a culture of stewardship of all resources within the system
- integration of health, social care, voluntary and community-led support.

Ensuring commissioning processes that support integration and collaboration

People value integrated seamless care, and this requires acknowledging the interdependence of different services, settings (acute, hospice, home, care home, care at home, prison, street/ hostel) and sectors (Independent, Third and Statutory).

Processes should support partnership and collaboration between different sectors (including hospices) and involve local communities. Evidence suggests that the building of trust and relationships is a key factor in strategic commissioning.

Commissioning plans should promote and support collaborative working through: effective e-communications; co-ordinating hubs; shared education (made easier through virtual delivery); regular system-wide reflective case reviews; system-wide service redesign, including up front funds to support changes which offer the prospect of efficiencies or savings aligned with quality improvements; funding models which provide financial sustainability for the leadership and innovation which Third Sector organisations such as hospices can bring.

Alliance commissioning and contracting is one way of encouraging collaborative ways of working.

In other chapters this paper explores the health economics of palliative care, the measurement of quality and outcomes, community engagement and examples (especially during the peak of the pandemic) of enhanced collaborative working and accelerated re-design. There is good work in existence to support and develop system-wide population-based commissioning.

RECOMMENDATIONS

Leadership by Scottish Government

Recommendation SG should signal its renewed and continuing commitment to improving people's experiences of living with serious illness, dying and bereavement by developing a national strategy which takes a whole system public health approach and which has clear aims and lines of accountability.

Recommendation SG should work with the palliative care and bereavement sectors to establish a national steering group which will lead, guide and support improvements in areas set out within this paper and identify areas where a 'once for Scotland' approach can support local change. The group should report regularly on progress to SG ministers and report biennially to the nation.

Recommendation Strengthening the connection between national ambitions and local planning, commissioning and delivery of change, the membership of the national steering group should comprise a range of perspectives, strategic knowledge and practical experience relating to palliative care, end of life care and bereavement, including senior representation from Integration Authorities.

Recommendation SG should create a formal palliative and end of life care national leadership role (or roles). Such a role(s) should ensure clinical/ strategic expertise and credibility to inform and influence SG; a focus on the development and implementation of a national strategy; provide support and connection to local leadership; provide high profile leadership and relationship building to support change across the health and care system.

Recommendation SG should resource the SPPC to provide network functions necessary to support change, together with relevant innovation activity where SPPC is best placed to lead this.

Recommendation Work at national level to develop and implement the strategy should be supported by clearly identified and effective project management.

Local Leadership

Recommendation Palliative and end of life care leadership should be identified at HSCP level, and these leaders should be supported and connected.

Recommendation Ensure national and local work is influenced by the perspectives and experiences of the public by: resourcing the Scottish Palliative Care Research Forum to identify or conduct relevant research; building user representation into national oversight of work proposed in this paper; enabling public involvement in local service design (see also Chapter 10 on Measurement).

Planning and Commissioning

Recommendation SG guidance on strategic commissioning of palliative care should be revised and a clear expectation set that IJBs develop whole system population-based plans and commissioning processes which identify, understand and invest to meet the palliative and end of life care needs of the local population.

Recommendation Planning, commissioning and procurement frameworks should enable the provision of person-centred flexible support.

Recommendation Commissioning processes should promote collaborative working and service integration spanning health, social care (and housing), across statutory, Third and Independent sectors.

Recommendation Commissioning plans should address the specific needs and circumstances of disadvantaged groups including issues around service accessibility and inclusivity.

Recommendation Commissioning processes need to be complemented by financial mechanisms which cover the transitional risks/costs of transformational change and support the reallocation of funds across the system where this delivers better outcomes and better value.

Recommendation Planners and commissioners should be asked what support would be most helpful to them in developing these plans, including, for example, the facilitation of a community of practice.

Research

Recommendation The Scottish Palliative Care Research Forum should be re-established as a mechanism identifying, generating and sharing evidence relevant to improving palliative and end of life care in Scotland.

10. MEASURING OUTCOMES AND QUALITY OF EXPERIENCE

This chapter explores how to improve the measurement of outcomes and quality of experience. Without ways of measuring these it is not possible to fully understand progress or make optimal decisions in terms of resource allocation. Such measures are also needed to inform service design, evaluation and improvement. Such measures have local and national value, including providing reassurance to the public.

Two of the suite of national Integration Indicators[xxxii] refer explicitly to the last 6 months of life. However, one is not informative about quality of experience of care or outcomes, whilst the other is not yet in operation and has been listed as requiring definition since its publication 5 years ago.

Despite the hundreds of thousands of people living with serious illness, dying and being bereaved every year there is currently no data at national level on their outcomes and quality of experience. This gap was recognised by the Health and Sport Committee inquiry in 2015[xxxiii] and by the SFA which stated:

> *"It is not currently possible to describe comprehensively how palliative care is being provided or experienced by those who receive it across Scotland. Measurement and monitoring are not yet embedded in routine clinical processes and practice. This makes it difficult to identify where to focus improvement support or describe the ways in which existing work is making a positive difference to individual and family outcomes."*

This gap has yet to be adequately filled and should be a priority for action. There is a risk of unintended consequences when using process measures as proxy indicators of the quality of care, particularly when allied to measures of cost and expenditure within resource-scarce systems. When the impacts on outcomes and quality of experience are not made visible it is easy to pursue cost savings which have harmful impacts.

Challenges in Measuring Outcomes and Quality of Experience

Measuring outcomes and quality of care towards the end of life is challenging for many reasons.

- **Defining the time period to measure is complex**. Are we looking at care in the last year of life, or the last 6 months, or the last few days and hours? Furthermore, the start of 'the last year of life' or other time periods can't be determined prospectively. People with cancer, organ failure (including neurological conditions), frailty and/or dementia all follow different trajectories of decline. Even if the scope is narrowed to the very end of life it is hard to define when dying 'starts', or to identify that point for a particular individual.
- **What constitutes 'a good death' is very individual and personal**. Therefore, it is a challenge to find one measure or even a suite of measures that meaningfully reflects this at scale. The term 'a good death' is itself problematic since it can be taken to apply the superiority and desirability of a particular approach to death. For example in the UK there is a dominant discourse that a good death is one where the person has engaged in preparation, avoids suffering in all circumstances and is not alone when dying. This narrative may be at odds with the wishes of particular individuals who may feel pressure to conform to values at conflict with their own. A further difficulty with the concept of 'the good death' is that it can create additional pressure for family carers who may strive to achieve an idealised notion of death for their loved one, and potentially suffer feelings of guilt and failure during bereavement should this ideal not be achieved.
- Whilst **'dying well' is important, it is only part of what matters** – emphasis should always be on optimising wellbeing for as long as someone remains alive, whether that turns out to be years, months or hours – a focus on living well, not on dying.   Optimised wellbeing may mean very different things for different people.
- **Proxy indicators have limited value when used in isolation** as they necessarily ignore the complexity and heterogeneity of individual preference and experience.

- **Care takes place within and across multiple formal and informal settings**. This means that indicators and targets based on specific distinct episodes are problematic.
- **Death can happen at any age**. Anyone from neonates, children and young people to centenarians may be nearing the end of life and dying.
- **Many traditional health outcome measures don't apply**. Often, the impact of a service is measured by looking at how it has improved the health or longevity of the population it serves. However, the population being considered here are experiencing a decline in their physical health, so traditional outcome measures such as 'survival' are not applicable.
- **Patient and family-reported outcomes may not always be possible**. People who are very ill, and families who are in distress may not be in a position to provide feedback on their experiences of care. (However, there is evidence that people want to provide feedback and that formal services can be overly protective in this regard).
- **Interaction of multiple factors and importance of context**. Care towards the end of life typically involves people in multiple interactions with services. The efficacy and quality of those interactions will also be influenced by contextual factors such as income, employment status, household structure, social networks, knowledge of and attitudes towards end of life issues.
- **Death can be traumatic even when optimal care is provided**. Even with the best possible care, the last weeks and days of someone's life can be complicated, difficult and upsetting. A bad experience may not be indicative of bad care.

Making better use of what we have

Though there are numerous challenges, there is also much work underway that can be built on or learnt from, and tools and methods already exist that can be used to improve measurement of outcomes and experiences towards the end of life.

Use of Existing Routinely Collected Data Sources

There has been significant investment in data linkage and analysis generally to support IJBs in their strategic commissioning roles. The provision of analyst resource as part of the SFA has supported some palliative care specific outputs, mostly of a pilot nature[xxxiv]. The SOURCE programme has seen some linkage of health and social care data sets, and this continues to evolve.

Using 'process mining' methods it is now possible to visualise people's interactions with, or pathways through, health and care services towards the end of life [xxxv]. This can be done from individual up to population level over different timeframes. A recent innovative study used this approach to explore how people choose initially to access out of hours service and the relationship with subsequent service use[xxxvi].

The Key Information Summary is another source of valuable information which has been used to generate insights around patient identification and anticipatory care planning[xxxvii] in primary care. A recent local study has demonstrated how KIS data can be used to better understand service responses to people with palliative needs[xxxviii] using sub-analysis of specific fields and dates of completion. This data, together with data about when the KIS is accessed in different settings can help to characterise what is going on within the system and should prompt further inquiry. The strength of KIS data lies in the contribution it can make to describing and informing an understanding of how the local system is operating.

As part of the Palliative Care Directed Enhanced Service[xxxix] GPs are funded to place patients identified as having palliative needs on a register. A KIS is then created for each patient. GPs are also resourced to undertake reflective practice based on Significant Event Analysis relating to a sample of deaths in each practice.

All of these sources are available locally and scalable to national level.

Local Approaches

There are many examples of different approaches being used locally to measure the quality of palliative and end of life care which we describe briefly below.

A wide range of **local data analyses** are feasible via the LIST resource available at each Health and Social Care Partnership. These can be useful for describing and understanding pathways and patterns of service use.

Data from complaints – review of individual complaints and thematic review are both useful approaches (both locally and nationally). A sudden change in the number or type of complaints may prompt focussed attention. **Patient Opinion** is another source of feedback.7858

The **Outcomes Assessment Complexity Collaborative (OACC)**[xl] has collated a suite of fit-for-purpose measures of both outcomes and quality of care designed to capture and demonstrate the difference that palliative care services make to patients and families receiving their care. Each of the components of the suite can be used independently. It is in use in at least 3 services in Scotland.

Systems for **real time patient and family feedback** are in use in some specialist palliative care settings. **The Integrated Palliative Outcome Scale (IPOS)**[xli] is a patient or proxy reported outcome measure which can be used at individual and organisational level, within and between settings.

Case note reviews and **significant event reviews** are in use and can be a rich source of learning for improvement.

Surveys of Bereaved Relatives

The VOICES survey which has been used in England, the NACEL Quality Survey and the Lothian project to pilot a form of VOICES are all examples of surveys of informal carers who have been bereaved. The advantages of such an approach are:

- Such a survey can generate findings on the quality of patient and carer experiences and outcomes, rather than measuring processes which are not adequate proxies for quality.
- Such a survey can cover a wide range of issues which patients, carers and the public say are important to them, and response rates can be good.
- Findings from such a survey can support a specific focus at national level on palliative and end of life care, providing public assurance and encouraging professional and public engagement on these issues.
- If centrally administered the survey allows a consistent nationwide approach with zero measurement burden for frontline staff.
- Such a survey is capable of repetition at different time points.
- With appropriate sample sizes such a survey can also be used at local level to provide data specific to local services. It would be possible to explore local variants to provide more rapid feedback.

The VOICES surveys, which was developed in collaboration with bereaved relatives and patients, have been in operation for years, so there is a body of methodological experience to build on[6].

A further model which might be drawn on is the end of life experience survey conducted as part of the Irish Longitudinal Study of Aging[xlii].

Scottish Government already runs the Scottish Care Experience Programme[xliii] which has relevant experience and expertise. Data from surveys within this programme is used to understand progress against some of the existing suite of Integration Indicators. The programme has expertise in identifying family members of people who have died since it is part of the methodology of the existing surveys to exclude these people[xliv]. There is potential to combine the expertise and approaches mentioned to develop a bespoke approach for Scotland.

RECOMMENDATIONS

There is no perfect or simple solution to measuring outcomes and quality of experience. However, there is very considerable scope for improving the current situation through a mixture of local and national action. This can be done by triangulating data from different sources. There is potential to make better use of existing sources of routinely collected data. This should be complemented by the collection of data directly from people and their families via new sources – we *need to ask not just 'What Matters to You?' but also establish 'How was/ is it for You?'.*

Governance and Management

Recommendation A Palliative Care Outcomes Data Group with a clear terms of reference should be established to oversee the development, review and publication of the measures and approaches proposed below. Part of the responsibility of this group should be to work with HSPCs to agree a limited common set of locally useful measures which are also capable of being scaled up to give a national picture.

NES Digital Service

Recommendation During the development of products such as ReSPECT and digital ACP the NES Digital Service[xlv] should ensure that

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[6] There are information governance issues which prevent straight forward replication of the VOICES approach in Scotland.

routinely gathered data can be used to inform understanding about people's experiences and outcomes.

Develop and Introduce a Scottish National Survey of Bereaved Informal Carers

Recommendation Scotland should develop a national survey of bereaved informal carers. This would encompass both their experiences as carers but also their views (as proxies) on the experiences of the person they cared for.

Local Data Development

Recommendation IJBs should be expected and supported to develop and use a suite of the local measurement approaches described above.

Recommendation Local Information and Support Team (LIST) analyst time should be allocated to support HSCPs to understand the local mortality landscape for their population. This should include both quantitative and qualitative characterisation based on measures in this paper.

Recommendation A central 'library' of locally developed LIST analyses to share learning about approaches should be developed.

Morbidity and Mortality Meetings[xlvi]

Recommendation Quality of death should be a part of every morbidity and mortality review meeting.

Coding

Recommendation A national approach to the coding of complaints should be developed so that instances relating to palliative and end of life care are readily accessible.

Recommendation There should be exploration of the systematic use of clinical codes to analyse the care of people who have been identified as expected to die and where their goals of care relate to palliative care.

External Assurance

Recommendation A national framework should be developed to establish and assure the quality of palliative and end of life care provided in Scotland.

Recommendation A thematic review of the provision of palliative and end of life care should be undertaken jointly by the Care Inspectorate and Healthcare Improvement Scotland.

Recommendation Since two Scottish Government action plans have passed since Audit Scotland published *A Review of Palliative Care Service in Scotland* (2006) [xlvii], and because palliative care represents a significant proportion of health and care expenditure, a follow-up review should be undertaken.

Recommendation A thematic review of complaints relating to end of life should be undertaken by the Public Service Ombudsman.

11. HEALTH ECONOMICS AND PALLIATIVE CARE: ALIGNING EXPENDITURE AND VALUE TOWARDS THE END OF LIFE

Introduction

Understanding and improving the cost effectiveness of expenditure towards the end of life should be a key concern for government and the health and social care system in Scotland because:

- Each year over 50,000 people, and their friends and family, are affected by the quality and accessibility of services provided towards the end of life and the outcomes achieved. The numbers of people affected by a bereavement each year in Scotland around 500,000[xlviii].
- A very significant proportion of Scotland's total health and social care expenditure relates to providing care and support for people approaching the end of life. Average costs increase steeply in the last few months of a person's life. For example, 95% of people use unscheduled care services in the last year of life, accounting for £190m of expenditure alone[xlix]. Based on a recent Scottish study annual secondary care costs for people in the last year of life can be conservatively estimated at £480m[l].

Many of these unscheduled episodes are avoidable with appropriate supportive and anticipatory care. Many of the poor outcomes experienced by people near end of life are also potentially modifiable: eg unmanaged pain, depression, falls. There is therefore vast potential to improve outcomes in end of life care, and improvements are usually cost-saving if they reduce inappropriate hospital admissions or unwanted high-intensity care.

Previous Policy Commitments

The SG *Strategic Framework for Action on Palliative and End of Life Care* recognised the importance of this area and made a commitment to 'support clinical and health economic evaluations of palliative and end of life care models' but little if any health economic evaluation has taken place as a consequence of the SFA. The suite of indicators against which Integration Authorities report includes an indicator relating to *'Expenditure on end of life care'* but this remains *'under development'* 5 years after publication and data of this sort is not routinely available.

There therefore remains unexplored potential for both improving outcomes and reducing costs.

Financial cost of providing care towards the end of life

On average as people approach the end of their lives the health and care system spends more money on providing care and support. Expenditure usually increases within the last year of life, and within that last year expenditure tends to rise rapidly in the last 3 months. The main driver of increased costs is increased rates of hospital admission towards the end of life. Although average costs rise steeply within the last year of life some studies suggest that the bulk of expenditure relates to care and support of people with chronic conditions in the 3 years prior to their death[li].

Most studies tend to emphasise healthcare expenditure because social care costs are less easily identified. Costs of informal care, largely borne by family and community members (disproportionately by women), are also significant but are seldom captured despite accounting for around 50% of total costs[lii].

Evaluating the Cost Effectiveness of Palliative Care

Palliative care is not a single intervention. People (of different ages, circumstances, diagnoses) typically experience a wide range of different 'interventions' and services delivered in different settings in the last years, months and days of life. Evaluating the cost effectiveness of these interventions and particular service models is challenging for many reasons:

- Most health economic evaluation focusses on health gain or extension of life. As described in preceding paragraphs measuring outcomes that really matter to people who are approaching the end of life is difficult; the context is uncertainty, deterioration, individual adaptation and maximising quality of life/ wellbeing in evolving circumstances.
- There is often not a simple distinction or choice between treating underlying disease and focusing on wellbeing/ comfort, and in some cases focussing on wellbeing can result in extension of life.
- People approaching the end of life often value things which require subjective assessment (dignity, sense of control, emotional wellbeing, being with the right people, human connection with health and care staff) yet systematic subjective assessment may feel intrusive and raise ethical issues.
- More easily captured proxy outcomes such as place of death are not reliable measures of what really matters to people or of quality of care or experience.
- People's preferences change over time. For example people's preferred place of care often changes as their circumstances and experiences unfold.
- Most people really value the reassurance of speedy access to support if needed, and smooth co-ordination and transition between different services/ settings. The quality of process itself is therefore an important 'outcome'. Measuring outcomes relating to discrete episodes will miss much of what matters to people.
- Similarly most people approaching the end of life have multiple conditions and complex needs so outcomes relating to single conditions are less relevant. In the context of multi-morbidity it is not appropriate to simply focus on treating each individual condition to maximum effect – the best combination of management of the different conditions recognises that there may be trade-offs.
- Carer perspectives can be a useful proxy, but carers and the people they care for may have different priorities and preferences.
- Changes in expenditure in one area may impact on expenditure in another though causality can be difficult to establish within complex systems[liii].

Evidence on the Cost Effectiveness of Investment in Palliative Care

In 2017 Public Health England (PHE) published an extensive review of evidence (both UK and international) on the cost effectiveness of palliative and end of life care[liv]. The review identified many methodological limitations in the studies reviewed which relate to the complexities described in the preceding section. The very low levels of funding for research on palliative care results in relatively few studies of high quality. However, these caveats notwithstanding the review concluded:

> *"where authors have done an economic analysis, the evidence seem to suggest that the existing breadth of palliative and end of life care interventions in the primary, social and community care settings are potentially cost-saving or cost-effective."*

There have been a number of relevant health economic evaluations in Scotland. In Fife work funded by Macmillan Cancer Support saw the development and establishment of a new '*Best Supportive Care*' model for people with incurable lung cancer demonstrated significant cost savings[lv]. The model was further extended to people with different cancers and also renal disease and was well received by people and their families. At least 2 hospices in Scotland have commissioned health economic evaluations of their services which demonstrate a very positive return on investment by statutory funders[lvi]. Pilot studies in Lothian[lvii], Lanarkshire[lviii] and Highland[lix] have shown reduced resource use as a result of anticipatory care planning in care homes and other settings.

It is not possible to produce a definitive list of candidate interventions for more effective investment – detail, local circumstances and the development of specific interventions are key. However, areas of activity where there is evidence suggestive of potential to improve outcomes whilst reducing costs include, but are not limited to:

- improving end of life care in care homes[lx]
- early specialist palliative care assessment/ involvement in acute hospitals[lxi] [lxii]
- improving rapid and easy access to palliative care in primary care and the community, including 'hospice at home'[lxiii]

- nurse-led phone/video support service for people in the last year of life[lxiv]
- earlier and ongoing anticipatory care planning[lxv]
- early integration of specialist palliative care in community settings[lxvi]
- public education and awareness.[lxvii]

Implementing Change

The rapid changes in service provision and place of death in response to COVID have demonstrated that radical change is possible (albeit that some changes may have led to worse outcomes for some people and some positive changes may turn out to be unsustainable).

Progress is being made in Scotland linking healthcare and social care costs to individual service use. This data can be aggregated to inform local decision making and commissioning at the level of Integration Authorities.

As highlighted in Chapter 10 there is a need to develop and apply better measures of quality and care experience in order to inform decisions on the best use of resources, ensuring that costs can be understood in the context of outcomes which are important to people.

A key barrier to more cost-effective investment is the need to redesign pathways across complex systems. The savings and/or improvements in outcomes resulting from investment in one part of the system may accrue to a different part of the system which can result in inertia.

RECOMMENDATIONS

Recommendation Commissioning processes should incentivise and support cross-system collaboration and endeavour to take a system-wide perspective of what constitutes better value.

Recommendation To enable shifts in ways of working which deliver better value there should be funding for the additional costs of implementing change. Given the uncertainties involved in complex system-wide change consideration should be given to more innovative funding models to unlock change such as revolving funds, social impact bonds or the central underwriting of risks.

Recommendation There should be investment in research capacity to strengthen the evidence base on cost effective expenditure towards the end of life. Developing this research capacity should be done alongside the development of new services.

Recommendation To promote spread redesigned pathways and new funding models should be subjected to health economic evaluation and where the model or programme offers good value then it, or its most successful components, should be implemented more widely in strong expectation of improving value in end of life care.

12. SPECIALIST WORKFORCE AND EDUCATION OF GENERALISTS

Introduction

Most palliative care is provided by non-specialist health and social care staff working in primary and community care, care homes and hospital wards. As highlighted in Chapter 7 a rising need for services, a changing ratio between the working and non-working population, and high levels of imminent retirement amongst key generalist groups such as district nurses, GPs and social care roles are already creating difficulties in recruiting and retaining an adequate workforce in Scotland's health and care system. Tackling these wider workforce challenges is essential for the provision of palliative care, and we acknowledge and support measures led by SG and others[lxviii].

This chapter looks more specifically at the specialist palliative care workforce, and at palliative care education and training for general staff. What needs to be done in order to ensure a workforce which is adequate to meet growing need for palliative care?

More workforce issues relating to specific settings are covered in Chapters 19-23.

Specialist Palliative Care Workforce

Specialist palliative care is delivered by highly qualified specialist multi-disciplinary teams. Ideally therefore workforce analysis and planning should be based on teams. The Scottish *Clinical Standards*[lxix] *for Specialist Palliative Care* described the essential and desirable composition of specialist palliative care teams in different settings. In this section we focus on the specialist medical and nursing workforce (as the two largest groups), whilst recognising that specialist chaplains, occupational therapists, pharmacists, physiotherapists and social workers should also be members of the core team.

As described elsewhere demographic change will see an increase in the scale and complexity for palliative care over the next 20 years. The specialist palliative care workforce will see increased demand for direct care and treatment. It will also see an increased need for advice, education and support for generalist colleagues. Designing and delivering many of the changes proposed in this paper will also require leadership and other input from specialist practitioners.

Palliative Medicine Workforce

The Association for Palliative Medicine (APM) reported 39.7 WTE consultant posts in Scotland in 2018[lxx]. NHS Scotland counted 34.8 WTE consultants[lxxi] at December 2018, rising to 35.7 by December 2020. The APM calculated that of the 4 UK nations Scotland has the fewest consultants per head of population (though with considerable variation within Scotland). As a specialty palliative medicine has a particularly high proportion of females (71%) and part time workers (69%). The APM estimates that around of third of consultants will retire during the next 10 years.

Training in palliative medicine

Major changes are underway in the training routes in palliative medicine. In future palliative medicine consultants will be need to have completed college exams in medicine (previously postgrad qualifications in general practice, surgery and anaesthetics were also options). From 2022, with the implementation of *Shape of Training*[lxxii], dual accreditation (internal medicine and palliative medicine) will be mandatory. Dual accreditation will offer more opportunities to work collaboratively with colleagues in acute internal medicine, a shared understanding of each other's roles, the opportunity to influence care at the front door of the hospital, better understanding of the changing context of acute internal medicine and the treatments available to patients and an understanding of hospital medicine in order to support better decision making in the community. The new system means palliative medicine trainees spend a year (out of 4 years in total) doing internal medicine. The changes in the curriculum and routes into the speciality have a number of practical implications which are currently still being worked through: potentially reduced speciality trainees in community (hospice settings); potential need for additional resource in community settings to provide supervision of increased numbers of internal medicine trainees rotating through.

Specialist Palliative Nursing Workforce

A recent census by Macmillan Cancer Support[lxxiii] describes the palliative care specialist nursing workforce (excluding non-NHS posts, leadership roles, and those based in primary care or hospices). The census identifies 130 WTE specialist palliative care nurse specialists. 60% work full time and 95% are female. The age profile is concerning – 74% are aged over 40 and 39% over 50. The posts have low vacancy rates.

Planning the specialist workforce

To inform medical manpower planning it is important to define a minimum requirement in relation to population and in relation to core service elements within different settings. In 2012 the APM, Marie Curie, National Council for Palliative Care, Consultant Nurse in Palliative Care Reference Group and the Royal Society of Medicine produced commissioning guidance which identified specific requirements for different staff groups[lxxiv]. These requirements should be updated in the light of demographic and other changes.

Education and Training for Generalists

One output of the SG SFA was a framework for learning and development which identified levels of skills and knowledge which can be mapped to different roles across the health and care system[lxxv]. Non-specialists need training and education to equip them to provide generalist palliative care.

Medical, nursing, social care and other staff often report difficulty, discomfort and a need for more preparation for dealing with palliative and end of life care[lxxvi] [lxxvii] [lxxviii]. Just under half of new medical graduates surveyed reported they hadn't received any training or advice on end of life care when they first had contact with a patient receiving end of life care[lxxix]. Equipping staff adequately to deal with death, dying and bereavement is not a *"nice to have"* extra to be approached in a haphazard and ineffective way. A lack of training is harmful to staff welfare (and a sustainable workforce) and harmful to people and their families when they most need competent, compassionate support.

Undergraduate Education

Continuing Professional Development

For continuing professional development, there are excellent and relevant education resources in Scotland (EC4H[lxxx], SAGE & Thyme[lxxxi], Macmillan

Cancer Support Manual: *Enhanced Palliative Care for Generalists*[lxxxii], Marie Curie Knowledge Zone[lxxxiii], NHS Education Scotland *Support Around Death*[lxxxiv], Scottish Palliative Care Guidelines[lxxxv] etc).

Online teaching and learning is growing and new resources are being developed by the Royal Colleges and NHS Education for Scotland[lxxxvi] [lxxxvii] [lxxxviii]. However, many core competencies in palliative care require communication and relationship abilities best developed through experiential teaching and learning and observation.

As well as formal structured training other approaches to role development should be available. One example in primary care is the First5 project which could be expanded[lxxxix].

A key challenge is ensuring that staff have access to adequate training in the context of other time pressures. This is easier in organisations with an explicit focus on improving palliative and end of life care and where staffing issues are addressed.

RECOMMENDATIONS

Workforce Planning

Recommendation An up to date national workforce plan should be developed to ensure an adequate supply of specialist palliative care staff to meet anticipated demand over the next decade.

Recommendation To support development of the workforce plan data on the specialist palliative care workforce should be updated and improved.

Recommendation To support local planning and commissioning indicative staffing levels for different specialist palliative care staff groups in relation to the local population size, service specifications, and within specific settings should be developed, taking account of the differing circumstances in remote and rural areas.

Recommendation As part of local planning and commissioning processes the NES Framework should be used to assess training needs across the health cand social care workforce.

Recommendation Commissioning of palliative and end of life care should include education and training activities across the health and social care workforce.

Undergraduate Education

Recommendation There should be an increased amount of time devoted to palliative care as part of undergraduate medical, nursing, AHP and social work training[xc].

Recommendation Undergraduate education should be broadened to include death and dying, bereavement and spiritual care[xci], covering different conditions, settings and demographics, utilising a shared curriculum, resources and learning experience across all disciplines.

Recommendation Additional Commitment to Teach (ACT) funding should be targeted to support medical education for students and to increase teaching capacity of future doctors, which has been highlighted as a priority for the long term.

Continuing Professional Development

Recommendation All generalist health and care roles should be mapped to the NES palliative care education framework, and postholders enabled to access sufficient relevant training to equip them for this part of their work.

Recommendation There is scope to further develop use of virtual training/education. The ECHO approach to supporting shared learning amongst generalists, which has been led and spread by Highland Hospice, could be further expanded.

Recommendation Training should be available to people in non-clinical roles such as cleaners, porters and clerical staff since they often interact with people and their families towards the end of life.

Recommendation Given the scale and importance palliative and end of life care within the health and care system, senior management and board members should have the opportunity to attend bespoke training on serious illness, dying and bereavement.

13. COVID-19 AND PALLIATIVE CARE

Introduction

The role of palliative care within a pandemic is to address suffering in all settings both for those who are dying and for those receiving disease modifying intervention[7].

As the threat of a COVID-19 global pandemic emerged and then struck Scotland high profile attention was paid to public health measures to prevent infection, reduce transmission, and to develop hospital and community capacity to deliver care and treatment to prevent death wherever possible. The wide range of measures put in place to reduce suffering understandably attracted less attention.

This chapter briefly outlines challenges presented by COVID-19 in relation to palliative and end of life care, identifies measures developed to meet the need for palliative care and makes recommendations about palliative care in relation to the current pandemic and future pandemics.

Challenges

Limited Knowledge Base

Prior to the first wave of the pandemic there was little published evidence about the trajectories of decline and symptoms to be expected amongst people dying with COVID-19. There was also limited evidence about how to adapt existing strategies for managing symptoms such as breathlessness amongst people with COVID-19.

Sudden Increased Need for Palliative and End of Life Care

By 28[6] March 2021 there had been 9,958 deaths registered in Scotland where COVID-19 was mentioned on the death certificate. During the

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[7] Amongst other sources this chapter draws on presentations from a meeting of the Scottish Parliament Cross Party Group on Palliative Care (August 2020) https://www.palliativecarescotland.org.uk/content/cross-party-group---26-aug-2020/

calendar year 2020 there were 6,324 excess deaths, 11% higher than the five-year average[xcii].

Procurement and Supply Chains

The infectious nature of COVID-19 and the sudden increase in dying led to concerns and difficulties relating to the availability of PPE, equipment and medicines for palliative care.

Rapid Change in Place of Death

There has been a major shift in the place of death. From the beginning of 2020 until mid-March 2021 the total number of all deaths at home increased by 36% compared to the average number of people who died at home in the equivalent period in 2015-2019[xciii]. The vast majority of these deaths at home (especially out with the COVID-19 waves) were from causes other than COVID-19. There was also an increase in the complexity of needs of people dying at home creating challenges for GPs, district nurses and other community staff[xciv].

Loss of Human Contact

Measures to control infection have had a huge impact on the experiences of dying people and their loved ones, and on the provision of end of life care. Visitor restrictions meant many people died without desired contact with loved ones. Staff's ability to connect and communicate with dying people they are caring for has been made much more difficult by masks, visors and restrictions on touch. Families (and some staff) have experienced bereavement in traumatic circumstances, at a time when funerals and other usual sources of solace such as the support of friends, family and community have been restricted. Many individuals experienced multiple losses.

Staff Wellbeing

Caring for people who are dying can often be psychologically, spiritually and emotionally challenging. During the pandemic these challenges have been compounded by specific circumstances: dying has tended to be concentrated temporally during the waves of the pandemic; much dying with COVID has been concentrated within the care home sector where many staff experienced, at least initially, inadequate support from the wider healthcare system; some staff who previously had little experience of end of life care have been deployed in areas with high levels of dying;

enforcing restrictions on visiting towards end of life can be traumatic for staff, as can facilitating final goodbyes via phone or video; relentless periods of intense and distressing work, when staff are already deeply fatigued; staff have had to deal with concern and fear about becoming infected and also infecting their own loved ones; usual coping strategies have been limited by restrictions on aspects such as social contacts and holidays.

Existing Weaknesses

In addition to the challenges identified above which are specific to COVID-19 the pandemic has highlighted pre-existing weakness. Key deficiencies have included:

- Many people who would benefit from an anticipatory care plan were found not to have one.
- Anticipatory care planning and DNACPR are widely unknown, misunderstood and/ or often negatively viewed by the public.
- Clinical decision making intended to avoid burdensome and non-beneficial treatments are sometimes perceived as denying access to life-saving treatment for old people, especially those in care homes.
- Care homes for older people are under-resourced and insufficiently supported by and integrated with health services.

Measures to meet the need for palliative and end of life care during the pandemic

A number of developments helped to build and spread capacity to provide palliative care and end of life care:

Guidance, Information and Education[8]

- the rapid development of two national COVID-specific clinical guidelines; *Guidance for when a person is imminently dying from COVID-19 lung disease*; and *Guidance for supporting end of life care when alternatives to medication normally given through syringe pumps are required*
- practical resources for professionals (and carers) administering medication

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[8] Many of the resources mentioned in this section (and not otherwise referenced) can be found on the Scottish Palliative Care Guidelines website https://www.palliativecareguidelines.scot.nhs.uk/covid-19-guidance.aspx

- *COVID-19:palliative care toolkit*[xcv] - a resource for health board planners aiming to identify key risks and ensure continuing access to and delivery of palliative care medicines
- local frameworks and guidelines
- guidance for GPs on rapid anticipatory care planning
- guidance on visiting in hospitals and care homes which addressed 'end of life' situations
- palliative and end of life care components of the Chief Medical Officer's national *COVID-19: Clinical Advice*[xcvi] and other guidance
- resources to support effective communication with people and their families about anticipatory care planning including DNACPR
- comprehensive public facing information specifically for people and/ or their loved ones at increased risk of getting seriously ill and potentially dying from COVID-19[xcvii]
- palliative care education for staff unaccustomed to or needing more help dealing with mortality[xcviii]
- online education module for informal carers[xcix].

Reconfiguration of Resources and Services

Specialist palliative care services and practitioners had a key role in change, usually in collaborative partnership with other parts of the health and care system[c]. This included a wide range of rapid clinical innovation by voluntary hospices[ci]. Changes which took place included:

- new community-based models (community teams, hospice at home, rapid response services)
- establishment of Hubs to support inter-agency & MDT communication and collaboration, and to provide information and support to people and their families
- redeployment/ refocussing of specialist palliative care staff from hospices and NHS specialist units to support care in other settings (acute hospital, care homes and community)
- provision of inpatient end of life care services for people dying of COVID-19 within hospices and NHS Specialist Palliative Care Units
- establishment of virtual services (day services, outpatients, consultations, bereavement support, virtual ward rounds)
- repurposing of buildings
- development/ extension of staff welfare services
- establishment of 24/7 easy access single points of access
- establishment of rapid response integrated teams.

Other Responses

- informal national leadership and co-ordination by the CMO's Palliative Medicine Specialty Advisor, with high levels of collaboration and mutual support amongst stakeholders
- use of ECHO and other approaches to virtual learning
- rapid establishment by SPPC of multiple virtual national networks which underpinned much collaboration, flow of intelligence and mutual support within and between settings, including linkage with Scottish Government
- leadership of and participation in research projects seeking to understand COVID-19 and palliative care
- rapid dissemination of guidance, research and resources.

RECOMMENDATIONS

Recommendation The scope of any future inquiry or reviews into the COVID-19 pandemic should include palliative and end of life care so that lessons about what went well and what might be improved are not missed.

Recommendation Palliative care should be included and fully integrated into planning for future pandemics.

Recommendation Plans to support the post-pandemic recovery of health and care services should reflect: increased need for bereavement support; increased need for palliative care following late presentation/diagnosis of serious illness.

Recommendation Further research should be commissioned to fully understand the increase in people dying at home during the pandemic. This should include exploration of the preferences and experiences of people and their families; the experiences of health and social care professionals; service responses and sustainability.

Recommendation People who have bereaved during the pandemic should get the bereavement support which is right for them. In chapter 18 we make detailed recommendations about how this can happen.

Recommendation Services to support staff experiencing burnout and trauma should be adequately resourced and sustained for as long as needed.

Recommendation Where service innovations which took place in response to COVID-19 are evaluated positively (eg rapid adoption of remote consultation, greater integration and collaborative working between primary care, social care, secondary care and hospices) planners and commissioners should seek to ensure that these are resourced on a sustainable basis and embedded as business as usual.

In addition to these specific recommendations the full suite of recommendations in this report will improve palliative and end of life care in Scotland, which is a key part of preparedness for a future pandemic.

14. INEQUALITIES

Introduction

In Scotland people's access to services, experiences of care and outcomes at the end of life are unequal. These inequalities must be understood and addressed if people's rights to care and support at the end of life are to be realised and their well-being maximised. This chapter looks briefly at what is known about some of the different circumstances and individual characteristics which disadvantage people and makes recommendations for action. It is important to remember that people can be disadvantaged in multiple ways at the same time. Whilst an improved understanding of the needs and experiences of specific groups is important, each person is an individual and within groups there will be heterogeneity.

The Equalities Impact Assessment undertaken by Scottish Government at the time of the publication of the SFA stated that *'There is a need for more data on all the protected characteristics groups and their use of and need for palliative care'*. Identifying, describing and understanding inequalities towards the end of life is a prerequisite for improving the situation, yet there remains a scarcity of good research and data analysis in Scotland or at UK level.

Socio economic deprivation

Scottish Government's latest report on the Long Term Monitoring of Health Inequalities[cii] showed premature mortality rates are four times higher in deprived areas. Deaths from COVID-19 are higher in areas of socio-economic deprivation. Whilst not all people dying prematurely will have palliative care needs, levels of multimorbidity increase with deprivation, and multimorbidity and palliative care need are closely linked[ciii].

People living in deprived areas have different patterns of service use/ access. They are less likely to access specialist palliative care, they are more likely to spend time in hospital towards during the last 3 months of life[9] [civ], more likely to die in hospital and less likely to die at home or in a hospice. Even when people living in deprived areas access specialist palliative care they are less likely to die in a hospice and more likely to die

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[9] However in Scotland during 2019-20 there was little difference in % of time spent out with hospital in the *last 6 months* of life between most deprived (88.9%) and least deprived (88.8%) quintiles.

in a hospital than those from affluent areas[cv]. People from the most deprived areas are less likely to report that they received sufficient support from health and social services to care for someone at home[cvi].

The Ritchie Report on Out of Hours (SG 2015)[cvii] highlights how primary care resources are maldistributed by health care needs, according to socio-economic status and the fact that levels of multimorbidity increase with increasing deprivation.

The impact of type of housing, material environment, and poverty on end of life experiences are not well understood. The *Dying in the Margins* project is exploring these issues in deprived communities in urban and rural areas in Scotland[cviii].

Gender

The experiences of different genders towards the end of life vary significantly. Women experience more years of ill health, report more pain, more fatigue, are less likely to die at home and provide more informal care than men. Women are less likely to express a preference for life extending treatments at end of life with this choice often seemingly linked to fears of being a burden. Research, policy and practice are heavily influenced by gendered assumptions, for example what may be expected of men and women as care givers[cix]. The inequalities experienced by women are so frequently viewed as objective norms that they are not considered as topics for research or as being relevant to the formulation of policy and practice. That the explicit and implicit policy emphasis on increasing dying at home is not accompanied by analysis of the impact on women as primary care givers is a good example of this blind spot. Similarly most economic analyses of palliative care fail to capture informal care costs which fall disproportionately on women (who are proportionately poorer in the first place, and who have been disproportionately impacted by a decade of austerity[cx]).

Gender stereotypes also impact negatively on men. Men are less likely to report stress, anxiety, depression and other emotional concerns, which probably reflects gender norms rather than levels of distress.

The experiences of trans men, trans women and people with non-binary gender identities towards the end of life are not well understood and not always considered in policy or needs accommodated in practice.

LGBTQ+[10]

LGBTQ+ people can feel anxious using health and social care services because of past discrimination, and this can lead people to delay or avoid accessing services. In turn this can increase pressure on LGBTQ+ carers who may be left isolated and unsupported. LGBTQ+ people approaching the end of life are often rightly worried that because of staff prejudice or unconscious bias their life partner may not be properly recognised as important and may be less included and supported both before and after death. Heteronormative assumptions by health and social care staff can make it hard for LGBTQ+ people to disclose their identity. LGBTQ+ people may experience greater isolation during bereavement and disenfranchised grief.

Ethnic Minorities

Census data shows that the number and proportion of older people from ethnic minorities is set to increase rapidly and the need for palliative and end of life care in these groups will increase. In England there is some evidence that to compared to White British people other ethnic minorities have less access to specialist palliative care services. Explanations for this include lack of referrals; lack of awareness of relevant services; previous bad experiences when accessing care; a lack of information in relevant languages or formats and family/ religious values conflicting with the idea of hospice care. A study of the Scottish population dying of cancer found that rates of hospital death were similar regardless of ethnic group[cxi]. Analysis[cxii] of the VOICES survey[11] in England found *'that people from BAME backgrounds were less likely to consider overall care in the last three months of life to be 'outstanding' or 'excellent'. They were also much less likely than people of White ethnicity to experience 'excellent' care (there is no 'outstanding category' for individual services) from care homes.'* The Prince and Princess of Wales Hospice in Glasgow is an example of a specialist palliative care service which has taken steps to improve its understanding of and services to the multicultural communities in its catchment[cxiii].

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[10] LGBTQ+ stands for lesbian, gay, bisexual, transgender and queer (or questioning) and others.

[11] VOICES is a national survey which collects information on bereaved people's views on the quality of care provided to a friend or relative in the last 3 months of life, for England.

Diagnosis

The type of condition someone has significantly influences where they are cared for, their referral pathways, who funds their support and accommodation (and the extent of charging), and therefore overall, the support they can access.

People whose 'main' diagnosis is organ failure (including neurological conditions), frailty and/or dementia are less likely to get the palliative care support they need and this applies both to specialist and generalist palliative care support. Paradoxically this position is reversed for children; those with cancer are less likely to access early palliative care.

Public and professional perceptions of palliative care as a specialist service for people dying with cancer persist. The *uncertainty* of prognosis in some conditions, for example chronic obstructive pulmonary disease (COPD) and dementia makes it harder for people with these conditions to access specialist palliative care services. Research suggests that care co-ordination for people with cancer is better than that for other conditions [though there is scope for improvement in all conditions][cxiv]. Professionals find it harder to initiate discussions about end of life issues when prognosis seems less certain, and also where options for referral for support may be more limited. Research shows that people's experiences and expectations are different depending on whether they have cancer, organ failure (including neurological conditions), frailty and/ or dementia[cxv].

Age

People of all ages from neonates to centenarians may need palliative care. However, an estimated 85% of people who die with palliative care needs are aged 65 or older[cxvi]. Factors such as the prevalence of different conditions and household circumstance vary with age. For example frailty and dementia become more common with age, people are more likely to live alone and this affects people's pathways of care. There is some evidence that people over 85 are less likely to receive specialist palliative care[cxvii], and that older people with cancer may have less adequate pain relief. There is often uncertainty in prognosis for old people with frailty and dementia and this can lead to late or absent identification of palliative care needs. A recent study in England describes how dying without an 'end of life diagnosis' makes it harder for frail older people to access good community care[cxviii]. A study comparing the experiences of frail very old people with younger cohorts suggests that the very old are less likely to have had ACP discussions or, perhaps counterintuitively, to be aware that they may be reaching the end of life (or to have had this acknowledged)[cxix]. Older people are more likely to experience the death of a life partner and to have smaller networks of social support when bereaved. Because such bereavements are so common in this age group older people may be expected to 'just cope', and complicated grief and depression may not be identified or addressed. A recent review found that bereaved people over 65 are as likely as adults bereaved at a younger age to experience prolonged grief disorder, around 10% of those bereaved[cxx]. Older people are less likely to seek help or to be referred for bereavement support[cxxi].

People in Prison

The Scottish prison population is experiencing a rapid growth in the proportion of older prisoners. This is largely explained by long sentences associated with historic sexual abuse. Prisoners typically experience accelerated aging, with the onset of ill health 10 years earlier than the general population. An increasing number of prisoners have palliative care needs. Compassionate release at end of life is less likely to be an option for many of these older sex offenders due to breakdown of relationships in the community: prison may be their preferred location for end of life care.

The Scottish Prison Service and the health and care system faces major challenges in providing care (including end of life care) for growing numbers of prisoners with multimorbidity and disability. Prisons are a difficult place to provide good palliative and end of life care for several reasons. The physical environment is not well suited to people with mobility issues and is difficult/expensive to adapt. There are difficulties accessing equipment and staffing levels are tight. There is a lack of overnight nursing cover. Maintaining necessary security is an obstacle to family contact, peer support and medicines availability.

A 4-year project funded by Macmillan Cancer Support has recently concluded, having raised awareness, promoted collaboration between Scottish Prison Service and voluntary hospices and NHS specialist palliative care units[cxxii], developed a pathway, established a Community of

Practice to help support and sustain change and made recommendations for future work[cxxiii].

Homeless People

Homelessness is often not just a housing issue but an indicator of multiple severe disadvantage and complex needs. There were 216 deaths in Scotland of people who were homeless[12] in 2019[cxxiv]. 70% of these deaths had external causes including drug-related deaths, accidents, suicides and assaults. Homeless people have complex palliative care needs and have worse symptoms at the end of life[cxxv], yet they have worse access to good quality palliative care and often die without accessing care[cxxvi]. Homeless people may be concerned about dying on the streets, dying alone, dying anonymously, losing control if admitted to hospital (and potentially having to deal with drug withdrawal), and being forgotten about after death. They may also have pressing practical concerns. People who are homeless, like most people, have a preference to die somewhere comfortable where they know people[cxxvii].

Homeless people with palliative care needs tend to be relatively young in comparison to the general population with such needs, and often have a particularly uncertain prognosis. Many have 'tri-morbidity – physical and mental health problems together with addictions. Many have also experienced trauma, which impacts their ability to access and benefit from services.

Mainstream services are not adequately configured to meet the needs of homeless people. Challenges for services include a lack of awareness; lack of flexibility; lack continuity of care (which is vital to establish trust); lack of 'assertive follow-up'; co-ordination between multiple agencies; lack of social support; hostels not designed to accommodate ill health.

Recent years have seen the evolution of service models in Scotland which try to meet these challenges. For example in Edinburgh a collaboration between St Columba's Hospice, Marie Curie Hospice, the Edinburgh Access Practice and Simon Community Scotland has implemented approaches which improve care such as the development of a pathway for homeless people to access palliative care and the development of a

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[12] These statistics are based on searching records for those people using emergency accommodation such as homeless shelters, hostels and temporary homeless accommodation at the time of their death. A significant number of people who are rough sleeping are likely to have been missed.

virtual palliative care community of practice for support workers in hostels.

Dying in the Cold, a recent report from Marie Curie Scotland, explores many of these issues in more depth[cxxviii].

Gypsy, traveller and Roma people

A recent study[cxxix] identified key themes in the views, experiences and needs of gypsy, traveller and Roma people approaching the end of life:

> *"(1) Strong family and community values include a preference for healthcare to be provided from within the community, duty to demonstrate respect by attending the bedside and illness as a community problem with decision-making extending beyond the patient.*
>
> *(2) Distinct health beliefs regarding superstitions around illness, personal care, death rituals and bereavement.*
>
> *(3) Practical barriers to non-community healthcare provision include communication difficulties, limited awareness of and access to services, tensions between patients and healthcare professionals and lack of training in delivering culturally appropriate care."*

People with Learning Disabilities

People with learning disabilities often die younger, are more likely to experience poor general health and have higher than average levels of unmet physical and mental health need[cxxx]. They often experience care which is uncoordinated and have less access to specialist palliative care services and opioid analgesia. Staff often lack confidence in meeting the particular and individual needs of people with learning disabilities.

Forced Migrants[13]

Forced migrants face a range of barriers to healthcare including palliative care. Language and communication issues are often an obstacle. Forced migrants may have a low baseline understanding of awareness of how the NHS works. They sometimes experience difficulties registering with a GP.

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[13] We use 'forced migrants' to refer to a range of immigration circumstances including people seeking asylum, refugees, people granted limited leave to remain, unaccompanied asylum-seeking children.

Their entitlement to care is often questioned by frontline staff. Forced migrants may have been charged for care in the past and be concerned about being unable to pay for care. In some cases forced migrants may face no-choice dispersal and frequent moves from one location to the next. Forced migrants are often fearful of breaches of patient confidentiality and subsequent harassment by the Home Office.

RECOMMENDATIONS

Inequalities towards the end of life generally reflect patterns of inequality and discrimination within wider society. Societal approaches which tackle inequality, poverty and discrimination are fundamental to improving experiences and outcomes at the end of life. There is now good evidence for how governments can address poverty-related health inequalities by addressing the wider social determinants of health[cxxxi]. Social movements, properly enforced equalities legislation and society-wide campaigns are the basis for challenging discrimination and stigma at societal level.

Measures which aim to make general services more accessible and person-centred will help to address inequalities in palliative and end of life care – for example work currently being done under the banner of health literacy[cxxxii]. However, there are also actions within the sphere of palliative and end of life care which can contribute to addressing inequalities, and some of these are recommended below. The first eight recommendations are of relevance to all the groups highlighted above.

Individual Personal Responsibility

Recommendation As individuals engaged in delivering and/ or improving care we should all seek to become more aware of the multiple ways in which inequalities are created, expressed and experienced towards the end of life. We all have personal and professional domains, however large or small, within which we can contribute to challenging stigma, discrimination and promoting more equitable outcomes. We can all take personal responsibility for becoming aware of and challenging our own unconscious biases.

Research

There is a need to better understand current inequalities in service use and access, and the specific needs and experiences of different groups.

Recommendation The Scottish Palliative Care Research Forum should be resourced to progress a programme of work to identify and address priority gaps in knowledge. It may make sense to take a nationally co-ordinated programmatic approach to understanding and better meeting the needs of different groups. This could make best use of limited research capacity to inform and work with local service improvement pilots. Local learning should be shared with the Palliative Care Research Forum and disseminated through local palliative care leads. (see chapter 9).

Policy-making

Recommendation All relevant SG policy making should include a more explicit and effective consideration of how to reduce inequalities experienced by people towards the end of life.

Commissioning, Service Design and Resource Allocation

Recommendation During strategic planning and commissioning processes the needs of disadvantaged groups should be identified and explicitly addressed in plans.

Recommendation Disadvantaged groups should be involved in service design to help planners and commissioners to understand and address barriers to access and deliver better outcomes.

Recommendation Investing in approaches which address the needs of disadvantaged groups should, if necessary, be enabled by reallocating resources away from those who are currently best served.

Education and Training

Recommendation In addition to standard equalities and health literacy training relevant staff should receive training specific to end of life issues. This could range from general awareness of inequalities at end of life to specific issues (for example the beliefs and practices around death of different ethnic groups).

Prisons

Recommendation SPPC supports wide-ranging recommendations likely to flow from the unpublished final report of the Macmillan Scotland funded project on palliative care in prisons. These are likely to encompass: creation of separate secure facilities for prisoners with palliative and end of life care needs; arrangements for families to maintain contact; improving staffing levels and skill mix; more education for healthcare and prison staff; robust guidance from senior management on how to manage prisoners; more flexible approaches to lockup of prisoners who are dying; incentivising and supporting those prison officers with an aptitude for providing care; careful development of 'peer carer' roles; knowledge-sharing by prisons and hospices which are already working collaboratively; improved access to controlled medications, whilst managing security and exploitation risks; further research to understand the perspectives of staff, prisoners and families.

People Who Are Homeless

Recommendation Activity should be undertaken to improve awareness of the distinct needs of homeless people amongst relevant health, social care and housing/homelessness staff.

Recommendation Specialist homeless GP practices, specialist palliative care services, homelessness services and other agencies should collaborate to identify and deliver pathways of care. The resourcing of CNS roles with a special interest can provide leadership and co-ordination for pathway development and delivery.

Recommendation Pathways, with palliative care MDT involvement, should include outreach, in-reach to hospitals and bereavement support.

Recommendation Specialist palliative care services should provide education and support to homelessness staff.

Recommendation Community palliative care beds should be provided within hostels perhaps in conjunction with medical respite/ intermediate care beds.

15. PUBLIC HEALTH APPROACHES TO DEATH, DYING AND BEREAVEMENT

People's experiences of declining health, death and bereavement are only partially determined in their interaction with traditional formal health and social care services. The social and cultural environment is a key influence on people's experiences as well as being a limiting factor in service improvement.

Education, workplace culture, family networks, the media, community support, individual experiences of mortality, and access to information all play an important role in shaping people's lives and deaths. Therefore, if we truly want to improve people's experiences we need to look at wider society and explore what can be done to foster more open and supportive attitudes and behaviours relating to death, dying and bereavement.

'Public health palliative care' is becoming the accepted term used to encompass a variety of approaches that involve working with communities and wider society to improve people's experiences of death, dying and bereavement.

Policy background

Scotland was one of the first countries in the world to recognise within government policy the importance of public health approaches to palliative care – initially within *Living and Dying Well* in 2008*.* Since then, a number of policy documents have highlighted the importance of encouraging more open and supportive cultures relating to death, dying and bereavement.[cxxxiii]

The need to develop public health approaches to palliative care is implicit in the aims and outcomes of Scottish Government Strategic Framework for Action on Palliative and End of Life Care (2015), and most explicitly referenced in Commitment 6: *"We will support greater public and* *personal discussion of bereavement, death, dying and care at the end of life."*

In 2017 Scottish Government asked the Scottish Partnership for Palliative Care to lead on the delivery of Commitment 6 and provided funding towards expanding the work of the pre-existing Good Life, Good Death, Good Grief Alliance. www.goodlifedeathgrief.org.uk

Progress since 2016

National work - Good Life, Good Death, Good Grief (GLGDGG)

Since receiving funding to lead on Commitment 6 in 2017, the SPPC has:

- researched and published *A Road Less Lonely,* a report which shares sources of current good practice in Scotland and sets out recommendations for future work in a variety of domains
- grown the *To Absent Friends festival*, most importantly with specific activities aimed at engaging people in socio-economically disadvantaged communities
- developed *End of Life Aid Skills for Everyone* (EASE), a public education course (with online and face-to-face versions) to help ordinary people become more comfortable and confident supporting friends/ family towards the end of life
- operated bi-annual small grants schemes to support local organisations to undertake local activities relevant to the aims of GLGDGG
- successfully secured funding from Macmillan to run the Truacanta Project, which aims to support five communities in different parts of Scotland to run local projects, following a community development approach and with planned evaluation
- enabled networking and information-sharing between interested stakeholders in Scotland through monthly e-bulletins, social media, two national conferences and several smaller-scale events, and the establishment of the Scottish Compassionate Communities Network
- developed the Bereavement-friendly workplaces toolkit
- developed the Scottish Compassionate Communities toolkit
- published accessible information for people in Scotland who may be worried that they, or someone they care about, is at increased risk of getting seriously ill and potentially dying from COVID-19

- brought together interested stakeholders to inform the current position paper.

Since its establishment in 2011, Good Life, Good Death, Good Grief has been a hub promoting and supporting public health approaches to palliative care, and this work continues to be a priority for SPPC members and funders. Additional funding from Scottish Government in recent years has enabled the continuation of existing work (for example annual Good Death Week, Death on the Fringe, and maintenance of a public-facing information website), alongside some scaling up of existing activities (eg networking and information-sharing events) and establishment of new projects and resources.

GLGDGG plays an important strategic role supporting this area work, for example by bringing people together for networking and information sharing, providing resources and by maintaining a long-term strategic focus on this area.

GLGDGG seeks to 'work with' people rather than imposing 'interventions', and its key messages are about supporting open cultures, rather than attempting to raise awareness and change attitudes in a top-down fashion.

GLGDGG exemplifies an approach which involves finding ways of 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.

Local work

Across Scotland, various work is underway at a local level working to improve societal approaches to encourage more supportive attitudes and behaviours relating to death, dying and bereavements. It is beyond the scope of this document to set out all these areas of good practice, but recent publications *A Road Less Lonely* and the *Scottish Compassionate Communities Toolkit* present many examples of Scottish work underway in this area led by a variety of organisations and communities.

International collaboration

Scotland's work in the field of public health palliative care and compassionate communities is internationally recognised. For example, those leading on Good Life, Good Death, Good Grief and Compassionate Inverclyde are frequently invited to share approaches and learning at international networking events and informally with international colleagues, most recently including Ireland, Canada, Denmark and Belgium. SPPC staff were invited to contribute a chapter on end of life literacy and public education to the new Oxford Textbook of Public Health Palliative Care. These active international connections have allowed Scotland to learn from work going on elsewhere.

What next?

A Road Less Lonely: What next for public health approaches to death dying and bereavement in Scotland? (2018) sets out a series of recommendations for next steps in this field. Though significant progress being made in many of the areas outlined in the document, other recommended actions remain to be progressed, and this document is a good starting point for determining future work in this area. We reproduce many of the recommendations at the end of this chapter.

COVID-19

Responses to the COVID-19 pandemic have highlighted some recurring issues relating to public perceptions of palliative care and society's general attitudes to death and dying.

The need for proactive communication to build understanding and trust

Early in the COVID-19 pandemic, every GP practice in Scotland was encouraged by official guidance to proactively call people on the shielding list to have discussions about an anticipatory care plan and to update Key Information Summaries. The aim was to ensure that those people most at risk from serious illness and death had opportunity to discuss and have recorded their preferences for care. Many helpful and meaningful ACP conversations resulted from this initiative. However, there were also many examples where these conversations were unwelcome, or where people felt that they were handled unsensitively.

There were reports in the media of 'blanket DNR orders' and of worries from 'high risk groups' that they would not receive some treatments because of their demographic rather than their individual chance of recovery. The concepts of ineffective and burdensome treatment were largely absent from this public narrative.

As well as causing significant individual distress, this type of incident and the high-profile media response around it results in a lack of trust which can make it harder for professionals to provide good care.

The pandemic created circumstances where GPs and others were required to have huge volume of ACP discussions, in a short space of time, without face to face contact, where the public was deeply anxious, and where there was even uncertainty as to the ability of the NHS to cope with demand. Whilst research shows that the public generally expect and prefer professionals to initiate these discussions, in these conditions it is not surprising that many of these conversations were problematic and that there was negative media coverage.

However, this type of occurrence is not unique - over recent years there have been various occasions when misunderstandings, myths and poor communication about palliative care have caused distress and anxiety among the general public. Since before the publication *More Care Less Pathway* in 2013, and its Scottish counterpart publication, the palliative care sector in Scotland has been aware of the need for proactive work to educate the public and journalists to prevent misunderstandings.

Despite many people recognising the need for this work, limited progress has been made. Challenges are presented by the fact that this type of work needs significant resource, needs to be handled sensitively, requires engagement from many stakeholders including high level Scottish Government and NHS, and needs to be guided by a genuine desire to work collaboratively and listen.

COVID-19 has again shown how much damage can be done to public trust by misunderstandings and poor communication, and that fire-fighting is far less effective than proactive communication to build trust.

Avoidance of explicit mentions of death and dying in public-facing communications

Though the GLGDGG website provides public-facing information about various aspects of planning ahead, dying and bereavement, NHS24 (via the NHS Inform website) is (and should be) the main trusted first point of information for the general public.

In the early stages of the COVID-19 pandemic NHS Inform quickly responded to many new needs through their COVID-19 pages *https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-COVID-19* which helpfully addressed a range of matters including testing, physical distancing, shielding, dealing with early symptoms, mental wellbeing, care planning and advice for key workers.

However, there was not a corresponding expansion of NHS Inform content to address people's new worries and concerns relating to death from COVID-19. GLGDGG quickly published authoritative public-facing information which was shared with NHS Inform, but the opportunity to promote, publish or link to this information from the NHS Inform website was not taken.

This is an example of a recurring issue that perhaps reflects a wider societal discomfort with death and dying – where influential organisations and individuals perhaps subconsciously avoid mention of death and dying when there are actions which could be taken to help address people's worries and concerns. Though ill health, dying, death and bereavement are very much on people's minds at present, it is rare to see this issue addressed directly through official public-facing communication channels.

The importance of planning ahead

It is widely recognised that encouraging and supporting people to plan ahead, through anticipatory care planning (ACP), makes people more likely to get the kind of care they would prefer. Depending on a person's circumstances and wishes, anticipatory care planning might include:

- granting a Power of Attorney/ welfare attorney
- talking with healthcare professionals, family and friends about personal concerns, values, understanding and expectations of illness, care and treatment preferences
- considering organ donation
- discussing available treatment and care options that may/or may not work and be of benefit to the person now or in future. This may include decisions about CPR, hospital admission, intensive care or other relevant interventions
- considering medical treatments they may or may not want to have and setting these down within an Advance Directive
- considering their digital legacy.

Within this position paper we consider those aspects of ACP that require the involvement of health and social care professionals within Chapter 17. However, it is worth noting here that though during the COVID-19 pandemic significant work was undertaken to build the capacity of health and care professionals to engage in these conversations, with initiatives such as ReSPECT and RED-MAP, little emphasis has been put on providing matching public education and communication.

Power of Attorney, organ donation, digital legacy, making a will, planning for future care costs and Advance Directives are all elements of forward planning that individuals and families can initiate themselves and which can have an important impact on their experiences towards the end of life.

RECOMMENDATIONS

Recommendation Scottish Government should adequately fund the Scottish Partnership for Palliative Care to lead a programme of activity in partnership with stakeholders to promote a culture of openness about death, dying and bereavement in Scotland, which should include the following key actions:

- Identify key outstanding actions from *A Road Less Lonely* and explore ways to move these areas of work forward. The issues addressed in this report are death education and bereavement support in schools; compassionate workplaces; compassionate communities; personal skills and knowledge; planning ahead; mass media campaigns; socio-economic disadvantage; funeral poverty.
- identifying priorities and actions in the context of changing circumstances due to COVID-19
- enabling networking and information-sharing between interested stakeholders in Scotland
- advising and influencing other work streams and consultations as appropriate
- running grants schemes to support local work
- widely promoting good practice and resources that exist in Scotland
- providing a strong voice for the sector, advising on and influencing other areas of work to take account of death, dying and bereavement issues
- widening the reach of this work to new groups and communities.

Recommendation A Scottish charter for a good end of life, as described within *A Road Less Lonely,* should be developed with explicit support and involvement from senior SG and NHS figures, cross-sector engagement and genuine efforts to listen to and work alongside members of the public and the media.

Recommendation The information available on NHS Inform relating to palliative care, dying and bereavement should be reviewed, improved and expanded, and this should include rapid work to provide better information for people worried about dying with COVID-19.

Recommendation Scottish Government communications functions should support and engage in proactive communication work around end of life preparation and planning.

Recommendation Scottish Government should commit to ensuring that relevant policy documents include and address in clear terms the dying phase of the life course.

16. INFORMAL CARERS

People who are ill or dying generally spend only a small proportion of their time seeing professionals and receiving formal services. Informal carers such as family and friends generally provide the bulk of support that is needed yet can be unsupported and undervalued themselves.

Knowledge and experience of carers

Carers can have a wealth of understanding, knowledge and experience relating to the preferences and needs of someone they've been caring for and are usually keen to share this knowledge with anyone who can use it to improve the person's care. It is therefore always important for formal services to recognise the value and knowledge of informal carers and work together with them in the best interests of the individual involved.

Identifying carers

The Carers (Scotland) Act (2016) places a duty on local authorities to prepare an Adult Carer Support Plan (ACSP) and a Young Carer Statement (YCS) for anyone they identify as a carer, or for any carer who requests one. The Act states that ACSPs and YCSs for carers of those in their final six months of life should be fast-tracked.

Work by Marie Curie highlighted the complex nature of identifying carers[cxxxiv], identifying many missed opportunities, for example a change in health status of the carer or cared-for person or their interaction with services. The research suggested that there should be a presumption that people have a carer rather than not, and that this presumption should lead to the offer of documented identification (ie on the KIS) and assessment for a carer.

The research concluded that identifying carers is everyone's responsibility, but although anybody can do this, many health and social care professionals often think it is someone else's responsibility, and consequently the carer remains unidentified. It also identified several potential opportunities for identifying or re-assessing carer needs, including:

- when someone is discharged from hospital
- admission to hospital

- completion of a DS1500 and/or BASRiS
- opportunistic interactions such as flu vaccine, attendance at pharmacies and public health-related interactions such as prompting at cancer screening
- disease specific registers in GP practices should be used as a means of pro-actively identifying carers.

Timely intervention is crucial to ensure carers feel supported and crises are avoided. Carers should ideally be identified early in the illness trajectory of the patient, preferably at diagnosis, so carer needs are assessed and met before end of life.

Support for carers

Being a carer can have huge impact on a person's life – emotionally, physically, socially and financially. Many carers will have multiple simultaneous caring roles for example looking after their children whilst caring for an elderly parent or relative.

Informal carers require support and information to deal with the practical and emotional difficulties they face. Research by Marie Curie[cxxxv] explored the support needs of carers and found that:

- Psychological support was valued, sometimes more than support with the physical aspects of caring, and this extended into bereavement.
- Peer support and basic compassion from health and social professionals were highlighted as key to feeling well supported.
- Respite was essential, so carers could have time away from the caring role.
- Primary care health professionals and social workers have a vital role, particularly with regard to co-ordination of care and the provision of information.
- The decline towards end of life was often faster than carers expected, and carers required access to quick support at this time.

Where carers (and the people they care for) do not get adequate and responsive support at home, the situation can deteriorate rapidly into a full-blown crisis. In a recent survey by Carers Scotland, 48% of carers caring for someone with palliative care needs reported that the person they cared for had an emergency admission to hospital in the last 12 months[cxxxvi]. Over a quarter (29%) felt that the emergency admission could have been avoided if the person they cared for had received more adequate support at home.

RECOMMENDATIONS

Recommendation Education should be undertaken to increase the extent to which health and social care professionals help carers identify themselves as having a caring role.

Recommendation A structured approach to assessing the needs of carers should be used. The Carer Support Needs Assessment Tool (CSNAT) is an evidence-based tool that facilitates tailored support for family members and friends (carers) of adults with long term life-limiting conditions[cxxxvii].

Recommendation The implementation of the fast-track arrangements for development of adult carer support plans should be carefully monitored.

Recommendation The extent to which identified carer needs are met should be systematically monitored and reviewed and the findings used to inform local commissioning (and the wider reforms of adult social care recommended by the Independent Review of Adult Social Care). The flexibility of services and their ability to respond to rapidly evolving situations are key considerations for carers of people approaching the end of life.

Recommendation Local and national providers of services and information should ensure that relevant and comprehensive information reaches carers, recognizing that carers often do not think of themselves as 'carers', and that their information needs may be different to the person they care for.

Recommendation Awareness should be raised that people can choose to have a family member or friend or advocate with them for most appointments, consultations and meetings with health and care professionals. Having someone there who knows the individual may help health professionals to make a better assessment of the wider needs of the individual. It also supports and empowers informal carers to be actively involved in supporting people at home or in other care settings.

Recommendation Where appropriate carers should be provided with training and support to help them look after their loved one and themselves. This may include a sensitive explanation of what supporting a death at home entails – uncertainty and not knowing what to expect is a central concern of people caring for a loved one towards the end of life.

Recommendation Supportive employment practices should be promoted for carers who are trying to balance caring with work or who are bereaved, with information and guidance for employers made available via key portals such as Healthy Working Lives.

Recommendation Information on carer benefits entitlement should be made available to carers. When carers of people with a terminal illness do apply for benefits, their applications should be dealt with as quickly as possible.

Recommendation – To support adjustment by carers following the death of the person they have been caring consideration should be given to an education and training fund to support return to the workplace; extension of eligibility for the Carer's Allowance and Carer's Allowance Supplement for up to 6 months after the person's caring role comes to an end. (See also chapter 18 on Bereavement Support).

17. THINKING AHEAD AND MAKING PLANS

Making plans when you're relatively healthy means there is less to think about if your health gets worse. This can reduce stress at an already distressing time and makes it more likely that a person can get the care that they would want in the place which they would prefer.

Planning ahead is routine in many areas of health and social care – eg diabetes and planning for low blood sugar events; asthma plans; birth plans; sick day rules in renal failure; having a trusted neighbour hold a spare key. It's so normal it's almost unnoticed.

In the context of mortality, thinking and planning ahead processes are often called Advance Care Planning or Anticipatory Care Planning. In Scotland the term Anticipatory Care Planning has become predominant in policy and practice and will be used in this chapter.

Anticipatory Care Planning

Anticipatory care planning is an essential part of many aspects of healthcare and is not restricted to people whose deteriorating health and risk of dying is now impacting on decision making. Thus anticipatory care planning may well start before a person has palliative care needs and will evolve over time as a person's prognosis, understanding and priorities evolve. Anticipatory care plans related to serious illness, potential last hours, days, weeks and months of life should reflect what matters to the individual. This may include financial, legal, practical, personal and spiritual matters in addition to clinical issues.

There are many aspects of anticipatory care planning that an individual can begin themselves. There are other aspects where the public generally expects discussion to be initiated by a health care professional, if there are signs an illness is likely to get worse. Depending on a person's circumstances and wishes, anticipatory care planning might include:

- granting a Power of Attorney/ welfare attorney
- talking with healthcare professionals, family and friends about personal concerns, values, understanding and expectations of illness, care and treatment preferences

- considering organ donation
- Discussing available treatment and care options that may/ or may not work and be of benefit to the person now or in future. This may include decisions about CPR, hospital admission, intensive care or other relevant interventions.
- considering medical treatments a person may or may not want to have and setting these down within an Advance Directive
- considering their digital legacy.

Within this position paper we consider Power of Attorney, organ donation, digital legacy, making a will, planning for future care costs and Advance Directives within chapter 15 on public health palliative care. Within the current chapter we focus on those aspects of forward planning that require the involvement of health and social care professionals – whilst recognising that anticipatory care planning is broader than this.

Benefits of anticipatory care planning

Anticipatory care planning which encompasses palliative and end of life issues can improve the outcomes experienced by an individual and their family[cxxxviii]. Potential benefits include: an individual can have more involvement in decisions about their care; care can be informed by an understanding of individual goals and preferences; avoidance of undesired treatments and investigations; an increased chance of being cared for and dying in a preferred place; an improved understanding of the uncertainties and realities of the clinical situation can inform wider life priorities and decisions; peace of mind gained from having prepared for future difficulties. Combined, these benefits can lead to a person being able to live as well as possible with the challenges of serious illness.

Not everyone will wish to engage in anticipatory care planning, and this must be respected. In this paper 'initiating' anticipatory care planning includes exploratory conversations which identify if an individual does not wish to engage further (at that time).

It is important to remember that:

- even with the best laid anticipatory care plans in place reactive unplanned care remains vital
- even when things don't go as planned or hoped the process of thinking about and developing a plan can build capacity and preparedness to deal with circumstances as they unfold.

Anticipatory care planning in Scotland

A huge amount of work has been done to promote anticipatory care planning in Scotland with major projects in many health board areas and work spanning all settings. This has been supported at national level by guidance, resources, evidence reviews and programmes of work by HIS[cxxxix], NES, the Third Sector and by the Palliative Care Direct Enhanced Service in primary care. NHS Inform provides some information for the public about anticipatory care planning, an app for the public was developed and Good Life, Good Death, Good Grief has promoted thinking and planning ahead through a range of public engagement activities and resources.

Complementary work has taken place to enable key information from anticipatory care planning discussions to be documented and shared across settings. Following the Electronic Palliative Care Summary the introduction of the Key Information Summary created more of a focus on identifying people for whom an anticipatory care planning process might be of benefit. A greater proportion of people with non-malignant disease are now being identified in primary care as having palliative care needs. A recent study[cxl] of all patients (n=1304) who died in 2017 across 9 GP practices showed that 69% of patients were identified for a KIS. 95% of the KISs held information which would be useful or highly useful in decision making in emergency or out of hours situations. 68% documented CPR status. 80% of people with cancer had a KIS, 66% of those dying with dementia/frailty and 47% of those dying from organ failure. On average people were identified 45 weeks before death, with a wide variation depending on the main underlying condition. People with frailty and/or dementia were identified 88 weeks before death, people with organ failure 82 weeks before death and people with cancer 15 weeks before death. People were more likely to die outside hospital if they had a KIS. Data published by HIS also suggests there has been a gradual increase in how often KIS records are accessed.

A Children and Young People Acute Deterioration and Management (CYPADM) plan has existed in Scotland for some years and more recently the *Anticipatory Care Plan for Babies, Children and Young People* [cxli].

Recent Developments and challenges

Digital developments

The NES Digital Service has identified the development of a digital anticipatory care plan as a successor to KIS as a priority and is piloting a digital implementation of the ReSPECT[cxlii] process. KIS's key limitations are that it is difficult to access in some clinical settings, is inaccessible to many parts of the health and care system and to patients and can only be amended/updated in general practice.

Resources for professionals

HIS has refreshed its webpages and resource, including a short-form digital ACP.   A range of resources to support professional to engage in anticipatory care planning conversations with patients[cxliii] has been developed drawing on the RED-MAP framework[cxliv] and there is increasing alignment of language within and across resources and institutions.

Public-facing resources

During the first wave of the pandemic Good Life, Good Death, Good Grief developed information specifically for people worried that they or someone they care about, was at increased risk of getting seriously ill and potentially dying from COVID-19[cxlv]. The information was designed to supporting thinking and planning ahead in the context of COVID-19. As discussed in Chapter 15 this information is not replicated or linked to from NHS Inform.

Key Information Summary

Early in the COVID-19 pandemic, every GP practice in Scotland was encouraged by official guidance to proactively call people on the shielding list to have discussions about an anticipatory care plan and to update Key Information Summaries. The aim was to ensure that those people most at risk from serious illness and death had opportunity to discuss and have recorded their preferences for care, including DNACPR.

By November 2020 1.7m people in Scotland had a KIS (a sevenfold increase driven by the COVID-19 pandemic). The scope and quality of KIS records is variable and HIS is now promoting a process through which they are reviewed and updated.

However, the pandemic has also highlighted that many people who might have benefited from having an anticipatory care plan did not have one in place and that public awareness and understanding of anticipatory care planning is extremely low.

Worries, concerns and misunderstandings

Many helpful and meaningful ACP conversations resulted from this initiative. However there were also many examples where these conversations were unwelcome, or where people felt that they were handled unsensitively, as discussed in chapter 15.

The pandemic created circumstances where GPs and others were required to have huge volume of ACP discussions, in a short space of time, without face to face contact, where the public was deeply anxious, and where there was uncertainty as to the ability of the NHS to cope with demand. In these conditions it is not surprising that many of these conversations were problematic and that there was negative media coverage, and this highlights the importance of future action to increase public understanding of ACP.

How do we ensure people have access to good anticipatory care planning?

There is broad consensus about the key components of a successful approach to anticipatory care planning:

Provide honest, comprehensive and accessible public facing information about ACP

It is important that people are empowered to initiate their own planning conversation if they wish to. In preparation for anticipatory care planning (whether initiated by a patient or a professional) it is also important that there is somewhere impartial and trusted that they can find honest, comprehensive, accessible and culturally sensitive information.

A recent UK review by Selman et al[cxlvi], found that there are some key weaknesses in the public information available about planning ahead for ill health and death:

> *"… existing guidelines and resources are to a major extent clinician-focused; there are few video- and web-based Advance Care Planning resources for the public and those*

> *that exist are scattered and piecemeal. This is a concern given good quality evidence that online and video ACP interventions are beneficial, particularly among people with limited English proficiency, poor health literacy and/ or from otherwise disadvantaged communities."*

Provision of public-facing information about serious illness and dying often appears guided by a desire to protect members of the public from anxiety, using indirect language or euphemistic content.

The desire to shield people from unwelcome information, and to avoid creating unnecessary worry is understandable. Learning that someone will not get better, or that the ideal support services are not available, or that the end of life is close, will likely always be difficult. Yet, without honest information, individuals and families are ill-equipped to make decisions or plan ahead.

Communicating sensitively is paramount when providing potentially unwelcome information, but it is possible to provide comprehensive, accurate information that acknowledges uncertainties, while maintaining a tone of kindness, empathy and respect for the reader.

Proactively identify people likely to benefit from ACP early

It is important to identify people who are likely to benefit from anticipatory care planning. This can be done in many ways: by screening primary care records for people with deteriorating health using ESCRO or the electronic frailty index; by the use of tools such as the SPICT (Supportive Palliative Indicators Tool)[cxlvii]; by using key points in a person's pathway to trigger review eg a diagnosis or significant deterioration, emergency admission, moving into a care home.

Undertake planning discussions between individuals and professionals

Sensitive, open and honest conversations about what matters to the person are the heart of anticipatory care planning. Where it has been identified that someone is likely to benefit from anticipatory care planning, an appropriate health or social care professional should initiate a person-centred care planning conversation with them. This might be their GP, nurse or other person involved in their care. Tools and training have been developed within Scotland that can help guide this process, including the RED-MAP model and EC4H programme.

Anticipatory care planning may include the development of personal emergency care plans which record what treatments will be of benefit and in line with the person’s preferences in the event of a sudden deterioration. Such plans should also include actions for informal carers. The ReSPECT process creates personalised recommendations for a person’s clinical care and treatment in a future emergency in which they are unable to make or express choices. Some areas of Scotland use hospital documentation (Treatment Escalation Plans [TEPS] or Treatment Escalation Limitation Plans [TELPS]) that is designed to provide clear guidance about interventions which are likely to be effective and in line with the person’s goals of care as well as limitations of treatment, so people do not receive harmful interventions of low benefit.

Sharing, reviewing and updating information

Documenting, reviewing, updating and sharing decisions and preferences identified during these discussions makes it more likely that care provided will reflect what the person considers important, and which is feasible within the constraints they are facing. Once discussions have taken place it is essential that a plan is made and stored where it can be accessed and updated as a person’s situation and preferences change. Transitions between settings can provide a useful trigger for updating planning, for example on discharge from hospital or soon after admission to a care home.

Initiating discussions and reviewing and updating plans may take place in any setting – whether a care home, hospice, hospital or in the community.

Ideally, anticipatory care plans should be accessible and recognisable across settings and regions, and therefore a consistent approach across Scotland can help, especially relating to eHealth systems and out of hours and emergency healthcare services. The public should have access to their anticipatory care plan and the ability to add and edit content.

Accessing and acting on anticipatory care plans when needed

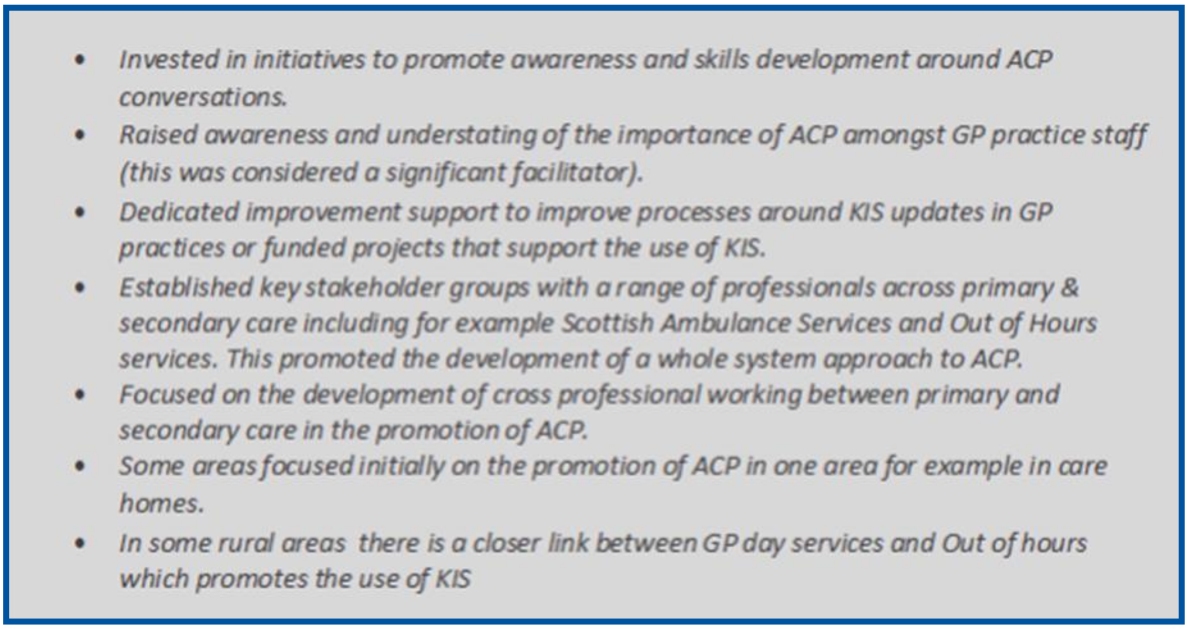
It is important that people involved in the person’s care can access and act upon someone’s anticipatory care plan, whatever setting they work in.

For example, it is important that care home and home care staff are engaged in the process and empowered to ensure the preferences recorded in a plan are respected, for example by not initiating an unwanted hospital admission without clinical assessment. Out of hours and ambulance services are key stakeholders who need access to anticipatory care plan

Improving Anticipatory Care Planning

Learning from Scottish Success

A paper by HIS[cxlviii] published in March 2020 reflected on practices and systems that support anticipatory care planning in Scotland. This review interviewed stakeholders from health and social care partnerships with the highest rates of KISs amongst their populations. Interviewees identified a range of factors which had contributed to progress with ACP:



- *Invested in initiatives to promote awareness and skills development around ACP conversations.*
- *Raised awareness and understating of the importance of ACP amongst GP practice staff (this was considered a significant facilitator).*
- *Dedicated improvement support to improve processes around KIS updates in GP practices or funded projects that support the use of KIS.*
- *Established key stakeholder groups with a range of professionals across primary & secondary care including for example Scottish Ambulance Services and Out of Hours services. This promoted the development of a whole system approach to ACP.*
- *Focused on the development of cross professional working between primary and secondary care in the promotion of ACP.*
- *Some areas focused initially on the promotion of ACP in one area for example in care homes.*
- *In some rural areas there is a closer link between GP day services and Out of hours which promotes the use of KIS*

Anticipatory Care Planning in Scotland:
Supporting people to plan ahead and discuss their wishes for future care
Healthcare Improvement Scotland, March 2020

Learning from others

A recent study[cxlix] aimed to provide an overview of how ACP support is resourced and delivered in twelve international health and care organisations and identified a range of issues and themes, and approaches for providing high-quality ACP support efficiently and at scale. It identified the following approaches as promising for the efficient delivery of high-quality ACP support:

- Team-based provision allows physicians to retain involvement while more time-consuming aspects are completed by less costly but skilled staff such as nurses and social workers. This approach aligns well with new models of care such as patient-centred medical homes or, in England, multi-specialty community providers and primary care homes.
- Some staff specialised in ACP conversation, having it incorporated into their work role and/ or having some work reallocated. Experienced staff are able to conduct conversations more efficiently and in-depth training can be better-targeted.
- ACP conversations were sometimes 'broken down' into multiple shorter conversations, for example, in chronic illness and other routine care. However, sufficient uninterrupted time is needed to raise and discuss potentially complex or emotional issues and care must be taken to ensure that ACP does not, as the study puts it, get 'squeezed out' or become too fragmented or 'gappy'.
- Some organisations had successfully used, or were considering, decision aids, particularly for common interventions that were poorly understood. These can simplify conversations, support non-clinicians to facilitate ACP conversations and ensure people receive consistent information.
- Group facilitations were led by trained facilitators, usually nurses or social workers in community and clinical settings. Many preferred this approach, benefiting from the wider discussion and feeling less need to pre-commit to making a written plan. Even where people do not complete documents, they are likely to be better prepared for later decision-making.
- Online videos, community events and public education can help to prepare people for later decision-making. Subsequent ACP conversations are also likely to take less time. However, encouraging participation from those traditionally less likely to engage with public education is important.

RECOMMENDATIONS

Recommendation There should be a strategic collaboration to inform and guide the next phase of development and implementation of anticipatory care planning in Scotland. This should include HIS, NES, NES

Digital Service, NHS Inform, NHS24, Scottish Ambulance Service, SG, SPPC, representative health and social care providers and public representation.

Improving public knowledge and public-facing information

Recommendation Efforts should be made to ensure popular public-information platforms (such as NHS Inform) include practical, comprehensive information about ACP that is clear and accessible to the public, and which directly addresses concerns and questions people may have about palliative and end of life care issues. This should draw on existing work, for example public information on the NHS Greater Glasgow and Clyde and GLGDGG websites, and research into the formats and language that the public find helpful (for example exploring the provision of short films, leaflets and posters as well as text-based web information). Public feedback should be sought, and revisions made as necessary.

Recommendation A proactive public information and awareness campaign about the purpose, benefits and practicalities of anticipatory care planning should be developed and delivered with the active support of SG.

Digital development

Recommendation The continued development of digital products to support anticipatory care planning and the sharing of plans should be a priority.

Recommendation Information governance frameworks should permit analysis of data contained in digital summary anticipatory care plans to inform monitoring of the scale, quality and impact of anticipatory care planning.

Professional development, training and support

Recommendation Responsibilities for initiating or revisiting an anticipatory care planning conversation should be clarified so that opportunities do not fall into gaps (for example between primary and secondary care). Where any practitioner with appropriate skills and competence identifies that anticipatory care planning might be beneficial (but hasn't begun or needs revisiting in the light of changed circumstances) they should either initiate that conversation themselves or communicate with other people involved in that person's care to agree and document who should and will initiate an anticipatory care planning conversation.

Recommendation Health and social care staff should have access to education and training to support anticipatory care planning and the scale and impact of such training and education should be monitored.

Recommendation Within primary care the role of non-medical professionals in initiating anticipatory care planning should be further explored and developed.

18. BEREAVEMENT SUPPORT

72% of people have been bereaved in the last five years[cl], and almost all of us will be affected by the death of someone close at some point. A recent study has described the prevalence of child bereavement in Scotland. Over 50% of all children are bereaved of a parent, sibling, grandparent or other close family member by age 8 and this rises to 62% by age 10[cli] Bereavement has a profound and long-term effect on people's health and wellbeing. People need to see that their loss is acknowledged and have access to the right support to help them deal with their loss.

Death is always difficult to deal with, but since restrictions came into place due to the COVID-19 pandemic, the circumstances of bereavement have been especially difficult[clii] for many reasons:

- COVID-19 has meant that more people than usual have been bereaved.
- Often, people have not been able to visit or be with their loved ones before they died.
- Lockdown and physical distancing measures have meant that people haven't been able to seek solace from friends, family, community and ritual in the usual way.
- Many practical aspects of dealing with a death such as funerals have been made more difficult by COVID-19 related measures.
- All of this has happened amongst financial insecurities and general anxiety and uncertainty about the future.
- Social care workers, NHS staff and others have experienced multiple bereavements, in the midst of longer working hours and time away from their usual support networks.

Where are we now?

We have much excellent work to build on in Scotland. Many people who are bereaved receive incredible support from their friends, family and community. Formal bereavement support services are offered by compassionate and skilled people working in the NHS, care sector, Third Sector, faith communities and elsewhere. Staff who aren't part of formal bereavement support or spiritual care services also support people who've been bereaved as an everyday part of their role.

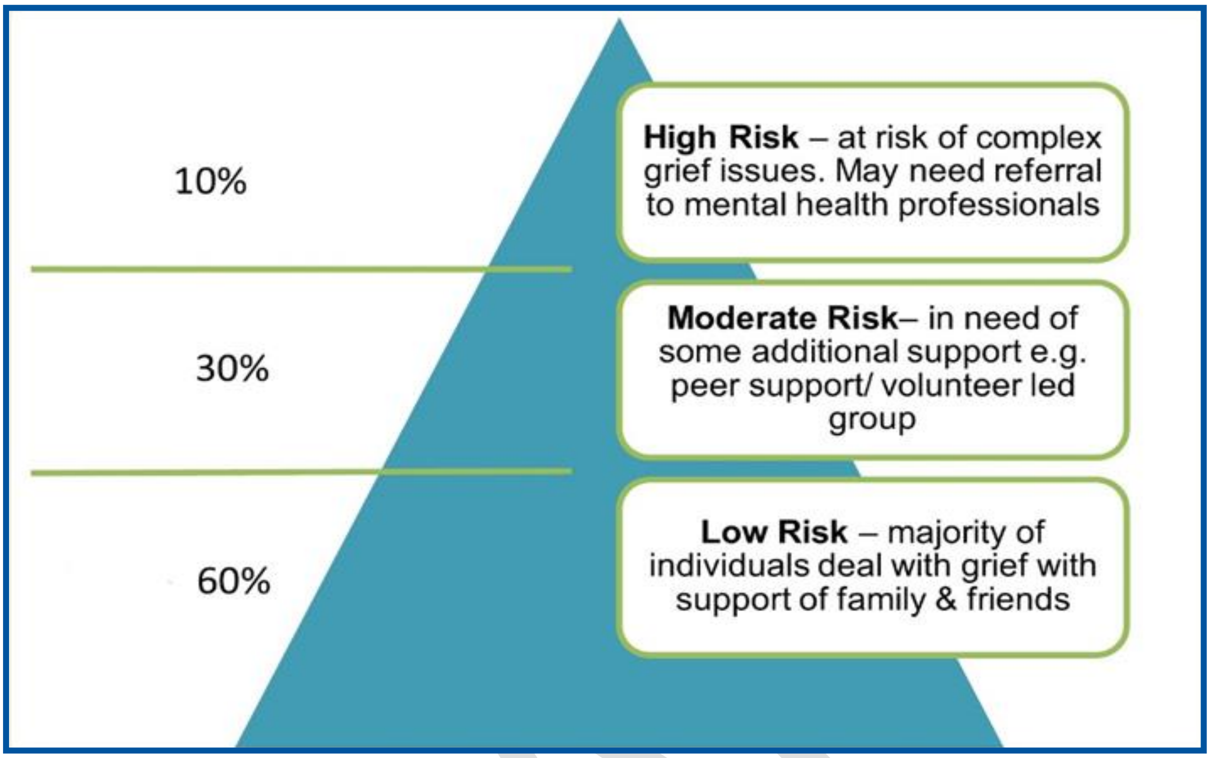
NHS Education for Scotland undertakes important work to educate doctors and other NHS and social care staff on bereavement issues and facilitates a learning network for NHS Board Strategic Bereavement Leads and Co-ordinators. 'Compassionate community' and 'kindness' initiatives are spreading, and *Good Life, Good Death, Good Grief*'s work to encourage informal support networks is gaining momentum. 2020 saw the publication of *Scotland's Bereavement Charter* which sets out a vision for a Scotland where people who are bereaved receive the support that they need. A scoping of childhood bereavement services in Scotland sponsored by Scottish Government is currently underway. The UK-wide National Bereavement Alliance organises regular information-sharing and networking events which are much valued by those working in bereavement in Scotland.

However, it is now nine years since Scottish Government published the *Shaping Bereavement Care* framework, and there is currently no coordinated approach or strategy relating to bereavement in Scotland. Bereavement services are provided by different organisations in different ways, and there is no clear picture of what kind of support bereaved people need, and whether there are disparities in access to bereavement support.

Different types of bereavement support

Informal social networks have an essential role to play in supporting people who are bereaved. Research from Ireland and Australia shows that the vast majority of bereaved people turn to family (94% Australia and 86% Ireland) and friends (88% Australia and 80% Ireland) for support, and that these are the people most likely to be present at/ close to the time of a death.

The pyramid diagram on the following page illustrates predicted percentages of the population requiring different levels of support, as represented by a public health model of bereavement support. This suggests that though formal bereavement services have an important role to play, this role should be seen as complementary to the informal support offered by wider society.



Who Needs Bereavement Support? A Population Based Survey of Bereavement Risk and Support Need, March 26, 2015 Samar M. Aoun, Lauren J. Breen, Denise A. Howting Bruce Rumbold, Beverley McNamara, Desley Hegney

Though informal support from friends, family, work colleagues and the wider community is essential, a lack of experience or confidence can prevent people from offering support when it is needed.

Challenges and complexities

'Bereavement support' encompasses many issues, and in shaping policy and action it is important to recognise there are several distinct but interrelated strands including:

- informal bereavement support provided by friends, families and communities
- formal bereavement support provided by bereavement support services in various sectors
- bereavement support provided by health and social care staff in the course of their role

- bereavement support provided to staff experiencing multiple bereavements, for example care home and home care workers, NHS staff, and first responders
- bereavement in times of COVID-19.

Bereavement is an issue that can’t be neatly categorised under one area of policy or practice. For example, though bereavement support is an integral part of palliative care, not everyone who is bereaved will have connections to palliative care support. Also, though bereavement experiences can impact on a person’s mental health, most bereavements don’t cause mental health problems.

Bereavement experiences permeate every area of life, and therefore it is essential that a range of organisations, professions and departments acknowledge its importance and take actions to provide supportive conditions for people who are bereaved.

Issues for future consideration include:

- how to create clear pathways into appropriate immediate, medium- and long-term support
- encouraging greater understanding among bereaved people of ways of supporting themselves, understanding how and when to reach out for further help
- upskilling people’s natural and usual support networks (eg schools, employers) for example through training, and mass communications on how to respond appropriately
- improved pathways into practical community help such as mutual aid, voluntary sector and where necessary statutory services
- increased link up for the first days and weeks between bereaved people and practical, community help such as mutual aid societies and where necessary statutory services
- increased awareness of the range of bereavement support services among the general public and the sector through improved signposting
- increased capacity of bereavement support services in the short, medium and long term to provide 1:1 and peer support opportunities in bereavement, reflecting the tiered model approach
- auditing of bereavement training and learning across all sectors
- targeted development of bereavement related educational resources to support diverse professional audiences to support people who have been bereaved

- clear pathways to support and resources for people experiencing multiple workplace bereavements
- a review of tools / models for those in leadership and management roles within a bereavement context.

Long-term improvements require a coordinated approach, and this can only be successfully developed with input, engagement and support of the wider bereavement community in Scotland.

RECOMMENDATIONS

Recommendation SG should resource the recent proposal and recommendations to improve bereavement support in Scotland developed by SPPC, Scottish Care, NHS Education for Scotland (NES) and NHS Greater Glasgow and Clyde.

The actions recommended included a blend of:

- **Fact-finding** in order to ensure that long-term work is focused on the areas that will have maximum impact. This should comprise a) Rapid review of the evidence/literature; b) Survey of public experiences of bereavement; c) Mapping of formal bereavement services.

- **Immediate action** to enable and support the general public in dealing with bereavement. This should take the form of a high-profile media campaign to encourage and educate the general public to feel more able to support friends/ family/ community who are bereaved.

- **Action planning** – formation of a Reference Group, with appropriate project-management/ administrative support to enable the group to reflect on findings from the fact-finding work, draw on other relevant resources and the views and experience of the wider bereavement sector, and develop recommendations for an Action Plan for improving bereavement experiences in Scotland.

19. PALLIATIVE CARE IN ACUTE HOSPITALS

Introduction

Hospitals are integral parts of the wider health and social care system. They are embedded within and serve their local communities.

In many countries, policy narratives have emphasised prevention of hospital admission towards the end of life[cliii] and campaigning organisations have highlighted that most people responding to opinion polls say they would prefer to die at home.

This narrative has the effect of positioning palliative care in acute hospitals as a problem to avoid, instead of recognising its necessary and valuable contribution. As a result, essential improvements in hospital palliative care can be marginalised.

Scottish Government's *Strategic Framework on Palliative and End of Life Care (2015)* notes the importance of good palliative care in all settings, but makes few specific recommendations about the role, essential contribution or improvement of hospital palliative care.

Where do people want to be cared for towards the end of life?

When asked in the abstract, 'where would you prefer to die?' people may give an uncomplicated answer based on a situation they've imagined rather than the reality they end up facing.

When faced with a real-life situation, individuals and families have many considerations, including safety, comfort and the demands placed on family carers. Options for treatment and care are often determined by place of care. All of these factors will affect a person's preferred place of care/death, and people's preferences often evolve as the realities of serious illness and carer burden are confronted.

- Cost-benefit comparisons between acute hospital and community care (including in care homes) are complex and should include indirect costs borne by informal carers and the wider community.

Current situation

A significant proportion of people currently in Scottish Hospitals are approaching the end of their life …

Palliative and end of life care is a core function of Scotland's hospitals, and represents a significant workload for NHS staff. Studies show that almost one-third of the people being cared for in Scottish acute hospital wards will have died within 12 months[cliv]. For patients aged 85+ nearly half die within a year of admission. Nearly 1 in 10 people in hospital will die during their current admission. Around half of all deaths in Scotland take place in hospital - about 27,000 deaths annually. In Scotland, during the last 6 months of life each person spends an average of three weeks in hospital[clv]. In 2016, each person had an average of 1.65 emergency admissions in the last year of life[clvi]. In a 2016 national cohort study[clvii], 94.9% of people contacted an unscheduled care service in the last year of life with 34% of these calls in the final month. Individuals with cancer had more acute hospital admissions than those with frailty or organ failure. The largest group overall was people dying with organ failure whose unscheduled care pathways often involved a hospital admission. Most people needing palliative care in hospital are in older age. However, people of any age including babies and children, with life-limiting or life-threatening conditions may need palliative care in hospital.

… and many people living with advanced illnesses may benefit from admission to hospital for all sorts of reasons.

Data focused on the last year of life, underestimate the burden of illness and unmet needs of people living with advanced illness over longer periods who can benefit from acute hospital interventions. Reasons for hospital admission include disease-focused investigations and treatment not available in the community, specialist assessment not possible in primary care or available remotely, and management of potentially reversible complications or unrelated conditions. In addition some palliative care interventions themselves are best provided in hospital settings (eg radiotherapy) or in-patient settings (eg some pain interventions).

Decision-making and responding to need when things are uncertain

Whilst population-level data describe patterns of admission, decisions about the risks and benefits of admission to hospital are always taken in the context of individual circumstances and uncertainties. Difficulty in reliably predicting dying is a key uncertainty. Managing uncertainty demands a health and care system which recognises and incorporates the need for proactive care, current care and reactive care. Hospitals play a key role in meeting evolving individual needs and preferences which emerge from uncertainty.

How palliative and end of life care is provided in Scottish hospitals

Generalist Palliative Care

Most palliative and end of life care which people receive in hospital is provided by a wide range of staff from different specialities and professions as part of their role. Many of these staff develop expertise in palliative and end of life care related to the population of patients they care for.

Specialist Palliative Care

Specialist palliative care in Scottish hospitals is provided by multidisciplinary hospital palliative care teams (HPCTs). These teams work primarily on an advisory/ consultative basis, providing expertise and support as requested by the clinical team caring for the patient (for CNS's there is a significant amount of 'doing' as well as advising). The focus of hospital palliative care teams is on complex situations where the needs of patient and family cannot be met by their current team.

Palliative care specialists work alongside and in partnership with other specialties. HPCTs vary greatly across Scotland in terms of their staffing and resources. Specialist medical and nursing staff are the core professionals in HPCTs. Teams may have access to designated physiotherapists, occupational therapists, pharmacists, social workers, psychologists or chaplains, but some rely on collaborative working with other hospital-based colleagues.

The configuration of HPCTs in cancer centres tends to be different. Within this category there is further variation as some cancer centres are on sites which also treat other conditions and the mix and size of site varies. The capacity of teams to meet local demands varies.

One acute hospital has 3 beds designated for palliative care, but most acute services do not operate this model of care. Designated beds have proved valuable in promoting engagement with other specialties and education.

The West of Scotland Interventional Cancer Pain Service is a multi-professional service for patients with cancer pain uncontrolled by conventional analgesia based at the Beatson West of Scotland Centre in Glasgow. The service accepts direct referrals from all West of Scotland health boards and extra contractual referrals from any Health Board. The service runs outpatient clinics and can admit directly into beds at the centre.

Key contributions by specialist palliative care in hospital are:

- assessment and management of complex physical, psychological and spiritual symptoms
- supporting complex clinical decision-making, seeking to apply relevant ethical and legal frameworks alongside clinical assessment and respect for personal autonomy and values
- direct provision and management of symptom management interventions
- providing care and support to those important to the person receiving care, including facilitating bereavement care
- providing specialist advice and support to the wider care team which is providing direct care to the person
- liaison with community and primary care services
- providing formal and informal education and training for the wider hospital community
- attending and providing input to multidisciplinary team meetings, including key decision-making contributions
- providing strategic expertise and leadership to ensure acute hospitals recognise and meet the needs of people approaching the end of their lives.

Through advice, support and education HPCTs build the confidence and capacity of generalists providing palliative care in hospital. They also advocate for a 'palliative' approach for appropriate patients.

What information is available about the quality and impact of palliative and end of life care provided in Scottish hospitals?

Academic Literature

There is evidence that earlier involvement of the HPCT can improve the patient and family experience, reduce length of stay (and internal transfers) and reduce costs of hospital episodes for people approaching the end of life. The scope and quality of this evidence [internationally] is limited. There is real scope for Scotland to contribute to the development of this evidence base.

National Audit of Care at the End of Life

The National Audit of Care at the End of Life[clviii] (NACEL) in England, Wales and Northern Ireland models a self-evaluation and benchmarking approach that could be adapted for Scottish priorities and systems. NACEL examines the adequacy of organisational arrangements and draws on case reviews and family experience measures to understand outcomes. NACEL provides national-level data as well as data to inform local improvement.

Evaluation by HIS

Although there are relevant norms and standards[clix] [clx] which could be used, to date HIS has not undertaken a programme of evaluation seeking to provide assurance about the quality of palliative and end of life care in Scottish hospitals.

Mapping by Scottish Network for Acute Palliative Care (SNAPC)

Through the recently established Scottish Network for Acute Palliative Care (SNAPC), the SPPC has started to map local and national models of acute palliative care in Scotland, adding to the international literature on different options for redesign and improvement.

Models which support joint working, better integration/ communication with community health and care services, and earlier specialist palliative care involvement have all proved to be valuable in improving outcomes. These approaches can also reduce unwarranted variation and waste by ensuring that care is individualised (warranted variation) and focused only on delivering what each person values. In some instances this will reduce costs.

Patient experiences

There have been local small-scale efforts seeking to understand patient experience[clxi] [clxii]. Data from Care Opinion provide useful insights and identify specific issues. Informal analysis by SPPC shows complaints escalated to the Ombudsman include a significant proportion relation to poor experiences of end of life care – though complaints analysis doesn't duly recognise all the good care provided which goes unacknowledged.

Local insights

Hospital palliative care teams generally have reliable insights into strengths and weaknesses of local practice and provision within their institutions. Those in working in the community also bring insights: about the care their patients receive whilst in hospital; about the effectiveness of information transfer into and out of hospital.

How good is palliative and end of life care in Scottish hospitals?

This is a difficult question to answer robustly as there are no national data sets which support conclusions.

However, bringing together the information that is available (as outlined above) it is possible to make the broad assertions outlined below.

Despite considerable challenges, much excellent palliative and end of life care is provided in Scotland …

Providing palliative and end of life care for all those who can benefit in the busy environment of a large acute hospital is challenging. Cultural attitudes which view death, dying and bereavement as failure are part of the challenge. Despite this, there is much good palliative and end of life care provided in Scottish hospitals. This is achieved through the commitment and compassion of many hospital staff, efforts to enhance their skills, knowledge and confidence in palliative care, and through effective collaboration between specialist and non-specialist staff.

Underpinning the provision of good palliative and end of life care are cultures that support shared decision-making, acknowledge uncertainty, and place value on care that focuses on quality of living and dying and reflects individual patient and family priorities.

… and there are areas where there is significant scope for improvement.

Although there are no data available to evidence the frequency of their occurrence, the following deficiencies[14] are identified by stakeholders, and represent scope for real improvement:

Failure to identify people with palliative care needs systematically

If HPCT advice is needed but sought too late, opportunities to improve patient and family experience and outcomes are missed. This mostly results in unmet need, but the lack of a systemic approach can also result in inappropriate referral to HPCT.

Failure to have timely, open and honest conversations in the context of uncertainty and deteriorating health[15]

Consequent missed opportunities to align care with what matters most to each individual include:

- patients and families left unaware of their health situation and available options for care
- burdensome investigations and interventions of low benefit
- treatments that do not reflect people's life goals and priorities
- missed opportunities for rapid discharge home.

Lack of anticipatory care planning and care coordination leading to avoidable re-admissions and poorer outcomes in the community

As noted in Chapter 17 admission to hospital represents an opportunity to identify systematically and reliably people with palliative and end of life care needs at an earlier stage. They should also be identified early in their hospital admission. If identification has already taken place in the community, robust processes to share this information are important. ACP discussions should follow identification. Triggers, tools, templates and

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[14] Most of these deficiencies are not unique to the hospital setting

[15] The responsibility for such conversations does not lie solely with hospital staff and, clearly, primary care and community staff have a crucial role. However, hospital staff necessarily encounter patients at crucial junctures in their journey (deterioration leading to admission, investigations leading to new information about diagnosis and prognosis) when good decisions can be made or opportunities missed.

guides can encourage and support this process[clxiii] [clxiv]. However, in many instances what is required is a broader approach that supports cultural, attitudinal and behavioural change. The barriers to identification and ACP need to be understood and addressed from the perspectives of generalists[clxv]. Such barriers may include time, confidence, ownership, skill, awareness of support and cultures. Relationships with HPCT, models of partnership working and formal and informal education are key.

Inadequate symptom management

Other unidentified and unmet holistic care needs (eg psychological, spiritual and practical concerns)

Spiritual and psychological concerns and the needs of family/carers are less likely to be assessed and addressed than physical symptoms in the absence of HPCT involvement (and there is scope for improvement when HPCT are involved also). When the care team recognise that someone is in the final days of life, symptoms and holistic care needs are often managed better. However, recognising that this point has been reached can be difficult, especially in situations of uncertainty.

Inadequate communication, involvement and support for the person's family

Lack of dignity/ privacy for people and families in the time around death due to the physical environment

The physical environment is important in enabling the privacy and dignity of people and their families towards the end of life. This can mean access to single rooms, or more personalised ways of returning the possessions of a person who had died. With 27 000 deaths occurring in Scotland's hospitals each year, privacy around death should be part of baseline provision. Innovative work in Ireland[clxvi] and promoted in England by the Kings Fund[clxvii] provide examples of small and larger measures, to add to examples of good practice across Scotland.

Variable generalist palliative care

The extent and quality of palliative care provided by generalists often varies by ward and even by practitioner. There are good examples across Scotland of collaboration and mutual learning between hospital palliative care teams and other specialities. This varies across boards, hospitals and specialties.

RECOMMENDATIONS

There are solutions to the current deficiencies and in many cases these are already in operation in some wards and hospitals. The challenge is to create conditions where the solutions are implemented consistently. Key to meeting this challenge are governance and resources.

With the right support and commitment, many of the necessary changes can be designed and delivered locally. Some aspects of palliative care, such as evidence-based pain and symptom management guidelines, benefit from national collaboration.

A recent report published by Marie Curie and Glasgow University, with input from Macmillan Cancer Support, Palliation and the Caring Hospital (PATCH), SPPC and other stakeholders, examines the past present and future of palliative care in acute hospitals in more depth than the space in this chapter permits. The report makes very similar recommendations to those set out below[clxviii].

Establish Effective Governance and Leadership

Recommendation Arrangements should be put in place to ensure local management and clinical leadership sustain a focus on improving palliative and end of life care in every acute hospital in Scotland. The most effective arrangements for this should be determined locally between NHS Board and HSCP management.

Recommendation As part of this process of maintaining focus a senior management-level nominated champion for care towards the end of life in hospital should be identified. These champions should link with the IJB lead roles suggested in existing Scottish Government guidance on the commissioning of palliative and end of life care[clxix].

Recommendation Alongside the National Leadership proposed elsewhere in this paper these local roles should create a network for leadership and whole system thinking and improvement.

Resource and Infrastructure for Collaboration, Improvement and Spread

There are a number of different models which SG and Healthcare Improvement Scotland (HIS) has used to support and enable local change in priority areas (improvement collaboratives, Change Funds, Scottish Patient Safety Programme(SPSP)).

Recommendation An appropriate infrastructure to support collaboration, improvement and spread should be developed with the input of key stakeholders. As part of this infrastructure, the Scottish Network for Acute Palliative Care (SNAPC) should be funded to develop and sustain the collaborative work that has been highly effective during COVID-19.

Recommendation Funding to support clinical leadership, support quality improvement, develop the evidence base, and meet other costs of implementing sustainable change should be available.

Recommendation There should be an explicit and properly resourced focus on palliative and end of life care within other established relevant programmes (eg Realistic Medicine, SPSP Acute Care Deteriorating Patient Programme).

Use and develop data for management and improvement

Recommendation Development of better data collection and analysis should run alongside service improvement.

Recommendation Routinely collected data should be better utilised to understand who is admitted and readmitted to hospital towards the end of life, the circumstances of that admission, their length of stay, what interventions they receive and the related outcomes, and how admissions sit in relation to other service use.

Recommendation Local specialist palliative care activity data should be developed and integrated with national datasets so that the impact of

HPCT can be better understood and evidenced. Work underway by the Scottish Network for Acute Palliative Care can provide the basis for this.

Recommendation As argued in Chapter 10 measures of quality and patient/family experience of care towards the end of life in hospital should be included within an approach that links an individual's care in different settings.

Scrutiny and Assurance

Recommendation As recommended in Chapter 10 a national framework for establishing and assuring the quality of palliative and end of life care should be developed, and the framework should encompass acute hospitals and include scrutiny conducted jointly by HIS and CI.

Recommendation Scotland should learn from the National Audit of Care at the End of Life and adapt that approach for Scottish systems, circumstances and priorities.

Identification and ACP

Recommendation Reliable systems need to be put in place which enable people admitted to hospital to have any palliative care needs identified at an early stage, with ACP discussions explored following identification.

Technology

Recommendation As discussed in Chapter 17 an editable ACP (with a patient portal) to support the handover of information between primary care, hospitals, unscheduled care services, the ambulance service and social care needs should be developed and implemented as a matter of urgency.

Public as Partners

Recommendation The potential to develop models of volunteer support to people reaching the end of life in hospital should be explored building on work by Marie Curie, Compassionate Inverclyde and others[clxx] [clxxi] [clxxii].

Physical Environment

Recommendation Each hospital site should review how changes to the physical environment could further promote dignity and privacy within their facilities.

Capacity of HPCTs

Recommendation The capacity of HPCTs should be reviewed in the light of their key role in many of the other recommendations in this paper (education, greater partnership working, leadership, improvement) and to ensure capacity to enable access to specialist hospital palliative care on a 24/7 basis in the face of rising population need.

20. PALLIATIVE CARE IN THE COMMUNITY: CONTINUITY, CARE CO-ORDINATION AND CAPACITY

Introduction

Whilst hospital use increases in the last years of life, in general people still spend most of their time living at home or in a care home (which becomes their home). At home people may need support from the primary care team and from social care support services, and this is generally referred to as 'care in the community'. As we explore in Chapter 22 hospices also play a key role in supporting people at home towards the end of life. The bulk of care and support is usually provided by family and other community members.

The Role of Primary Care Services

Primary care services play a central and vital role in ensuring good people receive palliative and end of life care. Key functions of primary care include:

- early identification of people with palliative care needs
- assessment or support needs[16]
- anticipatory care planning
- timely referral to other services
- service co-ordination
- the delivery of palliative and end of life care in the person's home or care home.

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[16] In last months of life people often start to struggle with mobility issues and are more at risk of falls. Early assessment and intervention from physio or OT services can help to reduce falls. Nutritional assessments with dietetic involvement can reduce loss of weight and muscular strength. Proactive assessment of vision and hearing can help people to remain connected and engaged within home even when they are dying. Failure to do so can lead to people withdrawing into themselves and becoming depressed.

Palliative care is recognised both nationally and internationally as a core activity for primary care teams.

In carrying out this lead role primary care teams need adequate time, skills/ knowledge and easy access to advice and support from different specialities including specialist palliative care. GPs, District Nurses and social care staff are key to the provision of high-quality palliative and end of life care.

The need for involvement of and interactions between GPs (as expert medical generalists) and clinicians working in other specialties will vary according to the complexity of the case in question. In non-complex cases towards the end of life there may be little need for medical or other clinical intervention. At the end of life people will often be very well cared for primarily by families/ unpaid carers and social care workers, with nursing support as required.

However, where a case is more complex, for example when someone has multiple conditions, unclear prognosis, cognitive issues, or there's a need difficult judgements about the utility of interventions/ investigations, there should be access to GPs and wider primary care team. Polypharmacy and regular medication review is also an important issue - the risk/benefit ratio of many drugs changes when people are nearing the end of their life, and harm can be caused by continuing some medication. Where complexity or other circumstance r***equires, the primary care team should have access to specialist palliative care advice and support.***

Current Position

Directed Enhanced Service

Since 2012 GP practices in Scotland have taken part in the Palliative Care Directed Enhanced Service (DES)[clxxiii] which has provided financial support to improve palliative care. Specifically the DES requires primary care teams to take a more systematic approach by: identifying people with palliative care needs and placing them on a register; creating a summary ACP which can be shared with other settings (now called the KIS); and undertaking reflective learning on a sample of deaths within the practice. In 2017 69% of people with advanced progressive illness had a KIS before they died[clxxiv]. This is explored in more detail in Chapter 17 on Thinking and Planning Ahead.

Unscheduled Care

A recent study[clxxv] has shown that nearly 95% of people in their last year of life have unscheduled care contacts with NHS24, Primary Care Out of Hours, Scottish Ambulance Service, A&E and or emergency admission. The median number of contacts is 5, with 5% of people having 20 or more contacts. Over 34% of contacts are in the last month of life. Patterns of access vary significantly according to the main underlying condition and also in relation to the level of deprivation. Even with further development and improvement of anticipatory care planning approaches reactive care, as evidenced by this data, will remain a critical and major component of good care towards the end of life.

Workforce and Workload

The workforce and workload issues in primary care, which are well recognised, impact on palliative and end of life care. The need to listen, to explore and to support shared decision-making in complex situations takes time and will often require longer than a 10-15 minute GP appointment. Community nursing staff also require more time to spend with people as they approach the end of life, and to move away from a task-driven workload. Multi-disciplinary team meetings are of key importance for people with complex health and palliative care needs. The increased use of virtual meetings over the last year due to COVID-19 (and reduction in travel required) has made it easier for these meetings to include specialists. Adequate priority and time must be dedicated to allow staff to attend these meetings, so that effective discussion and planning of care can take place.

Increase in deaths at home

During 2020 the number of people dying at home increased significantly. A total of 16,976 home deaths were recorded since the start of the pandemic and the end of 2020, or a 43% increase over the same period in 2015-19.

In Chapter 21 we explore current provision of social care support towards end of life, both in care at home and also care homes.

Integration and Co-ordination

People approaching the end of their life frequently move between institutions and settings (home, care home, hospital, hospice) and they often need rapidly responsive support from multiple professionals. People value smooth transitions, timely flow of information and continuity of high-quality care. This places a premium on collaborative integrated working between different parts of the NHS, and between Independent and Third Sector providers of health and social care. HIS has recently produced a useful review of evidence for improving continuity and care co-ordination in palliative care[clxxvi].

Care Homes

People living in care homes should be no different from people living in their own homes in terms of their ability to access healthcare services. Due to the particular characteristics that make it necessary for someone to live in a care home, there is an even greater need for high quality healthcare and primary care has a key function in achieving this outcome. The care home team and the person's keyworker should work with a core team that includes social work, pharmacy, general practice and community nursing. An extended MDT should surround and support the core team as required.

Inequalities

The *Deep End Project*[clxxvii] has highlighted the role of general practice in identifying and responding to social deprivation. The project also highlighted the operation of the inverse care law in Scotland which means that those communities with greatest need have proportionately fewer healthcare resources available. The measures advocated by the Deep End Project include: embedded co-workers (link workers, social care workers, alcohol nurses, financial advisors and mental health workers); extended consultations for some people. Such building of capacity in deprived areas will help to improve people's experiences of living with serious illness, dying and bereavement.

Looking Ahead – will more people die at home?

Recent research supported by Marie Curie has examined how the projected increase in deaths over the next 20 years could be reflected in changes in place of death . The study models four different scenarios showing the absolute number and proportion of deaths in four common settings (Home, Care Home, Hospice and Hospital). According to this modelling, if home and care home deaths remain at 2016 levels hospital deaths would increase by 30% by 2040. Whilst these are projections not predictions there is a clear need to consider how capacity in community settings can be increased to meet rising demand, and to plan for that outcome.

The rapid shift in place of care and death that took place in 2020 (outlined in Chapter 13) was clearly a direct result of the COVID-19 pandemic and the conditions it imposed. Though the specific reasons for this shift require further exploration, there were several reasons why people would endeavour to avoid hospital during 2020. Public health advice was to *'stay at home, protect the NHS, save lives'* and therefore people became accustomed to trying to reduce pressure on hospitals. Staying at home reduced the risk of catching COVID from staff and patients in busy hospitals. There were rigorous visiting restrictions in place, meaning that once a person was in hospital they feared becoming completely isolated from family.

This shift was enabled by community staff taking on an increased and more complex workload with, in some instances, enhanced support from specialist palliative care services which rapidly re-orientated.

It is important to find out more about the care these people were able to receive at home, to what extent this felt like a 'choice' or a COVID-driven necessity, and about the experience of families who were looking after people who died at home. We also need to understand what the impact has been on staff who have been providing care in very difficult circumstances.

Key questions which can help future development are: how many, if any, of these deaths at home were potentially avoidable by curative hospital treatment; what were the experiences and outcomes of individuals who died at home and their families; will public preferences in future be substantially different in the absence COVID-19; is the workload the primary care team and social care staff (and enhanced specialist support) experienced in 2020 in any way sustainable without increased investment [and if not what investment is required]; what are the education, training and other workforce implications of a significant increase in numbers of people dying at home?

RECOMMENDATIONS

Workforce

Recommendation There should be careful monitoring of the impact of the actions being taken by Scottish Government to ensure that there are enough GPs and primary care nurses[clxxviii]. Without a suitably skilled GP and District Nursing workforce of adequate size primary care cannot deliver palliative and end of life care adequately.

Recommendation An adequate social care workforce should be recruited and retained and is fundamental to the delivery of palliative care in the community. SPPC supports the relevant recommendations of the Independent Review of Adult Social Care[clxxix].

Recommendation The roles of Advanced Nurse Practitioners, CNSs and District Nurses are critical and should developed, with careful thought given to their interrelationships and the different needs in different in different geographies (and with each clinical case).

Integration, Co-ordination, Communication and Continuity of Care

Recommendation Primary Care professionals should have 24/7 access to specialist palliative care advice and input, alongside other specialities. Currently the degree of access varies by geography and time of day. There is a need to achieve consistent access, though the arrangements to achieve this will vary locally.

Recommendation Primary care teams should have better access to hospital at home and hospice at home[17] services, with clear criteria for referral.

Recommendation The availability and responsiveness of social care services should be improved building on models such as the Marie Curie

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[17] The term 'hospice at home' is applied to a wide range of different services which involve direct care by hospice staff in a person's home. Sometimes the service might include medical and nursing care. In other instances the service might consist of social care support. All hospice at home models work in partnership with other primary and social care services.

Fast Track Service which works in partnership with primary care and is proven to reduce unnecessary hospital admission and expedite discharge from hospital at the end of life[clxxx].

Recommendation A single integrated digital sharable health and social care record should be developed. (see also Chapter 17)

Recommendation Effective communication about palliative care needs should be facilitated by the consistent use of language based on shared definitions and understanding. A project in Fife has shown how taking this approach across the local health and care system can improve access to the right services at the right time, reducing delays, misunderstandings and mismatched expectations[clxxxi].

Recommendation People and their families should be able to access advice and support 24/7, and hubs such as the Goldline service (an NHS nurse-led 24/7 telephone and video consultation service) have been shown to play a valuable role in co-ordinating care, providing case management and in offering responsive out of hours support to people and their families[clxxxii].

Care Homes and Care at Home

(see also recommendations in Chapter 21)

Recommendation Local resourcing and organisation of primary care teams should be such that care homes receive the support they need in providing palliative and end of life care.

Recommendation Rapid access to medications is an important aspect of end of life care in care homes and SPPC supports a change in regulations to allow care homes to stock common end of life medications. Anticipatory prescribing for individual residents reduces the risk of delay but results in wastage when the medications are not used.

Anticipatory Care Planning

Recommendation A digital ACP which can be accessed and updated in all settings including social care should be developed in order to improve the flow of information needed to inform care to and from secondary care, hospices, care homes and Out of Hours services.

Recommendation The digital ACP should be accessible to the person whose preferences and future care it records.

Recommendation Barriers to timely and effective anticipatory care planning specific to primary care teams should be addressed. These barriers include: systems and processes for proactively identifying people who are likely to benefit; building the skills and confidence of staff; adequate time for sensitive conversations, including the review and update of plans; improved ICT for recording and sharing plans.

Recommendation Enhanced roles (these could be AHP, nursing, potentially complemented by lay people) within the primary care team with an explicit focus on ACP and eliciting values and preferences should be further developed.

Quality Measures

Recommendation Measures of care quality and experience for people approaching the end of life and receiving care in the community should be developed.

21. SOCIAL CARE

Introduction

People and their families want the care and support they need to live their lives in difficult circumstances. They do not generally differentiate between what the system chooses to define as health care or social care. Despite progress with integration, the cultural, philosophical and institutional distinctions between health and social care are deeply engrained and therefore need to be part of how we frame this analysis of improving people's experiences. Social care has a different emphasis from that found within traditional bio-medical/ clinical narratives of healthcare.

> *"What we [social care] do is get alongside people when they have very significant challenges in their lives and struggle to participate in society as full citizens, and we support them, wherever possible, to make their own decisions and move their life forward as best they can. Where the world makes it very difficult for people to do that because of their age, impairment or whatever, we do what we can to help by ensuring that they are comfortable, are cared for and can have at least some kind of independence and peace of mind in their individual circumstances."*
>
> Annie Gunner-Logan
> Director of the Coalition of Care and Support Providers in Scotland
> (Health and Support Committee Inquiry into Social Care)

The Significance of Social Care Towards the End of Life

The provision of adequate social care can make it possible for someone living with serious illness to maximise independence and quality of life, even as their health declines. Social care also supports people who are informal/ family carers, often making the difference between a role which is tough but sustainable and a role which ends in crisis and collapse. Social care staff can also play an important role in anticipatory care conversations and planning. Key social care supports to people approaching the end of life include care homes, care at home, respite care and housing support.

In an average week around 60,000 people receive around 700,000 hours of care at home. Well over half of these are frail elderly people[clxxxiii].

At 31 March 2017, there were nearly 33,000 older people living in a care home. This compares to just under 22,000 available staffed beds in all specialities in the NHS[clxxxiv]. The percentage of long stay residents living with dementia (either medically or nonmedically diagnosed) in a care home for older people was 62%[clxxxv].

There has been a general tightening of eligibility criteria to access social care (other than on a self-funding basis). People entering care homes now do so with high levels of acuity and at an older age than used to be the case.

In terms of levels of need care homes are now closer to being mini hospitals than to the retirement homes of old. The median completed length of stay for people living in care homes for older people is 18 months (2017)[clxxxvi]. The vast majority of people in care homes for older people have palliative care needs. 20% of deaths in Scotland are in care homes.

Current Position

There are a number of serious and interrelated challenges impacting on the quality, accessibility and sustainability of social care generally, including the palliative and end of life care provided by care at home support and in care homes. These fundamental sector-wide challenges were the focus of the recent Independent Review of Adult Social Care[clxxxvii] and its recommendations propose fundamental change. Scottish Care's report *Coileanadh*[clxxxviii] presents a vision and framework for necessary change in social care which complements the report of the Independent review.

Financial Pressures

There has been a longstanding failure across the UK to put the funding of social care for older people on a sustainable footing. Since 2010 this has been compounded by the impact on the public purse of the 2008 global financial crisis. In addition, as explored elsewhere demographic trends have seen (and will see further) increases in older people with care needs. Hard-pressed local authorities (now IJBs) have responded to acute budgetary pressures with procurement processes which have exerted downwards pressure on provider costs, eventually impacting on quality of care. Financial pressures have also led to a tightening of eligibility criteria, in turn restricting access to social care. Typically, social care is now only available later and at a higher level of need – opportunities for prevention are missed. Tightened access to respite care causes carer collapse, avoidable crises and unnecessary hospital admission.

Tightened budgets to commission social care are making it difficult for providers from the Independent and Third Sectors to continue providing support. A recent survey found that 86% of care at home providers are worried about sustainability and survival, with 24% extremely concerned[clxxxix]. Some Third Sector providers are being forced to withdraw from contracts because they are running at significant financial deficits and because the level of funding available doesn't allow support to be provided in an acceptable way and to acceptable standards[cxc].

Approaches to Commissioning

Linked to (and compounding) financial pressures the mode of funding social care has created further problems. For care at home strategic commissioning has been implemented through procurement processes which specify time and task rather than person-centred flexible care. Such approaches make things simpler for devising, monitoring and managing contracts and driving down costs. However, they result in services which are unresponsive to individual needs and circumstances, exemplified by the 15-minute visit.

The procurement of care home places has failed to adequately reflect the rising level of need of most residents.

Workforce

Recruitment and retention of staff is very difficult in the social care sector. There are several reasons for this:

- Rates of pay remain low and this reinforces the positioning of social care as a low status career with limited opportunities for progression.
- The UK government's approach to immigration (Brexit and the proposed replacement regime) make recruitment more difficult.
- Working predominantly with frail elderly people social care staff regularly experience the death of clients[cxci]. The individual and cumulative impact of these losses increases staff absence and harms staff retention.

All of this has an impact on staff development. It is harder for staff to find time to build the skills and confidence to provide palliative care when there are staff shortages. Even when this is achieved, high staff turnover undermines the building of sustained capacity.

The UK government's response to concerns about the new immigration regime is that recruitment and retention issues should be addressed via reforms to the sector (eg improved pay and conditions). However, since this will take time transitional sector-specific arrangements should be put in place. Social care roles should be acknowledged as an area of occupational shortage. Salary thresholds should be lowered so as to include social care roles. Social care roles should not be characterised as 'unskilled'. The mental health and emotional wellbeing of social care staff needs to be better supported.

Inadequate Integration

Although neither residential nor nursing homes are clinical settings many residents have significant clinical needs. It is important therefore that care homes have effective relations with and adequately resourced support from local primary care teams, but this is not always the case. Similarly social care services need to be more rapidly accessible to other parts of the health and care system. People approaching the end of life may have needs which change rapidly, so support needs to be flexible and responsive. Some hospital admissions may not be necessary where adequate social care can be put in place rapidly. Currently many discharges from hospital are delayed whilst social care support is put in place. In 2018-19, 35% of delayed discharges were caused by people waiting for care arrangements to be complete, 26% were waiting for a care home place and 16% were waiting for a community care assessment[cxcii]. Around 400 people died in hospital whilst waiting to be assessed for social care or for care arrangements to be made.

Whilst the broad philosophy of self-directed support is right, for many people approaching the end life, with poor health and rapidly changing circumstances, self-directed support as currently embodied in slow, unresponsive, bureaucratic systems of direct payments is not an attractive proposition.

Technology to Enable Care

The further introduction of technologies which promote independence, choice and control should be supported. However, there are complex ethical and practical issues surrounding the introduction of new technologies into care. This is particularly true where cost pressures provide drivers to introduce technology. Technology should not be used to replace human relationships which lie at the heart of social care:

> *"Social care is a human interaction which goes far beyond the carrying out of particular functional tasks. It is not solely about the maintenance of health, but rather the fullest achievement possible of individual potential in a manner which is holistic. The relationship dynamic involved is one which is mutual, reciprocal and trust-based."*
>
> Scottish Care
> Techrights: human rights, technology and social care (2019)

RECOMMENDATIONS

The Independent Review of Adult Social Care

SPPC supports the scope and broad approach of the recommendations produced by the Independent Review of Adult Social Care which recognise the need for radical change, the need for clearer accountability, the role of national approaches, the need for increased funding, the need for new approaches to commissioning and a focus on people's human rights, preferences and individual outcomes.

Recommendation In taking forward the recommendations of the Review SG and other stakeholders should, at each stage of the necessary developmental work, consider explicitly how proposed changes will impact on people living with serious illness and who are approaching the end of their lives and on the improvement of provision of palliative and end of life care.

Funding

Recommendation There must be increased, adequate and sustainable funding to deliver improved outcomes for people needing social care.

Without increased funding important programmes of structural and institutional reform will fail and palliative and end of life care will deteriorate.

Workforce

Immigration

Recommendation The UK government's new immigration regime should be revised to reflect the vital ongoing contribution of migrants to the provision of social care.

Pay, conditions and status

Recommendation Pay and conditions should be improved to support recruitment and retention of social care staff.

Recommendation The scale of efforts to promote social care roles as valuable and rewarding should be increased, alongside a continuation of the 'professionalisation' of social care roles.

Training and Development

Recommendation There should be further investment in training and development for social care staff, and funding to enable this should be a core component of future planning/commissioning processes.

Recommendation More use should be made of virtual learning approaches (such as ECHO), and formal and informal face-to-face training opportunities as part of improved integration of social care with primary care and specialist services.

Recommendation At a local level opportunities to co-locate health and social care staff should be exploited.

Rapid Access to Person-centred flexible care

Recommendation Planning, commissioning and procurement frameworks should enable the provision of person-centred flexible support. Referral, assessment and delivery processes should ensure that social care support can be put in place quickly to prevent crises, reducing inappropriate hospital admissions and delayed discharges.

Places for Care

Recommendation Planning and commissioning processes should take account of the increasing need for palliative and end of life care over the next 10 years, together with projected changes in household structure, and take a strategic approach to the adequate provision of places for care. Depending on local needs this may involve increasing care home capacity, care at home capacity, housing support, and flexible models such as 'care villages'.

Care Homes Integration

Recommendation Primary care services should be adequately resourced to provide support to local care homes (see also Chapter 20).

Recommendation Providers of specialist palliative care should be resourced to provide education, advice and support to care homes.

Recommendation Information systems should enable sharing of data between health and care settings to inform care.

Recommendation There should be support for all providers to ensure adequacy and compatibility of technology.

Advanced Dementia

Recommendation Support for people in care homes should encompass the specific needs of people with advanced dementia, including proactive and holistic approaches such as the Namaste Care program[cxciii] and Adaptive Communication[cxciv].

Technologically Enabled Care

As promoted by Scottish Care, a human-rights based Ethical Charter for Technology and Digital in Scotland should be developed, which would provide a framework and guidance to support local decision-making about technologically enabled care.

22. HOSPICES AND NHS SPECIALIST PALLIATIVE CARE UNITS

Background

In Scotland, there are 14 independent voluntary hospices for adults, six NHS specialist palliative care units (NHS SPCUs) and two hospices for babies, children and young people.

Adult hospices and specialist palliative care units serve similar functions, though they are funded and administered differently. Therefore, each NHS Board is served by either adult voluntary hospice(s) OR an NHS specialist palliative care unit.

Seven NHS Boards are served by the 14 independent voluntary hospices. Eight NHS Boards are served by six NHS specialist palliative care units (three island health boards share a link with one unit)[cxcv].

Children's Hospices Across Scotland (CHAS) runs two hospices. Its hospice and other services are available to children in every health board area.

In total these arrangements provide at least some access and cover for specialist palliative care across Scotland.

Terminology

'Hospice'

Some of the NHS units have 'hospice' in their title or are informally referred to as hospices locally. However, in this paper we use the term 'hospice' to refer to Third Sector organisations (charities) which provide specialist palliative care (including inpatient services).

'Hospice Care'

There are various definitions of 'hospice care'. In the USA the terms 'hospice' and 'hospice care' are generally used to refer to inpatient or at-home care for patients with terminal diseases *who are estimated to* *live six months or less* (a period relevant to their health insurance system).

In the UK some definitions of 'hospice care' are similar to definitions of specialist palliative care[cxcvi][cxcvii].

In this paper we use 'hospice care' simply to mean care provided by a hospice.

The Role of Hospices and NHS Specialist Palliative Care Units

Hospices and NHS SPCUs are both providers of specialist palliative care. The other key locus of specialist palliative care provision are the Hospital Palliative Care Teams which are discussed in Chapter 19. As described earlier in this paper specialist palliative care can help people with more complex palliative care needs and is provided by specially trained multi-professional specialist palliative care teams. Historically adult hospices and NHS SPCUs cared primarily for people with cancer. However, for many years they have increasingly provided care for people with any life limiting diagnosis (although people with cancer remain the biggest single group). At CHAS children with cancer represent a minority of those supported.

Hospices and NHS SPCUs make a huge contribution to the provision of palliative and end of life care in Scotland. Firstly they provide services directly to people approaching the end of life and their families. Secondly they support palliative care development and provision in other settings through advice, guidance, education, advocacy and leadership.

Direct Care

The range of services provided by each individual hospice and NHS SPCU varies. Core components include inpatient services, community palliative care (including remote care and support), bereavement support, family support, outpatient clinics and day care. CHAS has a strong in-hospital presence funding specialist palliative care teams in every children's hospital, helping to provide seamless care between settings. In 2018-19 hospices provided 254 inpatient beds and NHS SPCUs a further 84. During the pandemic hospices closed some beds so as to deploy staff to support care in other settings, and in some cases this is expected to be a permanent shift. It should be emphasised that the majority of care provided by hospices and NHS SPCUs takes place outwith the hospice/

unit. In addition to inpatient care other services may include: drop-in/ information centres; complementary therapies; lymphoedema services; respite care [CHAS]; volunteer support/ befriending services; transport; support to take part in activities or special experiences; support to transition from children's to adult services. Whilst hospices and SPCUs do provide end of life care onsite many admissions are for the purpose of assessment and management of complex symptoms after which people are often discharged, though there is often an ongoing relationship with the patient including advice and community care.

Support to the Other Settings

In addition to the delivery of direct care hospices and NHS SPCUs provide advice and support to non-specialists providing care in other settings including GPs, district nurses, care home staff and hospital ward staff, and also to staff working in prisons, homelessness services and learning disability services. This support is available whether or not the person being cared for is previously known to the hospice or NHS SPCU. Hospices and NHS SPCUs participate in local out of hours arrangements which provide telephone advice and support across the health and care system.

Education

Hospices and NHS SPCUs provide education and training for staff across the health and social care system on a range of topics including symptom management; breaking bad news; grief, loss and bereavement; and spirituality in healthcare. In addition to formally structured training and education activities (including undergraduate and postgraduate education), they support learning and development by other health and care professionals through routine joint working and the provision of advice and information.

The Distinctive Contribution of Scottish Hospices

Scotland's hospices are owned, governed and financially supported by the communities they serve. In the Scottish health economy hospices are unique – they are Third Sector organisations which deliver core clinical activities, including inpatient services, to meet the needs of their local populations. In 2018-19 hospices spent over £87m. Hospices need to raise over £56m each year from the public, with additional funding from the statutory sources accounting for around 35% of their income[18][cxcviii]. By contrast NHS units are 100% funded by government (although many have associated charitable funds to pay for ‘extras’). In 2015 hospice expenditure accounted for 18% of the Third Sector’s total contribution to Scotland’s health economy[cxcix] - hospices contribute significant financial resources to the provision of palliative and end of life care. Independent health economic evaluations have evidenced a very good return on investment of public funds in hospice services[cc].

In 2018-19 an estimated 19,000 people received clinical care from a hospice with 81% of care provided in the community[cci].

Hospices are leading advocates for improving people’s experiences of living with serious illness, dying and bereavement. Hospices listen to the views and experiences of the communities in which they are rooted. Hospices bring resulting insights to try to inform and influence local, regional and national decision-making processes. This includes working in partnership and being active contributors to strategic and clinical networks, planning processes and policy-development groups, responding to consultations, and proactively exploring how hospices can be helpfully involved as new processes emerge.

Hospices nurture innovation, and because of their size and structure can often explore new ways of working more easily than larger public sector organisations. Independent governance and funding can mean hospices are well placed to provide leadership and broker collaboration[ccii]. Many hospices are leading or involved in research to improve palliative and end of life care.

In recent years many hospices have instigated initiatives to build community capacity to provide informal support towards the end of life. These range from volunteer-delivered befriending services to compassionate communities projects which take a community development approach to foster community-led action[cciii]. This work isn’t about specialist palliative care, but about partnership with local communities, which builds community capacity to improve people’s experiences of living with serious illness, dying and bereavement in the broadest sense.

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[18] These figures exclude the 2 Marie Curie hospices since comparable data was not available.

Current Situation – Hospice and Specialist Palliative Care Unit Response to COVID-19

In Chapter 13 we explored the challenges presented by the COVID-19 pandemic and responses relating to palliative and end of life care. NHS SPCUs and hospices played a key role in leading change, usually in collaborative partnership with other parts of the health and care system[cciv].

The shift in the place of death was a key challenge. From the beginning of 2020 until mid-March 2021 the total number of all deaths at home increased 36% compared to the average number of people who died at home in the equivalent period in 2015-2019. This shift in place of death was supported by the rapid reconfiguration of services and refocussing of resources.

Developments responding to COVID-19 included:

- new and expanded community-based models (community teams, hospice at home, rapid response services)
- provision of an inpatient end of life care service for people diagnosed with COVID-19
- establishment of Hubs to support inter-agency and MDT communication and collaboration, and to provide information and support to people and their families
- 24/7 advice line across all care settings
- 7 day working patters
- redeployment/ refocussing of specialist palliative care staff from hospices and NHS specialist units to support care in other settings (acute hospital, care homes and community)
- establishment of virtual services (day services, outpatients, consultations, bereavement support, virtual ward rounds)
- delivery of meals to disadvantaged households
- repurposing of buildings
- development/ extension of staff welfare services, including staff in other settings (hospital, care homes)
- working to set up and sustain care packages in partnership with NHS and local authorities to facilitate more rapid discharge home from hospital (CHAS)
- establishment of 24/7 easy access single points of access
- establishment of rapid response integrated teams

- use of ECHO and other approaches to virtual learning
- support for care home staff dealing with multiple losses in traumatic circumstances
- expansion of bereavement services.

Scottish hospices have produced a summary of some clinical innovations they developed in response to COVID-19[ccv]. Other specific examples of reconfiguration, innovation and research can be explored in the SPPC's poster exhibition[ccvi].

Other Responses

In addition to service changes and delivery hospices and NHSSPCUs were also led or were key participants in a number of other developments:

- the rapid development of two national COVID-specific clinical guidelines; *Guidance for when a person is imminently dying from COVID-19 lung disease*; and *Guidance for supporting end of life care when alternatives to medication normally given through syringe pumps are required*
- practical resources for professionals (and carers) administering medication
- *COVID-19:palliative care toolkit*[ccvii] - a resource for health board planners aiming to identify key risks and ensure continuing access to and delivery of palliative care medicines
- local frameworks and guidelines
- guidance on visiting in hospitals and care homes which addressed 'end of life' situations
- resources to support effective communication with people and their families about anticipatory care planning
- palliative care education for staff unaccustomed to or needing more help dealing with symptom control and mortality[ccviii]
- leadership of and participation in research projects seeking to understand COVID-19 and palliative care.

Through the contribution of expertise, rapid innovation and leadership NHS SPCUs and hospices played a vital role in addressing the suffering brought by COVID-19. Their role in supporting the COVID-19 related shift in place of death demonstrates the importance of these organisations in meeting the challenge of increasing need for palliative care in the next 20 years.

RECOMMENDATIONS:

Recommendations Relating to Hospices and NHS SPCUs

Recommendation The workforce and models of care of hospices and NHS SPCUs should be reviewed to ensure they are adequately resourced to meet the projected growth in demand for and complexity of palliative care, especially in the community. This review should ensure that in addition to meeting demand for direct care through 24/7 services, that hospices and NHS SPCUs are resourced to build the capacity of the wider health and care system through 24/7 advice and support, education, partnership working, research, innovation and leadership.

Recommendation The experience and expertise of hospices and NHS SPCUs should be fully utilised by planners and commissioners in developing plans and programmes to identify, assess and meet the palliative care needs of the local population, including the needs of people in disadvantaged groups.

Recommendations Relating Specifically to Hospices

Recommendation Government and Integration Authorities should continue to work together with Scottish hospices to secure a long-term, sustainable and transparent funding solution for the charitable hospice sector. The solution should enable innovation and capitalise on hospice potential to further support the wider health and care system to deliver agreed outcomes to the benefit of local communities.

Recommendation Hospices should be supported to achieve fully functional integration with and access to NHS/ social care ICT systems. Development of NES Digital Service products such as the National Digital Platform, ReSPECT and ACP should include access by hospices (and other Third and Independent Sector providers) (see also Chapter 17).

Recommendation Hospices should be fully engaged by Integration Authorities as equal partners in the strategic commissioning of palliative and end of life care, recognising the expertise, significant financial resources and community engagement which hospices bring to the table.

23. BABIES, CHILDREN AND YOUNG PEOPLE

Introduction

Over 16,700 babies, children and young people (0-21) across Scotland are living with a life-shortening illness. Although the condition of most of these children is stable for now, at any one time around 2,000 children will unstable, deteriorating or dying. 149 of these children died in 2018/19, and 28% of those who died were under 1 year old[ccix]. The majority of deaths take place in hospital. The number of children living with a life-shortening condition has increased over time, by 37% between 2010-2019. Around a third of these children are affected by a congenital condition, with the remaining 2/3 split across a range of diagnoses.

Parents do not expect to learn that their child has a life shortening illness and the impact is enormous, emotionally, psychologically and practically. Palliative care can last for many years , continuing as the child grows up and becomes an adult. There are often high levels of uncertainty as to how the condition will develop and what the future may hold. The family is challenged to try to find ways of living as well as possible. Hopes and aspirations for the child's future, his/ her development and education have to be balanced with uncertainties about how well they will be and how long they may live. Parents have to try to balance the needs of different family members including siblings. Providing hands on care for the ill child can place huge physical demands on parents. Caring responsibilities can impact on employment possibilities. Housing changes may be needed. Lifestyle constraints can lead to social isolation over time. Siblings often experience isolation and challenges at school, including bullying.

The role of children's palliative care is crucial in supporting children and families to navigate this incredibly challenging journey. Children's palliative care also provide education, advice and support for other health and care staff involved.

Current Position

Scotland benefits from a renowned model of children's palliative care, in which CHAS – as the single national provider of children's hospice care – works in close partnership with the NHS and Local Authorities to deliver integrated care across a variety of settings: in hospices, in hospital, at home and – since the pandemic started - virtually.

Scottish Government's Strategic Framework for Action on Palliative and End of Life Care (2016) made a commitment to *'support and promote the further development of holistic palliative care for the 0-25 years age group'*. Developments during the past five years have been underpinned by an SG investment of £30m over 5 years to support hospice care in a range of settings, delivered by CHAS. This has enabled increased joint working between Children's Hospices Across Scotland, NHS Scotland and other partners. The first paediatric palliative medicine posts have been created as part of hospital teams in Glasgow, Edinburgh and Aberdeen. These medical posts work as part of multi-agency, multi-disciplinary teams of nurses, family support specialists and other professionals. In addition CHAS Diana Children's Nurse posts[ccx] have helped to build the skills and confidence of other staff, provided liaison between hospital and community, provided direct support to families and been advocates for improvement within their local systems.

End of life care is an important part of the broader field of children's palliative care. 2019 saw the commissioning of the national Paediatric End of Life Care Network (PELiCaN)[ccxi] with the aim of supporting delivery and improving access to high quality, patient and family centred, end of life care for children and young people; regardless of age, ethnicity or geographical location. This includes children who have been on a palliative journey.

The Children and Young People Acute Deterioration Management (CYPADM) Plan provides an approach to exploring and documenting preferences and plans for future care. There has been progress in widening use of this approach. An ACP has been developed by HIS and CHAS, and a neonatal ACP developed by NHS Lothian and CHAS will shortly be published.

Key Issues to Address

Despite recent positive developments some big challenges remain:

Babies

Around a third of children with a life shortening illness who die each year are under the age of 1. These babies have particular needs. Children's palliative specialists within neo-natal units can make a big contribution building the capacity of other staff and supporting families. There is a need for further development in this area, especially in the context of the expected redesign of neonatal care centres in Scotland.

Inequalities and poverty

Children with a life-shortening condition are 50% more likely to be living in the most deprived parts of Scotland compared with the least deprived, and also more likely to be admitted to hospital with that condition. There is also thought to be an association between the prevalence of life shortening illness in children and some minority ethnic groups. The reasons for higher prevalence in these groups need to be better understood and the implications for service accessibility, design, and provision explored. Life with a child with complex medical needs can result in additional expenses – such as specialist equipment and adaptations – yet family members are also often less able to work due to their caring responsibilities.

Place of Death

Most children with a life shortening illness will die in hospital. There is a need to widen provision of end of life care in hospice and community settings where this is what families want and where clinically feasible. This will require even more enhanced partnership working between CHAS, the NHS, and local authorities.

Most Community Children's Nursing services are resourced to work on an 'office hours' schedule, without the contractual flexibility to work out of hours to provide end of life care overnight and at the weekends. There is also a need to ensure 24/7 specialist medical support to primary care in relation to the paediatric and young adult population.

Transition to adult services

Thankfully, many children now live into adulthood who would not previously have done so. However, young people can find transition to adult services difficult – often there are no equivalent services available or the adult services are not oriented towards younger adults.

More demand on services

Thanks to medical advances, many children are living longer with their condition. This increases the need for specialist support both to provide direct care and also to support and build the capacity of other health and care staff.

Disjointed and unresponsive social care support

Families of children with life-shortening conditions often have to provide round the clock care, which can involve learning complex new skills and procedures. This can be socially isolating, stressful, and exhausting and good social care support can make a big difference.

Unfortunately many families experience slow assessment processes, gaps in their care and support with an inadequate level of skill[ccxii].

RECOMMENDATIONS

Recommendation Support should be continued for CHAS to work in partnership with the NHS and Local Authorities to develop and expand specialist hospice care for children, backed by sustainable resourcing to enhance the unique Scottish model of children's palliative care.

Recommendation Wide ranging partnership working, should be further developed to address trauma, isolation and grief felt by families, from diagnosis to bereavement care after death. This should include improvements in social care.

Recommendation There should be further investment in workforce education and overall capacity to support equitable access to 24/7 care at home for children, during the end of life.

Recommendation Dedicated training routes should be available in Scotland for paediatric palliative medicine and Community Children's Nursing, to secure the workforce of the future.

Recommendation Eligibility for the Carer's Allowance and Carer's Allowance Supplement should be extended for up to six months after the person's caring role comes to an end and carers should be supported to re-enter the workforce.

Recommendation All Local Authorities should work with CHAS and other third sector partners to compile comprehensive advice and guidance for families of children who have life-shortening conditions and may be entitled to financial support. This should pull together into one place all the support and resources that families in their Local Authority area may be entitled to, across public and third sectors.

Recommendation Bespoke support should be provided for young people with complex medical needs transitioning between child and adult services.

Recommendation Support should be improved for siblings who often experience isolation, bullying and challenges at school.

Recommendation Gaps in bereavement provision, particularly for bereaved siblings should be addressed and support for bereaved family carers increased (see also Chapter 18).

APPENDIX 1: TABLE OF RECOMMENDATIONS

Recommendations
9. Leadership, Governance, Planning and Commissioning
• SG should signal its renewed and continuing commitment to improving people's experiences of living with serious illness, dying and bereavement by developing a national strategy which takes a whole system public health approach and which has clear aims and lines of accountability. • SG should work with the palliative care and bereavement sectors to establish a national steering group which will lead, guide and support improvements in areas set out within this paper and identify areas where a 'once for Scotland' approach can support local change. The group should report regularly on progress to SG ministers and report biennially to the nation. • Strengthening the connection between national ambitions and local planning, commissioning and delivery of change, the membership of the national steering group should comprise a range of perspectives, strategic knowledge and practical experience relating to palliative care, end of life care and bereavement, including senior representation from Integration Authorities. • SG should create a formal palliative and end of life care national leadership role (or roles). Such a role(s) should ensure clinical/ strategic expertise and credibility to inform and influence SG; a focus on the development and implementation of a national strategy; provide support and connection to local leadership; provide high profile leadership and relationship building to support change across the health and care system. • SG should resource the SPPC to provide network functions necessary to support change, together with relevant innovation activity where SPPC is best placed to lead this. • Work at national level to develop and implement the strategy should be supported by clearly identified and effective project management.

- Palliative and end of life care leadership should be identified at HSCP level, and these leaders should be supported and connected.
- Ensure national and local work is influenced by the perspectives and experiences of the public by: resourcing the Scottish Palliative Care Research Forum to identify or conduct relevant research; building user representation into national oversight of work proposed in this paper; enabling public involvement in local service design (see also Chapter 10 on Measurement).
- SG guidance on strategic commissioning of palliative care should be revised and a clear expectation set that IJBs develop whole system population-based plans and commissioning processes which identify, understand and invest to meet the palliative and end of life care needs of the local population.
- Planning, commissioning and procurement frameworks should enable the provision of person-centred flexible support.
- Commissioning processes should promote collaborative working and service integration spanning health, social care (and housing), across statutory, Third and Independent sectors.
- Commissioning plans should address the specific needs and circumstances of disadvantaged groups including issues around service accessibility and inclusivity.
- Commissioning processes need to be complemented by financial mechanisms which cover the transitional risks/costs of transformational change and support the reallocation of funds across the system where this delivers better outcomes and better value.
- Planners and commissioners should be asked what support would be most helpful to them in developing these plans, including, for example, the facilitation of a community of practice.
- The Scottish Palliative Care Research Forum should be re-established as a mechanism identifying, generating and sharing evidence relevant to improving palliative and end of life care in Scotland.

10. Measuring Outcomes and Quality of Experience

- A Palliative Care Outcomes Data Group with a clear terms of reference should be established to oversee the development, review and publication of the measures and approaches proposed below. Part of the responsibility of this group should be to work with HSPCs to agree a limited common set of locally useful measures which are also capable of being scaled up to give a national picture.

- Scotland should develop a national survey of bereaved informal carers. This would encompass both their experiences as carers but also their views (as proxies) on the experiences of the person they cared for.
- IJBs should be expected and supported to develop and use a suite of the local measurement approaches described above.
- Local Information and Support Team (LIST) analyst time should be allocated to support HSCPs to understand the local mortality landscape for their population. This should include both quantitative and qualitative characterisation based on measures in this paper.
- A central 'library' of locally developed LIST analyses to share learning about approaches should be developed.
- Quality of death should be a part of every morbidity and mortality review meeting.
- A national approach to the coding of complaints should be developed so that instances relating to palliative and end of life care are readily accessible.
- There should be exploration of the systematic use of clinical codes to analyse the care of people who have been identified as expected to die and where their goals of care relate to palliative care.
- A national framework should be developed to establish and assure the quality of palliative and end of life care provided in Scotland.
- A thematic review of the provision of palliative and end of life care should be undertaken jointly by the Care Inspectorate and Healthcare Improvement Scotland.
- Since two Scottish Government action plans have passed since Audit Scotland published *A Review of Palliative Care Service in Scotland* (2006) [ccxiii], and because palliative care represents a significant proportion of health and care expenditure, a follow-up review should be undertaken.
- A thematic review of complaints relating to end of life should be undertaken by the Public Service Ombudsman.

11. Health Economics and Palliative Care

- Commissioning processes should incentivise and support cross-system collaboration and endeavour to take a system-wide perspective of what constitutes better value.
- To enable shifts in ways of working which deliver better value there should be funding for the additional costs of implementing change. Given the uncertainties involved in complex system-wide change

consideration should be given to more innovative funding models to unlock change such as revolving funds, social impact bonds or the central underwriting of risks.

- There should be investment in research capacity to strengthen the evidence base on cost effective expenditure towards the end of life. Developing this research capacity should be done alongside the development of new services.
- To promote spread redesigned pathways and new funding models should be subjected to health economic evaluation and where the model or programme offers good value then it, or its most successful components, should be implemented more widely in strong expectation of improving value in end of life care.

12. Specialist Workforce and Education of Generalists

- An up to date national workforce plan should be developed to ensure an adequate supply of specialist palliative care staff to meet anticipated demand over the next decade.
- To support development of the workforce plan data on the specialist palliative care workforce should be updated and improved.
- To support local planning and commissioning indicative staffing levels for different specialist palliative care staff groups in relation to the local population size, service specifications, and within specific settings should be developed, taking account of the differing circumstances in remote and rural areas.
- As part of local planning and commissioning processes the NES Framework should be used to assess training needs across the health cand social care workforce.
- Commissioning of palliative and end of life care should include education and training activities across the health and social care workforce.
- There should be an increased amount of time devoted to palliative care as part of undergraduate medical, nursing, AHP and social work training.
- Undergraduate education should be broadened to include death and dying, bereavement and spiritual care, covering different conditions, settings and demographics, utilising a shared curriculum, resources and learning experience across all disciplines.
- Additional Commitment to Teach (ACT) funding should be targeted to support medical education for students and to increase teaching

capacity of future doctors, which has been highlighted as a priority for the long term.
- All generalist health and care roles should be mapped to the NES palliative care education framework, and postholders enabled to access sufficient relevant training to equip them for this part of their work.
- There is scope to further develop use of virtual training/education. The ECHO approach to supporting shared learning amongst generalists, which has been led and spread by Highland Hospice, could be further expanded.
- Training should be available to people in non-clinical roles such as cleaners, porters and clerical staff since they often interact with people and their families towards the end of life.
- Given the scale and importance palliative and end of life care within the health and care system, senior management and board members should have the opportunity to attend bespoke training on serious illness, dying and bereavement.

13. COVID-19 and Palliative Care

- The scope of any future inquiry or reviews into the COVID-19 pandemic should include palliative and end of life care so that lessons about what went well and what might be improved are not missed.
- Palliative care should be included and fully integrated into planning for future pandemics.
- Plans to support the post-pandemic recovery of health and care services should reflect: increased need for bereavement support; increased need for palliative care following late presentation/diagnosis of serious illness.
- Further research should be commissioned to fully understand the increase in people dying at home during the pandemic. This should include exploration of the preferences and experiences of people and their families; the experiences of health and social care professionals; service responses and sustainability.
- People who have bereaved during the pandemic should get the bereavement support which is right for them (see Chapter 18).
- Services to support staff experiencing burnout and trauma should be adequately resourced and sustained for as long as needed.
- Where service innovations which took place in response to COVID-19 are evaluated positively (eg rapid adoption of remote consultation, greater integration and collaborative working between primary care,

social care, secondary care and hospices) planners and commissioners should seek to ensure that these are resourced on a sustainable basis and embedded as business as usual.

14. Inequalities

- As individuals engaged in delivering and/ or improving care we should all seek to become more aware of the multiple ways in which inequalities are created, expressed and experienced towards the end of life. We all have personal and professional domains, however large or small, within which we can contribute to challenging stigma, discrimination and promoting more equitable outcomes. We can all take personal responsibility for becoming aware of and challenging our own unconscious biases.
- There is a need to better understand current inequalities in service use and access, and the specific needs and experiences of different groups.
- The Scottish Palliative Care Research Forum should be resourced to progress a programme of work to identify and address priority gaps in knowledge.
- All relevant SG policy making should include a more explicit and effective consideration of how to reduce inequalities experienced by people towards the end of life.
- During strategic planning and commissioning processes the needs of disadvantaged groups should be identified and explicitly addressed in plans.
- Disadvantaged groups should be involved in service design to help planners and commissioners to understand and address barriers to access and deliver better outcomes.
- Investing in approaches which address the needs of disadvantaged groups should, if necessary, be enabled by reallocating resources away from those who are currently best served.
- In addition to standard equalities and health literacy training relevant staff should receive training specific to end of life issues. This could range from general awareness of inequalities at end of life to specific issues (for example the beliefs and practices around death of different ethnic groups).
- SPPC supports wide-ranging recommendations likely to flow from the unpublished final report of the Macmillan Scotland funded project on palliative care in prisons. These are likely to encompass: creation of separate secure facilities for prisoners with palliative and end of life care

needs; arrangements for families to maintain contact; improving staffing levels and skill mix; more education for healthcare and prison staff; robust guidance from senior management on how to manage prisoners; more flexible approaches to lockup of prisoners who are dying; incentivising and supporting those prison officers with an aptitude for providing care; careful development of ‘peer carer’ roles; knowledge-sharing by prisons and hospices which are already working collaboratively; improved access to controlled medications, whilst managing security and exploitation risks; further research to understand the perspectives of staff, prisoners and families.

- Activity should be undertaken to improve awareness of the distinct needs of homeless people amongst relevant health, social care and housing/homelessness staff.
- Specialist homeless GP practices, specialist palliative care services, homelessness services and other agencies should collaborate to identify and deliver pathways of care. The resourcing of CNS roles with a special interest can provide leadership and co-ordination for pathway development and delivery.
- Pathways, with palliative care MDT involvement, should include outreach, in-reach to hospitals and bereavement support.
- Specialist palliative care services should provide education and support to homelessness staff.
- Community palliative care beds should be provided within hostels perhaps in conjunction with medical respite/ intermediate care beds.

15. Public Health Approaches to Death, Dying and Bereavement

- Scottish Government should adequately fund the Scottish Partnership for Palliative Care to lead a programme of activity in partnership with stakeholders to promote a culture of openness about death, dying and bereavement in Scotland, which should include the following key actions:
    - Identify key outstanding actions from *A Road Less Lonely* and explore ways to move these areas of work forward. The issues addressed in this report are death education and bereavement support in schools; compassionate workplaces; compassionate communities; personal skills and knowledge; planning ahead; mass media campaigns; socio-economic disadvantage; funeral poverty.

    - identifying priorities and actions in the context of changing circumstances due to COVID-19
    - enabling networking and information-sharing between interested stakeholders in Scotland
    - advising and influencing other work streams and consultations as appropriate
    - running grants schemes to support local work
    - widely promoting good practice and resources that exist in Scotland
    - providing a strong voice for the sector, advising on and influencing other areas of work to take account of death, dying and bereavement issues
    - widening the reach of this work to new groups and communities.
- A Scottish charter for a good end of life, as described within *A Road Less Lonely,* should be developed with explicit support and involvement from senior SG and NHS figures, cross-sector engagement and genuine efforts to listen to and work alongside members of the public and the media.
- The information available on NHS Inform relating to palliative care, dying and bereavement should be reviewed, improved and expanded, and this should include rapid work to provide better information for people worried about dying with COVID-19.
- Scottish Government communications functions should support and engage in proactive communication work around end of life preparation and planning.
- Scottish Government should commit to ensuring that relevant policy documents include and address in clear terms the dying phase of the life course.

16. Informal Carers

- Education should be undertaken to increase the extent to which health and social care professionals help carers identify themselves as having a caring role.
- A structured approach to assessing the needs of carers should be used. The Carer Support Needs Assessment Tool (CSNAT) is an evidence-based tool that facilitates tailored support for family members and friends (carers) of adults with long term life-limiting conditions.
- The implementation of the fast-track arrangements for development of adult carer support plans should be carefully monitored.

- The extent to which identified carer needs are met should be systematically monitored and reviewed and the findings used to inform local commissioning (and the wider reforms of adult social care recommended by the Independent Review of Adult Social Care).
- Local and national providers of services and information should ensure that relevant and comprehensive information reaches carers, recognizing that carers often do not think of themselves as 'carers', and that their information needs may be different to the person they care for.
- Awareness should be raised that people can choose to have a family member or friend or advocate with them for most appointments, consultations and meetings with health and care professionals.
- Where appropriate carers should be provided with training and support to help them look after their loved one and themselves. This may include a sensitive explanation of what supporting a death at home entails – uncertainty and not knowing what to expect is a central concern of people caring for a loved one towards the end of life.
- Supportive employment practices should be promoted for carers who are trying to balance caring with work or who are bereaved, with information and guidance for employers made available via key portals such as Healthy Working Lives.
- Information on carer benefits entitlement should be made available to carers. When carers of people with a terminal illness do apply for benefits, their applications should be dealt with as quickly as possible.
- To support adjustment by carers following the death of the person they have been caring consideration should be given to an education and training fund to support return to the workplace; extension of eligibility for the Carer's Allowance and Carer's Allowance Supplement for up to 6 months after the person's caring role comes to an end. (See also chapter 18 on Bereavement Support).

17. Thinking Ahead and Making Plans

- There should be a strategic collaboration to inform and guide the next phase of development and implementation of anticipatory care planning in Scotland. This should include HIS, NES, NES Digital Service, NHS Inform, NHS24, Scottish Ambulance Service, SG, SPPC, representative health and social care providers and public representation.
- Efforts should be made to ensure popular public-information platforms (such as NHS Inform) include practical, comprehensive information

about ACP that is clear and accessible to the public, and which directly addresses concerns and questions people may have about palliative and end of life care issues. This should draw on existing work, for example public information on the NHS Greater Glasgow and Clyde and GLGDGG websites, and research into the formats and language that the public find helpful (for example exploring the provision of short films, leaflets and posters as well as text-based web information). Public feedback should be sought, and revisions made as necessary.

- A proactive public information and awareness campaign about the purpose, benefits and practicalities of anticipatory care planning should be developed and delivered with the active support of SG.
- The continued development of digital products to support anticipatory care planning and the sharing of plans should be a priority.
- Information governance frameworks should permit analysis of data contained in digital summary anticipatory care plans to inform monitoring of the scale, quality and impact of anticipatory care planning.
- Responsibilities for initiating or revisiting an anticipatory care planning conversation should be clarified so that opportunities do not fall into gaps (for example between primary and secondary care). Where any practitioner with appropriate skills and competence identifies that anticipatory care planning might be beneficial (but hasn't begun or needs revisiting in the light of changed circumstances) they should either initiate that conversation themselves or communicate with other people involved in that person's care to agree and document who should and will initiate an anticipatory care planning conversation.
- Health and social care staff should have access to education and training to support anticipatory care planning and the scale and impact of such training and education should be monitored.
- Within primary care the role of non-medical professionals in initiating anticipatory care planning should be further explored and developed.

18. Bereavement Support

- SG should resource the recent proposal and recommendations to improve bereavement support in Scotland developed by SPPC, Scottish Care, NHS Education for Scotland (NES) and NHS Greater Glasgow and Clyde.

The actions recommended included a blend of:

- **Fact-finding** in order to ensure that long-term work is focused on the areas that will have maximum impact. This should comprise a) Rapid review of the evidence/literature; b) Survey of public experiences of bereavement; c) Mapping of formal bereavement services.
- **Immediate action** to enable and support the general public in dealing with bereavement. This should take the form of a high-profile media campaign to encourage and educate the general public to feel more able to support friends/ family/ community who are bereaved.
- **Action planning** – formation of a Reference Group, with appropriate project-management/ administrative support to enable the group to reflect on findings from the fact-finding work, draw on other relevant resources and the views and experience of the wider bereavement sector, and develop recommendations for an Action Plan for improving bereavement experiences in Scotland.

19. Palliative Care in Acute Hospitals

- Arrangements should be put in place to ensure local management and clinical leadership sustain a focus on improving palliative and end of life care in every acute hospital in Scotland. The most effective arrangements for this should be determined locally between NHS Board and HSCP management.
- As part of this process of maintaining focus a senior management-level nominated champion for care towards the end of life in hospital should be identified. These champions should link with the IJB lead roles suggested in existing Scottish Government guidance on the commissioning of palliative and end of life care.
- Alongside the National Leadership proposed elsewhere in this paper these local roles should create a network for leadership and whole system thinking and improvement.
- An appropriate infrastructure to support collaboration, improvement and spread should be developed with the input of key stakeholders. As part of this infrastructure, the Scottish Network for Acute Palliative Care (SNAPC) should be funded to develop and sustain the collaborative work that has been highly effective during COVID-19.
- Funding to support clinical leadership, support quality improvement, develop the evidence base, and meet other costs of implementing sustainable change should be available.

- There should be an explicit and properly resourced focus on palliative and end of life care within other established relevant programmes (eg Realistic Medicine, SPSP Acute Care Deteriorating Patient Programme).
- Development of better data collection and analysis should run alongside service improvement.
- Routinely collected data should be better utilised to understand who is admitted and readmitted to hospital towards the end of life, the circumstances of that admission, their length of stay, what interventions they receive and the related outcomes, and how admissions sit in relation to other service use.
- Local specialist palliative care activity data should be developed and integrated with national datasets so that the impact of HPCT can be better understood and evidenced. Work underway by the Scottish Network for Acute Palliative Care can provide the basis for this.
- As argued in Chapter 10 measures of quality and patient/family experience of care towards the end of life in hospital should be included within an approach that links an individual's care in different settings.
- As recommended in Chapter 10 a national framework for establishing and assuring the quality of palliative and end of life care should be developed, and the framework should encompass acute hospitals and include scrutiny conducted jointly by HIS and CI.
- Scotland should learn from the National Audit of Care at the End of Life and adapt that approach for Scottish systems, circumstances and priorities.
- Reliable systems need to be put in place which enable people admitted to hospital to have any palliative care needs identified at an early stage, with ACP discussions explored following identification.
- As discussed in Chapter 17 an editable ACP (with a patient portal) to support the handover of information between primary care, hospitals, unscheduled care services, the ambulance service and social care needs should be developed and implemented as a matter of urgency.
- The potential to develop models of volunteer support to people reaching the end of life in hospital should be explored building on work by Marie Curie, Compassionate Inverclyde and others.
- Each hospital site should review how changes to the physical environment could further promote dignity and privacy within their facilities.
- The capacity of HPCTs should be reviewed in the light of their key role in many of the other recommendations in this paper (education, greater

partnership working, leadership, improvement) and to ensure capacity to enable access to specialist hospital palliative care on a 24/7 basis in the face of rising population need.

20. Palliative Care in the Community: Continuity, Care Co-ordination and Capacity

- There should be careful monitoring of the impact of the actions being taken by Scottish Government to ensure that there are enough GPs and primary care nurses[ccxiv]. Without a suitably skilled GP and District Nursing workforce of adequate size primary care cannot deliver palliative and end of life care adequately.
- An adequate social care workforce should be recruited and retained and is fundamental to the delivery of palliative care in the community. SPPC supports the relevant recommendations of the Independent Review of Adult Social Care
- The roles of Advanced Nurse Practitioners, CNSs and District Nurses are critical and should developed, with careful thought given to their interrelationships and the different needs in different in different geographies (and with each clinical case).
- Primary Care professionals should have 24/7 access to specialist palliative care advice and input, alongside other specialities. Currently the degree of access varies by geography and time of day. There is a need to achieve consistent access, though the arrangements to achieve this will vary locally.
- Primary care teams should have better access to hospital at home and hospice at home services, with clear criteria for referral.
- The availability and responsiveness of social care services should be improved building on models such as the Marie Curie Fast Track Service which works in partnership with primary care and is proven to reduce unnecessary hospital admission and expedite discharge from hospital at the end of life.
- A single integrated digital sharable health and social care record should be developed.
- Effective communication about palliative care needs should be facilitated by the consistent use of language based on shared definitions and understanding. A project in Fife has shown how taking this approach across the local health and care system can improve access to the right services at the right time, reducing delays, misunderstandings and mismatched expectations

- People and their families should be able to access advice and support 24/7, and hubs such as the Goldline service (an NHS nurse-led 24/7 telephone and video consultation service) have been shown to play a valuable role in co-ordinating care, providing case management and in offering responsive out of hours support to people and their families.
- Local resourcing and organisation of primary care teams should be such that care homes receive the support they need in providing palliative and end of life care.
- Rapid access to medications is an important aspect of end of life care in care homes and SPPC supports a change in regulations to allow care homes to stock common end of life medications.
- As discussed in Chapter 17 a digital ACP which can be accessed and updated in all settings including social care should be developed in order to improve the flow of information needed to inform care to and from secondary care, hospices, care homes and Out of Hours services.
- The digital ACP should be accessible to the person whose preferences and future care it records.
- Barriers to timely and effective anticipatory care planning specific to primary care teams should be addressed. These barriers include: systems and processes for proactively identifying people who are likely to benefit; building the skills and confidence of staff; adequate time for sensitive conversations, including the review and update of plans; improved ICT for recording and sharing plans.
- Enhanced roles (these could be AHP, nursing, potentially complemented by lay people) within the primary care team with an explicit focus on ACP and eliciting values and preferences should be further developed.
- Measures of care quality and experience for people approaching the end of life and receiving care in the community should be developed (see also Chapter 10).

21. Social Care

- In taking forward the recommendations of the Review SG and other stakeholders should, at each stage of the necessary developmental work, consider explicitly how proposed changes will impact on people living with serious illness and who are approaching the end of their lives and on the improvement of provision of palliative and end of life care.
- There must be increased, adequate and sustainable funding to deliver improved outcomes for people needing social care. Without increased

funding important programmes of structural and institutional reform will fail and palliative and end of life care will deteriorate.

- The UK government's new immigration regime should be revised to reflect the vital ongoing contribution of migrants to the provision of social care.
- Pay and conditions should be improved to support recruitment and retention of social care staff.
- The scale of efforts to promote social care roles as valuable and rewarding should be increased, alongside a continuation of the 'professionalisation' of social care roles.
- There should be further investment in training and development for social care staff, and funding to enable this should be a core component of future planning/commissioning processes.
- More use should be made of virtual learning approaches (such as ECHO), and formal and informal face-to-face training opportunities as part of improved integration of social care with primary care and specialist services.
- At a local level opportunities to co-locate health and social care staff should be exploited.
- Planning, commissioning and procurement frameworks should enable the provision of person-centred flexible support. Referral, assessment and delivery processes should ensure that social care support can be put in place quickly to prevent crises, reducing inappropriate hospital admissions and delayed discharges.
- Planning and commissioning processes should take account of the increasing need for palliative and end of life care over the next 10 years, together with projected changes in household structure, and take a strategic approach to the adequate provision of places for care. Depending on local needs this may involve increasing care home capacity, care at home capacity, housing support, and flexible models such as 'care villages'.
- Primary care services should be adequately resourced to provide support to local care homes.
- Providers of specialist palliative care should be resourced to provide education, advice and support to care homes.
- Information systems should enable sharing of data between health and care settings to inform care.
- There should be support for all providers to ensure adequacy and compatibility of technology.

- Support for people in care homes should encompass the specific needs of people with advanced dementia, including proactive and holistic approaches such as the Namaste Care program and Adaptive Communication.
- As promoted by Scottish Care, a human-rights based Ethical Charter for Technology and Digital in Scotland should be developed, which would provide a framework and guidance to support local decision-making about technologically enabled care.

22. Hospices and NHS Palliative Care Units

- The workforce and models of care of hospices and NHS SPCUs should be reviewed to ensure they are adequately resourced to meet the projected growth in demand for and complexity of palliative care, especially in the community. This review should ensure that in addition to meeting demand for direct care through 24/7 services, that hospices and NHS SPCUs are resourced to build the capacity of the wider health and care system through 24/7 advice and support, education, partnership working, research, innovation and leadership.
- The experience and expertise of hospices and NHS SPCUs should be fully utilised by planners and commissioners in developing plans and programmes to identify, assess and meet the palliative care needs of the local population, including the needs of people in disadvantaged groups.
- Government and Integration Authorities should continue to work together with Scottish hospices to secure a long-term, sustainable and transparent funding solution for the charitable hospice sector. The solution should enable innovation and capitalise on hospice potential to further support the wider health and care system to deliver agreed outcomes to the benefit of local communities.
- Hospices should be supported to achieve fully functional integration with and access to NHS/ social care ICT systems. Development of NES Digital Service products such as the National Digital Platform, ReSPECT and ACP should include access by hospices (and other Third and Independent Sector providers) (see also Chapter 17).
- Hospices should be fully engaged by Integration Authorities as equal partners in the strategic commissioning of palliative and end of life care, recognising the expertise, significant financial resources and community engagement which hospices bring to the table.

23. Babies, Children and Young People

- Support should be continued for CHAS to work in partnership with the NHS and Local Authorities to develop and expand specialist hospice care for children, backed by sustainable resourcing to enhance the unique Scottish model of children's palliative care.
- Wide ranging partnership working, should be further developed to address trauma, isolation and grief felt by families, from diagnosis to bereavement care after death. This should include improvements in social care.
- There should be further investment in workforce education and overall capacity to support equitable access to 24/7 care at home for children, during the end of life.
- Dedicated training routes should be available in Scotland for paediatric palliative medicine and Community Children's Nursing, to secure the workforce of the future.
- Eligibility for the Carer's Allowance and Carer's Allowance Supplement should be extended for up to six months after the person's caring role comes to an end and carers should be supported to re-enter the workforce.
- All Local Authorities should work with CHAS and other third sector partners to compile comprehensive advice and guidance for families of children who have life-shortening conditions and may be entitled to financial support. This should pull together into one place all the support and resources that families in their Local Authority area may be entitled to, across public and third sectors.
- Bespoke support should be provided for young people with complex medical needs transitioning between child and adult services.
- Support should be improved for siblings who often experience isolation, bullying and challenges at school.
- Gaps in bereavement provision, particularly for bereaved siblings should be addressed and support for bereaved family carers increased (see also Chapter 18).

APPENDIX 2: HOW THIS PAPER WAS PRODUCED

This paper was informed by both routine and bespoke engagement.

It is part of SPPC's routine work to facilitate groups and networks of stakeholders with an interest in improving palliative care. Through its establishment and leadership of *Good Life, Good Death, Good Grief,* SPPC also engages with a wide range of different community groups on issues around death, dying and bereavement.

Bespoke activity which informed this paper included:

January 2020 – workshop of SPPC Council to consider scope and approach

Summer 2020 – survey of SPPC members and other stakeholders

August 2020 – workshop of palliative care specialists

September 2020 – workshop with national charity members

September 2020 – workshop on bereavement

October 2020 – key themes and priorities workshop (all stakeholders)

November 2020 – key informant discussions of key topics

January 2021 – workshop of SPPC Council on key priorities

May – July 2021 – wide consultation on final draft

July 2021 – *final changes will be made in response to consultation*

The paper was drafted by SPPC staff. Early drafts of different sections were shared with key informants and stakeholder groups for comment.

GLOSSARY/ DEFINITIONS

World Health Organization 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 patient's 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 Organization Definition of Palliative Care for Children[19]

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for

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[19] An alternative and commonly used definition is provided by Together for Short Lives 'Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.' *www.togetherforshortlives.org.uk*

children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- 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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