EVERY STORY'S ENDING

Proposals to improve people's experiences of living with serious illness, dying and bereavement in Scotland

Summary Version

Scottish
Partnership
for Palliative Care

good life
good death
good grief

This paper explores what can be done in Scotland to improve people's experiences of serious illness, dying and bereavement.

It looks at what people need when they are seriously ill, dying or bereaved, and how these needs can be met. It explains how death is changing in Scotland, creating an imperative for the health and social care system to respond in new ways. And it suggests a series of recommendations for making improvements.

This is a summary version of a much more comprehensive paper which provides a detailed analysis and recommendations. The full report can be viewed here: www.palliativecarescotland.org.uk/content/everystoryending/

An issue that effects everyone

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 if providing care, and throughout bereavement.

It Takes a Village   1

When someone is seriously ill, dying or bereaved, people need support from the health and social care system. But wider social networks, including workplaces, family networks, neighbours, colleagues, education institutions, and other communities have a key role to play in whether people feel supported, empowered and understood.

What support does a person need when they are seriously ill, dying or bereaved?
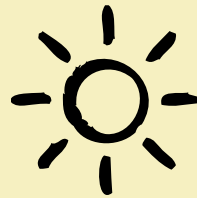
Depending on their circumstances and personal preferences, people can need...

autonomy, honesty and the opportunity to explore personal preferences
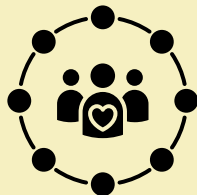
empathy

access to short breaks/ respite

information

relief from distressing symptoms

understanding and support from family, friends, colleagues and communities when dealing with loss and bereavement
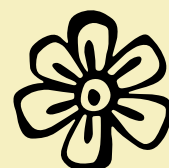
support to get the most out of whatever time is left with the people they care about

support with financial, legal and other practical issues

access to support and advice

a sense of meaning, purpose and spiritual wellbeing

The need for action

Much outstanding care is provided by our health and social care system. However, some people have experiences that could have been better, and which leave a legacy of regret and avoidable distress.

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

Post-Brexit and post-COVID-19 public finances will tighten further creating a strong imperative to make use of interventions and approaches such as palliative care that can both reduce costs and improve outcomes.
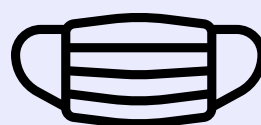
The COVID-19 pandemic has left a legacy of loss and highlighted key weaknesses in our response to serious illness, dying and bereavement.
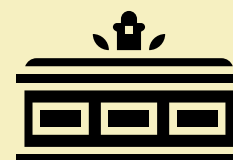
The number of people dying each year is set to rise by 16% between 2016 and 2040 and more people will need palliative care.

An increasing number of children are living with life-shortening conditions

An increasing number of older people will live alone.

A sharply increased number of people will die in advanced old age after living with complex multimorbidity.

Workforce shortages will require remodelling of services.

What is palliative care?

Many of the recommendations in this report relate to 'palliative care'.

Palliative care is good care when someone's health is in irreversible decline, optimising wellbeing during whatever time is left.

Generalist palliative care

In Scotland most of the formal 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.

Specialist palliative care

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.

Resource implications

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

Most people who live in **care homes** for older people are in their **last 18 months of life.**

1 in 3 hospital beds are occupied by people in the **last year of their life.**

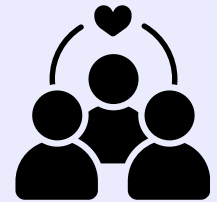Over **30,000 frail older people** receive **care at home** each week.

Recommendations

The following pages outline some practical recommendations that can improve experiences of serious illness, dying and bereavement in Scotland.
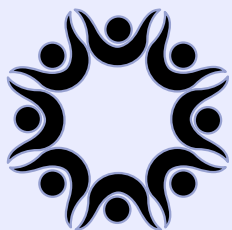
The recommendations are aimed at:

Creating the conditions for change

Delivering good palliative care in all care settings

Empowering communities and individuals

Improving understanding

These recommendations have been produced by the Scottish Partnership for Palliative Care in collaboration with: those working in hospitals, hospices, communities and policy; people working in the statutory, third and independent sectors; those responsible for planning and managing services; and with professional bodies and academia.

A full list of detailed recommendations, alongside a thorough exploration of the issues raised is available in the full report: www.palliativecarescotland.org.uk/content/everystoryending/

Recommendations
Creating the conditions for change

Leadership and collaboration

There needs to be the development of a **national strategy**, supported by a national steering group, national and local leadership roles and a realistic **framework for accountability and delivery** which translates the intentions of policy into real change.

Planning

Planning should take account of the **increasing need for palliative and end of life care over the next 10 years**, adopting a whole-system population approach and taking a **strategic approach** to the adequate provision of places for care. This should include **bespoke support for children and their families** and **clear pathways for transition** to age-appropriate services for young adults.

Commissioning

Commissioning and procurement frameworks and processes should be revised to enable the provision of person-centred flexible support and promote collaborative working across public, independent and voluntary sectors.

Workforce

A national workforce plan needs to ensure an **adequate supply of specialist palliative care staff**, informed by indicative staffing levels in relation to population size and service specifications. There need to be **dedicated paediatric training routes.**

Recommendations
Delivering good palliative care in all care settings
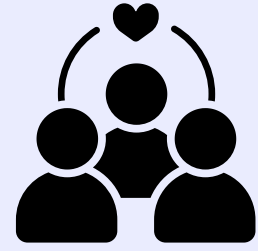
Hospitals

There should be acknowledgement of the valuable role of palliative care in hospitals towards the end of life; every acute hospital should have **local management and clinical leadership** focused on palliative and end of life care; there needs to be a **network and infrastructure to support leadership, collaboration and improvement**; and funding to support the implementation of sustainable change. Improvements should include early identification of palliative care needs on admission; taking opportunities for Anticipatory Care Planning (ACP) discussions; and potel changes to the physical environment to promote dignity and privacy.

## Hospices and Specialist Palliative Care Units

There needs to be **adequate and sustainable resourcing to meet the projected growth in demand/complexity of palliative care.** This will include direct care 24/7, and also support to the wider health and care system through 24/7 advice and support, education, partnership working, research, innovation and leadership. **Hospices need to be fully-integrated with NHS IT systems** and engaged as equal partners within strategic commissioning processes.

Social care support in communities

The National Care Service should be established in a way which reflects that people approaching the end of life are the single biggest group served. The social care workforce should receive **adequate funding, education and support for their wellbeing**.

NHS support in communities

There is a need: to ensure an **adequate primary care workforce** supported by 24/7 access to specialist palliative care advice; to **develop the roles** of Advanced Nurse Practitioners, CNSs and District Nurses; for **24/7 access to advice and support** for people and their families.

Recommendations
Empowering communities and individuals
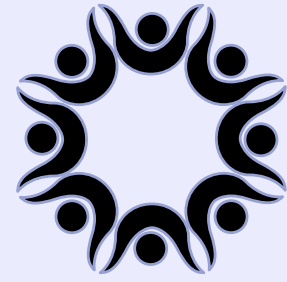
Growing people's confidence and knowledge

There should be continued resourcing of **Good Life, Good Death, Good Grief**'s collaborative work to **support the general public to be more confident and knowledgeable** supporting each other through the difficult times that can come with death, dying, loss and care.

Anticipatory Care Planning

There should be a **co-ordinated national approach** that encompasses **earlier identification, public awareness and information**; staff education; **clarity of staff roles and responsibilities**, and underpinned by a **digital Anticipatory Care Plan** which supports citizen access and allows updating and sharing across health and social care settings, including independent and Third Sectors.

Support for informal carers

There needs to be: a more **structured approach** to identifying carers & assessing their needs; more easily **accessible information, training and support for carers**; and easier to access benefits and support to return to the workplace.

Public Information

NHS 24 and the SPPC **should work together to improve accessibility and practicality of public-facing information** for people affected by serious illness, dying and bereavement.

Bereavement Support

Clear responsibility for bereavement needs to be established at Scottish Government level, and action taken to find out more about bereaved people's needs, what can help and what is available, and collaboratively **develop an Action Plan for bereavement.**

Recommendations

Improving understanding

Research

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

Equity

There needs to be a research, policy and operational focus on **understanding and addressing current inequalities in service access and outcomes**, and the specific needs and experiences of different groups.

Networking and Innovation

We recommend utilising and supporting the **Scottish Partnership for Palliative Care**'s networks and expertise to facilitate collaboration and innovation across the sector in Scotland.

Measurement

A **Palliative Care Outcomes Data Group** should be established to oversee the development, review and publication of measures of quality of care and experience towards the end of life which should inform commissioning decisions, inform the focus of improvement work and provide public assurance at local and national level.
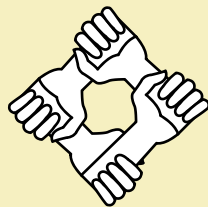
Education of generalists

There is a need to increase the time devoted to palliative care as part of **undergraduate training** and continuing professional development, make available training to people in **non-clinical roles** such as managers, cleaners, porters and clerical staff; and use the **NES/SSSC Framework** to assess and meet training needs across the health and social care workforce.
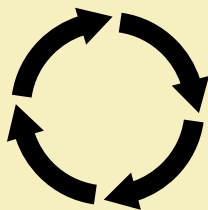
Making change happen

It is clear that to improve people's experiences of living with serious illness, dying and bereavement many different things need to change.

The recommendations above require different approaches to suit different circumstances. For example:

Nurturing neighbourhood networks of informal support may best be achieved through **Community Development** approaches.

Some changes require **innovation** and development of new solutions.

Sometimes the challenge is to take **long-established well-evidenced solutions** and implement them reliably at greater scale.

Designing and testing improved communication processes between clinical staff might be best approached using **Quality Improvement** methods.

Policy and practice should be underpinned by **robust research evidence**.

Different organisations bring expertise in different approaches, and also varied skills, experience, networks and levers for change. Working together, we can realise the changes outlined in this report and improve every story's ending.

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