

**HEALTH AND
SOCIAL CARE**
STRATEGIC PLAN FOR
PALLIATIVE, END OF LIFE
AND BEREAVEMENT CARE



DUMFRIES AND GALLOWAY
Health and Social Care

2018 - 2021

**DRAFT FOR
CONSULTATION AND
CO-DESIGN**

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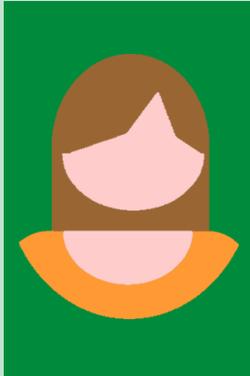
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Foreword



Access to person centred, safe, effective Palliative, End of Life and Bereavement Care should be available to individuals, families and carers who need it at the right time in the right place with the right people regardless of age, gender, diagnosis, social group or location.

To do this we must engage with our communities on an equal, accessible and respectful basis if, together, we are going to address the barriers which can exist for some who live in Dumfries and Galloway. We will strive to hold meaningful two way conversations based not only on listening to the experiences of our communities but also the activities and support that families, neighbours, church groups, community groups, third and independent sectors are delivering on a day to day basis and of course our local heroes who go the extra mile to help someone in need. A major part of this work will be to learn from our communities regarding what is working, what isn't working and what we all need to do to ensure that people who live in our region have a dignified end of life.

In order for this Palliative, End of Life and Bereavement Strategy to be an honest, achievable document which will steer the work needed to meet the needs of everyone, it must be coproduced and co owned by our communities, this will take time. However, we pledge that the timescales will be transparent and realistic, that feedback regarding progress will be regular and accessible for everyone until completion.

The evidence illustrates that people experience a variety of inequalities accessing palliative and end of life care particularly based on their individual needs. We also know that traditionally we are uncomfortable talking about death and dying; this can cause untold misery not only for the individual but also their family, friends, partner, and the community they live in.

It is of paramount importance that everyone in Dumfries and Galloway should have a good death; this will be the first step on our journey towards this objective and the first of many conversations about death and dying.

Penny Halliday

A member of Dumfries and Galloway Community

Chair of the Integration Joint Board

April 2018

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Who is this plan for?

This plan is for anyone living in Dumfries and Galloway who requires palliative care, or end of life care, families, Carers or loved ones who may need bereavement support. This is regardless of diagnosis, place of residence or any of the protected characteristics identified by the Equality Act 2010.

Therefore this plan is for people of all ages, whatever their life limiting illness is, and whether they live at home or in another setting such as a care home.

Defining Palliative Care, End of Life Care, Bereavement, Grief and Mourning

In 2015 the World Health Organisation stated:

“Palliative care is an approach that improves the quality of life of people (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.”

Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help people live as actively as possible until death.

Palliative care is explicitly recognised under the human right to health. It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals.

The Scottish Government endorses this description of palliative care.
(ref strategic framework for P&EOL Care)

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

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

Bereavement is the objective situation of having lost someone significant through death.

Grief is the primarily emotional reactions to the loss of a loved one through death.

Mourning is the public display of grief, the social expressions or acts that are shaped by the (often religious) beliefs and practices of a given society or cultural group. (ALL FROM CEL 9)

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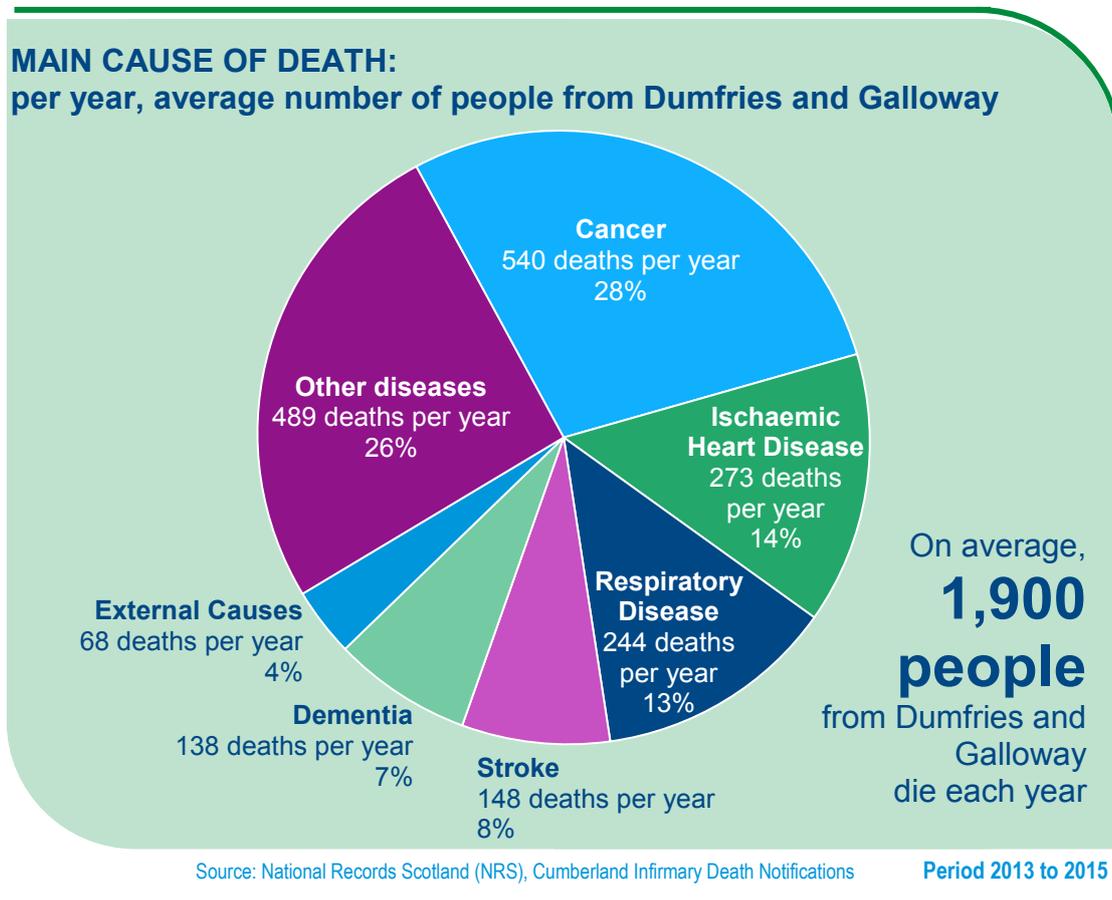
Introduction

In 2014 the World Health Assembly (the governing body of the World Health Organisation) passed a resolution requiring all governments to recognise palliative care and to make provision for it in their national health policies. Scotland's Strategic Framework for Action 2015 is a response to that call. It builds on many actions and policies already in place and sets out the goals, challenges and direction for future improvement.

Each year around 1,900 people die in Dumfries and Galloway. Many of these people receive outstanding palliative, end of life and bereavement care and support. However, we recognise that more and more people are living with long term conditions and some of those who could currently benefit from palliative and end of life care and bereavement support are not receiving it.

This is an exciting and opportune time in Dumfries and Galloway to plan new ways of working. The new Dumfries and Galloway Royal Infirmary (DGRI) opened successfully at the end of 2017 and the integration of health and social care is on the way to changing the way that health and care services are planned and delivered.

This plan sets out the national vision for palliative, end of life and bereavement care and support. As well as the case for change, key challenges for the region and the draft priority areas of focus. This plan links with and supports the overarching Dumfries and Galloway Health and Social Care Strategic Plan and the 9 national outcomes.



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Vision and Purpose

In 2015, the Scottish Government stated its vision for palliative and end of life care...

“By 2021 everyone who needs palliative, end of life care and bereavement support will have appropriate access, regardless of age, gender, diagnosis, social group or location”

“We aim to provide a “good death” for all, one which emphasises respect and dignity, underpinned by patient and carer preferences and choices and the provision of genuinely person centred care”.

Our Ambitions for Dumfries and Galloway

Our ambition is to allow people to spend more time in their preferred place of care, alleviate unnecessary suffering, minimise emergency admissions where avoidable, and support person centred choices.

We will adopt the principles of “Best Value” in the services we provide and commission to achieve best experiences of care, best possible outcomes and best use of resources.

Specifically, we are seeking to:

- Provide greater equity of provision that respects people’s choice in their preferred place of death and creates sustainable services within the available resources
- Progress in shifting the balance of palliative and end-of-life care towards greater community-based care
- Improve our ability to identify people with palliative, end of life and bereavement needs. To plan care in anticipation, and in advance, of an individuals persons needs
- Improve coordination of care, across all settings, to support people and their families who have palliative and end-of-life care and bereavement needs
- Increase public awareness of, and community involvement in relation to death, dying and bereavement.

“We want to work together with people and communities, including those who use and those who deliver services to deliver this vision in Dumfries and Galloway; so that everyone will be clear about what we want to achieve and what is going to be possible to achieve within the resources that we have.”

“We also need to work together to explore how we can promote a co-ordinated approach to bereavement care, both within the health and social care services and in partnership with relevant agencies and third sector partners. So that bereavement care is available to people following a death, in ways that are responsive to their needs and which reflect their spirituality, religion and culture. Recognising that most people will be supported following bereavement by their families, friends and communities”.

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The Case for Change

Death and bereavement are experiences that affect all of us. The increase in life expectancy over the past 30 years (although this appears to have slowed during the last 2 years)* as well as changing beliefs, values and expectations means that there is an increased awareness and interest in good palliative and end of life care and appropriate bereavement support.

However, we know that despite living longer on average, people are not always living in good health, and are living often for many years with ill health.

HEALTHY LIFE EXPECTANCY:

number of years people live in good health (Scotland)



Figures for Scotland in 2015 show that men can expect to live 22% of their life in ill health and women 23.1% of their life.

Source: ScotPHO 2015

In Dumfries and Galloway there were 9 deaths in 2014 and 13 deaths in 2013 amongst people aged 0-19 years old. The evidence shows us that

- Over half of deaths in childhood happen before the child's first birthday. This is more likely to happen with pre-term delivery and low birth weight; and with other risk factors including mother's age, smoking and poverty
- After the age of one year, injuries are the most common cause of death; over three quarters of deaths due to injury in the age bracket of 10-18 year olds are related to traffic incidents
- Suicide is a leading cause of death in young people in the UK, and the number of deaths due to intentional injuries and self-harm have not gone down in the last 30 years

We also need to be aware that some children are affected by complex illnesses or disabilities and that this may lead to death during childhood.

We know that the number of children with profound disabilities in Dumfries and Galloway who are supported by Dumfries and Galloway Council has risen from 34 in 1997, 149 in 1999, 215 in 2005 to 280 in 2014. Around half of these children will have more than one medical diagnosis or condition.

* National Records of Scotland, Life expectancy in Scottish areas, 2014-2016: Key Findings <https://www.nrscotland.gov.uk/files//statistics/nrs-visual/le-areas-1416/life-expect-2016-infograp.pdf>

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Most of these children will grow into adulthood and reach their potential. However we need to ensure that we are able to respond appropriately to the palliative, end of life and bereavement needs of those children, families and carers who require these supports.

Our approach seeks to ensure that a person's wellbeing, and that of their family, is supported, even as their health declines. It should enable people to live as well as possible up until their death and offer appropriate support to those who are bereaved. We know that many people have had positive experiences of death and dying in Dumfries and Galloway. However, people have told us that there is still a need to improve the way that we support and care for those at the end of life and their families across Dumfries and Galloway.

At a time of rising demand for services, growing public expectation and increasing financial restrictions, it is essential to ensure that services work well together.

During this financial year alone (2018/19) NHS Dumfries and Galloway has to make savings of around £25 million, the Integration Joint Board is required to save around £18 million and Dumfries and Galloway Council needs to save around £8 million.

Therefore, there is a broad recognition that we need to enhance care and support by involving our whole community, including Third and Independent Sector and making best use of the skills, abilities and resources that we as individual people all have.

People's Story - INSERT

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Key Challenges

Using information from the Strategic Needs Assessment, we have identified the following key challenges for Dumfries and Galloway in delivering, palliative, end of life and bereavement care and support:

- Health inequalities lead to poorer outcomes for people's health and wellbeing
- More people with multiple long term conditions, including dementia, who require higher levels of support to enable them to live as independently as possible at home or in a homely setting
- More Carers who require greater levels of support to continue in their caring role and maintain their own health and wellbeing
- Maintaining high quality, safe care and protecting vulnerable people in the face of increasing need and reducing resources
- Future sustainability of community based services (including GP, out of hours and care at home services)
- There are fewer people of working age to provide care and support to increasing numbers of older people
- National challenges in relation to recruitment of health and social care staff
- Present and anticipated rise in hospital admissions and delayed discharges resulting in increased pressures across all of health and social care.



POPULATION CHANGES IN DUMFRIES AND GALLOWAY: dependency ratio

2014
For every 10 working age people there were...



non-working people

2039
For every 10 working age people there will be...



non-working people

Source: National Records of Scotland (NRS)

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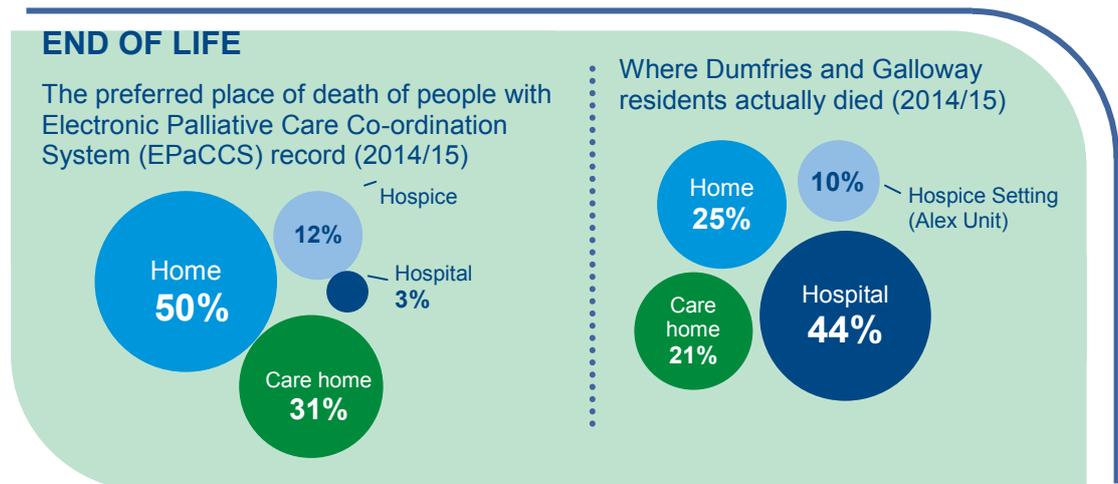
Achieving Our Ambitions

We need to effectively tackle the key challenges above. To do this we have identified 11 priority areas of focus which link to the 9 national outcomes for health and social care and the Dumfries and Galloway Health and Social Care Strategic Plan.

The table below illustrates these links, however it is important to note that the identified areas of focus, are likely to positively impact on more than one of the national outcomes.

National Outcome	Priority Area of Focus
People are able to look after and improve their own health and wellbeing and live in good health for longer	Include all diagnoses, ages, groups of people
People, including those with disabilities or long term conditions, or who are frail, are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community.	Individualise every person's care to their needs Improve and continuously develop services
People who use health and social care services have positive experiences of those services and have their dignity respected	Involve people in discussions about palliative and end of life care and bereavement support
Health and social care services are centred on helping to maintain or improve the quality of life of people who use those services	Identify everyone who might benefit and how they might benefit from palliative and/or end of life care Integrate relevant services and resources
Health and social care services contribute to reducing health inequalities	Investigate how well palliative, end of life care and bereavement support is being delivered
People who provide unpaid care are supported to look after their own health and wellbeing, including reducing any negative impact of their caring role on their own health and wellbeing	Identify those with caring responsibilities who may need support
People using health and social care services are safe from harm	Identify learning and development needs for those providing services and supports
People who work in health and social care services feel engaged with the work they do and are supported to continuously improve the information, support, care and treatment they provide	Innovate to respond to emerging need
Resources are used effectively and efficiently in the provision of health and social care services	Investigate the available resource for palliative, end of life care and bereavement support

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Source: National Records of Scotland (NRS), Carlisle death records

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

We are planning to establish a Dumfries and Galloway Palliative Care Network. Representation will include Carers, families, NHS, Local Authority, Third and Independent sectors. The programme of work overseen by this group aims to improve the way palliative and end-of-life care and bereavement support is provided across Dumfries and Galloway.

The development of this draft Strategic Plan is the first step in making our ambitions for palliative, end of life and bereavement care and support across Dumfries and Galloway a reality.

We want to work in together with people and communities, including those who use and those who deliver services so that we can plan how to achieve our ambition within the resources that we have available.

Good Governance and Evaluating this Strategic Plan

Governance of this strategy is via the IJB who will review progress against this work on a 3 monthly basis.

We will assess our progress in achieving our vision - using measures that relate to the priority areas of focus articulated in this document; alongside a range of pre-existing performance measures.

These measures will form part of annual reporting to the Integration Joint Board and can be found in the supporting Dumfries and Galloway Palliative, End of Life and Bereavement Care and Support Action Plan.

Throughout 2018 we will engage with our population and practitioners across all sectors to develop the action plan and identify measures of success.

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Appendix 1

Consultation Mandate

The co-design of the Dumfries and Galloway Strategy for Palliative and End of Life Care and Support

We, the Dumfries and Galloway Palliative Care Network need to understand the views of key stakeholders (TBC), concerning the development of the Dumfries and Galloway Strategy for Palliative and End of Life and Bereavement Care and Support so that the Integration Joint Board (IJB) of Dumfries and Galloway Health and Social Care can approve the strategy by May 2019, so as to accomplish our ambitions of achieving a good death for all, regardless of diagnosis, place of residence or any of the protected characteristics identified by the Equality Act 2010 and that those who are bereaved receive support appropriate to their needs, culture, beliefs and values within the resources we have available.

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Appendix 2 National Palliative and End of Life Outcomes and Objectives

The Scottish Government has set out 4 national palliative and end of life outcomes:

- People receive health and social care that supports their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death.
- People have opportunities to discuss and plan for future possible decline in health, preferably before a crisis occurs, and are supported to retain independence for as long as possible.
- People know how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.
- People access cultures, resources, systems and processes within health and social care services that empower staff to exercise their skills and provide high quality person-centred care.

Scottish Government aims to achieve these outcomes by implementing the 6 national objectives for palliative and end of life care:

- Improved identification of people who may benefit from palliative and end of life care.
- An enhanced contribution of a wider range of health and care staff in providing palliative care.
- A sense among staff of feeling adequately trained and supported to provide the palliative and end of life care that is needed, including a better understanding of how people's health literacy needs can be addressed.
- A greater openness about death, dying and bereavement in Scotland
- Recognition of the wider sources of support within communities that enable people to live and die well.
- Greater emphasis in strategic plans, research activities and improvement support programmes on enhanced access to and quality of palliative and end of life care.

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dg.ijbenquiries@nhs.net or
telephone 01387 241346**