

Dumfries and Galloway Integration Joint Board

(Draft)
A Plan for Palliative Care (working title)

2020 - 2025



FOREWORD
EXECUTIVE SUMMARY4
1 INTRODUCTION
2020-2025 (the Plan)?
1.3 What do we mean by palliative care? 6 1.4 What do we mean by specialist palliative care? 7
1.5 Who is this plan for?
2 VISION AND PURPOSE
2.1 What is the vision for palliative care and support in Dumfries and Galloway?
2.3.1 Relevant national palliative care documents
3 THE CASE FOR CHANGE10
3.1 Demographic change
3.2.1 Finance
3.3 What people told us14
4 PLANNING FOR THE FUTURE 17 4.1 Building on good work 17
4.2 The new model for palliative care and support in Dumfries and Galloway
5 MAKING IT HAPPEN
GLOSSARY OF TERMS
APPENDICES
Appendix 1: Membership of the Strategy Development Group
Appendix 3: Impact Assessment

Foreword



There is little that can be more important than ensuring that people are well supported when they have a progressive and/or advanced condition that is life limiting. Dying, death and bereavement affects every single person at some point and that is why the Integration Joint Board (IJB) is committed to ensuring that people's experience of palliative care and support is as good as it is possible to be. This includes the experience of families, Carers and friends. Palliative care and support is about so much more than just care in the last days and hour of life. It is about ensuring that there is a quality of life for both the person and their family at every stage of the life-limiting disease process

from diagnosis onwards.

We know that there is much that can be done to further improve people's experience of palliative care and support. People having greater choice and control, ensuring services integrate around the needs and wishes of a person and supporting them to live as well as possible for as long as possible are principles already embedded within our strategic plan.

This plan will help us to ensure that anyone who might benefit from palliative care and support, irrespective of their diagnosis, are identified and supported, along with those closest to them, to voice their wishes and preferences.

Our thanks go to all of those many people, including members of the public, who have contributed to and supported the development of this plan.

Andy Ferguson – Chair of the Dumfries and Galloway Integration Joint Board

Executive Summary (to be completed once draft agreed)



1 Introduction

1.1 What is the Dumfries and Galloway Integration Joint Board (IJB) Plan for Palliative Care 2020-2025 (the Plan)?

The Plan has been developed using feedback from individuals and communities who have experience of receiving or delivering palliative care and support. The Plan

- defines what palliative care and support is within the context of this document
- describes the vision and model for palliative care and support in Dumfries and Galloway
- highlights the current challenges in sustaining and maintaining safe, effective, high quality palliative care and support
- describes how Dumfries and Galloway Health and Social Care Partnership (the Partnership) will action and implement relevant local, regional and national strategies

1.2 Why do we need a plan for palliative care in Dumfries and Galloway?

The IJB recognises that, with an ageing population, there is a growing need for palliative care and support. (Please see section 3.1)

Given the demographic, financial and workforce challenges highlighted in section 3 of this plan, we need to ensure that our model of palliative care, particularly our current specialist palliative model, remains sustainable.

The Scottish Government Strategic Framework for Action on Palliative and End of Life Care 2016-2021 sets out the guidelines and commitments for palliative care in Scotland. This plan sets out what we need to do locally to fulfill these commitments and implement other key local and national policy and guidance. (Annex X)

Developing the Plan for Dumfries and Galloway provides strategic guidance which, when implemented, will ensure

- health and social care professionals are supported to identify people with palliative care and support needs at an early stage
- people have local access to timely palliative care and support
- people's experience of palliative care and support is improved by ensuring that people with life limiting conditions are able to benefit from a palliative care approach, including assessment of their holistic needs, from an early stage
- people, their families and Carers (including Young Carers) are able to have timely conversations with all those involved
- a better, shared understanding of what palliative care and support is and how it can impact positively on quality of life
- we are able to sustain provision of high quality palliative care and support in the region
- the needs of Carers, including Young Carers, are assessed throughout the person's illness and appropriate support put in place at each stage
- people living in Dumfries and Galloway have a better understanding of palliative

- care, death and bereavement and are empowered to support others living with life limiting conditions
- Whenever possible, people will be supported to have treatment and care that is aligned with their goals and preferences as they approach the end of lives
- People can access high quality care and support on the basis of need
- Staff and Carers are supported to provide care and support to the best of their ability

1.3 What do we mean by palliative care?

In this plan, palliative care is

- care and support for adults who have serious life limiting, progressive, incurable illnesses
- the period from diagnosis until death, including care in the last days of life
- support that enables people to live as well as possible, for as long as possible whether that is for hours, days, months or years
- support for Carers, family and loved ones of all ages including bereavement¹ support

Serious life limiting, progressive, incurable illnesses can include neurological or neurodegenerative conditions (including Alzheimer's disease), cancer, organ failure or progressive, irreversible frailty from multiple conditions or old age.

Palliative care considers the person as a whole and includes

- emotional and psychological support such as when people are feeling worried or sad
- social support such as needing extra help at home, financial support or support for Carers and family members
- spiritual support for example finding a sense of meaning and understanding of what makes a person 'them'
- management of **physical** symptoms such as pain and feeling sick



6

¹ Bereavement is described as "the entire experience of family members and friends in the anticipation, death and subsequent adjustment to living" following a death. Parkes, C. And Weiss, R. (1983)

1.4 What do we mean by specialist palliative care?

In this plan, specialist palliative care

- is provided by specially trained multi disciplinary, multi professional teams
- provides advice to people providing general palliative care and support
- can be delivered in a range of locations

Access to specialist palliative care should be available in all settings, including people's homes, care homes, prisons, homeless accommodation, hospitals and specialist palliative care units or hospices.

In Dumfries and Galloway, the specialist palliative care unit is the Alexandra Unit (Ward B1) in the Dumfries and Galloway Royal Infirmary. This is an NHS funded unit. Whilst it operates in a similar way to an inpatient hospice, a hospice usually refers to charitably funded, independent organisations.

Specialist palliative care, including care and support from the Alexandra Unit, can be accessed throughout a person's life limiting illness for symptom management and psycho – social support or care in the last days of life. Referrals to the Unit come from a variety of sources including but not exclusively, GP's, community nurses, clinical nurse specialists, hospital staff, Allied Health Professionals, Social Workers, Carers or patients directly.

There is a separate process for the planning and delivery of specialist palliative care for children. This occurs at a national level through Children's Hospice Across Scotland.

1.5 Who is this plan for?

This plan is for

- adults in Dumfries and Galloway with serious life limiting, progressive, incurable illnesses
- Carers, families (all ages) and friends of people with serious life limiting, progressive, incurable illnesses in Dumfries and Galloway
- people working in health and social care in Dumfries and Galloway

1.6 How has this plan been developed?

This plan was developed by engaging with people who receive and deliver palliative care and support. Views were gathered using

- one to one meetings
- focus group sessions
- an online survey with hard copy questionnaires

Details of these activities are shown in the Statement of Consultation (Appendix 2) and the report from the engagement can be found here (Link to be inserted) (www.dghscp.co.uk/macmillan/palliative)

The timeframe for the development of this document was

- Pre-consultation phase (August November 2018)
- Draft of Consultation Document (December 2018)
- Consultation period (January April 2019)
- Draft of Plan for Palliative Care (May September 2019)
- Engagement on Draft Plan for Palliative Care (November December 2019)
- Co-development of final draft (December 2019)
- Submission to IJB (January 2020)

2 Vision and Purpose

2.1 What is the vision for palliative care and support in Dumfries and Galloway?

Adults in Dumfries and Galloway who need palliative care and support will have access to it.

People who need palliative care and support are

- identified at an early stage
- enabled to express their wishes and preferences
- able to access high quality, effective support
- enabled to live and die well.

2.2 How will we achieve this?

This will be achieved by focusing on the aims and outcomes of the Strategic Framework for Action on Palliative and End of Life Care, the priorities within the Dumfries and Galloway Health and Social Care Integration Joint Board Strategic Plan (2018-2021) and what people have told us.

This will be brought together under Section 5, Making it happen.

2.3 How does this document fit with other national and local plans?

2.3.1 Relevant national palliative care documents

Strategic Framework for Action on Palliative and End of Life Care (2016-2021) (Strategic Framework)

This document directs all Integration Authorities to develop local palliative and end of life care strategies to ensure that the national vision, "by 2021 everyone in Scotland who needs palliative care will have access to it", is achieved.

It sets out a shared understanding of the importance of palliative and end of life care to the wellbeing of communities and includes 4 specific outcomes. These are that

- 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

This framework builds on Living and Dying Well: A national action plan for palliative and end of life care in Scotland published in 2008 by the Scottish Government.

To support the implementation of this framework, an educational framework and learning resource, 'Palliative and end of life care: enriching and improving experience' was published in 2018 by NHS Education for Scotland. Its aims are to support the learning and development needs of the workforce across health and social care in Scotland. (Link to document)

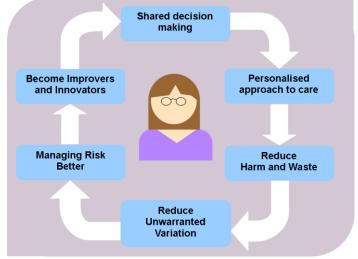
National Health and Wellbeing Outcomes (2015)

These outcomes are high level statements of what health and social care partners are hoping to achieve through integration of health and social care (*Link to document*)

Realising Realistic Medicine: Chief Medical Officer for Scotland Annual Report 2015-2016

This report was published in 2017 and describes Realistic Medicine using the 6 themes shown here. These themes influence how palliative care and support are planned and delivered with the person receiving health and social care at the centre of the decision making process.

(Link to document)



Clinical Standards for Specialist Palliative Care (2002)

The Clinical Standards were developed in partnership with the Scottish Partnership for Palliative Care. They relate to 8 elements of specialist palliative care delivery and are used to assess performance in relation to these specific areas. (Link to document)

2.3.2 Relevant local documents

Dumfries and Galloway Health and Social Care Integration Joint Board, Strategic Plan (2018 – 2021)

This document is a plan for making progress against the 9 National Health and Wellbeing Outcomes. To help achieve this, it identifies 10 priority areas of focus for health and social care in Dumfries and Galloway. (Link to document)

Links to other relevant local strategies

The Carers Strategy 2017-2021

The Dumfries and Galloway Digital Health and Care Strategy (Link to be added) Housing with Care and Support Strategy (Link to be added) Learning Disability Strategy for Dumfries and Galloway (2020-2024) (Link to be added)

3 The case for change

3.1 Demographic change

"There were **53,870** deaths in Scotland during 2016/17, excluding those where an external cause such as unintentional injury was recorded. Of these people, **87%** of their last 6 months of life was spent at home or in a community setting with the remaining **13%** of that time spent in hospital. This has remained briefly similar over the seven years from 2010/11 to 2016/17.

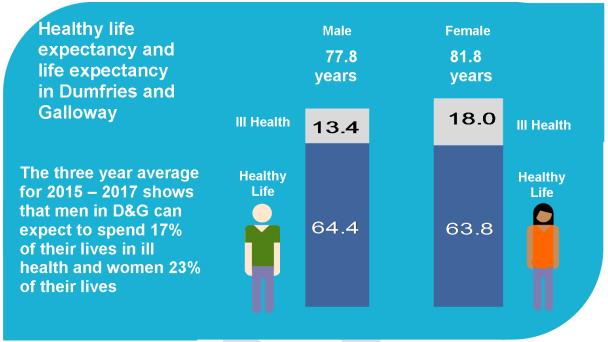
The percentage of the last 6 months of life at home or in a community setting for those living in the most deprived areas is the same as those living in the least deprived areas." (Information Services Division 30 May 2017).

In 2018 there were **1,950** deaths in Dumfries and Galloway. Around **77**% were people who had needs arising from living with deteriorating health for the years, months or weeks before they died. The number of deaths in Dumfries and Galloway is expected to rise to just over **2,100** by 2041.

In 2018, **45**% of people in Dumfries and Galloway died in their usual place of residence (**27**% at home and **18**% in care homes). **7**% of people died in the Alexandra Unit and the remaining **48**% of people died in other hospital wards (including cottage hospitals).

People are living with long term conditions for longer. Comparing life expectancy with healthy life expectancy for Dumfries and Galloway indicates that a woman born today can expect to live for 18 years in ill health. Similarly for a man this is around 13 years see figure 1.

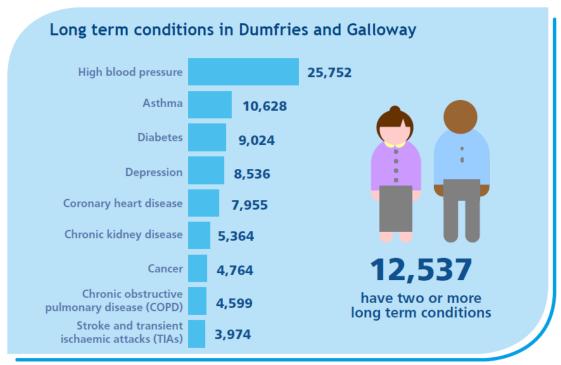
Figure 1: Healthy life expectancy and life expectancy for Dumfries and Galloway (average 2015-2017)



Source: NRScotland.gov.uk (2019)

Across Dumfries and Galloway more than **27,000** people have at least 1 long term condition. Of these, **12,500** have 2 or more long term conditions. The number of people with long term conditions in Dumfries and Galloway is expected to rise to over **35,800** people by 2037, an increase of **32%.** This presents a significant challenge for health and social care services including palliative care and support.

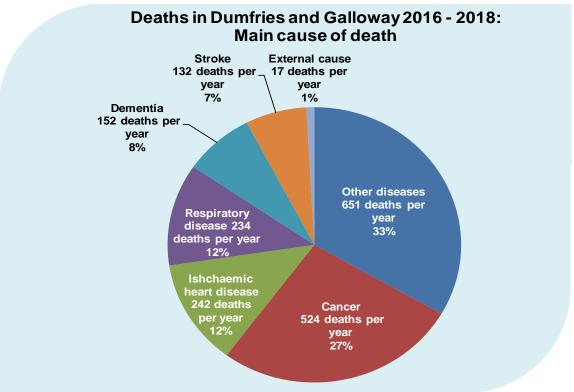
Figure 2: Long term conditions in Dumfries and Galloway



Source: Information Services Division Scotland: Quality and Outcomes Framework 2015/16 and SPARRA

Looking at the main causes of death shows that over **90**% of people die from long term conditions and illnesses. This would indicate that, each year, there are approximately **1,800** people who could benefit from palliative and end of life care and support.

Figure 3:



Source: D&G local data source 2016-18

3.2 Resources

3.2.1 Finance

This plan will consider how we make best use of existing resources and also how we sustain and develop services to meet the outcomes set out in section two.

Where changes to models of care and support or developments are required, we will seek to achieve this using existing resource. We will

- prioritise effectively
- consider how palliative care and support might be delivered differently
- consider what we might stop doing or do less of to enable us to develop new models of care

The provision of care and support for people close to death has a significant impact on Partnership budgets. "On average each year about 15% of partnership budgets are spent on people dying in that year. By far the largest contributor to this is unplanned hospitalisation with 25% of unplanned bed days every year being used by those who go on to die. 29% of all acute bed days are used by people in their last

year of life." (Palliative and End of Life Care by Integration Authorities: advice note 8 May 2018).

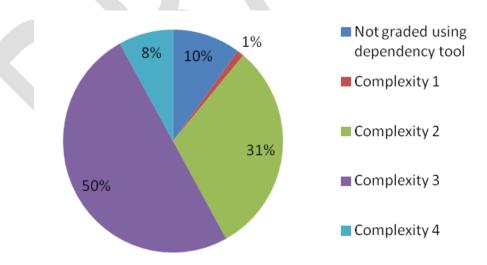
In Dumfries and Galloway

- 580 people in receipt of Care at Home packages died in 2018/19
- 1,015 people were in care homes, nursing homes or Elderly Mentally Infirm (EMI) placements across Dumfries and Galloway on 30 September 2019
- 476 people died in care homes, nursing homes or EMI placements across Dumfries and Galloway in 2018/19
- 139 people died between 1 January and 31 December 2018 in the Alexandra Unit
- there were **4,253** home visits by the Marie Curie care and support service in Dumfries and Galloway in 2018/19.
- Marie Curie made 995 pre-planned variable home visits and 3,258 out of hours (rapid response) visits. 3,053 (72%) of visits were to people with cancer related illnesses and 1,200 (28%) were to people who had non-cancer related illnesses
- there were around 225,000 home visits by Community Adult General Nursing (CAGN sometimes known as District Nurses) in Dumfries and Galloway in 2018

The majority of CAGN visits were described as having a primary aim in relation to wound and palliative care.

The dependency tool a National Validated Workforce Workload Planning Tool indicates that most people visited have a high dependency rate, with a complexity level of 3 or 4.

Figure 4: Monthly locality caseload by complexity as % (M.Hastings, 2018)



The highest dependency/complexity score currently available is 4

3.2.2 Workforce

For future models of care and support to be sustainable and to comply with legislation and best practice, it is important to employ people with the right skills. Recruiting and retaining people is becoming an ever greater challenge both

nationally and locally. Medical and nursing staff, Allied Health Professionals (AHP) and social care professionals all now present significant recruitment challenges. Legislation and guiding documents which set standards for quality of care and staffing levels across health and social care include

- Health and Social Care Standards: My support my life (2017) available here
- Health and Care (Staffing) (Scotland) Act (2019) available here
- Health and Social Care: Workforce Plan (2016-2019 (2018 Edition) available here

'Much of the need related to palliative care and support is being met by families, Carers, primary care, community nursing, care at home and in care homes though some of this care and support may not be identified as palliative.' (Palliative and End of Life Care by Integration Authorities: advice note 8 May 2018)

Ensuring health and care professionals and Carers are supported with appropriate information, advice and training to effectively meet the needs of the anticipated **2,000** people a year who will require palliative care and support in Dumfries and Galloway will be essential.

We identified earlier in this document that approximately **90%** of people die from long term conditions. These people frequently experience complex journeys of care and support through health and social care. Therefore, it is essential that frontline staff take an integrated approach to care delivery that ensures these journeys of care are seamless and well coordinated. This not only results in an improved experience of care for the person, their family, friends and Carers but also helps make best use of the available staffing resource.

Consideration will need to be given to developing enhanced roles across health and social care to ensure long term sustainability of services.

3.3 What people told us

From January to April 2019 we asked people from Dumfries and Galloway to provide their views on palliative care and end of life support. The full report on that engagement is available on www.dghscp.co.uk/macmillan/palliaitve.

The information people provided during the engagement was analysed and broken down into specific themes (please see figure 4 below). There was a consistency around what matters to people.

Dumfries and Galloway Integration Joint Board Health and Social Care Strategic Plan 2018-2021 identified 10 priority areas of focus. We have linked what people have told us to these priorities on page 15.

IJB Priority areas of focus

What people have told us

Enabling people to have more choice and

There are challenges in accessing appropriate information at the right time in the right format to help people make informed choices

More people should complete Anticipatory Care Plans and have Power of Attorney in place so that their views and wishes are known across health and social care partners

Supporting Carers

There is limited availability and access to learning opportunities for staff, volunteers and Carers

Identification and access to support for Carers (including Young Carers) and family should be improved, to help maintain their health and wellbeing

Developing and strengthening communities

There needs to be more of an asset based approach to working with communities, making better use of or developing what is already available

Making the most of wellbeing

Referrals to Allied Health Professionals and other care and support needs to be timely and appropriate, to ensure people receive the right support at the right time to make the most of their wellbeing

Maintaining safe, high quality care and protecting vulnerable

There is a need for more access to community

Access to equipment and medication, particularly in

There is a need for more access to community based training in relation to treatment and medication options for palliative illnesses

Shifting the focus from institutional care to home and community based care

Need to address the increasing number of people unnecessarily admitted to hospital

There is increasing pressure on care at home and care home providers due to capacity issues

Delayed discharges mean people are in hospital and away from their communities for longer than they need to be

Integrated working, including communication **Integrated ways** between statutory, third and independent sectors of working and communities needs to be improved Providing equity of access to the full range of care Reducing health and support is challenging due to the rural nature of inequalities **Dumfries and Galloway** Information sharing between disciplines needs to be Working more effective efficiently and effectively Processes and protocols for accessing resources such as equipment and support needs to be made more efficient Making the best Technological solutions should be used more

Making the best use of technology

Technological solutions should be used more consistently to support wellbeing and reduce unnecessary journeys

Person centred care (143)Integrated Communication working (126)(83)**Themes** Access to community Access to based care resources (104)(113)High quality of care (112)

Figure 5: Emerging themes from surveys and other engagement activities

Please note

(The numbers in the brackets on the above graphic represents the number of people making the comment).

4 Planning for the future

4.1 Building on good work

Our engagement with people across Dumfries and Galloway highlighted those areas of palliative care and support that are working well. This will inform the development of models of care that fit the needs of people receiving and delivering palliative care and support.

People told us



Advance care planning meant the "family felt that the person who died had some choice and control at the end of life"

"Very skilled staff across integrated Health and Social Care services"

"Pain management is really good in palliative care"





Quality of care given in the community is good"

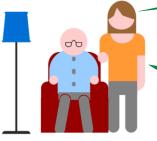


"GP was a great support and was really good at explaining what would happen at death and end of life"



"If a patient dies, the Senior Charge Nurse ensures that staff gets the support they need"

"Care received from care at home service is excellent"

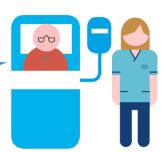


"Carers centre is really useful"

Macmillan centres provide "Lots of useful information"

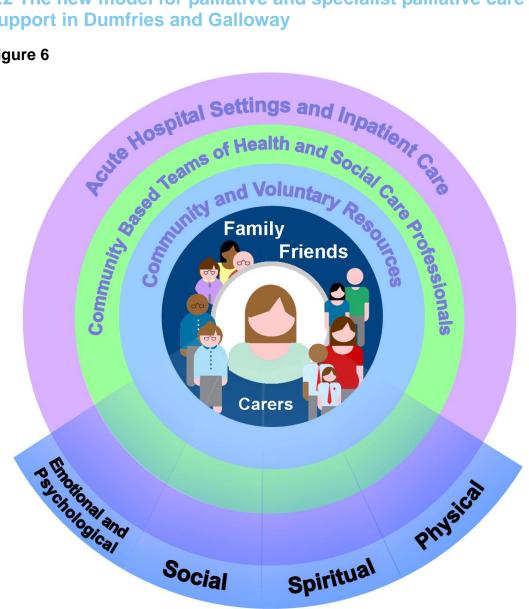


Community hospital provides "High standard of care, genuine nurturing care"



4.2 The new model for palliative and specialist palliative care and support in Dumfries and Galloway

Figure 6



4.3 Existing and developing initiatives within the new model of palliative care and support

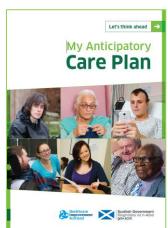
Developing a new model of community teams

Changing how we provide care and support to people in their usual place of residence is a fundamental element of delivering a model of care that better meets people's needs and preferences.

We know from extensive community engagement during the development of our strategic plan that people want choice and control over their own care and support. They also want their care and support to be flexible, seamless and compassionate. We need to develop and implement a model of care closer to people's own place of residence that will deliver this consistently.

Anticipatory Care Plans (ACP)

ACPs are documents that help people to make informed choices about how and where they want to be treated and supported in the future to achieve the best outcomes for them. They do this by encouraging conversations between people, their families, health and social care professional to help identify what matters to them. Health and social care professionals work with people and their Carers as partners to co-develop an ACP.



People can indicate in an ACP who they would like to help make decisions about their health and wellbeing should the need arise. Completing an ACP can raise awareness of and start dialogue about other paperwork such as Power of Attorney (PoA).

Completed ACPs provide valuable information enabling GP Practices to update the person's electronic Key Information Summary (eKIS), ensuring the person's wishes and preferences can be shared with relevant professionals. This supports people receiving or delivering palliative care and support, and can improve bereavement outcomes for family members.

New digital technologies

Digital technologies can

- provide more options in how care at home or closer to home is accessed
- benefit people by providing a more effective and efficient way of doing things
- reduce unnecessary travel
- improve communication
- provide reassurance and confidence

These include

MORSE is an online tool that enables healthcare professionals in the community to access data offline, make changes to it and then update the main system when they have a secure internet connection.

Florence is a Home and Mobile Health Monitoring text messaging system that enables people to provide practitioners with up to date information about their condition. It also enables people to request information and be sent messages relating to their conditions and treatments.

NHS Attend Anywhere enables people to use video conferencing for medical consultations. One example of this is a person in rural Wigtownshire who previously would have undertaken a 50 mile round trip to attend renal appointments at the Galloway Community Hospital. The results of the blood test from that appointment would be discussed over the telephone several days later. Using NHS Attend

Anywhere, the person now goes to their GP Practice to have their bloods taken a few days before their virtual appointment and the results are discussed during a video consultation at home between the person and the clinician.

Dementia Post Diagnostic Support (PDS)

Post diagnostic support for dementia has been tested in Nithsdale locality.

Recent ISD figures indicate that around **1,544** people in Dumfries and Galloway have a dementia diagnosis. This is under half of the predicted number indicating that the majority of people living with dementia in Dumfries and Galloway are without a formal diagnosis and therefore not accessing post diagnostic support.

People living with undiagnosed and unsupported dementia (including their Carers) can struggle to manage symptoms. This often results in people reaching crisis point and can lead to unnecessary hospital admissions.

The traditional method of diagnosing dementia required referral for specialist assessment by a community mental health nurse and a psychiatrist. This process could take approximately 32 weeks, with people waiting a further 11 weeks to access PDS.

Outcomes of the test have included

- Reduction in Psychiatrist time to diagnose an individual from 1 ½ hours to 15 minutes
- Reduction in GP time for pre-diagnostic assessment from an average of 3 appointments to zero
- **Increase in diagnostic rates**: 186% increase on one GP dementia register since April 2019 than in the preceding 3 month period
- Reduction in waiting time for diagnosis from 224 days to 23 days
- Reduction in the number of diagnostic appointments required by the person

Building compassionate communities

The NHS Health Improvement Team in Stewarty is working with third and independent sector partners to support the development of compassionate communities that build resilience and capacity in relation to dying, death and loss. Improving knowledge and understanding of death and dying and supporting people to talk more openly about it can positively impact on their experience of dying, death and loss.

As part of the development of compassionate communities, local communities, schools and care homes are being encouraged to get involved with an intergenerational approach to care of the elderly and people who are dying. Visits and supported discussions are part of a programme of palliative care training and education around death and dying being delivered in partnership with Child Bereavement UK.

'You Behind the Uniform' training delivered by Cruse Bereavement UK is supporting staff in uniformed services to assist colleagues and grieving families during difficult times following loss.

The above work is receiving guidance and support through the Truacanta Project. Truacanta is a Scottish Partnership for Palliative Care (SPPC) project funded by Macmillan Cancer Support to support the development of compassionate communities in Scotland.

Introduction of Scotland's House of Care

With the introduction of the new GP contract there are opportunities to rethink how General Practice can adapt to the needs of people living with long term conditions. Scotland's House of Care Programme is a collaboration between the Health and Social Care Alliance of Scotland, Year of Care Partnerships and the Scottish Government.

House of Care is a framework that

- enables conversations about care and support planning for people with long term conditions to support self management
- offers practitioner training to develop a person centered ethos, building skills and leadership
- promotes the principles of self management by adopting an asset based approach to care and support

As part of Scotland's House of Care Programme, workshops are being offered to GPs and Practice Managers.



The workshops

- · clarify what House of Care is
- look at ways of working differently
- explore the impact of the House of Care on care and support planning
- provide an opportunity to identify what is required to adopt this approach

5 Making it happen

Dumfries and Galloway IJB Strategic Plan priority area of focus:

Enabling people to have more choice and control

Strategic Framework for Action on Palliative and End of Life Care Outcomes: 2,4

	Actions	By Whom	By When	How will we know we are making a difference?		
•	Deliver training that supports people to have 'good conversations'. Conversations that provide opportunities to discuss personal outcomes, wishes and what matters to them	Organisational Development and Learning		Number of participants completing the course - Patient Experience feedback complaints /compliments		
•	Apply the principles of Realistic Medicine to determine how palliative care and support is planned and delivered, ensuring the person is at the centre of their own decision making	Service Leads		Feedback in relation to person centred communication recorded using collaboRATE score and Datix system (NHS)		
•	Undertake awareness raising initiatives to encourage discussions about death and dying and ongoing community engagement	Locality Leads				
	Engage with Scotland's House of Care Programme.	Primary and Community Care Leads		Number of surgeries adopting this model		
	Review how and when people access information relating to palliative care, ensuring accessibility in different formats, and support and consider how this might be built upon.	Palliative Care Steering Group		Feedback in respect of access to information (for people receiving and delivering palliative care)		
•	Support people to complete Anticipatory Care Plans (ACPs)	Service Leads		Increase use of ACPs – measure to be completed		

Supporting Carers

Strategic Framework for Action on Palliative and End of Life Care Outcomes: 1, 3

	Actions	By Whom	By When	How will we know we are making a difference?		
•	Carer Positive used as an approach, to identifying and support Carers, including staff across Health and Social Care who have personal caring roles	Workforce Director		Number of Carer Positive Awards awarded across Health and Social Care including the third and independent sector		
•	Signpost or refer staff who are Carers to occupational health or spiritual care where appropriate	Line Managers		Staff sickness absence levels.		
•	Signpost or refer Carers to third sector support such as Alzheimer's Scotland, Dumfries and Galloway Carers Centre, Child Bereavement UK and Cruse Bereavement to improve their resilience and develop coping strategies	Service Leads		Record of number of referrals received by relevant organisations and feedback from Carers		
•	Support Carers providing palliative care and support to maintain their own health and wellbeing, including 'short breaks' Carer drop-ins	Carers Programme Board		Record of attendance at Carer drop-ins and number of short breaks awarded		
•	Consider how to address the support needs of Carers who are bereaved	Carers Programme Board		To be developed		

Dumfries and Galloway IJB Strategic Plan priority area of focus: **Developing and strengthening communities** Strategic Framework for Action on Palliative and End of Life Care Outcomes: 3, 4 By Whom By When How will we know we are making a **Actions** difference? Number of compassionate Locality With third and independent sector partners, explore Public Health communities being developed opportunities to develop new initiatives that build capacity and Teams strengthen community resilience.

Making the most of wellbeing

Strategic Framework for Action on Palliative and End of Life Care Outcomes: 1,2

	Actions	By Whom	By When	How will we know we are making a difference?
•	Apply the '4 dimensions of palliative care and support' throughout a person's journey of care to improve their sense of wellbeing and quality of life	Service Leads		Feedback from people receiving palliative care.
•	Resource the collection of qualitative data development to better understand people's experiences of palliative care and support that, in turn, will inform service development	Health Intelligence		Improved experience of care. Higher levels of qualitative data
•	Apply a reablement and asset based approach to care and support	Service Leads		
•	Streamline referral processes to ensure they are more effective and efficient	Service Leads		Feedback from staff and people receiving care and support
•	Early identification of people who may be in the last 12 months of their life to enable timely palliative care and support to be put in place using appropriate tools, cross sector training and awareness raising	Service Leads		Measure to be completed
•	Seek agreement from the Palliative Care Steering Group to ratify the 'Palliative care identification tools comparator ² for use in Dumfries and Galloway	Strategic Planning		

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² Using 'Palliative care identification tools comparator' is highlighted as supporting Commitment 10 of the Strategic Framework for Action on Palliative and End of Life Care (Health Improvement Scotland:ihub, 2018).

Maintaining safe, high quality care and protecting vulnerable adults

Strategic Framework for Action on Palliative and End of Life Care Outcomes: 1,4

	Actions	By Whom	By When	How will we know we are making a difference?
F	Make links between this Plan and those workstreams or programmes of work focussed around the palliative care and support needs of vulnerable adults	Programme and Workstream Leads		Measure to be completed
ŀ	Fransitions of care between hospital, home, community nospital and care home should be established so that they are robust, seamless, clear and purposeful	Service leads		Measure to be completed
i	ncrease opportunities for learning and support by creating a community of practice for palliative care with the goal of mproving decision-making by collaborative problem solving using video conferencing. This would involve sharing knowledge and skills through programmes such as ECHO (Extension of Community Healthcare Outcomes)	Lead Clinician Palliative Care in partnership with community representatives		Measure to be completed

Shifting the focus from institutional care to home and community based care

Strategic Framework for Action on Palliative and End of Life Care Outcomes: 1, 2, 3, 4

	Actions	By Whom	By When	How will we know we are making a difference?
•	Support people who wish to die in their own home or homely setting to do so by providing the person, their Carers and/or community based health and social care professionals with the right level of support in those settings to enable this	Service Leads		% of people in Dumfries and Galloway who died in their usual place of residence Number of home visits provided
•	Develop and implement a model of care that will provide people with greater levels of support in their own home	Planning and Service Lead		Comprehensive specialist palliative care team in place
•	Define what the core membership of a specialist palliative care team should be to support a model of care that will provide people with greater levels of support in their own home	Health and social care professional leads		Health and social care professional leads
•	Maintain robust and high level of dialogue with the public to make them aware of the positive outcomes that community based care can deliver to them, their families, friends and Carers	Service Leads		Community based teams feeling supported in their role to deliver high quality palliative care in people's usual place of residence Improved experience of care (collection of qualitative data)

Integrated ways of working

Strategic Framework for Action on Palliative and End of Life Care Outcomes: 1,2,3

Actions	By Whom	By When	How will we know we are making a difference?
 Explore developing further the hospice model of inpatient care to be a cross sector model of delivery 	Strategic Planning		Measure to be completed
 Review the membership of the Palliative Care Steering Group and ensure it is representative of all relevant stakeholders 	Strategic Planning		Measure to be completed
 Seek agreement from the Palliative Care Steering Group to ratify the Supportive and Palliative Care Indicators Tool (SPICT), to be used across Health and Social Care 	Strategic Planning		
 Implement the Rockwood Frailty Scale to support a proactive multi-disciplinary approach to identifying people who are frail and potentially require palliative care earlier and prior to crisis 	Frailty Steering Group		Increased number of eKIS being completed
			Reduction in number of unscheduled GP visits and inappropriate hospital admissions

Reducing health inequalities

Strategic Framework for Action on Palliative and End of Life Care Outcomes: 1,4

Actions	By Whom	By When	How will we know we are making a difference?
 Identify where there are inequalities in relation to the provision and use of palliative care and support in Dumfries and Galloway analyse any information that helps us to understand if, and at what level, inequalities in provision exist in each locality use the 'Dumfries and Galloway Inequalities Action Framework' (2016) to identify ways in which we can mitigate, prevent or undo health inequalities in palliative care and support 	Health Intelligence Team		Measure to be completed
Explore ways in which multi-disciplinary and cross sector partners can work together to find ways to identify and address any health inequalities relating to palliative care, including those experienced by protected characteristic groups	Palliative Care Steering Group		Apply relevant existing inequalities measures

Working efficiently and effectively

Strategic Framework for Action on Palliative and End of Life Care Outcomes: 2, 4

Actions	By Whom	By When	How will we know we are making a difference?	
Optimise technology enabled care to reduce unnecessary travel and improve communication.	Digital Health Programme Board		Number of e-clinics attended by people in receipt of palliative care (in last 6 months of life) Reduction of complaints about unnecessary travel	
Recruit to vacant posts and retain existing staff to ensure safe staffing levels and appropriate skill mix are maintained.	Workforce Sustainability Programme Board		Achieve recruitment of (tbc)% of hard to recruit posts – target figure to be completed	
Ensure that staff and social care professionals across the partnership are supported to improve their personal and collective resilience and develop positive coping mechanisms	Workforce Leads		Levels of staff sickness absence	

Making the best use of technology

Strategic Framework for Action on Palliative and End of Life Care Outcomes: 1, 3, 4

Actions	By Whom	By When	How will we know we are making a difference?	
Ensure that the benefits of the digital approaches identified within this plan are realised for people receiving or delivering palliative care	Digital Health Programme Board		Feedback from Programme Board	
Ensure there are technological options available to people regarding how they receive and access information relating to palliative care and support	Digital Health Programme Board		Feedback from Programme Board	
Explore with Primary Care Leads if there are ways in which partners can support the updating of electronic Key Information Summaries (eKIS) to ensure that the person's most up to date wishes and preferences are shared between relevant professionals	Primary Care Leads			

Glossary of terms

Allied health professionals (AHPs)

Professionals related to healthcare distinct from nursing and medicine. Examples include podiatrists, physiotherapists, occupational therapists and speech and language therapists.

Anticipatory care

A term used to describe an approach where the actual or potential care and support needs of someone are predicted. By doing this, steps can be taken much earlier to minimise or avoid altogether the impacts of these. (See also forward-looking care).

Asset based approach

Identifying and making best use of all the resources that exist at both an individual and community level.

Bereavement Care and Support in palliative care

Care and support for people in respect of any expected or unexpected death and loss. This can be provided by the statutory, third or independent sector and the wider community.

Care and support plan

An agreed document, between the person and their health and/or social care professional that identifies and records discussion with regard to personal aims and outcomes, needs, risk and any required action. It can be electronically stored or written on paper and accessible to the person.

Carer

Someone who provides unpaid care and support to a family member, neighbour or a friend.

Carers Emergency Card

A Carers Emergency Card identifies you as a Carer so that if you have an accident or suddenly fall ill, anyone finding the card will know you are a Carer and should contact the named person on the card.

Co produce

A way of working where people and professionals share power to plan and deliver support together.

Delayed discharges

A term used to describe an incidence whereby someone clinically ready for discharge cannot leave hospital because care, support or accommodation they require is not available.

Dementia

A term used to describe a group of symptoms that occur when brain cells stop working properly, which can affect thinking, memory and communications skills.

EHealth

Technology which enables health systems to work together so that health professionals can access real time, relevant information about people's health and care.

Forward looking care

A term used to describe an approach whereby the actual or potential care and support needs of someone are predicted. By doing this, steps can be taken much earlier to minimise or avoid altogether the impacts of these. (See also anticipatory care).

Good death

A good death, as defined by Marie Curie (2015) is "the best death that can be achieved in the context of the individual's clinical diagnosis and symptoms, as well as the specific social, cultural and spiritual circumstances, taking into consideration" the person and "Carer wishes and professional expertise."

GP

General Practitioner sometimes referred to as a family doctor.

Health and social care integration

Bringing together adult health and social care in the public sector into one statutory body, for example an integration authority.

Health inequalities

A term that refers to the gap between the health of different population groups, such as the wealthy compared to poorer communities or people with different ethnic backgrounds.

Home and mobile health monitoring (HMHM) also known as remote monitoring

The use of technology to monitor someone's health outside of traditional clinical settings. For example someone's health can be monitored in their home enabling real time clinical review and early action.

Impact assessment (see also protected characteristics)

A process to assess the impact of applying a proposed new or revised plan, policy, function or service.

Independent sector

A general term for non-statutory bodies including private enterprise, voluntary, charitable or not-for-profit organisations.

Integration authority

An integration joint board or lead agency, responsible for services delegated to it by the NHS and council.

Integration Joint Board (IJB)

A body established where a health board and local authority agree to put in place a Body Corporate model. The Integration Joint Board is responsible for the planning of integrated arrangements and onward service delivery.

Locality

The term outlined in the Public Bodies (Joint Working) (Scotland) Act 2014 to identify local areas. Every local authority must define at least two localities within its boundaries for the purpose of locality planning. In Dumfries and Galloway there are four localities - Annandale and Eskdale, Nithsdale, Stewartry and Wigtownshire.

Long term conditions

These are health conditions that last a year or longer, impact on a person's life, and may require ongoing care and support. These are also known as chronic conditions.

Mobile technologies

Technology that is portable, including mobile phones, tablet devices and laptops.

Personalised

Tailoring health and/or social care and support specifically to an individual's needs.

Person centred

Focuses care and support on the needs of a person and is a way of thinking and doing things that sees the people using health and social care as equal partners in planning, developing and monitoring care to make sure it meets their needs.

Personal outcomes

The end result or impact of activity on a person. A personal outcomes approach identifies what matters to people through good conversations during care and support planning.

Power of Attorney

A continuing (financial) and/or welfare power of attorney (PoA) is a written document giving someone else authority to take actions or make decisions on your behalf. It details the names of the people, known as attorneys, who you want to help you and lists the individual powers that you want them to have.

The PoA states when your attorneys can begin acting for you and provides legal authority for them to make decisions for you.

Primary care

Health care provided in the community. For example services provided by GP practices, dental practices, community pharmacies and high street opticians, as well as community nurses and allied health professionals.

Protected characteristics

It is recognised that people may face discrimination due to these characteristics the Equality Act 2010 describes age, disability, sex, race, religion or belief, pregnancy and maternity, marriage and civil partnership, sexual orientation and gender reassignment as protected characteristics.

Protected Groups

People who share a protected characteristic or protected characteristics.

Public Health

Promoting and protecting health and wellbeing and preventing ill-health.

Realistic medicine

Realistic medicine encourages shared decision making about care and is about moving away from a "doctor knows best" culture. This means doctors or health professional should understand what matters to the person and what their goals are. People are encouraged to ask questions about their condition and the possible care offered.

Short breaks for Carers

This is part of a selection of support and consists of a short break which provides respite for the Carer and includes replacement care if required

Supportive & Palliative Care Indicators Tool (SPICT)

It lists general indicators of deteriorating health to look for. This can support the identification of people with advanced health conditions who are at risk of deteriorating and dying.

Statutory

In this case statutory refers to health and social care services delivered by the National Health

Service (NHS) and local authorities (councils).

Strategic needs assessment (SNA)

An analysis of the health and social care and support needs of a population that helps to inform health and social care planning.

Strategic plan

A high level plan that sets the future direction of travel for health and social care by identifying key challenges and priority areas of focus and aligning resources to activity.

Technology enabled care (TEC)

A Scottish Government programme to enable a major roll out of Telehealth and Telecare in Scotland. Technology Enabled Care (TEC) is the utilisation of a range of digital and mobile technologies to provide health and social care support at a distance.

Telehealth

The provision of healthcare remotely by means of telecommunications technology.

Telecare

Telecare is the term for offering remote care of elderly and physically less able people, providing the care and reassurance needed to allow them to remain living in their own homes, for example, personal alarms or sensors.

Third sector

A vast range of organisations which have a social purpose and are not-for-profit, such as voluntary organisations, charities, or social enterprises. The types of services and the opportunities they provide include health and social care and support, information, advocacy and volunteering.

Volunteering

Any activity that involves spending time, unpaid, doing something that aims to benefit the environment or someone (individuals or groups) other than, or in addition to close relatives.

Vulnerable adult

A person over the age of 18 at risk of being harmed by reason of disability, age or illness.

Wellbeing

Wellbeing is a complex combination of a person's physical, mental, emotional and social health. Wellbeing is strongly linked to happiness and satisfaction in life.

Young Carer

Young Carers are Carers aged under 18, that provide unpaid care to a friend or family member.

Appendices

Appendix 1: Membership of the Strategy Development Group

Appendix 2: Statement of Consultation

Appendix 3: Impact Assessment

Appendix 4: Equality and diversity statement

Appendix 5: Good governance and evaluating the strategy

References and Links



Links to documents which helped us produce this plan

- Burns, H. (2017) Review of targets and indicators for health and social care in Scotland https://www.gov.scot/publications/review-targets-indicators-health-social-care-scotland/ (last accessed 07/11/19)
- Carers Strategy 2017– 2021 https://dumgal.gov.uk/media/18053/Carers_Strategy-2017-2021/pdf/0586-16_Carers_Strategy_1_November.pdf?m=636495343371870000 (last accessed 07/11/19)
- Clinical Standards Board for Scotland (2002) Clinical Standards for Specialist Palliative Care https://www.palliativecarescotland.org.uk/content/publications/ClinicalStandardforSPC.pdf (last accessed 07/11/19)
- Health Improvement Scotland (2018) Living Well in Communities
 https://livingwellincommunities.com/2018/04/11/comparing-tools-that-can-help-to-identify-people-who-could-benefit-from-a-palliative-care-approach/ (last accessed 07/11/19)
- Health Improvement Scotland (2019) Living Well in Communities
 https://ihub.scot/improvement-programmes/living-well-in-communities/
 (last accessed 07/11/19)
- Health and Social Care Alliance Scotland (2019) House of Care Model https://www.alliance-scotland.org.uk/health-and-social-care-integration/house-of-care/house-of-care-model/
 (last accessed 07/11/19)

Information Services Division Publication (2017) Report 'Percentage of End of Life Spent At Home Or In A Community Setting' https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2017-05-30/2017-05-30-End-of-Life-Report.pdf (last accessed 07/11/19)

Marie Curie (2015) An answer to the question of what is a good death? https://www.mariecurie.org.uk/blog/what-is-a-good-death/48655 (last accessed 07/11/19)

Marie Curie (2019) Caring for LGBTQ+ people at the end of life https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/equality-diversity/lgbt-end-life (last accessed 07/11/19)

National Health and Wellbeing Outcomes Framework (2015)

https://www.gov.scot/publications/national-health-wellbeing-outcomesframework/pages/5/ (last accessed 07/11/19)

National Institute for Health and Care Excellence (NICE) (2011) End of life care for adults - Quality statement 10: Specialist palliative care https://www.nice.org.uk/guidance/qs13/chapter/quality-statement-10-specialist-palliative-care (last accessed 07/11/19)

NHS Education for Scotland (2017) Palliative and End of Life Care Enriching & improving experience

https://www.nes.scot.nhs.uk/newsroom/features-and-articles/palliative-and-end-of-life-care-enriching-and-improving-experience.aspx (last accessed

07/11/19)

Office for National Statistics (2015) National Survey of Bereaved People (VOICES): England

https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015#preferences-and-choice-at-the-end-of-life (last accessed 07/11/19)

Parkes, C. and R. Weiss, Recovery from bereavement. 1983. New York: Basic Books as quoted https://www.gov.scot/publications/strategic-commissioning-palliative-end-life-care-integration-authorities/pages/4/ (last accessed 07/11/19)

Scottish Community Development Centre (2015) National Standards for Community Engagement https://www.scdc.org.uk/what/national-standards/ (last accessed 07/11/19)

Scottish Co-production Network (2019)

http://www.coproductionscotland.org.uk/about/vision-for-co-production/ (last accessed 07/11/19)

Scottish Government (2012) A Framework for the Delivery of Palliative Care for Children and Young People in Scotland

https://www.gov.scot/publications/framework-delivery-palliative-care-childrenyoung-people-scotland/ (last accessed 07/11/19)

Scottish Government (2015). Strategic Framework for Action on Palliative and End of Life Care 2016–2021. Edinburgh: Scottish Government http://www.gov.scot/Topics/Health/Quality-Improvement-
Performance/peolc/SFA (last accessed 07/11/19)

Scottish Government (2015B) Excellence In Care - Scotland's National Approach to Assuring Nursing and Midwifery Care Event Report https://www.gov.scot/publications/excellence-care-scotlands-national-apporach-assuring-nursing-midwifery-care-event-report/pages/3/ (last accessed 07/11/19)

Scottish Government (2016) A Fairer Scotland for Disabled People: delivery plan https://www.gov.scot/publications/fairer-scotland-disabled-people-delivery-plan-2021-united-nations-convention/ (last accessed 07/11/19)

Scottish Government (2016) A National Clinical Strategy for Scotland https://www.gov.scot/publications/national-clinical-strategy-scotland/pages/5/ (last accessed 07/11/19)

Scottish Government (2016) New principles for National Care Standards http://www.gov.scot/Topics/Health/Support-Social-

<u>Care/Regulate/Standards/NCSreview/NCSPrinciples</u> (last accessed 07/11/19) **Scottish Government** (2017) Health and Social Care Standards: My support, my life https://www.gov.scot/publications/health-social-care-standards-support-life/ (last accessed 07/11/19)

Scottish Government (2017) Realising Realistic Medicine: Chief Medical Officer for Scotland annual report 2015-2016

https://www.gov.scot/publications/chief-medical-officer-scotland-annual-

<u>report-2015-16-realising-realistic-9781786526731/</u> (last accessed 07/11/19)

Scottish Government (2018) Strategic Commissioning of Palliative and End of Life Care by Integration Authorities

https://www.gov.scot/publications/strategic-commissioning-palliative-end-life-care-integration-authorities/ (last accessed 07/11/19)

Scottish Government (2019) Health and Care (Staffing) (Scotland) Act 2019 https://www.legislation.gov.uk/asp/2019/6/introduction (last accessed 07/11/19)

Scottish Partnership for Palliative Care (2015) Grasping the Nettle. What Action Can We Take to Improve Palliative and End of Life Care in Scotland http://www.parliament.scot/S4_HealthandSportCommittee/Inquiries/PCA_Grasping-the-Nettle_SPPC.pdf (last accessed 07/11/19)

Scottish Partnership for Palliative Care (2019) What is palliative care https://www.palliativecarescotland.org.uk/content/what_is_palliative_care/ (last accessed 07/11/19)

Scottish Partnership for Palliative Care (2019) Specialist palliative care services in Scotland

https://www.palliativecarescotland.org.uk/content/services_in_scotland (last accessed 07/11/19)

Scotland's National Dementia Strategy 2017-2020

https://www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020/ (last accessed 07/11/19)

- The Gold Standards Framework (2019)
 https://www.goldstandardsframework.org.uk/ (last accessed 07/11/19)
- The Scottish Commission for Learning Disability (2013) The keys to life https://keystolife.info/strategy/ (last accessed 07/11/19)
- World Health Organisation (2017). WHO Definition of Palliative Care http://www.who.int/cancer/palliative/definition/en (last accessed 07/11/19)

Annex 1: Link to Strategic Needs Assessment (2018)

http://www.dg-change.org.uk/strategic-needs-assessment-second-edition/

Annex 2: Link to Health and Social Care Strategic Plan (2018) http://dghscp.co.uk/wp-content/uploads/2018/12/Strategic-Plan-2018-2021.pdf

Annex 3: Link to the Strategic Framework for Action on Palliative and End of Life Care (2015) https://www.gov.scot/publications/strategic-framework-action-palliative-end-life-care/

Annex 4: Link to all four Dumfries and Galloway Locality Plans https://dghscp.co.uk/useful-documents/

Annex 5: Realising Realistic Medicine: Chief Medical Officer for Scotland Annual Report 2015-2016 https://www.gov.scot/publications/chief-



Appendix details to be confirmed during editing process

Appendix 4

Equality and diversity statement

We have a shared responsibility under the Equality Act 2010, in relation to the 9 protected characteristics of Age, Disability, Gender Reassignment, Marriage and Civil Partnership, Pregnancy and Maternity, Race, Religion and Belief, Sex and Sexual Orientation to:

- Eliminate discrimination, harassment and victimisation
- Advance equality of opportunity between those who share a protected characteristic and those who do not by removing or minimising disadvantage related to a protected characteristic, taking steps to meet the needs of people from protected groups where these are different from the needs of other people and encouraging people from protected groups to participate in public life where their participation is proportionately low
- Foster good relations between those who share a protected characteristic and those who do not

This applies equally to all individuals regardless of their protected characteristics.

Appendix 5

Good governance and evaluating the strategy

Governance structure and evaluation template to be added

If you would like some help understanding this or need it in another format or language please contact dg.ijbenquiries@nhs.net or

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