

**Dumfries and Galloway  
Integration Joint Board**



# **(Final Draft) A Plan for Palliative Care**

**2020 – 2025**

Final Draft – August 2020

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## 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 including

- giving people greater choice and control over decisions relating to their care and support
- ensuring services integrate around a person's needs and wishes
- supporting people to live in their own communities as well as possible for as long as possible and to die with dignity

These principles are embedded within this plan for palliative care.

The plan will help us to ensure that anyone who might benefit from palliative care and support is 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 and health and social care professionals, who have contributed to and supported the development of this plan.

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

## Executive Summary

The Dumfries and Galloway IJB plan for palliative care defines palliative care as

- care and support for people who have serious life limiting illnesses
- the period from diagnosis until death
- support that enables people including families, friends and Carers to live as well as possible
- health and social care professionals, friends, families and Carers are supported to provide care and support to the best of their ability

The vision for palliative care in Dumfries and Galloway is that

*‘All people in Dumfries and Galloway who need palliative care and support will have access to it’.*

People have told us that what matters to them in relation to palliative care is

- person centred care
- communication
- access to resources
- high quality of care
- access to community base care
- integrated working

The plan demonstrates that partners across health and social care already work together to deliver the 4 dimensions of palliative care and support (See page 6). The dimensions relate to the holistic needs and preferences of the person’s health and well being and include

- emotional and psychological (including mental health)
- social
- spiritual
- physical

To achieve the vision for palliative care, the plan highlights changes in demographic and disease profiles as well as financial and workforce challenges that need to be addressed.

The model of palliative care in Dumfries and Galloway (on page 17), illustrates

- the person at the centre, supported and empowered to make informed choices and decisions about their own care
- the critical role of families, friends and Carers, community and voluntary resources, statutory and non-statutory sector community and hospital based teams
- how specialist palliative care provides support across all levels of palliative care
- the 4 dimensions of palliative care through all levels of care and support

Supporting staff teams, volunteers and Carers, with the resources to provide people

with life limiting conditions with the right care and support at the right time in the right place is paramount.

The 'Making It Happen' section (on page 31), identifies some of the key actions that need to be undertaken to implement this plan.

# 1 Introduction

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

This is a plan to

- define what palliative care and support is within the context of this document
- describe the vision and model for palliative care and support in Dumfries and Galloway
- highlight the current challenges in sustaining and maintaining safe, effective, high quality palliative care and support
- describe 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 (see section 3 The case for change).

Given the demographic, financial and workforce challenges highlighted in section 3 of this plan, we need to ensure that the model of palliative care in Dumfries and Galloway is able to provide adequate and sustainable generalist and specialist services.

The [Scottish Government Strategic Framework for Action on Palliative and End of Life Care 2016-2021](#) (National Strategic Framework) sets out the guidelines and commitments for palliative care in Scotland (see section 2.3.1). This plan identifies what we need to do locally to fulfill these commitments and implement other key local and national policy and guidance through a partnership approach.

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 overall experience of palliative care is improved and people are supported to die with dignity
- people, their families and Carers (including Young Carers) are able to have timely conversations with all those involved in their care and support
- a 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 and across communities

- the needs of Carers, including Young Carers, are assessed throughout the person's illness and appropriate support put in place at each stage
- people are empowered to support others living in their communities with life limiting conditions
- that wherever possible, people will be supported to have treatment and care that is aligned with their goals and preferences
- people can access high quality care and support on the basis of need
- health and social care professionals, friends, families and Carers are supported to provide care and support to the best of their ability

### 1.3 What do we mean by palliative care?

Palliative care is

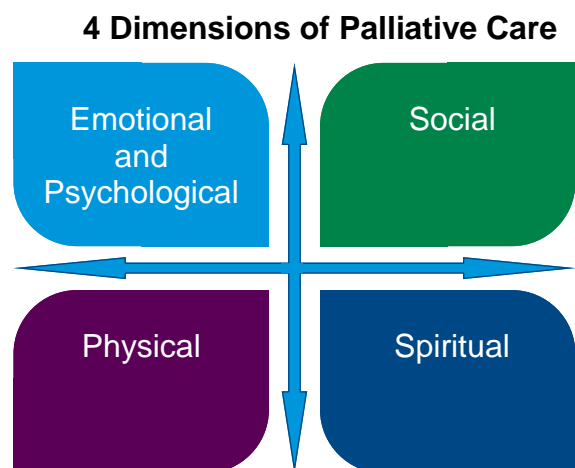
- care and support for people who have serious life limiting illnesses
- the period from diagnosis of a life limiting illness until death, including care in the last days of life
- support that enables people to live as well as possible, for as long as possible whether that is for hours, days, months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

Palliative care should be available for people who have any serious life limiting, progressive illness such as

- Alzheimer's disease
- dementia
- cancer
- motor neurone disease
- organ failure (including lung disease, heart failure, kidney failure or liver failure)
- Parkinson's disease
- progressive, irreversible frailty from multiple conditions or old age

Palliative care considers the person as a whole and includes

- **emotional and psychological** support with issues such as anxiety or depression following a palliative diagnosis
- **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

The 4 dimensions of care are highlighted in the [Palliative and End of Life Care by Integration Authorities: Advice Note](#) (see glossary for definitions of each dimension)

## 1.4 What do we mean by specialist palliative care?

Specialist palliative care is care provided by multi disciplinary, multi professional teams with specific palliative care training and expertise. Specialist palliative care can be delivered in a range of different locations, including people’s homes, care homes, prisons, homeless accommodation, hospitals and specialist palliative care units or hospices.

Specialist palliative care professionals provide advice, support and education across all settings, to people providing generalist palliative care and support including Carers.

In Dumfries and Galloway, the specialist palliative care unit is the Alexandra Unit in Dumfries. This is similar to a hospice model of inpatient specialist palliative care. However, the funding model is dissimilar to that of a hospice in that it is wholly NHS funded.

Specialist palliative care, including community care and care and support from the Alexandra Unit, can be accessed throughout a person’s life limiting illness for all 4 dimensions of support or care in the last days of life. Referrals to the service can be made by a variety of people including, GPs, community nurses, clinical nurse specialists (CNS), hospital doctors, Allied Health Professionals, Social Workers, Carers and people that have a life limiting illness directly.

“My condition is palliative; I understand there is no other treatment that could cure me. My quality of life is good because the Macmillan nurse and district nurses keep me pretty much pain free and comfortable at home. I live rurally and a fair distance from the hospital so this is important to me and my family”.

“I have symptoms just now that they have been unable to manage at home, so have had to come in to the Alexandra Unit. I have had this before and know they can sort it out. The staff here are great and do their best to support me to get home as quickly as possible, as they know that’s where I want to be”.

*Anonymous engagement participant*

## 1.5 Who is this plan for?

This plan is for

- people aged 18 years and over in Dumfries and Galloway with serious life limiting, progressive, incurable illnesses
- Carers, families and friends of all ages of people with serious, life limiting illnesses in Dumfries and Galloway
- people working in health and social care in Dumfries and Galloway

### 1.5.1 Palliative care for children and young people

The number of children and young people who receive palliative care and support is small in comparison to adults. Nonetheless, their care and treatment is as complex as that required for adults, and needs active management.

Providing high quality care and support in a sparsely populated area is challenging. It is recognised that children and young people living a significant distance from specialist palliative care provision can experience a range of challenges accessing care and support.

The Scottish Government report, '[A Framework for the Delivery of Palliative Care for Children and Young People in Scotland](#)' (2012), highlights that care and support for children and young people should be equitable, sustainable, age appropriate and independent of geography.

Whilst the Partnership seeks to consistently provide care and support that meets the needs of children and young people, it is recognised that symptom management and other aspects of palliative care and support can, at times, be fragmented. To address this, work is being taken forward at a local level to review the palliative care and support available for children and young people, their families, friends and Carers. This is in the early stages of development.

The planning and delivery of specialist palliative care for children in Dumfries and Galloway is with the national Children's Hospice Across Scotland (CHAS) organisation supporting local teams.

## 1.6 How has this plan been developed?

This plan has been developed by engaging with people who have had experience of, currently receive, or deliver palliative care and support. Views were gathered using

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

Details of the engagement activities and a timeframe for the development of the plan are included within the full Statement of Consultation in Appendix 1. A report from the first round of engagement can be viewed online [here](#).

## 2 Vision and Purpose

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

The vision for palliative care in Dumfries and Galloway is aligned to that of the National Strategic Framework

*‘All people 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
- encouraged and enabled to express their wishes and preferences
- able to access high quality, effective care and support
- enabled to live and die well with dignity in their preferred place of care

### 2.2 How will we achieve the vision?

The vision will be achieved by

- listening to what people have told us and responding to this
- delivering the aims and outcomes of the National Strategic Framework
- addressing the priorities of the Dumfries and Galloway Health and Social Care Integration Joint Board Strategic Plan (2018-2021)
- adapting current ways of working to meet the ambitions in this document

Details on the actions to be taken forward are provided in 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

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

This document requires the support and action of a wide range of statutory, independent and third sector organisations nationally and locally including Integration Authorities, to deliver the national vision that *“by 2021 everyone in Scotland who needs palliative care will have access to it”*.

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

1. People receive health and social care that supports their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death
2. 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
3. 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
4. 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

To support the implementation of this document, 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 in relation to palliative care.

## The Nine National Health and Wellbeing Outcomes

These outcomes are high level statements of what health and social care partners are hoping to achieve through the integration of health and social care.



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

[Realising Realistic Medicine](#) is a report published by the Scottish Government in 2017. Its vision is that “by 2025, everyone who provides healthcare in Scotland will demonstrate their professionalism through the approaches, behaviours and attitudes of Realistic Medicine”.

Realistic Medicine encourages an approach whereby decisions about care and support are shared between the person receiving it and the health and/or care professional, moving away from a "doctor knows best" culture. To achieve this health and care professionals need to be aware of what matters to the person including what the goals are that they want to achieve for themselves.

## Clinical Standards for Specialist Palliative Care (2002)

The [Clinical Standards](#) were developed in partnership with the Scottish Partnership for Palliative Care (SPPC). They relate to 8 standards of care delivery that are used to assess performance in relation to specific elements of specialist palliative care.

### 2.3.2 Relevant local documents

#### **Dumfries and Galloway Health and Social Care Integration Joint Board, Strategic Plan (2018 – 2021) ([the Strategic Plan](#))**

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. The 'Making it Happen' section of this plan has been linked to these priorities.

#### **Links to other relevant local strategies**

[The Carers Strategy 2017-2021](#)

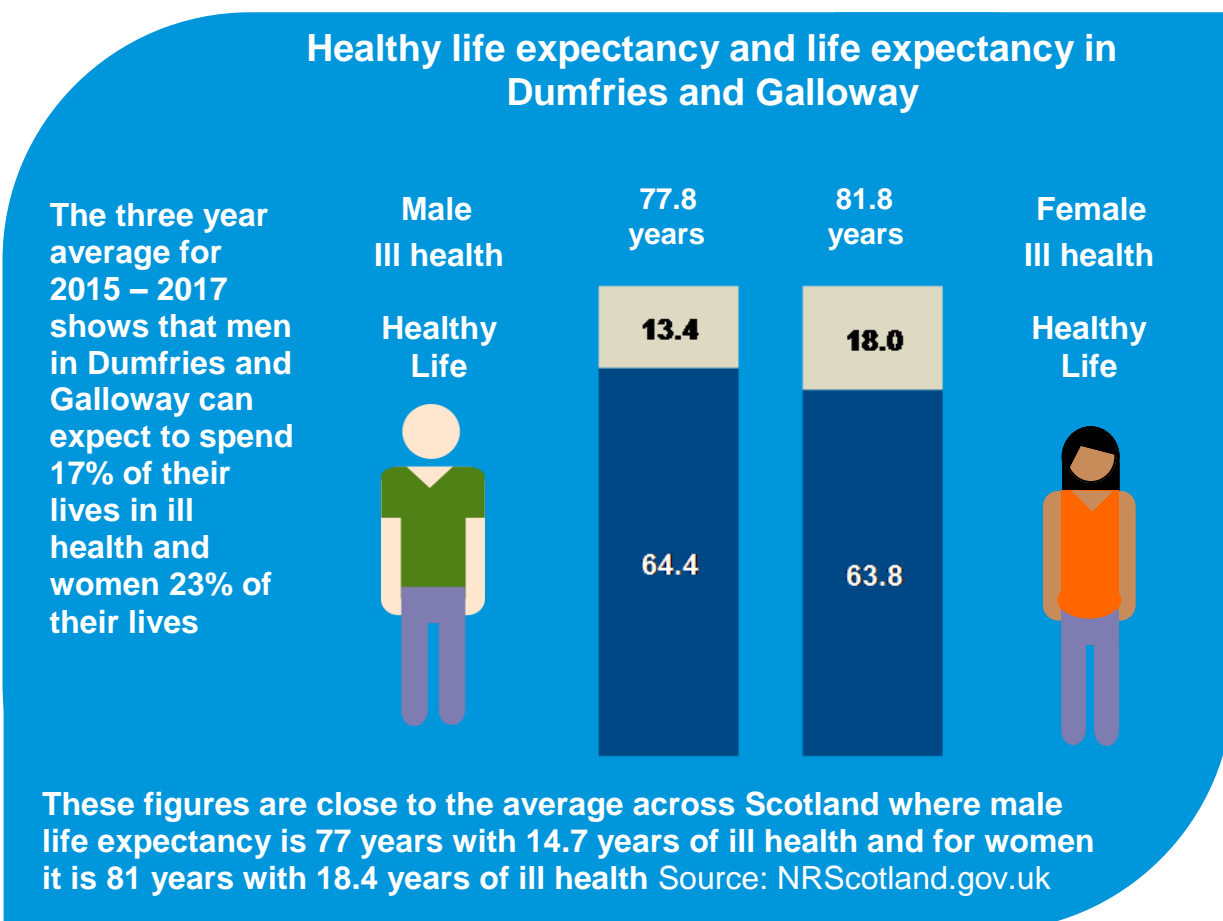
[Dumfries & Galloway Children's Services Plan April 2017 – March 2020](#)

The Dumfries and Galloway Digital Health and Care Strategy 2020-2024 (Link to be added)

Dumfries and Galloway IJB Housing with Care and Support Strategy 2020-2024 (Link to be added)

## 3 The case for change

People in Dumfries and Galloway are living longer but often in ill health. This changing demographic is contributing to an increase in health and social care needs which, in turn, is leading to a rising demand for services including palliative care and support. The challenge of this is compounded further by the increasingly limited availability of workforce and financial resources.



To address these challenges, we must work together as partners to plan the changes needed to sustain and improve the way that we currently provide care and support.

### 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.” (Information Services Division 30 May 2017).

In Dumfries and Galloway

- the number of people who died in 2018/19 was **1,950**
- excluding those who died of external causes such as sudden unexpected death, and those whose death was registered in England, there were **1,831** deaths
- the percentage of the last 6 months of life spent at home or in the community was **88.8%** (this is similar to the national figures of, **87%**)
- the percentage of time people spent in hospital was **11.2%** (an average of **20** days)
- the total number of deaths is expected to rise to just over **2,100** by 2041

(Source Health and Social Care Integration Indicators, NI15, Dashboard 2)

#### Place of death

- In 2018, **44%** of people died in their usual place of residence (**26%** at home and **18%** in care homes)
- **7%** of people died in the Alexandra Unit and the remaining **49%** died in other hospital wards (including cottage hospitals)

(Source: Business Objects, NHS Dumfries and Galloway)

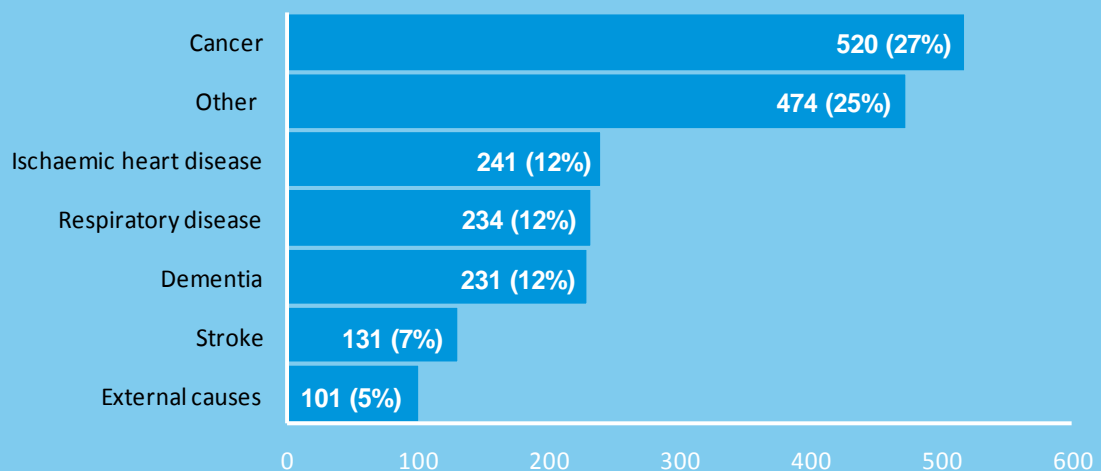
Research by the University of Glasgow has shown that a person's cause of death can influence where they die. For example people with dementia or that have experienced a stroke, are more likely to die in a care home rather than their own home (Black et al 2016).

#### Cause of death

Over **90%** of people die from long term conditions and illnesses. This would indicate that, each year, approximately **1,750** people could benefit from palliative and end of life care and support in Dumfries and Galloway.

(Source: National Records of Scotland Vital Events figures 2016-2018)

## Causes of Death: Number of Deaths per year



Source: National Records of Scotland Vital Events

### 3.2 Finance

This plan considers how we make best use of existing resources and develop care and support that meets the outcomes set out in section 2.3.1.

The annual budget of the IJB is shown below.

Combined integrated draft finance plan – 2018 - 2021				
	2017/18 £million	2018/19 £million	2019/20 £million	2020/21 £million
Council services	67.1	71.1	73.8	75.3
NHS services	291.5	273.7	278.0	282.0
Total integrated finance plan	358.6	344.8	351.8	357.3

We will

- prioritise effectively
- consider how palliative care and support might be delivered differently for example building on work with third sector organisations
- consider what we might stop doing or do less of to enable us to develop services
- work as efficiently and effectively to make best use of existing resources

The provision of care and support for people close to death has a significant impact on Partnership resources. The 'Palliative and End of Life Care by Integration Authorities:

Advice Note' (2018), states that people in their last year of life account for approximately

- **15%** of health and social care partnership costs
- **25%** of unplanned bed days (emergency admissions)
- **29%** of all general hospital bed days annually

A priority is to support people to remain in their own home or be cared for as close to home as possible. We aim to use resources effectively to ensure that people can access hospital services when needed, but return home as soon as appropriate.

Shifting the balance away from institutional care depends on families, friends, Carers, organisations, geographical communities and communities of interest, such as faith groups working together to deliver palliative care and support.

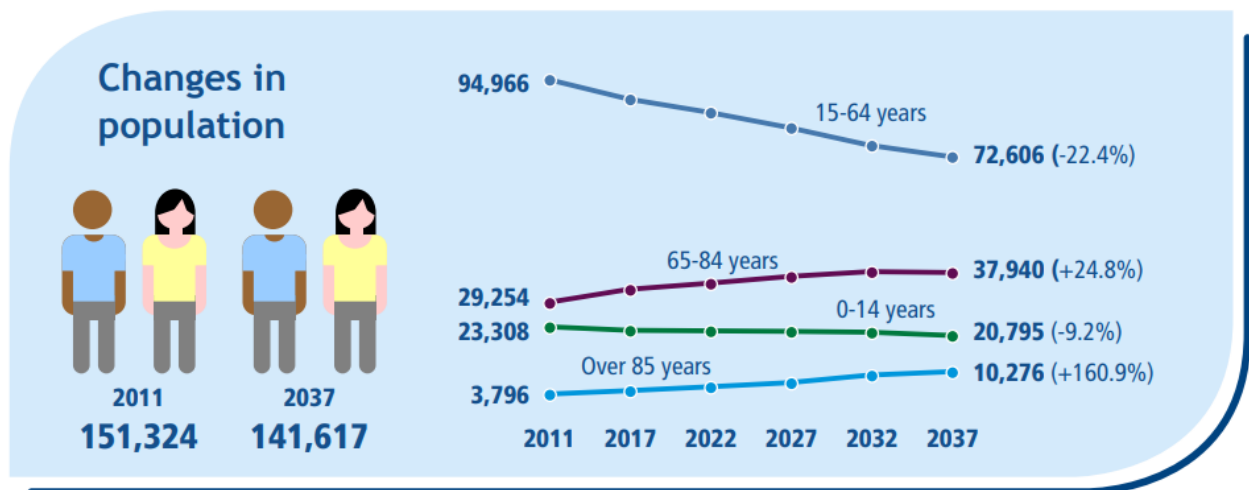
### 3.3 Workforce

#### Recruitment and retention

In the 'Grasping the Nettle' report published in 2015, the SPPC acknowledge that generalist settings in the health and social care system are under significant pressure. The majority of palliative care, other than that provided by unpaid Carers, is currently provided directly by them, with support from specialist services. The report highlights that "substantial changes are required to create a health and social care system that is sustainable".

For future models of care and support to be sustainable and to comply with legislation and best practice, it is important to ensure people providing palliative care (paid or unpaid) have the right skills.

Recruiting and retaining people is becoming an ever greater challenge both nationally and locally. Medical and nursing staff, Allied Health Professionals (AHPs) and social care professionals all now present significant recruitment challenges. The Dumfries and Galloway IJB Interim Workforce Action Plan 2019/20 (the Workforce Plan) highlights risks to future service provision due to the age profile of Dumfries and Galloway.



Source: National Records of Scotland 2012

Legislation and guiding documents setting standards for quality of care and staffing levels across health and social care are included in the 'Links to documents which helped us produce this plan' section (see page 49).

Appropriate information, advice and training for people providing care and support, including unpaid Carers, is essential to effectively meet the needs of the anticipated **1,900** people a year in Dumfries and Galloway who may need it. Opportunities for formal and informal learning such as on-line and practical training should be accessible to everyone and shared across all areas of the workforce.

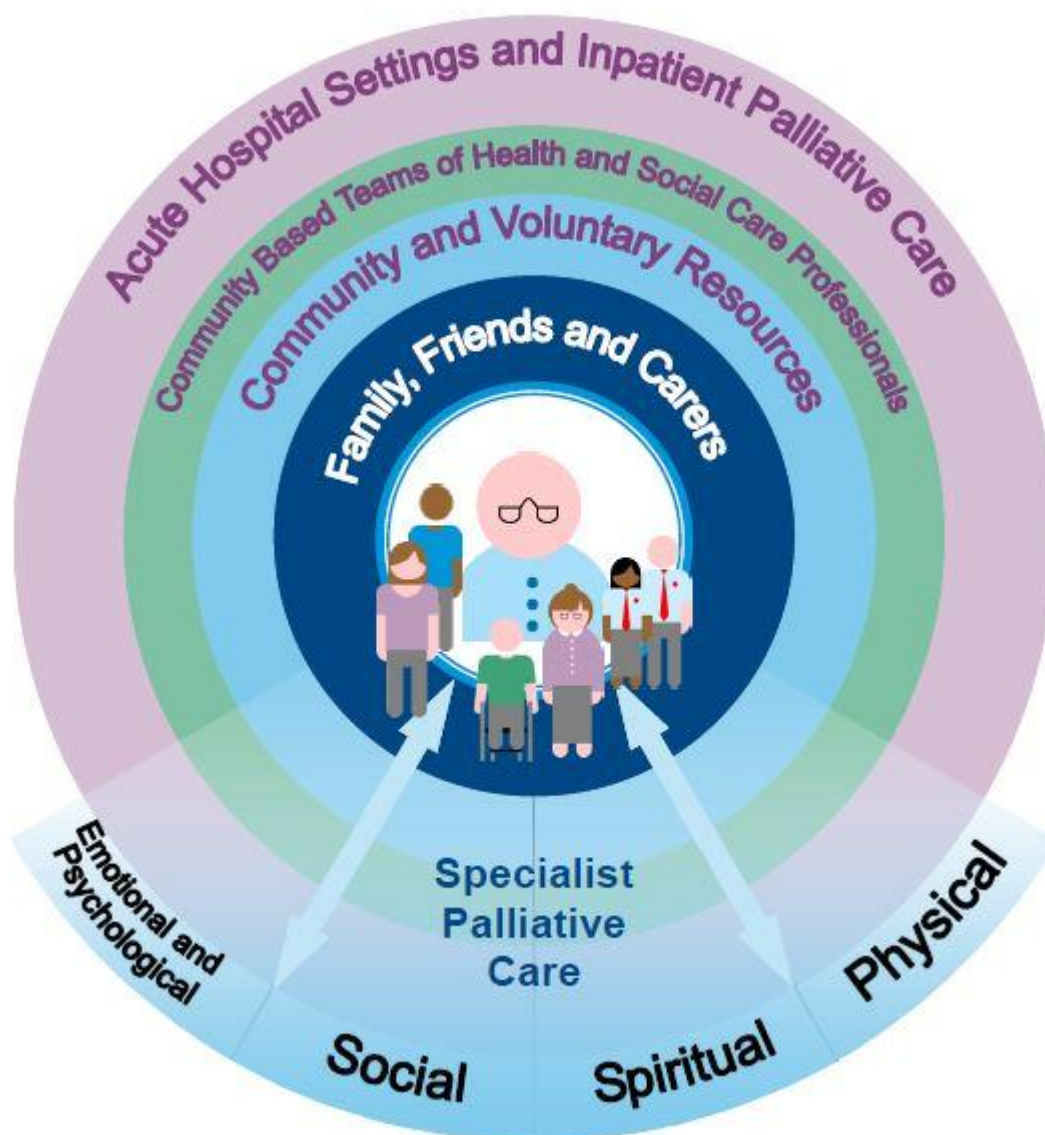
## 4 Planning for the future

### 4.1 The model for palliative care and support in Dumfries and Galloway

National and local priorities and 'what matters to people' in Dumfries and Galloway clearly identify that a person must be at the centre of their own, care, support and decision-making. 'Good Conversations' lie at the heart of this. These are conversations that provide opportunities to discuss personal outcomes, wishes and what matters to them.

The model for Dumfries and Galloway has the person receiving care supported by their family, friends and Carers within the community in which they live in the first instance. They, in turn, are supported by services, paid and unpaid, community and hospital based, specialist and non-specialist. All of these people work together to ensure that the person is supported holistically through the '4 dimensions of care'.

The model below supports a public health approach to palliative care and illustrates the '4 dimensions of care' within each layer of available care and support. This is based on the World Health Organisation's Conceptual Framework for Person-Centred and Integrated Health Services (2015).



Some aspects of each section of the model have been described below.

#### 4.1.1 Family, friends and Carers

It is widely recognised that family, friends and Carers providing informal and unpaid care, supply the most significant amount of support to people towards the end of their life. Providing timely and appropriate support for this group of people to look after their own health and wellbeing is very important to sustain this invaluable resource. Some initiatives which aim to do this are highlighted in section 4.2.

Much of people's need in relation to palliative care and support is being met by families, friends, Carers, Primary care, community nursing, care at home providers and in care homes. Some of this care and support may not be formally identified as palliative care. (Palliative and End of Life Care by Integration Authorities: advice note 8 May 2018)

### 4.1.2 Community and voluntary resources

“A public health approach to end of life care, views the community as an equal partner in the long and complex task of providing quality healthcare at the end of life” (Public health Palliative Care International, 2019). It makes the best use of assets including the skills, capacity and knowledge of families, friends, Carers and communities and builds resilience.

Public health approaches include school projects, compassionate communities, intergenerational work with care homes and the EASE (End of Life Skills for Everyone) course run by the SPPC.

It is important to recognise the vital contribution of families, friends, Carers and local communities in supporting a person with palliative care needs. Their support can have a significant impact on people’s ability to live as well as possible with their illness.

There is a wide range of independent sector, third sector and informal support available to people receiving or delivering palliative care in Dumfries and Galloway including

- befriending services
- support for Carers
- information, advocacy and advice services
- care at home provision
- supported housing
- care homes, nursing homes and Elderly Mentally Infirm (EMI) Units
- Macmillan Move More and Transforming Care After Treatment (TCAT) exercise groups

580 people in receipt of care at home in Dumfries and Galloway died in 2018/19, of these 37 had been identified as likely to be in the last 6 months of life. (Source Financial Information Office, Dumfries and Galloway Council, 2019)

There were **1,015** people resident in care homes, nursing homes and EMI Units in Dumfries and Galloway in September 2019. Figures show that **476** people died in these placements across Dumfries and Galloway in 2018/19 (Source Financial Information Office, Dumfries and Galloway Council, 2019). It is likely that most required palliative care in the period before they died.

Having the right staff in the right place at the right time, with the right skills and knowledge to support and provide safe, effective, high quality palliative care in all settings is very important. This would benefit people receiving and delivering palliative care by contributing to sustaining services and improving access to palliative care and support.

### 4.1.3 Community based teams of healthcare professionals

It is essential that everyone involved in delivering palliative care and support works together to ensure the person experiences seamless and well coordinated care. This

not only results in improved care and support for the person, their family, friends and Carers but also helps make best use of the available staffing resource.

### General Practitioners (GPs)

As expert generalists, GPs provide people with care, advice and signposting to other appropriate community and specialist support. As with many other roles across health and social care, filling vacant GP posts is challenging. The Dumfries and Galloway IJB Interim Workforce Action Plan 2019/20 highlights a shortage of GP trainees nationally, particularly in rural areas.

### Community Nursing

There were around **225,000** home visits by Community Adult General Nursing (usually known as District Nurses) in Dumfries and Galloway in 2018. The majority of these visits were described as having a primary aim in relation to either wound care or palliative care. It is not possible to provide more specific breakdown of this statistic using current available data.

Marie Curie community nursing care supports people at home via the Planned Variable Service, (also known as the overnight or 'sitting' service) and Rapid Response (also known as the out of hours service). Between 9pm and 7am the Rapid Response Service can provide administration of medication and other practical assistance across Dumfries and Galloway (with the exception of DG8 and DG9 postcode areas). This service is currently supported by the DGRI endowment fund. The Planned Variable Service provides 'sitting' service either at night or during the day to allow unpaid Carers to have a break.

Marie Curie Nurses, work with partners across health and social care, including specialists in palliative care. In the 6 months up to November 2019, Marie Curie reported that, of the people referred to them, around **80%** of these were able to be supported, "to reach their preferred place of death".

### Clinical Nurse Specialists (CNS)

CNSs provide care and support in a range of areas of care including some that are potentially life limiting such as organ failure, motor neurone disease, respiratory disease and multiple sclerosis. They provide clinical and non-clinical care and support to people throughout their palliative care journey. This can include helping people to complete Anticipatory Care Plans and other relevant documentation that ensure their wishes and preferences with regards to their ongoing care and support are recorded. There are also Specialist Palliative Care CNSs (Macmillan Nurses).

The number of referrals to the Specialist Palliative Care CNSs in the community is growing annually, increasing by **50%** over 3 years from **302** referrals in 2016 to **456** in 2019.

### Clinical Nurse Specialists in Palliative Care

There are 4 Macmillan clinical nurse specialists, providing **142.5** hours of specialist nursing care per week in communities across Dumfries and Galloway. This involves all 4 dimensions of palliative care (shown in Section 1.3) for the person but also support and advice for family and Carers.

“The Macmillan nurse was so kind, knowledgeable, compassionate and caring to the person who was dying (of a non-cancerous condition) and to their partner. She provided not just clinical care but emotional reassurance and practical support as well as information and referrals to other services. It was very humbling”.

*Anonymous*

### Cottage hospitals

Some people currently have their palliative care and support needs met in cottage hospitals. This can sometimes mean supporting a person to transition from an acute hospital setting to their own home.

Work is being undertaken to develop enhanced roles in cottage hospitals such as advanced nurse practitioners and the use of Workforce Workload Planning tools for Community Cottage Hospitals to support staff and people in receipt of palliative care.

### Pharmacists

Pharmacists play an important part in meeting the needs of people in receipt of and those delivering palliative care. The Strategic Commissioning of Palliative and End of Life Care by Integration Authorities: Advice Note (2018) states that preventing and relieving suffering through “early identification, correct assessment and treatment of pain and other problems” improves quality of life for people with life limiting illnesses. Pharmacists can help by providing medicines information, undertaking medicines reviews, considering the best aid for dispensing medication if needed, and identifying those whose health is deteriorating.

### Community based Allied Health Professionals (AHPs)

Community based AHPs such as occupational therapists, physiotherapists, speech and language therapists and dieticians provide care and support to people in the communities in which they live. They help people meet their own goals such as remaining independent as their health declines and work as part of a team to support transitions from hospital to home.

## 4.1.4 Acute hospital setting (DGRI and Galloway Community Hospital) and inpatient care

### General hospital wards

One person in 3 admitted to hospital is in their last year of life (Clark, D et al, 2014). This means that many people in the acute hospital setting have palliative care needs. It is important therefore, that the specialist palliative care team have capacity to support colleagues to do this well.

### Specialist palliative care team

The Clinical Standards for Specialist Palliative Care (2002), highlight that specialist palliative care teams should include staff from a broad range of disciplines. This enables the team to provide direct support and comprehensive guidance to others involved in a person's palliative care. Identifying a sufficient level of capacity and skill mix within the specialist palliative care team locally to offer the range and level of support needed is a challenge. There is no identified funding to support all of the posts that provide the core mix of disciplines required of a specialist team and inpatient unit. There is funding identified for a second Consultant in Palliative Medicine but this post has proved difficult to recruit to.

### Alexandra Unit

Between 1 January and 31 December 2019

- **242** people received care and support from the Specialist Care Team in the Alexandra Unit (this does not include the support or advice provided to staff, family, friends and Carers).
- **83** people received symptom or pain management care and were discharged
- **159** people died in the Alexandra Unit

(Source: Topas, 2019)

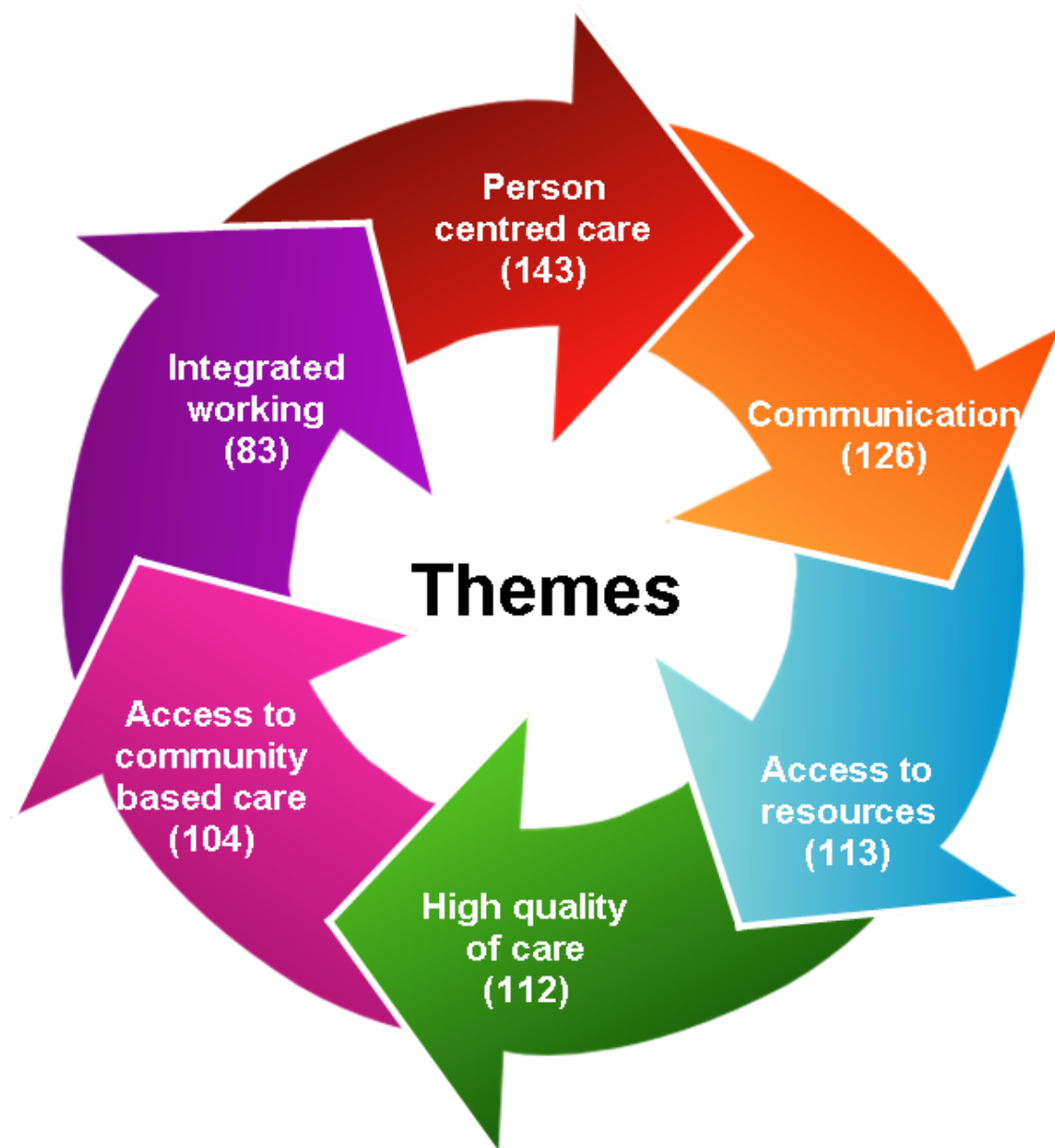
## 4.2 What people told us

From January to April 2019, **565** people from across Dumfries and Galloway shared their views on 'what is working well', 'what is not working well' in palliative care and end of life support. The engagement questions included a request for suggestions for improvement. The full report on the engagement is available at

[www.dghscp.co.uk/macmillan/palliative](http://www.dghscp.co.uk/macmillan/palliative)

The information people provided during the engagement was collated and grouped into themes (as shown below).

### Themes from engagement activities



Please note

*(The numbers in the brackets on the above graphic represents the number of comments received).*

The engagement with people across Dumfries and Galloway highlighted some areas of palliative care and support that are working well and some that are not. This feedback will influence and inform the development of services that better fit the needs of people receiving and delivering palliative care and support.

“Very skilled staff across integrated Health and Social Care services”

“More Out of Hours cover needed” particularly in the west of the region



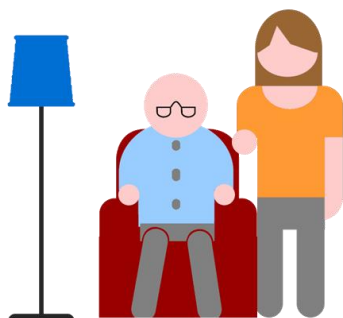
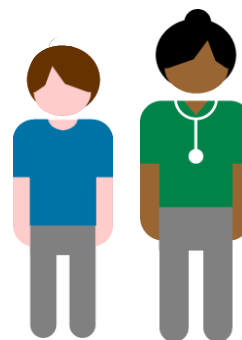
“Need better access to specialist drugs, particularly out of hours”



“Poor communication can cause distress” for families, Carers and staff

“Hospice beds in community would take pressure off acute services”

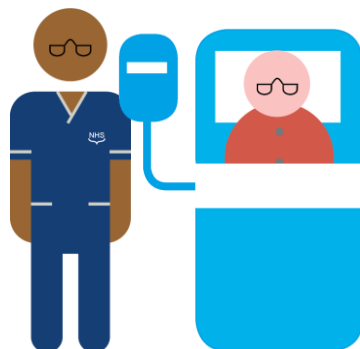
“Carers centre is really useful”



“Training should be available for everyone delivering palliative care” (paid and unpaid)

“GP was a great support and was really good at explaining what would happen at

Services across health and social care “need to work in a more ‘joined up’ way”



“The Alex Unit was fabulous in providing care to both of my parents”

“My family member had terminal cancer and was receiving fabulous care from the community nurses, Macmillan nurse, GP’s, respiratory nurses and his wife. He and his wife had had open and honest discussions with their family and those involved in his care about death and dying. They had Do Not Attempt Resuscitation documents, anticipatory care plans, Power of Attorney and end of life plans in place. He made it clear he did not want to die in hospital. He wanted to die at home”.

“In what we now know were the last hours of his life, he fell out of bed having taken a turn for the worse and was transported by ambulance to the hospital 1 hour away. On arrival at the hospital, staff expected to carry out life sustaining resuscitation and clinical intervention. It was only upon arrival in Accident and Emergency that it became known to clinicians that none of this was needed or wanted. He died, receiving excellent care and attention, with his family around him, in a busy assessment receiving ward”.

“It was disappointing that everything planned so well, was let down at the last hour and that what he wanted was not provided”.

*Anonymous Carer*

### **4.3 What we are doing and what we are going to do**

There is a range of care and support available to help people across Dumfries and Galloway have a positive experience of palliative care. However, engagement with stakeholders has identified where further improvement or development may be needed.

Below are some examples of initiatives that aim to sustain, build or improve palliative care and support in Dumfries and Galloway.

#### **4.3.1 Development of ‘Home Teams’ in communities**

Dumfries and Galloway are taking forward an initiative to develop ‘Home Teams’. These are teams of multidisciplinary, multi agency groups of health and social care professionals that are neighbourhood based and that take an integrated approach to care delivery. This approach will provide care and support to people in or as close to their own home wherever possible and be responsive to the changing needs of the person.

#### **4.3.2 Post diagnostic support (PDS)**

Good post diagnostic palliative care and support for people with life limiting conditions relies on early diagnosis and intervention. Having an early awareness of their condition can help the person voice their needs and preferences and provide the opportunity for these to be recorded. Placing someone at the centre of planning their

own care and support provides them with more choice and control.

The SPICT (Supportive & Palliative Care Indicators Tool) and the Rockwood Frailty Scale can help to identify people with life limiting conditions who are at risk of deteriorating and dying earlier (see glossary for details).

### Supporting People Living With Dementia

Information Services Division (ISD) data for 2017/18 indicates that **1,451** people in Dumfries and Galloway were diagnosed with a dementia in that period. Figures also indicate that there may be a similar number of people with dementia with no formal diagnosis who will therefore not access PDS. People living with undiagnosed dementia and their Carers, can struggle to manage symptoms and access services to maintain living in their preferred place of care for as long as possible. This often results in people reaching crisis point and can lead to unnecessary hospital admissions.

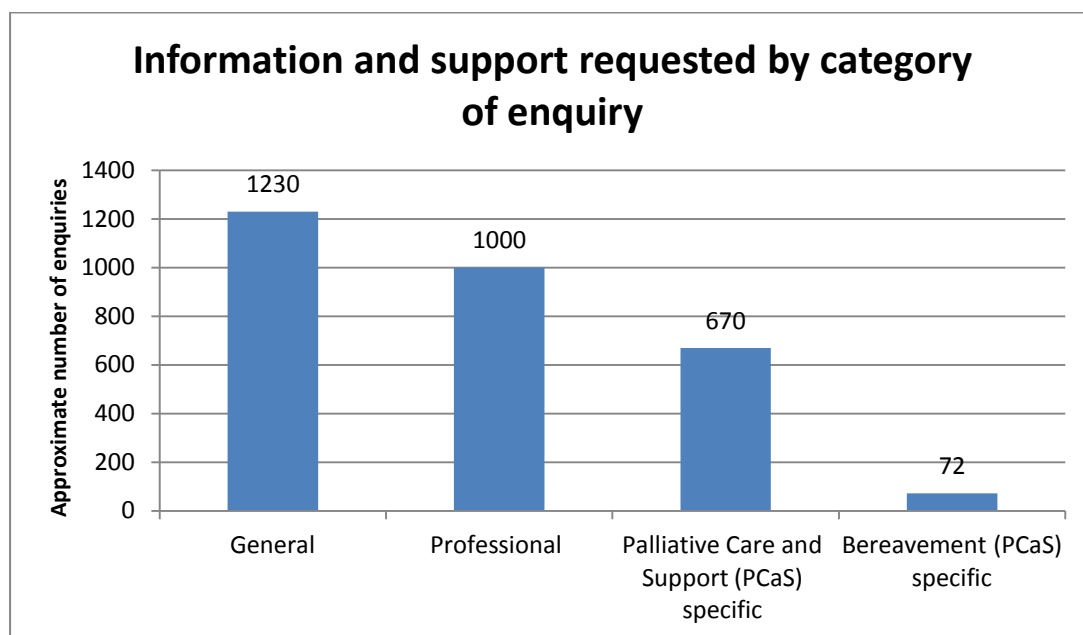
Work has been undertaken in Dumfries and Galloway to improve access to diagnosis and PDS for people living with dementia. This has resulted in

- more efficient and effective referral and diagnosis processes
- a significant (186%) increase in the number of people who have been able to access a diagnosis
- a more efficient process for specialist assessment, reducing the waiting time for support from 224 days to 23 days

### Macmillan Cancer Information and Support Centre

The Macmillan Cancer Information and Support Centre, is based in DGRI. This centre provides information, support, advice and services to people of all ages, their families, friends and Carers who are affected by cancer and other life limiting conditions.

- Over one third of visits to the centre are professionals providing care, treatment and support including the palliative phase of illness seeking information or advice
- Individually tailored confidential emotional support, complimentary therapies and sign posting to support groups are some of the services provided by the centre
- There is currently 1 full time CNS employed by NHS Dumfries and Galloway and 11 volunteers (see Volunteering section below) providing support within the centre
- In 2019 there were **2,970** contacts from people using the service.
- The number of contacts relating specifically to palliative care and support (including **72** bereavement contacts), is estimated to be between **20-25%** of the total level of activity.



### Stranraer Cancer Drop In Centre

The Stranraer Cancer drop-in Centre provides a similar service to that described above. Located at the Galloway Community Hospital, the centre also provides a drop-in service in Newton Stewart.

- 20 volunteers (see Volunteering section below) support the centre and are key to meeting the needs of those people that use the service
- There is currently 1 part-time CNS (**21.75** hours per week) employed by NHS Dumfries and Galloway
- **2,963** people used the Stranraer Cancer Drop In Centre including Carers and health and social care professionals who are looking for information, support and advice
- The number of people receiving palliative care and support from the centre in 2019 was **550**, approximately **20%** of the workload

### Cancer services outwith Dumfries and Galloway

The two Cancer Treatment Centres at the Western General Hospital, Edinburgh and The Beatson West of Scotland Cancer Centre in Glasgow have a variety of cancer specific information and support facilities.

### Maggie's Centres

There are Maggie's Centres at both Cancer Treatment Centres. Maggie's Centres are usually buildings based and offer complimentary therapies, support and information to people receiving cancer treatment at the hospital which includes people from Dumfries and Galloway. Whilst we are aware that people from Dumfries and Galloway can access the Maggie's Centres at these hospitals, we do not know what percentage of the overall number do this.

### Beatson Cancer Charity

The Beatson Cancer Charity provides a cancer Wellbeing Centre within the hospital. This is available to anyone receiving cancer treatment there, including people from Dumfries and Galloway.

### 4.3.3 Anticipatory Care Planning

Anticipatory Care Plans (ACPs) are completed by the person with their families, friends, Carers and health and social care professionals, to

- provide information that enables GP Practices to update the person's electronic Key Information Summary (eKIS) (see glossary for details)
- ensure their wishes and preferences can be shared with families, friends, Carers and relevant professionals to support and improve outcomes
- indicate who, if anybody, they want to help make decisions about their health and wellbeing
- raise awareness of and encourage people to talk about other relevant documents that may support them to have choice and control such as Power of Attorney (PoA) and care and support plans

An ACP can be completed at any point in a person's life. In the context of palliative care, it is often completed in the knowledge that health is deteriorating and death is expected. Increasing the number of completed ACPs is something which partners across health and social care in Dumfries and Galloway have been working together to achieve.

### 4.3.4 Digital Health and Care

A local strategy has been developed to identify and support the changes needed to optimise the use of technology, including mobile technologies, that will help support more people to remain at home in their own communities.

Digital health and care builds on existing technology such as telecare, telehealth and eHealth

- **Telecare** – is the use of technology to provide support and assistance to vulnerable people living at home or in a homely setting. It does this by using equipment connected to emergency alarms that trigger a request for help.
- **Telehealth** – is the use of technology to gather and provide information electronically to support long distance delivery of clinical care.
- **eHealth** – is the use of technology to join health information systems together. This enables health professionals to access real time, relevant information about people's health and care.

Technology enabled care (see glossary for details) can benefit people by

- providing more options for how care at home or closer to home is accessed and delivered
- providing a more effective and efficient way of doing things



- avoiding unnecessary travel
- improving communication
- helping to reduce health inequalities

### 4.3.5 Learning disability

People with a learning disability have a shorter life expectancy compared to the general population largely due to life limiting illnesses being more prevalent in this group. These include

- higher levels of particular cancers including stomach and bowel cancer and
- higher risk of developing heart conditions, dementia and leukaemia (specific to people with Down's Syndrome)

For various reasons, people with a learning disability can be less likely to access specialist palliative care.

The Partnership is committed to meeting the 4 dimensions of care for everyone, including people with learning disabilities, their families, friends and Carers.

The Scottish Commission for Learning Disability (2013) [‘The Keys to life’](#) is the National Learning Disability Strategy.

### 4.3.6 Building compassionate communities

Partners across health and social care are developing ‘compassionate communities’. This is part of a public health approach (as described in section 4.1.2).

Compassionate communities are communities that have developed networks of support that improve people’s experience of death, dying, loss, care and support.

Learning has been taken from initiatives such as ‘Compassionate Inverclyde’ (2018), where local people, working alongside formal and informal forms of support, have been enabled to tap into their “desire to be kind, helpful and neighbourly”.

Compassionate communities initiatives include

- Working with communities to look at ways to support people to be more open when discussing death, dying and bereavement.
- Empowering people to support each other when they know someone in their community is experiencing loss.

These initiatives involve participation, partnerships, education and population health approach to achieve high levels of community involvement in the delivery of their own health and well being, including their experiences of death, dying, loss and care (Public Health Palliative Care International, 2019).

### 4.3.7 Volunteering

Volunteers can play a significant role in the delivery of palliative care and support. The NHS Volunteering Programme provides recruitment, training and development for volunteers throughout Dumfries and Galloway and is exploring opportunities for volunteers in mental health care and support and care and support in rural communities.

Although over **200** people currently volunteer for NHS Dumfries and Galloway, it is recognised that volunteering in palliative care and support is an area that has scope and potential for future development.

#### Spiritual Care

Spiritual Care in Dumfries and Galloway currently has **6** volunteers covering DGRI, the Galloway Hospital and **3** GP surgeries. Volunteers listen and support people receiving care to reconnect with the things in their lives that promote wellbeing and coping skills. These volunteers are supported by a Volunteer Co-ordinator and the Spiritual Care and Wellbeing Lead.

#### Marie Curie Helper Volunteers

There are **19** Marie Curie volunteers across Dumfries and Galloway who volunteer up to 3 hours of their time per week to provide

- Companionship and emotional support
- Practical help
- A break for families and Carers
- Information on further support
- Bereavement support

#### Macmillan Cancer Information and Support Centre, Dumfries

There are **11** volunteers supporting the Dumfries centre. They provide people with life limiting conditions their families, friends, Carers and health professionals with access to information, advice, support and services.

#### Stranraer Cancer Drop In Centre (Registered Scottish Charity)

There are **20** volunteers supporting people at the Stranraer Drop in Centre and drop-in service at Newton Stewart.

This again includes a wide range of people such as Carers and health and Social Care professionals who are looking for information and advice.

The number of people receiving palliative care and support in 2019 was **550**, approximately **20%** of total level of activity.

#### Support for Carers

The Palliative and End-of-Life Care by Integration Authorities: Advice Note (2018) acknowledged that informal and unpaid Carers of all ages provide the greatest share of support to people at the end of life. In line with the National Health and Wellbeing Outcome, the IJB recognises that “people who provide unpaid care should be given

appropriate support to look after their own health and wellbeing including reducing any negative impact of their caring role on their own wellbeing”.

Initiatives provided by cross sector partners to support Carers (including Young Carers) in Dumfries and Galloway, include

- ‘Adult Carer Support Plans’ and ‘Young Carer Statements’ identifying the needs of Carers
- ‘Carer Positive’ work places
- Carers Support (groups and one to one)
- Earlier identification of Carers by health and social care staff
- Emergency Card and Young Carers Card
- Financial advice services
- Self directed support
- Short breaks including respite
- Short courses for Carers

The Dumfries and Galloway IJB Carers Strategy 2017 -2021 is a useful source of information for Carers and can be found [here](#)

#### 4.3.8 Scotland’s House of Care

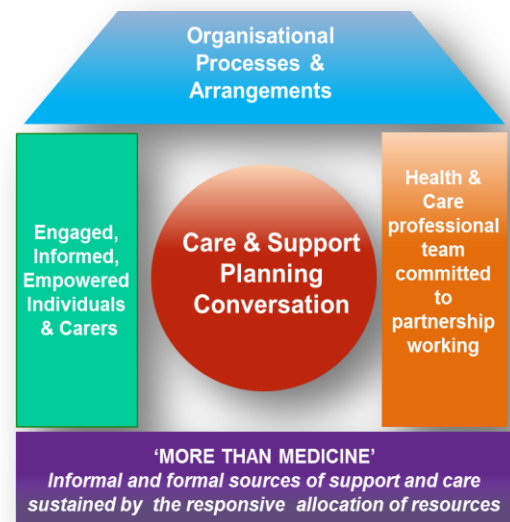
The House of Care Model is an integrated, whole system approach that supports and enables joint decision making, goal setting and action planning.

With the introduction of the new GP contract, there are opportunities to rethink how Primary Care can adapt to the needs of people living with long term conditions including people that are in the palliative stage of their illness.

Scotland’s House of Care Programme fits the aims of the National Strategic Framework. Its focus, shifting to more collaborative, personalised care and supports the Realistic Medicine approach outlined in section 2.3.1.

The House of Care is a framework that

- encourages conversations about care planning for people with long term conditions that support self management
- offers training to develop a person centred approach, building skills and leadership
- promotes the principles of self management by adopting an ‘asset based approach’ (see glossary for definition) to care and support



For future models of care and support to be sustainable it is important to

- recruit and retain people with the right skills
- offer appropriate support and training
- promote a healthy working environment
- adhere to standards for quality of care

Consideration needs to be given to developing enhanced roles across health and social care to support a skilled, adaptable and compassionate workforce and ensure long term sustainability of services (NES Strategy, 2019). Enhanced roles are roles where the skills of the practitioner are extended to incorporate a broader range of more specialist practice and are multidisciplinary, including pharmacy, AHP, social work and other clinical roles.

## 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 (See Section 2.3.1): 2,4

Actions	By Whom	How will we know we are making a difference?
Deliver training in communication skills to support Anticipatory Care Planning and shared decision making, e.g. 'Good Conversation'. Training	Organisational Development and Learning/Specialist Palliative Care Team	Feedback from people delivering and receiving palliative care and support
Apply the principle of Realistic Medicine's shared decision making to determine how palliative care and support is planned and delivered	Professional Leads	Feedback from people's experience of using the service Datix records
Promote Anticipatory Care Planning in Dumfries and Galloway	Locality Managers/Professional Leads	Number of people with an ACP ACP Audit Plan
Home Teams supported by Specialist Palliative Care to work in partnership with people living with deteriorating health to have choice and control	Home Team Leads/Specialist Palliative Care	Feedback from people delivering and receiving palliative care and support

*Dumfries and Galloway IJB Strategic Plan priority area of focus:*

**Supporting Carers**

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

Actions	By Whom	How will we know we are making a difference?
Achieve and promote 'Carer Positive', to identify and support Carers in the workplace	Workforce Director	Number of organisations across Dumfries and Galloway identified as Carer Positive
Signpost or refer Carers to third sector organisations that provide support to improve resilience	Professional Leads/Clinical Leads/Locality Teams	Number of referrals received by relevant organisations and feedback from Carers on level of support
Support Carers providing palliative care and support to maintain their own health and wellbeing	Professional Leads/Clinical Leads/Locality Teams	Number of Carers accessing the range of available supports including 'Adult Carer Support Plans' and 'Young Carer Statements'
Early identification of Carers when someone is admitted to hospital as an inpatient, to enable the Carer to be involved in the decisions relating to, and delivery of, their care, including discharge /transfer from hospital	Professional Leads/Clinical Leads	Outcomes from the Carer Facilitator Project and adoption of the Triangle of Care model in acute and intermediate settings

*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

Actions	By Whom	How will we know we are making a difference?
Develop and support 'compassionate communities', working in partnership with the SPPC and local groups, including research groups where appropriate	Locality Managers  Palliative Steering Group	Feedback from localities on their activities in relation to developing compassionate communities  Feedback from people in communities
Explore opportunities for volunteering in palliative care and support	Volunteer Leads/Service Leads	Number of people participating in volunteering roles in palliative care and support
Use of palliative care website and other materials to signpost people to local support networks	Palliative Care Network Locality Teams	Feedback from those delivering and in receipt of palliative care including Carers, friends and family

*Dumfries and Galloway IJB Strategic Plan priority area of focus:*

**Making the most of wellbeing**

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

Actions	By Whom	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 including when a person is identified as having deteriorating health to improve their sense of wellbeing and quality of life	Professional Leads/Clinical Leads	Feedback from people receiving palliative care and support
Proactively capture and understand people's experiences of palliative care and support that, in turn, will inform service improvement	Patient Experience	Feedback from people receiving palliative care and support
Apply a focus on reablement to support the person to be as independent and autonomous as possible	Professional Leads/Clinical Leads	Feedback from people delivering and receiving palliative care and support
Use of identification tools e.g Rockwood frailty score and SPICT to support early identification of people who may benefit from a palliative care approach	Professional Leads/Clinical Leads	Feedback from people delivering and receiving palliative care and support

**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	How will we know we are making a difference?
Make links between this Plan and those workstreams and programmes of work focussed around the palliative care and support needs of vulnerable adults	Programme and Workstream Leads	Reference to palliative care and support within all new strategies and programmes of work
Improve the transition of care and support between hospital, home, community hospital and care home	Professional Leads/Clinical Leads/Service Leads	Feedback from staff teams across health and social care and the people who use services
Ensure that people with learning disabilities, their families and Carers are kept fully informed of and, involved in, all aspects of their palliative care and support	Professional Leads/Clinical Leads/Service Leads	Feedback from people with learning disabilities, their families and Carers

**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	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 them and their Carers and community based health and social care professionals with the right level of support to enable this	Locality Managers/ Professional Leads	Feedback from people delivering and receiving palliative care and support  Number of people supported to reach their preferred place of death
Develop models of care including Home Teams that help ensure that people have the right support at the right time in the right place, including their own home	Planning and Service Leads	Models of care identified and implemented
Develop opportunities to capture and understand people's experiences of palliative care and support in their communities	Locality Managers/ Professional Leads	Feedback from people delivering and receiving palliative care and support
Consider new ways of working, third sector partnerships and alternative funding models to create a sustainable multi professional specialist palliative care team	Palliative Care Steering Group	A comprehensive specialist palliative care team with a broad range of specialist professionals is in place

*Dumfries and Galloway IJB Strategic Plan priority area of focus:*

**Integrated ways of working**

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

Actions	By Whom	How will we know we are making a difference?
Develop and deliver an education plan for palliative care, in line with the NHS Education for Scotland (NES) Framework to support formal and informal learning	Palliative Care Specialist Team/ Organisational Development and Learning (ODL)/Clinical Educators	Educational Plan Developed  Number of people taking up opportunities for learning including on-line courses through University of Glasgow End of Life Studies Group
Regularly review the membership of the Palliative Care Steering Group and ensure it is representative of all relevant stakeholders	Strategic Planning	Membership reviewed within the last 2 years and up to date
Develop a local Palliative Care Network	Palliative Care Steering Group	Network established with cross sector representation
Develop and use a single, shared, web based system (a Health and Social Care Portal) to support improved joint working for people delivering health and social care	Sustainability and Modernisation Programme (SAM)	Staff feedback regarding improved access to information safely and securely for all sectors working across health and social care
Ensure that palliative care is included within the Partnership's major plans and programmes e.g. service plans, SAM Programme, etc	Palliative Care Steering Group	Palliative care is featured within Partnership's major plans and programmes

*Dumfries and Galloway IJB Strategic Plan priority area of focus:*

**Reducing health inequalities**

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

Actions	By Whom	How will we know we are making a difference?
<p>Identify inequalities in relation to the provision of palliative care and support in Dumfries and Galloway by</p> <ul style="list-style-type: none"> <li>• analysing information that identifies if, and at what level, inequalities in provision exist</li> <li>• using the 'Dumfries and Galloway Inequalities Action Framework' (2016) to identify ways to mitigate, prevent or undo health inequalities in palliative care and support</li> </ul>	Palliative Care Steering Group	Inequalities measures
Explore ways in which digital technology might help reduce health inequalities	SAM Programme	<p>Number of people in receipt of palliative care and support using digital technology</p> <p>Feedback from people delivering and receiving palliative care and support</p>
Deliver equitable palliative care and support across Dumfries and Galloway, including out of hours care	Professional Leads/Clinical Leads	Review of services to meet out of hours demand for people in receipt of palliative care

**Working efficiently and effectively**

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

Actions	By Whom	How will we know we are making a difference?
Reduce unnecessary travel	SAM Programme	Feedback from people delivering and receiving palliative care and support  Number of complaints about unnecessary travel
Recruit to vacant posts and retain existing staff delivering palliative care and support	Workforce Leads	Achieve recruitment targets
Ensure people delivering palliative care and support across the Partnership have opportunities to improve their personal and collective resilience and develop positive coping mechanisms	ODL/ Workforce Leads	Increased opportunities for improving staff wellbeing  Improved feedback from staff in relation to feeling more supported and resilient  Reduced levels of staff sickness absence
Explore ways in which to address identified gaps within the specialist palliative care team including pharmacy, AHP's and specialist nursing	Palliative Care Steering Group	An increase in the range of disciplines and capacity of the specialist palliative care team
Reviewing pharmacy services to ensure that they meet the needs of the palliative care community across Dumfries and Galloway	Palliative Care Steering Group	Evaluation of scoping project identifying the need for specialist pharmacy input

*Dumfries and Galloway IJB Strategic Plan priority area of focus:*

**Making the best use of technology**

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

Actions	By Whom	How will we know we are making a difference?
Promote understanding of palliative care through development of a local palliative care website providing information and signposting to local support networks and services	Palliative Care Steering Group	Website available for use  Feedback from people delivering and receiving palliative care and support
Ensure that the benefits of the digital approaches identified within this plan, including how people receive and access information, are realised for those receiving or delivering palliative care	SAM Programme	Feedback from SAM Programme  Feedback from people delivering and receiving palliative care and support
Ensure professionals across Health and Social Care support Primary Care colleagues to maintain electronic Key Information Summaries (eKIS) to ensure that people's wishes, preferences and current medication needs are able to be shared between relevant professionals	Health and Social Care Professionals	Number of completed eKIS forms  Feedback from people delivering and receiving palliative care and support

## 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 negative impacts of these.

Anticipatory Care Planning has been described as

*“A process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness”.* (Sudore et al 2017 p821)

### **App**

A mobile application, often referred to an app is a computer program or software application designed to run on a mobile device such as a phone, tablet, or watch.

### **Asset based approach**

Identifying and making best use of all the resources that exist at both an individual and community level such as voluntary sector support, local knowledge or community buildings.

### **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. In the Strategic Commissioning of Palliative and End of Life Care by Integration Authorities: Advice Note, bereavement is described as “the entire experience of family members and friends in the anticipation, death and subsequent adjustment to living” following a death.

### **Care at Home package**

Care at home is defined as any personal care and support provided to people by paid carers in their own home. This may include personal and/or oral hygiene, continence management, incontinence laundry and bed changing, funded by the Health and Social Care Partnership (HSCP).

### **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 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.

**Datix**

Datix is a national reporting and investigation system used by NHS Dumfries and Galloway for recording clinical incidents, complaints and compliments. It monitors key safety issues and helps identify areas for improvement. The data gathered is used to support individuals, teams and the organisation to learn and improve.

**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.

**Emotional and psychological** (as an aspect of the 4 dimensions of palliative care)

Emotional and psychological distress is common among people receiving palliative care. It is an understandable reaction to an upsetting and distressing experience. People often draw on resources such as family and friends to help them to cope. However, some people need additional professional psychological support because of the level and nature of their distress (NICE, 2019)

**Equality Impact Assessment (see also protected characteristics)**

Equality Impact Assessment is a process to assess the impact of a new or updated plan, policy, function or service on people who might be affected.

**GP**

General Medical 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.

### **Holistic Needs Assessment (HNA)**

The HNA gathers information from the person about their physical, practical, emotional, spiritual and social needs, to ensure they are met in a timely and appropriate way.

### **Independent sector**

A general term for non-statutory bodies including private enterprise, voluntary, charitable or not-for-profit organisations such as care homes, some home care providers or support 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.

### **Life limiting conditions**

Conditions where there is no reasonable hope of a cure and from which the person will ultimately die prematurely.

### **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.

### **MORSE**

MORSE is technology that supports people delivering care and support in the community to access and update information when and where they need it. The 'app' enables staff to use mobile technology like tablets or phones to view and record information while on their home visits.

### **Personalised**

Tailoring health and/or social care and support specifically to a person's own needs.

## **Person centred**

The principles of person centred care are that people are treated with dignity, compassion and respect and that care is coordinated, personalised and enabling. This supports people to be active partners in their health and care and helps them to live independent and fulfilling lives. (The Health Foundation, 2016). Person centred care places the person at the centre of their own care and focuses on their needs, wishes and desires.

## **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.

## **Physical** (as an aspect of the 4 dimensions of palliative care)

Physical pain and symptoms can impact significantly on a person's quality of life and experience of palliative care and support. Effective pain and symptom management can need specialist clinical input to achieve. This can include specialist pharmacy, AHP, nursing and medical support and access to complimentary therapies which can reduce symptoms such as distress, anxiety, pain and nausea (Nice, 2019).

## **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. "A public health approach to end of life care, views the community as an equal partner in the long and complex task of providing quality healthcare at the end of life" (Public health Palliative Care

International, 2019).

### **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.

### **Rockwood Frailty Scale**

The Rockwood Frailty Scale can be used by health and social care professionals to identify a person's degree of frailty and can provide valuable information about the level of support that person needs. The scale can be seen [here](#).

### **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.

### **Social** (as an aspect of the 4 dimensions of palliative care)

The social impact of a palliative diagnosis can reach beyond the person and those closest to them. Maintaining their social networks and usual activities such as personal care, cleaning, shopping and providing for their family can be important. Other matters, such as employment and financial concerns can impact on the person's health and well being.

Support around these matters can be through various sources including voluntary and community resources and should be planned with the person in response to their needs and wishes (NICE, 2019).

### **Spiritual** (as an aspect of the 4 dimensions of palliative care)

The diagnosis of life-limiting illness can cause some people to re-examine their philosophical, religious or spiritual beliefs. It is important that this is recognised by health and social care professionals as it can impact on people's experience of palliative care and their quality of life. Staff across health and social care should be aware of the spiritual needs of the people they are supporting, during life and after a person's death (NICE, 2019).

### **Supportive and Palliative Care Indicators Tool (SPICT)**

SPICT (Supportive and Palliative Care Indicators Tool) is a clinical checklist of general indicators of deteriorating health. It can be used to improve the care of people with advanced illnesses and their families. To find out more click [here](#)

### **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.

**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.

## Links to documents which helped us produce this plan

**Black, H., Waugh, C., Munoz-Arroyo, R., Carnon A., Allan, A., Clark, D., Graham F., and Isles, C.** (2016) Predictors of place of death in South West Scotland 2000–2010: Retrospective cohort study <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4994701/> (last accessed 09/09/20)

**Carers Strategy 2017– 2021** [https://dumgal.gov.uk/media/18053/Carers-Strategy-2017-2021/pdf/0586-16\\_Carers\\_Strategy\\_1\\_November.pdf?m=636495343371870000](https://dumgal.gov.uk/media/18053/Carers-Strategy-2017-2021/pdf/0586-16_Carers_Strategy_1_November.pdf?m=636495343371870000) (last accessed 09/09/20)

**Clark, D., Armstrong, M., Allan, A., Graham, F., Carnon, A. and Isles, C.** (2014) Imminence of death among hospital inpatients: Prevalent cohort study <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4845030/> (last accessed 09/09/20)

**Clinical Standards Board for Scotland** (2002) Clinical Standards for Specialist Palliative Care <https://www.palliativecarescotland.org.uk/content/publications/ClinicalStandardforSPC.pdf> (last accessed 09/09/20)

**Compassionate Inverclyde** (2018) Evaluation Summary Report [https://ardgowanhospice.org.uk/wp-content/uploads/2018/12/CI-evaluation\\_-\\_summary.pdf](https://ardgowanhospice.org.uk/wp-content/uploads/2018/12/CI-evaluation_-_summary.pdf) (last accessed 09/09/20)

**Dumfries and Galloway Integration Joint Board** (2019) Interim Workforce Action Plan 2019/20 [https://www.nhs.uk/scot.nhs.uk/About\\_Us/Publications/Files/Health\\_Social\\_Care\\_Workforce\\_Plan\\_2019\\_Final.pdf](https://www.nhs.uk/scot.nhs.uk/About_Us/Publications/Files/Health_Social_Care_Workforce_Plan_2019_Final.pdf) (last accessed 09/09/20)

**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 09/09/20)

**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 09/09/20)

**National Health and Wellbeing Outcomes Framework** (2015) <https://www.gov.scot/publications/national-health-wellbeing-outcomes-framework/pages/5/> (last accessed 09/09/20)

**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 09/09/20)

**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 09/09/20)

**NHS Education for Scotland (2019) NHS Education for Scotland Strategy 2019 – 2024**  
[www.nes.scot.nhs.uk/media/4267243/nes\\_strategic\\_framework\\_2019\\_2024.pdf](http://www.nes.scot.nhs.uk/media/4267243/nes_strategic_framework_2019_2024.pdf) (last accessed 09/09/20)

**NICE (2019) Guidance on Cancer Services Improving Supportive and Palliative Care for Adults with Cancer The Manual** <https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005> (last accessed 09/09/20)

**NICE (2020) Caring for an adult at the end of life**  
<https://pathways.nice.org.uk/pathways/end-of-life-care-for-people-with-life-limiting-conditions/caring-for-an-adult-at-the-end-of-life> (last accessed 09/09/20)

**Public health Palliative Care International (2019) The Public health Approach to Palliative Care** <http://phpci.info/public-health-approach> (last accessed 09/09/20)

**Scottish Community Development Centre (2015) National Standards for Community Engagement** <https://www.scdc.org.uk/what/national-standards/> (last accessed 09/09/20)

**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-children-young-people-scotland/> (last accessed 09/09/20)

**Scottish Government (2015) Strategic Framework for Action on Palliative and End of Life Care 2016–2021. Edinburgh: Scottish Government**  
<https://www.gov.scot/publications/strategic-framework-action-palliative-end-life-care/> (last accessed 09/09/20)

**Scottish Government (2015) National health and wellbeing outcomes framework**  
<https://www.gov.scot/publications/national-health-wellbeing-outcomes-framework/> (last accessed 09/09/20)

**Scottish Government (2016) A National Clinical Strategy for Scotland**  
<https://www.gov.scot/publications/national-clinical-strategy-scotland/pages/5/> (last accessed 09/09/20)

**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 09/09/20)

**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-report-2015-16-realising-realistic-9781786526731/> (last accessed 09/09/20)

**Scottish Government (2017) Mental Health Strategy 2017-2027**  
<https://www.gov.scot/publications/mental-health-strategy-2017-2027/> (last accessed 09/09/20)

**Scottish Government** (2017) Achieving excellence in pharmaceutical care: a strategy for Scotland <https://www.gov.scot/publications/achieving-excellence-pharmaceutical-care-strategy-scotland/> (last accessed 09/09/20)

**Scottish Government (2017)** Scotland's National Dementia Strategy 2017-2020 <https://www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020/> (last accessed 09/09/20)

**Scottish Government** (2018) Strategic Commissioning of Palliative and End of Life Care by Integration Authorities: Advice Note <https://www.gov.scot/publications/strategic-commissioning-palliative-end-life-care-integration-authorities/> (last accessed 09/09/20)

**Scottish Government** (2019) Health and Care (Staffing) (Scotland) Act 2019 <https://www.legislation.gov.uk/asp/2019/6/introduction> (last accessed 09/09/20)

**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](http://www.parliament.scot/S4_HealthandSportCommittee/Inquiries/PCA_Grasping-the-Nettle_SPPC.pdf) (last accessed 09/09/20)

**Scottish Partnership for Palliative Care** (2019) What is palliative care? [https://www.palliativecarescotland.org.uk/content/what\\_is\\_palliative\\_care/](https://www.palliativecarescotland.org.uk/content/what_is_palliative_care/) (last accessed 09/09/20)

**Scottish Partnership for Palliative Care** (2019) Specialist palliative care services in Scotland [https://www.palliativecarescotland.org.uk/content/services\\_in\\_scotland](https://www.palliativecarescotland.org.uk/content/services_in_scotland) (last accessed 09/09/20)

**Sudore, R.L., Lum, H.D., You, J.J., Hanson, L.C., Meier, D.E., Pantilat, S.Z., Matlock, D.D., Rietjens, J.A., Korfage, I.J., Ritchie, C.S. and Kutner, J.S.,** (2017). Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. <https://www.ncbi.nlm.nih.gov/pubmed/28062339> (last accessed 09/09/20)

**The Health Foundation (2016)** Person-centred care made simple [https://www.health.org.uk/sites/default/files/PersonCentredCareMadeSimple\\_0.pdf](https://www.health.org.uk/sites/default/files/PersonCentredCareMadeSimple_0.pdf) (last accessed 09/09/20)

**World Health Organisation** (2017) WHO Definition of Palliative Care [www.who.int/cancer/palliative/definition/en/](http://www.who.int/cancer/palliative/definition/en/) (last accessed 09/09/20)

## Local links

[Health and Social Care: Workforce Plan \(2016-2019 \(2018 Edition\)](#)

[Strategic Needs Assessment \(2018\)](#)

[Health and Social Care Strategic Plan \(2018\)](#)

[Dumfries and Galloway Locality Plans](#)

[Dumfries and Galloway Children's Services Plan April 2017 – March 2020](#)

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## Appendix 1: Statement of Consultation

Consultation of Dumfries & Galloway's Integration Joint Board (IJB)  
Draft Plan for Palliative Care

**Statement of Consultation**  
**January 2019 – February 2020**

A number of consultation and engagement exercises were carried out as part of the development of the IJB Draft Plan for Palliative Care (the Plan). This process used the 7 [National Standards for Community Engagement](#) (2016) to develop the plan.

### Included

Over the course of the initial 14 week consultation period approximately 600 people engaged with the process including almost 50 people who completed the survey. Multiple opportunities to engage were provided across the region in a variety of locations and formats such as team meetings, focus groups, and partner events, presentations to groups, 1-2-1 meetings and engagement activities.

Over the second engagement period from 8 November 2019 to 19 January 2020, over 160 organisations and individual stakeholders were sent a copy of the plan and asked for comments. This included individuals and groups which had previously expressed an interest in being involved in the development of the plan as well as others that had been identified as missing from the initial engagement using Plan Do Study Act methodology. This involved 31 separate engagement activities and an additional survey which 40 people engaged with.

Period of consultation	Approximate number of people reached
1	614
2	250 - 300

In total there were:

30 events with a regional focus  
24 events in Annandale & Eskdale  
19 events in Nithsdale  
6 events in Stewartry  
14 events in Wigtownshire

### Communication

Multiple methods of communication such as email, hard copy flyers, posters, phone calls, social media, local press and radio were used to provide opportunities for people to engage with the consultation. This included invitations to individuals, partner organisations across health and social care, the third and independent sectors to get involved.

## Methods of Communication

- circulation of emails containing consultation details and link to the online survey to a wide range of stakeholders
- mail shot to community councils, libraries, GP practices, supermarkets, funeral directors, pharmacies and locality offices
- Articles in the local newsletters including CORE briefing, Third Sector D & G, D & G What's Going on etc
- Press Releases in local newspapers
- articles on NHS intranet
- documents available to download online
- social media updates
- flyers pre-door knocking (Travellers site following guidance of site manager)

## Engaged

A total of 864 people were engaged with across the two phases of consultation. This number is an estimation based on information from:

- online and hard copy questionnaire returns (49)
- the number of people recorded at engagement events (565)
- information sent electronically to stakeholders and interested parties (250)

All comments received during both phases were recorded and analysed to identify any emerging themes. The themes captured in the first phase were considered in the development of the draft plan and are shown in the Report from First Round of Stakeholder Engagement. This can be found at [www.dghscp.co.uk/macmillan/palliative/](http://www.dghscp.co.uk/macmillan/palliative/). The comments received in the second phase of the consultation were used to refine the draft plan.

## Methods of Engagement/Involvement

- public events and drop in sessions
- focus groups
- partner organisations staff meetings and events
- papers presented at various governance groups for comment
- display materials at Child Bereavement UK conference
- display materials at partner events
- display materials and engagement in DGRI Atrium and Mountainhall Treatment Centre
- display materials in community hospitals
- presentations and discussions at existing meetings across all sectors

## Groups Engaged

- Area Committees
- Alzheimer Scotland
- Ambulance Service Scotland
- AHP's
- Carers
- Care Homes
- Care at Home providers
- Collin Travellers site
- Community Councils
- Community Mental Health Team
- Community Nurses
- Community Pharmacists
- Day Centres
- DGHP
- DG Voice
- Dumfries and Galloway Carers Centre
- Dumfries and Galloway Multicultural Association
- Fire Service
- Funeral Directors
- General Practice visits
- GP Sub Group
- Hard of Hearing Group
- Health Improvement
- Health & Wellbeing Partnership
- Learning Disability
- LGBT plus
- Library service
- Locality Forums
- Loreburn
- Macmillan Nurses
- Macmillan Centres
- Men's Sheds
- National Conferences
- Nurse Managers
- Oncology CNS's
- Older People's Consultative Group
- Palliative Care Steering Group
- Police Scotland
- Practice Mangers
- Scottish Care
- SHAP
- Social Work
- Speech and Language Therapy
- Strategy Development Group
- University of Glasgow
- UWS
- Visibility Scotland

DATE	ITEM	VENUE	TOWN
12.10.18	Palliative Care Lead attended Community Nursing Team East	Community Nurse offices	Annan
31.10.18	Palliative Care Lead attended Community Renal SCN	Renal Ward, Mountainhall Treatment Centre	Dumfries
12.12.18	Palliative Care Lead & Programme Manager Cancer attended Scottish Care Regional Meeting	Crichton Hall	Dumfries
07.01.19	Palliative Care Lead & Programme Manager Cancer attended Travellers Site, Collin to meet with Alan Kerr	Collin Travellers Site	Dumfries
14.01.19	Palliative Care Lead & Programme Manager Cancer attended Breast Cancer Support Group	Baptist Church	Dumfries
16.01.19	Palliative Care Lead & Programme Manager Cancer attended Third Sector Road Show	Victoria Halls	Annan
21.01.19	Palliative Care Lead & Programme Manager Cancer attended MCA Focus Group	Multi Cultural Association offices	Dumfries
23.01.19	Palliative Care Lead & Programme Manager Cancer attended Third Sector Road Show	Burns House	Stranraer
24.01.19	Palliative Care Lead & Programme Manager Cancer attended Women Affected by Cancer Group	North West Castle	Stranraer
29.01.19	Palliative Care Lead & Programme Manager Cancer attended Third Sector Road Show	The Cat Strand	New Galloway
30.01.19	Palliative Care Lead & Programme Manager Cancer attended Travellers Site	Collin Travellers Site	Dumfries
30.01.19	Palliative Care Lead & Programme Manager Cancer attended New Horizons – Long Term Conditions Group	Support in Mind offices	Annan
01.02.19	Palliative Care Lead & Programme Manager Cancer attended Flow Coordinators Team meeting	DGRI	Dumfries
04.02.19	Palliative Care Lead & Programme Manager Cancer attended Locality Managers Meeting	Lahraig, Nithbank	Dumfries
04.02.19	Palliative Care Lead attended Lockerbie Practice to meet Irene Penrice	Medical Practice	Lockerbie
04.02.19	Palliative Care Lead & Programme Manager Cancer attended Dryfemount Care Home and met with Manager John Whitehouse	Dryfemount Care Home	Lockerbie
06.02.19	Palliative Care Lead & Programme Manager Cancer met with Moira Dale	University of West Scotland	Dumfries
12.02.19	Palliative Care Lead, Programme Manager Cancer, Manager of the Project attended Galloway Hospital, to meet Dr	Galloway Community Hospital	Stranraer

	Baird		
<b>14.02.19</b>	Palliative Care Lead attended Lockerbie Carers Group arranged by Rachel Byers, Alzheimer Scotland	Town Hall	Lockerbie
<b>18.02.19</b>	Palliative Care Lead, Programme Manager Cancer & Manager of the Project met with Finlay Carson MSP	Mountainhall Treatment Centre	Dumfries
<b>18.02.19</b>	Palliative Care Lead & Programme Manager Cancer met with June Watters & Lynda Mckie, Wigtownshire Locality Team	Mountainhall Treatment Centre	Dumfries
<b>19.02.19</b>	Programme Manager Cancer attended Third Sector Roadshow	Community Centre	Gatehouse of Fleet
<b>19.02.19</b>	Palliative Care Lead met with Food Train Friends	Food Train offices	Annan
<b>19.02.19</b>	Palliative Care Lead met with Kate's Kitchen	Kate's Kitchen	Annan
<b>19.02.19</b>	Palliative Care Lead attended Annan Dental	Dental Clinic	Annan
<b>19.02.19</b>	Palliative Care Lead met with Visibility Service Users	King's Arms Hotel	Annan
<b>20.02.19</b>	Palliative Care Lead & Programme Manager Cancer met with Sarah Pickstock, Consultant Palliative Care and her team	DGRI	Dumfries
<b>21.02.19</b>	Palliative Care Lead & Programme Manager Cancer attended	Atrium DGRI	Dumfries
<b>21.02.19</b>	Palliative Care Lead & Programme Manager Cancer attended Annan Social Work Team meeting	Council Offices	Annan
<b>25.02.19</b>	Palliative Care Lead & Programme Manager Cancer attended Cumloden Manor Nursing Home	Cumloden Manor Nursing Home	Newton Stewart
<b>25.02.19</b>	Palliative Care Lead & Programme Manager Cancer attended Visibility Group, Newton Stewart	Cafe	Newton Stewart
<b>27.02.19</b>	Palliative Care Lead attended Annan One Team meeting	Annan Hospital	Annan
<b>27.02.19</b>	Palliative Care Lead & Programme Manager Cancer attended Nithsdale Locality Team meeting	Lahraig, Nithbank	Dumfries
<b>28.02.19</b>	Programme Manager Cancer attended Podiatry Team meeting, Stewartry & Wigtownshire	Town Hall	Castle Douglas
<b>28.02.19</b>	Programme Manager Cancer did 1:1 interview re Cancer, Dumfries	The Usual Place	Dumfries
<b>28.02.19</b>	Programme Manager Cancer did 1:1 interview re Cancer, Dumfries	The Usual Place	Dumfries
<b>04.03.19</b>	Palliative Care Lead attended Lockerbie Social Work Team meeting	Town Hall	Lockerbie
<b>04.03.19</b>	Palliative Care Lead attended Visibility	Kings Arm's Hotel	Lockerbie

	Group		
<b>04.03.19</b>	Palliative Care Lead & Programme Manager Cancer attended Development Day, Physical Disability Team	Cargen Towers	Dumfries
<b>05.03.19</b>	Palliative Care Lead attended Visibility Group	Burns House	Stranraer
<b>06.03.19</b>	Palliative Care Lead & Programme Manager Cancer attended Upper Annandale District Nurses meetings	Lockerbie Medical Centre	Lockerbie
<b>06.03.19</b>	Palliative Care Lead attended Men's Shed	Men's Shed	Lockerbie
<b>07.03.19</b>	Palliative Care Lead, Programme Manager Cancer & Project Support Officer attended Atrium, DGRI	Atrium, DGRI	Dumfries
<b>07.03.19</b>	Palliative Care Lead & Programme Manager Cancer attended Senior Charge Nurse meeting	DGRI	Dumfries
<b>08.03.19</b>	Palliative Care Lead met with District Nurses	Medical Practice	Stranraer
<b>12.03.19</b>	Palliative Care Lead & Programme Manager Cancer attended AHP meeting	DGRI	Dumfries
<b>13.03.19</b>	Palliative Care Lead attended Langholm Surgery	Langholm Surgery	Langholm
<b>13.03.19</b>	Palliative Care Lead met with Specialist Children's Nurses, Dumfries	DGRI	Dumfries
<b>14.03.19</b>	Programme Manager Cancer attended Alzheimer's Carers Support Group	Town Head Hotel	Lockerbie
<b>18.03.19</b>	Palliative Care Lead met with East Care & Support Services (CASS)	Cargen Tower	Dumfries
<b>20.03.19</b>	Palliative Care Lead met with Esk Valley District Nurses	Gretna Medical Practice	Gretna
<b>21.03.19</b>	Palliative Care Lead shadowed Macmillan Nurse	Various	Newton Stewart & Stranraer
<b>27.03.19</b>	Palliative Care Lead met with Moffat Hospital staff	Moffat Hospital	Moffat
<b>27.03.19</b>	Palliative Care Lead met with Dryfemount Care Home Manager	Dryfemount Care Home	Lockerbie
<b>28.03.19</b>	Palliative Care Lead & Project Support Officer attended Alzheimer's Carers Support Group	Church Hall	Kirkcudbright
<b>28.03.19</b>	Palliative Care Lead & Project Support Officer attended a 1-2-1 visit	Person's home	Palnure
<b>28.03.19</b>	Palliative Care Lead & Project Support Officer met with Community Link Project Workers	Community Hospital	Newton Stewart
<b>02.04.19</b>	Palliative Care Lead & Programme Manager Cancer attended Flow Coordinators Team meeting	DGRI	Dumfries
<b>02.04.19</b>	Palliative Care Lead & Programme Manager Cancer attended Can Survive focus group	Sun House (Alzheimer offices)	Stranraer

<b>03.04.19</b>	Palliative Care Lead met with Acute Elderly / Respiratory Ward CN	DGRI	Dumfries
<b>03.04.19</b>	Palliative Care Lead met with Specialist Palliative Care Nurses	DGRI	Dumfries
<b>04.04.19</b>	Palliative Care Lead & Programme Manager Cancer attended Carers Centre	Carers Centre	Dumfries
<b>09.04.19</b>	Palliative Care Lead met with Dr Sarah Pickstock, Palliative Care Consultant	DGRI	Dumfries
<b>09.04.19</b>	Palliative Care Lead & Programme Manager Cancer attended Podiatry Team East	Annan Clinic	Annan
<b>10.04.19</b>	Palliative Care Lead & Programme Manager Cancer met with staff at Thornhill Hospital	Thornhill Hospital	Thornhill
<b>11.04.19</b>	Palliative Care Lead & Programme Manager Cancer attended Occupational Therapist meeting	Town Hall	Castle Douglas
<b>11.04.19</b>	Palliative Care Lead met with Nurse Manager Oncology	DGRI	Dumfries
<b>15.04.19</b>	Palliative Care Lead met with Heart Failure Specialist Nurse	DGRI	Dumfries
<b>17.04.19</b>	Programme Manager Cancer attended Head & Neck Support Group	Baptist Church	Dumfries
<b>18.04.19</b>	Palliative Care Lead met attended Renal Team	DGRI	Dumfries
<b>22.04.19</b>	Palliative Care Lead & Programme Manager Cancer met with LGBT Plus, phone meeting	Mountainhall Treatment Centre	Dumfries
<b>23.04.19</b>	Palliative Care Lead & Programme Manager Cancer attended Community OT Assistants	Town Hall	Castle Douglas
<b>23.04.19</b>	Palliative Care Lead & Programme Manager Cancer attended Acute & Community Dieticians	DGRI	Dumfries
<b>01.05.19</b>	Palliative Care Lead attended Thornhill Medical Practice	Thornhill Medical Practice	Thornhill
<b>01.05.19</b>	Palliative Care Steering Group meeting	Mountainhall Treatment Centre	Dumfries
<b>11.06.19</b>	Palliative Care Steering Group meeting	Mountainhall Treatment Centre	Dumfries
<b>16.07.19</b>	1 <sup>st</sup> meeting of the Strategy Development Group	DGRI	Dumfries
<b>18.07.19</b>	Palliative Care Steering Group meeting	Mountainhall Treatment Centre	Dumfries
<b>23.08.19</b>	2 <sup>nd</sup> meeting of the Strategy Development Group	Mountainhall Treatment Centre	Dumfries
<b>05.09.19</b>	Editing Group meeting	Mountainhall Treatment Centre	Dumfries
<b>09.09.19</b>	Editing Group meeting	Mountainhall Treatment Centre	Dumfries
<b>10.09.19</b>	Palliative Care Steering Group	Mountainhall Treatment Centre	Dumfries

<b>11.09.19</b>	Radio interview BBC Scotland, Deputy Head of Strategic Planning and Commissioning following publication of engagement reports	BBC Offices	Dumfries
<b>17.09.19</b>	Final meeting of the Strategy Development Group	Mountainhall Treatment Centre	Dumfries
<b>20.09.19</b>	Editing Group meeting	Mountainhall Treatment Centre	Dumfries
<b>24.09.19</b>	Editing Group meeting	Mountainhall Treatment Centre	Dumfries
<b>02.10.19</b>	Editing Group meeting	Mountainhall Treatment Centre	Dumfries
<b>09.10.19</b>	Editing Group meeting	Mountainhall Treatment Centre	Dumfries
<b>07.11.19</b>	Palliative Care Lead attended meeting with Manager of Briery Park Care Home	Briery Park Care Home	Thornhill
<b>07.11.19</b>	Palliative Care Lead & Head of Strategic Planning attended IJB Workshop on the Plan	Dumfries College	Dumfries
<b>11.11.19</b>	Palliative Care Lead attended meeting with Manager of Abbey Gardens Care Home	Abbey Gardens Care Home	Dumfries
<b>13.11.19</b>	Palliative Care Lead & Programme Manager Cancer attended GP Cluster meeting (11 people)	Gardenhill Primary Care Centre	Castle Douglas
<b>14.11.19</b>	Palliative Care Lead & Programme Support Officer attended Atrium, DGRI (17 people)	Atrium DGRI	Dumfries
<b>19.11.19</b>	Equality Impact Assessment meeting	Mountainhall Treatment Centre	Dumfries
<b>20.11.19</b>	Palliative Care Lead attended GP Practice Managers Network	Casa Mia	Dumfries
<b>25.11.19</b>	Palliative Care Lead met with Manager of Care Home at Mead Medica	Burnfoot Coach House	Lockerbie
<b>25.11.19</b>	Palliative Care Lead met with Heart Failure Nurse Specialists	Mountainhall Treatment Centre	Dumfries
<b>25.11.19</b>	Palliative Care Lead met with Naomi Richards, Lecturer in Social Sciences – End of Life studies, University of Glasgow	University of Glasgow	Dumfries
<b>28.11.19</b>	Palliative Care Lead to meet with GP's and Practice Manager at Thornhill Health Centre	Thornhill Health Centre	Thornhill
<b>28.11.19</b>	Palliative Care Lead attended Third Sector Roadshow, Balmaclellan	Community Hub	Balmaclellan
<b>09.12.19</b>	Palliative Care Lead to meet with GP's and Practice Manager at Cairn Valley Medical Practice	Cairn Valley Medical Practice	Dunscore
<b>11.02.20</b>	Palliative Care Lead and Programme Manager Cancer met with Professor David Clark	University of Glasgow	Dumfries

<b>21.08.20</b>	Update Clinical and Operational Leads	MSTeams	
<b>04.09.20</b>	Health and Social Care Executive Team	MSTeams	

## **Events**

### **What happens next?**

Build on the learning from the consultation and engagement activities undertaken during the development of the Plan for Palliative Care to inform the development of future strategic plans.

Identify and record key findings from the development process to share with colleagues and improve future consultations and engagement across health and social care.

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## Appendix 2: Membership of the Palliative Care Steering Group

### Spiritual Care and Bereavement

- **Dr Ewan Kelly**, Spiritual Care and Wellbeing Lead, NHS Dumfries and Galloway

### Clinical Services

- **Sarah Pickstock**, Consultant in Palliative Medicine, NHS Dumfries and Galloway
- **Natalie Adams**, Nursing and Service Manager, NHS Dumfries and Galloway
- **Kelly Lumsden**, Senior Charge Nurse Alex Unit, NHS Dumfries and Galloway

### General/Operational Management

- **Nicole Hamlet (Co-Chair)**, Deputy Chief Operating Officer, NHS Dumfries and Galloway
- **Graham Abrines**, General Manager, Community Health and Social Care
- **Mhairi Hastings**, Lead Nurse, Health and Social Care Community
- **Carole Morton**, General Manager Acute and Diagnostics, NHS Dumfries and Galloway

### Macmillan Cancer Support

- **Julie Atkin-Ward**, Macmillan Partnership Quality Lead, Macmillan Cancer Support

### Marie Curie

- **Jess English**, Marie Curie Senior Nurse, Marie Curie
- **Liz Baines**, Clinical Nurse Manager, Marie Curie

### Mental Health / Psychology

- **Ross Warwick**, Consultant Clinical Health Psychologist and Lead for Clinical Health Psychology, NHS Dumfries and Galloway

### Scottish Care

- **Jill Rennie**, Engagement Officer, Scottish Care

### Social Work Services

- **Margaret Biggar**, Senior Social Worker, Dumfries and Galloway Council

### Strategic Planning, Commissioning & Performance

- **Vicky Freeman (Co-Chair)**, Head of Strategic Planning, NHS Dumfries and Galloway
- **Liz Forsyth**, Macmillan Project Palliative Care Lead, NHS Dumfries and Galloway
- **Laura Grierson**, Macmillan Project Support Office, NHS Dumfries and Galloway

### Third Sector – Notes only

- **Claire Brown** – Operations Manager, Third Sector Dumfries and Galloway

### Appendix 3: Equality and diversity statement and Equality Impact Assessment

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.

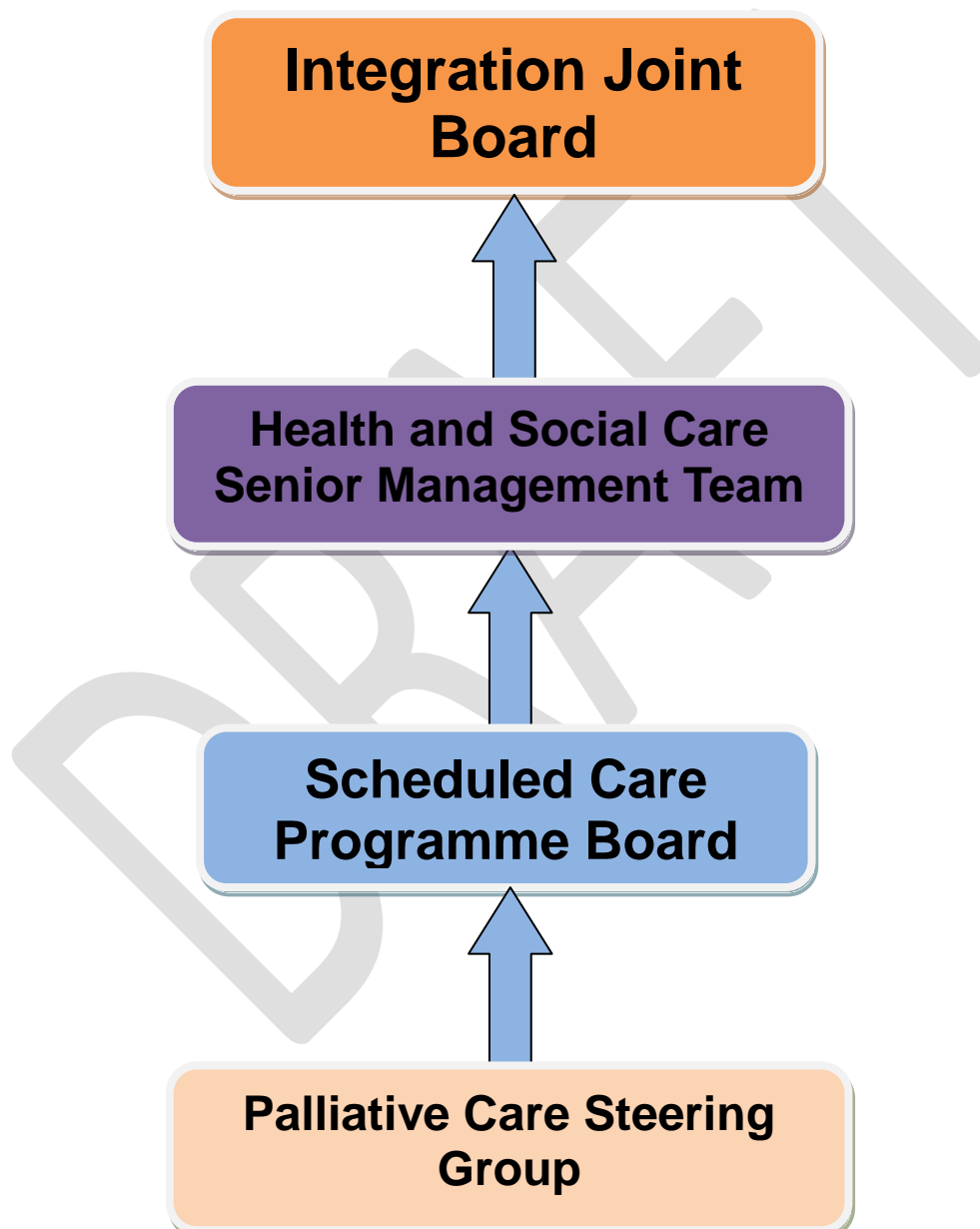
A summary of the Equality Impact Assessment completed during the development of the plan can be found in Appendix 5 of the Statement of Consultation

<b><u>Impact Area</u></b>	<b><u>Positive Impact</u></b>	<b><u>No Impact</u></b>	<b><u>Negative Impact</u></b>
Age	2	1	
Disability	4	1	
Sex	2	1	
Gender reassignment and Transgender	2	1	
Marriage and Civil Partnership	2	1	
Pregnancy and Maternity		2	
Race	2	2	
Religion or belief	2	1	
Sexual orientation	1	2	
Human Rights		2	
Health & Wellbeing & Health Inequalities	2	1	
Economic & Social Sustainability	3		
Environmental Sustainability, Climate Change and Energy Management	2		
	Total Positive Impacts = 24	Total No Impacts = 15	Total Negative Impacts = 0

## Appendix 4: Governance structure

The Palliative Care Steering Group will oversee progress against the implementation of this plan.

Progress against the actions in this plan will be monitored through the governance structure illustrated below.



**If you would like some help understanding this or  
need it in another format or language please contact  
[dg.ijbenquiries@nhs.net](mailto:dg.ijbenquiries@nhs.net) or  
Telephone 01387 241346**