Palliative Care Matters for All

Palliative care strategy (2025–30)

Scottish Government
Riaghaltas na h-Alba

Palliative Care Matters for All

Working together to improve life, health and care for people of all ages living with life shortening conditions or dying in Scotland.

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Ministerial Foreword

We will all experience life shortening conditions, dying and bereavement at some point in our lives, so palliative care matters to us all. Palliative care aims to help people of all ages live as well as possible over years rather than weeks or months.

I have seen first-hand the huge commitment and dedication across all sectors, partners, and services who deliver palliative care and wider support for people of all ages and their families and carers.

Scotland has an ageing population. We are living longer and often with multiple health conditions. We know that increasing numbers of people of all ages will need palliative care along with other health and social care. The value to people of all ages, and their families and carers of receiving palliative care is often overlooked.

We can do more as a society to talk about life shortening health conditions and what those may mean for us and those close to us. Societal taboos around death, dying and bereavement still make it harder for us to support ourselves and others. When a person is dying, we want to make sure they are comfortable, well cared for and with their family and friends who are also supported into bereavement.

A key priority for the Scottish Government is that our public services are sustainable, person-centred and deliver effective support for individuals in their communities. The strategy aligns with the Health and Social Care Service Renewal Framework (June 2025) within which our system, service leaders and staff will plan services for the future alongside people who use them, by building on what we already know works well. By focusing this strategy on deliverable outcomes and actions, we aim to ensure that across the country, people of all ages who need palliative care receive it and that they and their families and carers have flexible support based on their individual needs.

To those who contributed to developing this strategy and delivery plan, I would like to express my heartfelt thanks. I would also thank the many individuals and organisations who replied to our strategy consultation. The Scottish Government needs everyone who plans, funds and delivers palliative care in Scotland to work together and in partnership with people of all ages with life shortening conditions, their families, carers and communities.

Through the delivery of this strategy – Palliative Care Matters for All – I hope we raise people's awareness and appreciation of palliative care. We want everyone in Scotland who needs it to receive palliative care, care around dying and bereavement support based on what matters to them.

Jenni Minto MSP
Minister for Public Health and Women's Health

Terms used in this Strategy

Term	Meaning
Allied Health Professionals (AHP)	A large group of healthcare staff including physiotherapists, occupational therapists, dietitians, speech and language therapists, radiographers, paramedics, podiatrists, art therapists, drama or music therapists.
Care around dying	Care around dying means holistic care of a person of any age who is dying and in the last hours, days or few weeks of their life, that focuses on comfort and includes people close to them who are supported into bereavement. We now use the term 'care around dying' instead of 'end of life care' because the older wording causes confusion with palliative care which can be important long before someone is dying.
Compassionate communities	Compassionate community is a broad term that can include a person's own networks of family, friends, neighbours, work colleagues, social or faith/belief groups and others they meet. Some compassionate communities are more organised groups that actively encourage, support and facilitate care for one another, seeing that as everyone's responsibility.
Family and carers	By family we mean anyone who is close or important to a person such as their family members, relatives, partners or close friends. A carer is a person of any age who provides unpaid care and support to a family member, friend or neighbour.
Frailty	When a person is living with frailty, their body gradually loses its in-built reserves. This leaves them vulnerable to changes in their health or circumstances and makes it harder to recover from an injury, infection or illness.
Future care planning	Future care planning is ongoing, shared decision-making that supports people of all ages and their families and carers to manage changes in their life, health and care. Personalised future care plans include what matters to the person and options to guide staff in a health or social care emergency.
General palliative care	Palliative care for people of all ages that is provided by many different health and social care staff as part of their usual care of people living with life shortening conditions, wherever they live or have care. General palliative care is sometimes called 'a palliative care approach'.

Health and Social Care Partnership (HSCP)	HSCPs are partnerships that integrate delegated services provided by Health Boards and Local Authorities/Councils in Scotland. Each partnership is run jointly by the NHS and local authority. HSCPs are usually directed by their area Integration Joint Boards (see definition below).
Holistic care	Holistic care is person-centred and helps people with managing symptoms, emotional, psychological, social or financial problems, and spiritual wellbeing, regardless of faith or belief.
Independent hospice	An independent hospice is a registered charity regulated by Healthcare Improvement Scotland that operates through a combination of charitable and NHS funding to provide specialist palliative care services (see definition below)
Integration Authority	Integration Authorities are partnerships between local authorities and Health Boards for delivering health and social care services with integration of budgets. There are different models for establishing Integration Authorities, including lead agencies (one authority is leading) or body corporates (such as Integration Joint Boards (IJBs)).
Integration Joint Board (IJB)	IJBs are a type of Integration Authority (see definition above) and are responsible for planning and commissioning health and social care services for the people living in their areas.
Life shortening conditions	Any illnesses or health conditions that mean a person's health will deteriorate over a variable time and, at some point in the future, they will die with these conditions.
Life threatening illness	An illness or condition that means the person is very ill and may die soon, even with the best available treatment and care.
Long term conditions	Long term conditions (sometimes referred to as chronic diseases) last a year or longer, limit what a person can do, and require ongoing medical care. Some long term conditions become life shortening conditions that cause or contribute to a person's death. These include heart, lung, kidney or liver conditions, neurological conditions, blood vessel (vascular) diseases including stroke, and some types of cancer.
Multidisciplinary team	Groups of health and/or social care staff from different professions or backgrounds who work together to provide care and support for people of all ages, their families and carers.

Palliative care	Palliative care is holistic care of a person of any age living with life shortening conditions and their family and carers that focuses on what matters to them. It can start from around the time of diagnosis and includes care when someone is dying.
People of all ages	This is babies, children, young people, adults and older people.
Realistic medicine	Realistic Medicine means decisions about a person's care are made jointly between the individual and their care team. It is kind and careful care that delivers better outcomes and experiences for people, supports healthier lives, reduces unnecessary treatments, adverse events and hospitalisations, and uses available resources sustainably.
Specialist palliative care unit	A specialist palliative care unit provides inpatient care from palliative care specialists. This can be in a separate building or be specialist beds within a hospital ward. Sometimes called a 'hospice', it can be run by the NHS or an independent hospice service (see definition above).
Specialist palliative care service	Any team or service (NHS or independent hospice service) providing specialist services delivered by a multidisciplinary team of staff who are specialists in palliative care, and sometimes trained volunteers. Specialist palliative care services are for people of all ages wherever they live or have care. Specialist care is important when the person's care is more complicated and harder to manage. Specialists offer advice and education to staff providing general palliative care.

Introduction

Palliative care matters more than ever. Over 90% of people who die in Scotland each year have health conditions that mean they could benefit from palliative care. More of them will be older people living and dying with frailty, dementia or long term conditions who are likely to need palliative care over years rather than months. More children with life shortening conditions are living into adulthood but may die at any age.

This requires us to plan and deliver palliative care earlier and more effectively, to meet the increasing and varied needs of people of all ages, their families and carers.

When someone is dying, what matters is being comfortable and well cared for wherever they are. Care includes people important to them who are supported into bereavement.

In this strategy, we explain what palliative care is and how it helps people of all ages, and their families and carers to live as well as possible with life shortening conditions.

Changes in health, caring for others, dying, death and bereavement affect us all at some time in our lives. We highlight the importance of palliative care and its relevance to many current and future health and social care system priorities across policy areas.

Our Aims

This strategy has two overarching aims. These are underpinned by eight outcomes that set out the changes we hope to achieve. The strategy delivery plan has 23 actions and describes the steps and governance needed to deliver them.

Enabling people and communities

Scotland is a place where people of all ages and their communities can help and support each other to live as well as possible with life shortening conditions, dying, death and bereavement.

Strengthening palliative care

People of all ages with life shortening conditions and their families and carers receive palliative care, care around dying and bereavement support based on what matters to them.

About Palliative Care

What is palliative care?

Palliative care focuses on what matters to people. For people of all ages that means living as well as possible with life shortening conditions. Palliative care goes beyond treating health conditions to supporting each person and their family and carers to maintain quality of life, wellbeing and independence.

Palliative care is holistic care of a person of any age living with life shortening conditions and their family and carers that focuses on what matters to them.

Palliative care helps people with pain and other symptoms, emotional, psychological, social or financial problems, and spiritual wellbeing regardless of faith or belief.

Palliative care can start from around the time of diagnosis of a new life shortening condition as well as being important when someone's health is declining.

Life shortening conditions mean a person's health will deteriorate and, at some point in the future, they will die with those conditions. These changes in health and wellbeing are unpredictable. What will happen to each person and when is often uncertain. Increasing health or care needs at home, having to use urgent care services or an emergency hospital admission are signs it is time to consider adding palliative care to other treatments or as the main approach to care.

Palliative care is much more than care of people who are dying. This misunderstanding can mean people of all ages with different life shortening conditions miss out on palliative care and wider support that should be offered earlier. Treatments for these conditions may prolong life, but it is important for people to receive palliative care as well. Starting palliative care does not mean stopping treatments that are working now or could help in the future. People can continue to receive treatments for their health conditions with palliative care.

Many inequalities continue to affect the care and support people need and receive across Scotland. These can be due to factors such as where a person lives, health conditions like mental illness, being in prison, disabilities including learning disabilities, neurodiversity, poverty, language or communication barriers, culture, faith or belief, age, sex, gender, sexual orientation or personal circumstances. Inclusive, flexible and person-centred palliative care means taking steps to address inequalities and inequities experienced by people of all ages with life shortening conditions and their families and carers in delivery of all our outcomes.

Care around dying

Palliative care may start around diagnosis of a life shortening condition but also includes care of a dying person of any age and their family and carers. Health and social care staff and teams need to be able to recognise when someone is dying and talk with them and the people close to them about what is happening. When someone is dying the focus of treatment and care changes to reflect what matters now. Family, carers and others close to the person are included and supported.

Care around dying is holistic care of a person of any age who is dying that focuses on their comfort and includes people close to them.

Care around dying is given in the last hours, days or few weeks of a person's life and includes care after their death.

Care around dying involves and supports family, carers and other people close to the person throughout this time and when they are bereaved.

Who provides palliative care?

People of all ages living with life shortening conditions spend most of their time living at home supported by their own networks of families, friends and neighbours, local communities, volunteers, and different support groups. Support for carers is essential.

Integration Authorities are responsible for planning and resourcing adult palliative care in their communities and hospitals. Palliative care is provided across the NHS, by local authorities, independent hospices, and other third-sector organisations. Care homes and care at home services are other independent providers of palliative care.

General palliative care for adults is provided by many health and social care staff as part of their care for people with life shortening conditions in all places of care. Some have additional training or qualifications in palliative care. All staff and students need relevant training in palliative care in line with the NHS Education for Scotland/Scottish Social Services Council Palliative Care Education Framework.

Adult specialist palliative care services are provided by multidisciplinary teams with specific expertise and specialist training. All Health and Social Care Partnerships have access to community specialist palliative care services, and most Health Boards have hospital specialist palliative care teams. In Scotland there are 14 independent hospices serving 7 Health Board areas, and 7 NHS specialist palliative care units or hospices serving 8 Health Board areas.

Palliative care for children is provided by Health Boards, local authorities, Integration Authorities, and third sector organisations in all places of care, including within community children's services. Children's Hospices Across Scotland (CHAS) provides specialist paediatric palliative care services from two hospices, and a community service. CHAS collaborates with NHS Boards to provide specialist services in hospital and at home, including through shared posts.

Connecting palliative care

This palliative care strategy is relevant to the delivery of many Scottish Government policies, national standards and frameworks as well as relevant legislation.

This includes but is not limited to:

- Adults with Incapacity Act consultation
- Ageing and frailty: standards for the care of older people
- Benefits Assessment for Special Rules in Scotland (BASRiS)
- Bereavement charter for children and adults in Scotland
- Cancer strategy and Cancer Action Plan for Scotland
- Cancer strategy for children and young people in Scotland
- Cardiopulmonary resuscitation decisions: integrated adult policy 2016
- Carers support payment
- Dementia strategy Scotland and Dementia strategy delivery plan
- Excellence in care and Excellence in care measures
- Getting it Right for Everyone (GIRFE) and GIRFE Toolkit
- Heart disease action plan
- Health and social care: data strategy and Care in the digital age: delivery plan
- Health and social care: national workforce strategy
- Health and Social Care Service Renewal Framework (2025)
- Health and social care standards
- Human rights - childrens' rights
- Illnesses and long term conditions
- Learning/intellectual disability and autism: transformation plan
- My Health, My Care, My Home: framework for adults living in care homes
- National carers strategy
- National health and wellbeing outcomes
- Neurological care and support: framework for action
- Population Health Framework (2025)
- Realistic Medicine
- Rehabilitation and recovery: a person-centred approach
- Remote and rural healthcare enquiry
- Respiratory care action plan
- Scottish polypharmacy guidance: realistic prescribing
- SIGN Guideline: care of deteriorating patients
- Urgent and unscheduled care standards
- UK Commission on Bereavement
- Value based health and care: action plan

Strategy Development

This strategy was developed with a Strategy Steering Group (SSG) chaired by a National Clinical Lead for Palliative Care and supported by a Clinical and Professional Advisory Group (CPAG) and six working groups. Wider engagement involved key stakeholders, including Health Boards, Health and Social Care Partnerships, primary care, care homes, unscheduled care services, hospital services, and third sector organisations.

Strategy development was informed by evidence set out in four additional papers.

- **Lived Experience and Public Views:** research with adults, children, and their families and carers from a wide range of backgrounds and circumstances, about their experiences and understandings of palliative care.[1]
- **HIS Gathering Views:** a public consultation delivered by Healthcare Improvement Scotland (HIS) asking people across Scotland, including rural and island communities, to talk about their understanding and experiences of palliative care.[2]
- **Population Data and Research:** data on current and future Scottish population palliative care needs for adults and children.[3] By 2040, the total number of people dying with palliative care needs is projected to rise by at least 12% with the greatest increase in people aged 85 or over.
- **Service Mapping Survey:** surveys of palliative care delivery across Scotland[4] followed by consultation and engagement meetings with service providers to discuss palliative care in the community, urgent palliative care and palliative care in acute hospitals.

A draft strategy was published on 02 October 2024. Responses to the public consultation are summarised in the consultation report and inform the final strategy and the initial delivery plan (2025-28).

1 Additional paper: Lived Experience and Public Views
2 Additional paper – HIS Gathering Views
3 Additional paper: Population Data and Research
4 Additional paper: Service Mapping Survey

Strategy Outcomes

Outcome 1: Supportive communities

People of all ages have the information and support they need to help themselves and others to live well with life shortening conditions, and through death, dying and bereavement.

1.1 What happens now

Public information

People have a better understanding of palliative care when they receive it directly for themselves, for their relatives and friends, or through working in health or social care. People of all ages and their families and carers talk about wanting to feel cared for in a personal way. However, there are many misunderstandings that stop people getting the general palliative care or specialist palliative care services that could help them.[5,6]

People in Scotland may be more open to talking about death, dying and bereavement than in the past but there are many different views, values and ways of coping with how to live well with life shortening conditions. Accessible information developed with people from different communities can enable more of us to talk about these sensitive topics.

NHS Inform provides a range of online public information about health and care in Scotland including palliative care, care around dying and bereavement. The Scottish Partnership for Palliative Care and other third sector organisations seek to improve awareness and knowledge about palliative care through national and local community networks, public events, campaigns, social media, and websites (for example Good Life, Good Death, Good Grief).

Supportive communities

Local communities play a key and often natural role in supporting people of all ages and their families and carers. For example, initatives by so called "Compassionate Communities" take a community development approach and support local people to take action to improve people's experiences of living with life shortening conditions, dying, death, loss and caring. Local community action is about complementing not replacing the need for formal services. Scotland has a wide range of third sector projects and groups which provide support locally and/or nationally. These include social media and peer support groups, older people's groups, meeting centres for carers, faith communities and belief groups.

There are community-led education projects about palliative care and care around dying. For example, End of Life Aid Skills for Everyone (EASE) and Last Aid. These aim to help people to be more comfortable and confident in supporting family, friends, neighbours

5 Additional paper: Lived Experience and Public Views
6 Additional paper – HIS Gathering Views

and community members who are dying or bereaved. Such resources could be made more widely available to families, carers and members of the public. Social care staff may find them helpful too.

Benefits Assessment Under Special Rules in Scotland (BASRiS) helps people of all ages across Scotland apply for rapid access to disability benefits. Carers may also be entitled to financial support. People who are bereaved and need financial support can apply for the Social Security Scotland Funeral Support Payment.

1.2 What we can do better

Public information

Many people say information about palliative care and how to access it should be available from when a life shortening condition is diagnosed as well as when someone's health is getting worse with long term conditions or frailty. Public information campaigns can help raise awareness about what palliative care can do for people and their families and carers. Health and social care staff can offer and provide palliative care earlier.

Information about living as well as possible with life shortening conditions, palliative care, dying and bereavement needs to be adapted to suit people of all ages with different personal circumstances, health conditions, cultures and languages. Inclusive information in different formats can be shared on social media, by community groups, in libraries, schools, community centres, colleges, universities, and workplaces. GP practices, hospitals, outpatient clinics and health and social care staff can provide information and signpost people to more advice and support. Help with health literacy and/or digital literacy is particularly important. Advocacy services and community link workers have key roles.

Supportive communities

Scottish Partnership for Palliative Care, Macmillan Cancer Support, Marie Curie, and other third sector organisations, community groups and networks can help to enable people living with life shortening conditions and those close to them to support themselves and others[7]. Integration Authorities can work collaboratively with local community groups and help share information about what support and resources are available for people and their families and carers. They could provide financial support for community activities and initiatives and should include these local resources in their planning and commissioning processes.

7 NHS inform: support groups and organisations

Outcome 2: Adult palliative care

Adults of all ages with life shortening conditions and their families and carers receive general palliative care tailored to their needs with specialist palliative care if required.

2.1 What happens now

People's experiences of palliative care across Scotland can differ. Variation in delivery of general palliative care and specialist palliative care services can be appropriate. Change is needed when variation leads to inequalities or inequities.[8,9]

General palliative care

People living at home or in a care home or in other places of care in the community receive palliative care from many different staff and teams, including district nurses, general practitioners, practice nurses, advanced nurse practitioners, pharmacists, allied health professionals, social workers, care at home staff and care home staff.

Palliative care in acute hospitals is provided through outpatient services, day assessment units and emergency departments, as well as during hospital admissions.

All health and social care staff caring for people with life shortening conditions need to recognise when a person should be offered general palliative care, and when to ask a specialist palliative care service for help. Staff and organisations can use recommended tools to help them identify people and offer a palliative care review. These include:

- SPICT (Supportive and Palliative Care Indicators Tool) and SPICT-4ALL
- Spectrum of Palliative Care poster
- Palliative care Outcome Scales (POS)
- Carer Support Needs Assessment Tool Intervention (CSNAT-I)
- Support Needs Approach for Patients (SNAP).
- Assessment tools for people with frailty

Palliative care reviews should be offered by health or care staff who know the person. Different aspects of palliative care may matter to a person at different times. This could be managing pain or other symptoms, mental health or spiritual wellbeing, family, social or financial problems. Shared decision-making conversations are about treatment and care options that are right for this person while reducing unnecessary tests, treatments, medicines, adverse events and hospital admissions in line with Realistic Medicine.

8 Additional paper: Service Mapping Survey
9 Additional paper – HIS Gathering Views

Specialist palliative care

Specialist palliative care services offer specialist advice to support care by other staff and teams as well as being involved directly if a person's palliative care is complex and harder to manage. These specialist services should be available for people who need additional specialist help in all places of care. Specialist palliative care services are cost-effective and of proven value.[10]

Community specialist palliative care services support people and their families and carers where they live. Specialist palliative care may also include outpatient and day care services as well as a small number of specialist inpatient beds.

Hospital specialist palliative care teams support early identification of people with life shortening conditions in emergency departments, wards and clinics. Palliative care specialists contribute to shared decision-making about the risks and benefits of tests, treatments, medication or intensive care as well as improving people's pain, symptoms and overall quality of life. Specialist palliative care input can help reduce prolonged hospital stays and addresses inequalities because the people least likely to receive palliative care have more emergency hospital admissions.[11]

2.2 What we can do better

General palliative care

People with life shortening conditions depend on care in the community. All organisations responsible for palliative care delivery need to recognise the importance of providing early general palliative care for people where they live. A palliative care approach must be part of other adult health and social care as it can be needed over years rather than a few months.

Integration Authorities, Health Boards, local authorities, third sector organisations and other delivery partners can continue to promote recommended tools to improve early recognition of changes in a person's health and care so they can receive palliative care.

People with life shortening conditions, their families and carers may need urgent or emergency care due to unexpected changes in their health or situation. Experiences improve with future care planning, but not all crises are avoidable. Having access to a 24/7 palliative care helpline gives people confidence and valued support when they need help. Palliative care telephone support services are available in some but not all HSCPs and Health Boards so more local and national options are needed.

10 A casemix classification for those receiving specialist palliative care during their last year of life across England: the C-CHANGE research programme (nihr.ac.uk)
11 Costs-and-cost-effectiveness-of-adult-palliative-and-end-of-life-care-evidence-briefing-summary.pdf

Specialist palliative care

Specialist palliative care services support and train health and social care staff and teams who provide general palliative care in all places of care and should be better integrated with them. Many specialist palliative care services across Scotland already offer designated professional advice lines but it is important that specialist advice is available at all times.

Many people receiving treatments for incurable cancers now live longer but have ongoing symptoms and emergency hospital admissions. Specialist palliative care should be available to them as part of cancer care pathways.[12] Providing specialist palliative care within other specialist services for people with life shortening conditions such as kidney, lung, liver, heart or vascular conditions, stroke, neurological conditions, dementia or frailty improves people's experiences of treatment and care, and their quality of life.

Outcome 3: Paediatric palliative care

Babies, children and young people living with life shortening conditions, or those transitioning to adult services, and their families and carers receive paediatric palliative care tailored to their needs, with specialist paediatric palliative care if required.

3.1 What happens now

Children and young people have different life shortening conditions from adults and distinctive needs.[13] Children are also living longer and becoming young adults who need tailored support as they make this transition. Paediatric palliative care includes holistic care for parents and the wider family.

Paediatric palliative care is provided by other paediatric specialties, neonatal and paediatric intensive care, as well as general and community paediatrics and wider children's services. Paediatric palliative care involves a range of staff including medical and nursing staff, pharmacy, allied health professionals, social work, family support, spiritual care, psychology, education and play therapy.

Specialist paediatric palliative care services work flexibly alongside other specialists and teams to support children, families and staff if a child's symptoms are hard to manage or care is more complicated. Children's Hospices Across Scotland (CHAS) provides specialist palliative care and support for babies from before birth up to young people aged 21 years across all places of care – home, hospital and hospice. There are multidisciplinary specialist palliative care teams in the two children's hospitals, and for one Health Board.

12 Illness trajectories of incurable solid cancers | The BMJ
13 Additional paper: Population Data and Research

3.2 What we can do better

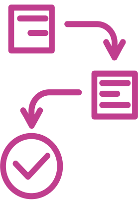
Paediatric palliative care is often being provided by medical and other staff who have relevant skills and experience, but this may not be included in their job plans.

It is important to recognise when a child can benefit from palliative care. Tools are being developed but are not used widely yet. Examples are the Paediatric Palliative Screening Scale (PaPaS Scale), and the Palliative care Outcome Scale for children (C-POS)

Our paediatric palliative care survey found gaps in services, especially outside standard working hours and for children cared for at home.[14] CHAS and Health Boards are working together to develop a national specialist paediatric palliative care clinical advisory service available 24/7 to offer expert advice and enhanced services supporting paediatric palliative care and care around dying for children and families at home and in hospital.

Moving from children's to adult services can be challenging for young people with complex health and care needs due to life shortening conditions. CHAS and some adult specialist palliative care services support these young people with their individual needs. As more young people live into adulthood, healthcare, social care, education and other services will need to provide the right care and support. Coordinated palliative care for babies, parents and families might start during antenatal care, continue throughout neonatal care and be important as they move into paediatric palliative care.

14 Additional paper: Service Mapping Survey



Outcome 4: Future care planning in palliative care

People of all ages living with life shortening conditions, their families and carers are supported to have person-centred conversations themselves and with their health and social care team about managing and planning for changes in their life, health and care.

Future care planning is shared decision-making conversations with people of all ages and their families and carers about managing changes in life, health and care.

Future care plans record what matters to the person and guide staff providing urgent health or social care; plans are updated through further conversations when things change.

4.1 What happens now

Future care planning is person-centred and helps people have their views heard. It is important for people of all ages living with long term conditions, disabilities, frailty in older age or rare conditions as well as people with life shortening conditions. Planning ahead can help people manage or avoid crisis situations and improves experiences of urgent or emergency health and social care. Conversations may include other aspects of life like finances, making a will, plans for a pet or property, or digital legacy planning.

Conversations about future care planning usually involve people important to the person like family, carers, and support workers. If a person is unable to make their own decisions, advocacy and involving any legal proxies is essential. These could be people named in a welfare Power of Attorney, a guardian, parents or carers with parental responsibility.

A future care plan summarises what matters to the individual and has key information for staff providing urgent or emergency care about the person, their health and care. A plan changes over time and needs to be updated in further discussions when that happens.

4.2 What we can do better

Public information about future care planning is available (Future care planning | NHS inform) but needs developed and improved in partnership with community groups to make it accessible and relevant to everyone who would like a care plan. Health and social care staff need education, training and support to enable them to provide future care planning.

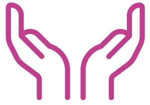
Future care planning should be offered when someone is well or stable and may start with talking about help needed now. Many more health and social care staff can contribute to future care planning. Community groups can also offer advice and support.

Digital recording of future care plans allows them to be shared securely and kept up to date. A Key Information Summary (KIS) recorded in primary care can include a future care plan. Digital developments need to provide future care plans that work better

across health and social care. This will enable more health and social care staff to create and use these plans with people of all ages. Some people wish to have their own plan on a mobile application.

The NHS Scotland Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) integrated adult policy and Children/Young People Acute Deterioration Management (CYPADM) guidance provide a clear, national framework for shared decision-making, recording of this advice, and sharing these important plans using widely recognised paper forms. Updating this guidance is an action within the strategy delivery plan.

From: NHS inform - future care planning information.



Outcome 5: Care around dying

People of all ages who are dying are cared for and comfortable wherever they die, with people close to them involved and supported.

5.1 What happens now

Care of a person of any age who is dying begins with recognising that someone may be in the last hours, days or few weeks of their life, even though there is still some uncertainty. That leads to conversations with the person, their family and carers about what happens when someone is dying, what matters now and how we care for them all throughout this time. Shared decision-making focuses on discussing available care and support along with stopping tests, treatments and medicines that no longer work or help.

If a person has a life threatening illness or infection, it can be difficult to know if they will improve or are dying. It is important to acknowledge that the person may be "sick enough to die". They may benefit from palliative care alongside other treatments.

People usually say they would like to die at home but may change their mind due to worsening health problems, increasing care needs, or home circumstances. People who have life shortening conditions, bereaved families and carers think that being comfortable, feeling safe and cared for, and having those close to them around may be more important than being in their own home. The burdens of caring or not having a carer matter too.

Dignity and respect for a person's views, wishes, belief, faith or religious practices and culture are all part of person-centred care around dying.

Family members, close friends and other informal carers experience loss and grief before and after a person of any age dies. People who are bereaved need support throughout this time and afterwards.

Bereavement support is part of care around dying for people of all ages. Bereaved people may have support from their families, friends, places of work or education and their communities, including faith and belief groups, as well as from health and social care staff. Public education about loss and grief helps everyone to understand and support each other better through this time and later on. Some people will need additional support beyond their own networks such as counselling or more specialist bereavement care.

5.2 What we can do better

Dying at home or in a care home

Improving care and offering the right support at home for people who are dying, and their families and carers, remains a priority for multiple teams, agencies and services. District nurses, general practitioners, and other members of the primary care team provide integrated care with social care staff, and specialist palliative care services if needed. This can be more challenging if a person has no informal carer or rapidly changing needs.

A palliative care helpline number supports families and carers to feel more confident when someone is dying at home. So does a key professional to coordinate care, such as a district nurse. A personalised care plan that is up to date and shared within teams and with other services including urgent and emergency care is vital. Reliable processes to assess needs and deliver equipment quickly are essential for safe care around dying at home.

Most care home residents are frail older people, and many have dementia. Some homes care for younger adults or children with complex needs. People who live in a care home can receive care around dying from trained care home staff. Support from a wider multidisciplinary team including primary care and out-of-hours services with input from specialist palliative care services, if required, is important. If a resident who is dying needs palliative care medicines these must be arranged in advance in the same way as for someone in their own home. A trained nurse must be available to give these medicines.

People in prison and those who are homeless or have insecure housing need care around dying tailored to them and their situation.

Dying in a hospital, hospice or specialist palliative care unit

People admitted to hospital for appropriate treatment of life shortening or life threatening conditions may die during that admission. Some may already be in hospital for treatment when their health deteriorates. Once it becomes clear they are dying, some people prefer to stay in hospital. Care around dying is a fundamental part of hospital care.

Specialist palliative care units (independent hospices and NHS units) provide care around dying for people with highly complex holistic care needs. They only have a few inpatient beds but provide specialist support for many more people being cared for in another place.

Bereavement support

Everyone who is bereaved in Scotland can receive information about what to do when someone has died through the updated leaflet, "When someone has died – information for you". This includes legal, practical and financial information and links to bereavement support. Third sector organisations and NHS inform offer further public information and advice. Support around death provides staff resources on bereavement.

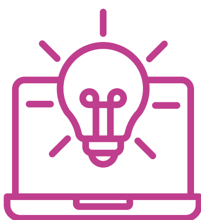
Staff need access to support for themselves when providing care around dying, and when care has been particularly challenging for an individual or the whole team. Staff will also experience personal losses or bereavements that affect their wellbeing. Employers can opt to use the Bereavement Charter for guidance on supporting staff.

Care around dying for children and families

Babies under one year account for around 65% of deaths in children, with about 90% dying in hospital.[15] Hospital care may be appropriate but offering realistic alternatives is important. Care around dying for a child and family at home is individualised with multi-agency collaboration (hospital, community teams and hospice) It may include support from the national paediatric clinical advisory service, if needed.

When a child dies, loss and grief may have multiple overlapping phases from diagnosis. Grief reactions affect the child, parents, carers, wider family, friends from school and social networks. People can support themselves and each other but may need more help. The right support through bereavement when someone young dies has lasting impact on the people who are bereaved.

15 Additional paper: Population Data and Research



Outcome 6: Education and learning

Health and social care staff caring for people of all ages with life shortening conditions have access to recommended education and learning resources to support and enable them to provide palliative care, care around dying and bereavement support.

All health and social care staff who deliver palliative care, care around dying and bereavement support as part of their roles in the NHS, social care, third sector or independent organisations should have the education and training they need.

6.1 What happens now

The NHS Education for Scotland/Scottish Social Services Council Palliative Care Education Framework provides a clear and robust structure for education and training. It continues to be the basis for planning and delivery of palliative care education for health and social care staff caring for people of all ages, their families and carers.

The Scottish Palliative Care Guidelines provide practical, evidence based information to support safe and consistent symptom management and wider aspects of palliative care and care around dying by health and social care staff across Scotland. The guidelines are freely available on the Right Decision Service and widely used in training and education.

Many education and training programmes for health and social care staff or students in Scotland include palliative care to some extent. Alongside formal education and workplace learning, staff and students use online resources for self-directed learning.

National palliative care networks are for staff delivering palliative care for people of all ages or interested in improving it. They bring people together to share learning, challenges, solutions and innovations. Organisations, teams and individuals, including members of the public, can all contribute to the networks relevant for them. These include – but are not limited to – Community Palliative Care Network, Scottish Network for Acute Palliative Care in hospitals (SNAPC), Specialist Palliative Care Group, Scottish Children and Young People Palliative Network (SCYPPN), Project ECHO (Extension for Community Healthcare Outcomes) online learning networks, and the NHS Education for Scotland Bereavement Network.

6.2 What we can do better

Palliative care education needs to be delivered consistently across Scotland within pre-registration programmes for doctors, nurses and other health and social care staff, and in further education college programmes. Palliative care education should be included wherever relevant in undergraduate university programmes. This includes understanding the importance of early palliative care as well as how to provide care around dying.

Vocational qualifications (NVQs and SVQs) can provide training that offers learners opportunities to develop essential skills and knowledge on palliative care and care around dying, and an understanding of loss, grief and bereavement.

The updated Palliative Care Education Framework (2025) can support consistent education and training in all sectors and for a wide range of health and social care staff working in adult or children's services. Health and Social Care Partnerships can contribute to delivery of relevant palliative care training and education. Health Boards need to provide appropriate education and training for hospital staff.

The Scottish Palliative Care Guidelines remain central to palliative care delivery, education and improvement for health and social care staff and organisations. The guidelines programme provides regular reviews of current content and supports the addition of new resources relevant to palliative care for people of all ages.

A national Palliative Care Learning Hub linked to the Palliative Care Education Framework can make palliative care learning resources accessible and freely available to health and social care staff and students wherever they work or study as well as supporting education providers. The Learning Hub can bring together recommended education resources on palliative care, care around dying and bereavement for people of all ages from many sources including NHS Education for Scotland, Scottish Social Services Council, Healthcare Improvement Scotland, Health Boards and third sector organisations.

Outcome 7: Palliative care data

National and local service providers gather, use and share palliative care data to inform service planning and delivery, monitoring, evaluation and reporting, including experiences of palliative care and care around dying.

We need to understand, measure and learn from people's experiences of palliative care, care around dying and bereavement. What matters to an individual, their family and carers varies. So do the best ways of enabling their views to be heard.[16] Person-centred palliative care means that all organisations responsible for palliative care need to gather and report these outcomes to drive service improvements.

Collecting, using and reporting population data at national and local levels is key to improving palliative care and care around dying. Mapping and monitoring population palliative care needs must inform service planning, delivery and outcomes measurement.

7.1 What happens now

People's experiences of palliative care

Some person-reported experience measures (PREMs), and person-reported outcome measures (PROMS) are being used to collect information about people's experiences of palliative care services, but this is variable.[17] Care Opinion feedback can be used to highlight care that people valued as well as their concerns. Complaints about palliative care and care around dying are addressed and recorded in local systems but wider learning is limited.

Population palliative care data

Public Health Scotland (PHS) publishes annual information on the percentage of time that people of all ages spend at home or in a community setting in the last six months of life, on unscheduled healthcare service use, and on place and causes of death through their data dashboards. Further population data analyses show increasing numbers of people will die with multiple conditions including heart and circulation system diseases, dementia, neurological conditions and lung disease. Cancer remains a major cause of death.[18]

The Care Inspectorate and Healthcare Improvement Scotland inspect and support improvement in delivery of health and social care services by Integration Authorities in line with the national standards for adult health and social care. This includes care homes, care at home and independent hospices.

16 Additional paper: Lived Experience and Public Views
17 Additional paper: Service Mapping Survey
18 Additional paper: Population Data and Research

7.2 What we can do better

People's experiences of palliative care

Experiences of palliative care and care around dying are not gathered, analysed or reported consistently across Scotland. Person-centred measures of palliative care developed for health and social care and for specialist palliative care in different formats are available and could be used more effectively by organisations responsible for palliative care. When a person's health is declining over time or they are very ill and may be dying, different approaches to learning from people's experiences are needed such as gathering information from their families and carers or from these people after the person has died.

Population palliative care data

In the past, place of care and death have underpinned palliative care population data, but these have important limitations. Changes in a person's health or care needs and circumstances can mean what matters to them when they are ill or dying is different from when their health was more stable. Hospital-based care may be needed and wanted when tests or treatment can improve health and quality of life. Whether a person with life shortening conditions, their family and carers, have received the right care, in the right place, at the right time are more person-centred outcome measures.

Integration Authorities and Health Boards use the current national data on palliative care, but they need better access to local population data dashboards and more clarity on what data should be collected, shared and reported. Work is underway to review palliative care population data measures for people of all ages and to improve how data is gathered from, and shared with, Integration Authorities, Health Boards, and third sector delivery partners including independent hospices.

Few Integration Authorities or Health Boards reported having a dedicated resource for managing, reporting or collecting local data on palliative care and care around dying. Those that did were more able to integrate and use data effectively to improve care.[19]

Standards for evaluating and reporting on delivery of adult specialist palliative care services and for paediatric specialist palliative care services are needed. Minimum data sets including quantitative and qualitative measures and templates for data reporting can support improved service planning and delivery for both general palliative care and specialist palliative care services.

Relevant data and public engagement should inform strategic planning so people can receive the right health and social care for them, including palliative care. An important part of this is taking steps to reduce inequalities and uphold people's rights.

19 Additional paper: Service Mapping Survey

Outcome 8: Governance

Organisations responsible for health and social care work together and with third sector partners to improve planning, delivery, reporting and accountability for general palliative care and specialist palliative care services.

8.1 What happens now

Since 2018, adult palliative care has been delivered in an integrated health and social care system led by Integration Authorities (either through Integration Joint Board (IJB), or Lead Agency arrangements). They work across NHS services and local authorities, and with independent or third sector organisations including hospices, care homes and care at home services. Integration Authorities are required to deliver well-coordinated palliative care for their local populations through collaborative service planning and partnership working. This has proved challenging in a complex delivery landscape with workforce and funding pressures.

Health boards, local authorities, integration authorities, and third sector organisations all have responsibilities around paediatric palliative care. Organisational arrangements between CHAS and Health Boards support funding and delivery of specialist paediatric palliative care in the community and hospitals.

Our surveys reported gaps in funding for consultants in palliative medicine, doctors, nurses and other staff needed to provide a multidisciplinary specialist palliative care service.[20] NHS specialist palliative care services and independent hospices are trying to work with Integration Authority, NHS and local authority services in innovative ways. For example, some rural and island communities rely on joint working arrangements with palliative care specialists based in other Health Boards.

8.2 What we can do better

Local strategies and delivery plans within each Health Board area should set out how people of all ages who need palliative care will be identified and offered person-centred care. Then, they need to show how palliative care, future care planning and care around dying will be delivered with key measurable outcomes monitored and reported. Health and social care service planners need to work out how general palliative care and specialist palliative care services can be improved, integrated and co-ordinated across all places of care, in collaboration with delivery partners. These planning and delivery processes need to involve people with life shortening conditions, families, carers, volunteers, local groups and communities.

An executive lead for palliative care in each Health Board area could bring together Integration Authorities, NHS Boards, education providers, third sector and other key stakeholders to allow strategic oversight and accountability for delivery of palliative care for people of all ages.

20 Additional paper: Service Mapping Survey

Managed care networks within Health Board areas can have an important role in local service planning of palliative care for people of all ages if they have broad representation across all service providers and agencies, designated leadership from senior staff, and involve local communities and support groups. National guidance can support existing managed care networks and help establish them in other Health Board areas.

Independent hospices are key delivery partners in some Health Board areas. Sustainable arrangements for commissioning and funding specialist palliative care services from independent hospices are required to enable them to participate as equal partners with NHS palliative care services to meet future population needs in their areas.

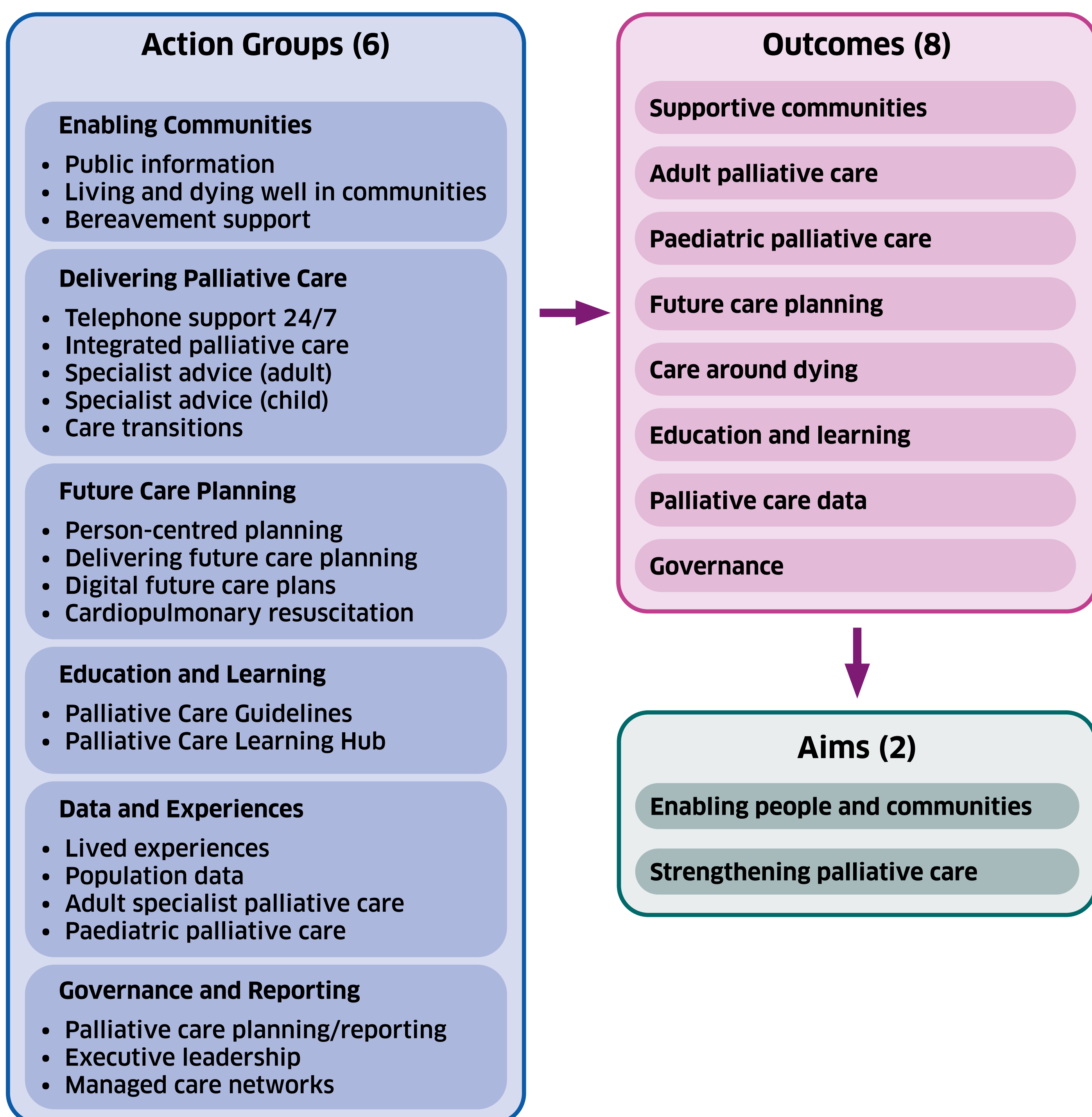
NHS specialist palliative care services make important contributions to delivery of system-wide priorities in the community, hospitals and through NHS specialist inpatient units but these NHS services may not be recognised or supported well enough.

Population-based palliative care commissioning should consider how to leverage current resources to greatest impact. With increasing numbers of people requiring palliative care, delivery partners must work together to identify, analyse and respond to local and national population needs. Engagement with local communities can make sure changes match people's needs and respond to what matters to them.

Palliative Care Strategy Delivery Plan

An initial delivery plan (2025-28) is published alongside our strategy – Palliative Care Matters for All. It sets out how the Scottish Government will work with everyone who plans and delivers palliative care in Scotland and in partnership with people of all ages who have life shortening conditions, their families, carers and communities to deliver the changes needed.

There are 23 actions in six groups in the delivery plan that together will enable us to achieve the eight strategy outcomes for people of all ages across Scotland.



The strategy delivery plan is not based on substantial additional funding given the challenging financial climate, but rather seeks to improve the resources and data that are needed to support staff and organisations to deliver high quality palliative care and care around dying. The Scottish Government is promoting and recognising this invaluable care by giving it greater recognition in conjunction with Integration Authorities, Health Boards, and third sector organisations.

This delivery plan outlines how the actions will be delivered, measured and monitored, along with governance arrangements and reporting. All the actions in the delivery plan include a requirement to address inequalities and improve inclusion. People of all ages with life shortening conditions and their families and carers should receive the right care and support for them, in the right place, at the right time, and from the right people.

Success is the responsibility of no single organisation, but a shared partnership. The strategy's delivery will be supported through regular reporting on the specific actions and progress against the outcomes, as well as responding flexibly to changes over time.

In June 2025, the Scottish Government published the Health and Social Care Service Renewal Framework which sets out the strategic intent for health and social care services. At the same time, the Population Health Framework outlined the long term, collective approach to improving Scotland's health and reducing health inequalities for the next decade.

The palliative care strategy emphases early identification, shared care planning and community empowerment so is aligned with how both frameworks shift towards preventative, person-centred and sustainable care.

Annex A shows how the palliative care strategy actions reflect the vision in both these frameworks.

Annex A: Palliative Care Strategy alignment with Scottish Government Frameworks

Action Group	Individual Actions	Health and Social Care Renewal Framework (2025)	Population Health Framework (2025)
1. Enabling communities	1.1 Public information 1.2 Living and dying well in communities 1.3 Bereavement support	Community-based models of care and person-centred delivery	Empowers communities, reduces stigma, promotes health literacy and inclusion
2. Delivering palliative care	2.1 Telephone support 24/7 2.2 Integrated palliative care 2.3 Adult specialist palliative care advice 2.4 Paediatric specialist palliative care advice 2.5 Care transitions	Integrated, multidisciplinary care; improved access and responsiveness	Reduces inequalities in access; supports continuity of care across all life stages
3. Future care planning	3.1 Person-centred future care planning 3.2 Delivering future care planning 3.3 Digital future care plans 3.4 Cardiopulmonary resuscitation	Digital transformation; future care planning; shared decision-making	Promotes autonomy, early intervention, and equitable planning and support
4. Education and learning in palliative care	4.1 Scottish Palliative Care Guidelines 4.2 Scottish Palliative Care Learning Hub	Workforce development; capability building across sectors	Enhances skills to address population needs and reduce unwarranted variation in care

5. Palliative care data and experiences	5.1 Lived experience data 5.2 Population data 5.3 Adult specialist palliative care data 5.4 Paediatric palliative care data	Data-driven improvement; outcomes-based commissioning	Informs targeted interventions; supports equity and service planning
6. Governance and reporting in palliative care	6.1 Palliative care for adults 6.2 Specialist palliative care services for adults 6.3 Paediatric palliative care 6.4 Executive lead for palliative care 6.5 Managed care networks	Strengthened local leadership, accountability and commissioning	Enables local responsiveness and community engagement in planning

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