

Palliative Care Matters for All

Working together to improve life, health and care for people of all ages living with serious illnesses and health conditions or dying in Scotland (2025 - 2030)

Ministerial Foreword



Palliative care matters to us all. Serious illness, dying and bereavement are universal experiences, which we will all face at some point in our lives. When that happens, we all hope that we, and our loved ones, will be well cared for and supported.

I have seen first-hand the huge commitment and dedication across all sectors and partners who work to deliver palliative care in this country, and we have been collaborating closely with them throughout the development of this new strategy. I know that staff and teams in health and social care are doing their best to ensure people have access to palliative care whenever and wherever they need it.

I know how much pressure there is on our NHS and social care system, and that this pressure is growing. Scotland has an ageing population. We are living longer and with more complex needs. By 2040 it is projected that deaths will outnumber births, so planning for rising palliative care population needs is essential. The benefits and value of palliative care to those who need it – including families and carers – as well as its role in reducing NHS pressures, are too often overlooked. With variable access across Scotland, we can – and must – do better.

In Scotland, we still struggle as a society to talk openly about serious illness and death. Societal taboos around dying and stigma, or fears about the withdrawal of treatment, can lead to the marginalisation of palliative care services for adults and children. Many of us – professionals and members of the public – still think palliative care only means care in the last weeks or days of life, when the reality is that some adults and children can benefit from palliative care over many years.

Through this new strategy, we hope to raise the profile of palliative care so that Scotland becomes a place where people and communities can support each other, take action and talk more openly about living well and planning ahead for serious illness, dying and bereavement.

One of the key priorities for the Scottish Government is that our public services are sustainable, person-centred and effective in the delivery of all that is required to support individuals in their communities. By focusing, in this strategy, on deliverable outcomes and actions, we aim to ensure that across the country, adults and children who need palliative care services have equal access to it, and that they, their families, and carers are provided with flexible support based on their individual needs.

All of this is being done within the wider context of a strategic redesign and reform of NHS services and wider health and social care, through the upcoming National Care Service.

Timely access to palliative care and person-centred care planning in our hospitals, as well as in the community, can improve people's experiences, help us make better use of unscheduled care services and provide more care at home.

To those who took the time to engage with, and contribute to, this draft strategy throughout its development, I would like to express my heartfelt thanks for all your efforts. I look forward to continuing to work with you as we develop the actions further, in preparation for the publication of the final strategy, and as we work to deliver on them over the coming years.

The Scottish Government cannot deliver the ambitions set out in this strategy alone. We need everyone who plans, funds and delivers palliative care services in Scotland to work together, in partnership with the users of palliative care services, to drive forward the changes that we want to see.

Through the delivery of this strategy – Palliative Care Matters for All – I hope that everyone in Scotland who needs it will receive well-coordinated, timely and high-quality palliative care, care around dying and bereavement support based on what matters most to them at this time in their lives.

Jenni Minto MSP

Minister for Public Health and Women's Health

CONTENTS

Introduction	5
Our Cornerstones	8
Our Outcomes	10
Outcome 1: People have the understanding, information, skills and confidence to support themselves and others to live well with serious illnesses or health conditions; to plan for the future; and to support each other through dying and bereavement.	10
Outcome 2: Leaders, stakeholders and delivery partners will work together in partnership, with clear roles and responsibilities, to make sure there is reliable and effective planning, delivery, accountability and improvement of palliative care services and wider support.	14
Outcome 3: National and local leaders will have access to relevant data to inform planning and delivery of services, and will put in place improved ways to monitor and evaluate the outcomes and experiences of children and adults receiving palliative care, as well as their families and carers.	18
Outcome 4: Adults with serious or life-threatening illnesses will be identified earlier and be able to access general palliative care and specialist palliative care services whenever and wherever needed.	20
Outcome 5: Adults living with serious or life-threatening illnesses and children with serious health conditions will be offered person-centred future care planning involving their families and carers, and care plans will be recorded and shared using national digital systems	26
Outcome 6: Quality and experiences of care around dying and bereavement support are improved for adults, their families and carers, in all places of care.	29
Outcome 7: Babies, children and young people living with serious health conditions, and their families and carers, will experience improved support as their distinctive needs are recognised and addressed by paediatric palliative care, including care around dying, or as they transition into adult services.	35
Outcome 8: Employers, professional bodies and education providers will make sure that staff who deliver palliative care are trained, skilled and supported.	40
Annex A: Terms used in this strategy	43
Annex B: Planning and delivery of palliative care	46

Introduction

People with serious or life-threatening illnesses, or with a child who has a serious health condition, often say that what matters most to them is living their life as well as possible.

We know that what makes a difference to people is person-centred care; clear and sensitive communication; information about what to expect and how to ask for help; being free of pain and other symptoms; and effective coordination of services. Just as important are wellbeing and social, practical and spiritual support from health and social care services and from wider social, personal and community networks.

Palliative care focuses on what matters to people in their lives, in the context of their own personal, family, social and cultural circumstances, as well as on their health conditions. It goes beyond treating illnesses, to supporting each adult or child, and their family and carers, to maintain their quality of life, wellbeing and independence.

Palliative care provides opportunities to respond to different people and situations over months or years, as well as when someone is dying. It is important to make sure each adult or child has equitable access to the right palliative care and support for them where and when they need it.

Adults and children with palliative care needs spend most of their lives at home, supported by their families, friends and neighbours, local communities, volunteers, and many different support groups, rather than by health and social care services. Those providing that support often need care and support themselves.

What is palliative care?

Palliative care prevents and relieves suffering through the early identification of people who need this care, individualised assessment and management of pain and other symptoms, along with mental health, social, family, or spiritual problems.¹ It can be provided at home, in hospitals, in care homes and in any other place of care.

Person-centred palliative care, along with community-led support, can signpost people to help with practical issues like social isolation, financial benefits, housing issues, and legal advice. When an adult, child or young person is dying, palliative care shifts to making sure they are free of pain and other symptoms; well cared for; and that they have people who matter to them around.

While bereavement is the time after someone has died, grief is the emotional response to loss and can begin well before someone dies – sometimes from the point of diagnosis. Loss and anticipatory grief can be experienced by the person who is ill, as well as their families, friends and carers. There may be wider impacts for people who are bereaved, such as loss of future hopes, changes in family relationships, and financial or housing insecurity. Bereavement support is an essential part of palliative care.

¹ [Palliative care \(who.int\)](https://www.who.int)

When is palliative care delivered?

The best time and ways of providing palliative care will be different for each adult and child. Palliative care can be introduced when a life-threatening illness or serious health condition is diagnosed, as soon as we recognise that an adult or child has increasing problems affecting their quality of life, or when it becomes clear that they will not recover from these serious illnesses and health conditions.

People who have experienced palliative care know that it can support adults and children, as well as their families and carers, to live well over years, and not just when someone is dying.

Many people still believe that introducing palliative care means someone will die soon, and some worry that starting palliative care may mean withdrawal of other treatments and care. However, people can, and do, continue to receive treatment for their underlying health conditions alongside palliative care.

Our aims

Through this strategy, we aim to ensure that, by 2030:

- adults and children in Scotland have more equitable access to well-coordinated, timely and high-quality palliative care, care around dying and bereavement support based on what matters to them, including support for families and carers.
- Scotland is a place where people, families and communities can support each other, take action and talk more openly about planning ahead, serious illnesses or health conditions, dying and bereavement.
- adults and children have opportunities to plan for future changes in their life, health and care with their families and carers.

Working in partnership across health and social care, and with local authorities, as well as local communities and wider support networks, will be key to achieving these aims, and leaders at national and local levels will need to have in place whole-system, population-based approaches to planning and delivering palliative care and community-led support.

Strategy development

This draft strategy has been developed through a Strategy Steering Group (SSG), representing the wide range of partners involved in palliative care, chaired by a National Clinical Lead for Palliative Care and supported by a Clinical and Professional Advisory Group (CPAG). Wider engagement through six working groups and with other key stakeholders, including Health Boards, Health and Social Care Partnerships, Primary Care and third sector delivery partners, has also contributed to the draft strategy.

The strategy has been informed by evidence gathering guided by the SSG and its working groups. Additional papers, which set out the data and evidence, have been published alongside it. This evidence includes:

- 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 care².
- HIS Gathering Views: a new 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 care³.
- Population Data and Research: data on current and future Scottish population palliative care needs for adults and children⁴.
- Service Mapping Survey: surveys of palliative care delivery across Scotland⁵ followed by consultation and engagement meetings to validate and discuss the survey findings, and additional meetings with service providers to discuss palliative care in the community, urgent palliative care and palliative care in acute hospitals.

Strategy delivery

Work has already begun on the delivery of some of the actions within this draft strategy. Alongside the final version of the strategy, we will publish a delivery plan setting out our approach to actions within this strategy. The delivery plan will explain who will be responsible for delivery; the delivery steps to be taken, and the timescales for doing so; the outcomes they are expected to achieve; and how we will measure improvements. The final version of the strategy itself will also provide further clarity around responsibility and accountability for the delivery of each individual action.

The SSG will oversee our response to the consultation and will then evolve to oversee delivery of the actions. We will also review and develop the current working groups to make sure we have all the working groups and partnerships required to deliver the agreed aims, outcomes and actions in the final strategy.

This Strategy, and its delivery, will reflect the principles within the National Clinical Framework, which sets out a strategic approach to delivering the needs of the population in a safe and sustainable way. This strategic approach is based around portfolios of care, to ensure appropriate direction is provided to all aspects of care delivery. Palliative care is one of the categories of care.

As a key delivery mechanism, Strategic Networks will be responsible for supporting the development of the strategic direction, linked to the national vision across Scotland for the portfolio of care, for which they are responsible. They will establish service standards and outcomes, provide oversight for each clinical area within that portfolio, and will be the owners of the respective Operating Models.

We will publish a palliative care annual report on the Scottish Government website outlining progress on delivery of the final strategy outcomes and actions, including measures of access to palliative care and care quality indicators.

² [Additional paper: Lived Experience and Public Views](#)

³ [Additional paper – HIS Gathering Views](#)

⁴ [Additional paper: Population Data and Research](#)

⁵ [Additional paper: Service Mapping Survey](#)

Our cornerstones

We have identified four cornerstones as the foundations of this strategy, which will underpin delivery and improvements to the understanding and experiences of palliative care for adults, children, and their families and carers. These are:

1. Working together to provide the care that's right for each adult or child, their family and carers

Person centred care and shared decision-making mean making sure that all decisions about a person's care are made jointly between them and their health and care team. We want people using health and care services, and those close to them, to feel empowered to discuss what matters to them, as well as their care and treatment options, fully with the staff caring for them. Involving people close to an adult or child, and anyone with legal responsibilities for their health and welfare, is central to palliative care.

This ethos sits at the heart of many of our existing programmes of work, including [Realistic Medicine](#), which focusses on the delivery of [Value Based Health and Care](#), meaning care that is not only of high quality, but delivers the outcomes and experiences that really matter to people. As part of this, palliative care aims to ensure that people have access to treatments that are of real value to them, improve their quality of life, and reflect their priorities, while keeping any hospital admissions as short as possible.

Getting it Right for Everyone (GIRFE) and Getting it Right for Every Child (GIRFEC) also seek to improve care across the whole life course by keeping the adult, child or young person, and their family and carers, at the centre of multi-agency care and all decision making, addressing inequities and giving equal value to their community support networks and access to wider public services, alongside health and social care services.

2. Taking a whole-system population health approach using data and people's experiences ⁶

A population-based approach to palliative care helps us understand current and future palliative care needs nationally and locally, and uses population data to inform national and local strategies, delivery plans, actions and outcomes.

We know that Scotland has an ageing population with increasing numbers of people living and dying with multiple health conditions (multimorbidity). Around 90% of the 61,000 people dying each year (including over 200 children) will have one or more serious illnesses that mean they have palliative care needs. By 2040, the total number of people dying with palliative care needs is projected to rise by at least 12%. The greatest increase is expected in people aged 85 or over. A growing number of children are also living with serious health conditions for longer, and more young people will be transitioning to adult services.

National and local population data are essential to underpin local and regional planning of whole system approaches that are delivered across social care, primary health care, hospital care and with specialist palliative care; to plan for investment of services in

⁶ [Additional paper: Population Data and Research](#)

supporting people to be in their preferred place of care wherever possible; and to ensure co-ordinated pathways into and between services as the person's needs change.

3. Ensuring equity and equality of access to palliative care for anyone who needs it

The right of everyone to the highest attainable standard of physical and mental health is enshrined in international human rights law in Article 12 of the International Covenant on Economic, Social and Cultural Rights. The World Health Organisation recognises palliative care, pain relief and bereavement support within these rights.

How adults and children, their families and carers, experience living and dying with different illnesses, and how they access health and care services and community support networks, is affected by a wide range of factors, including their health conditions, socio-economic situation, location, culture, beliefs and personal circumstances.⁷

Through this strategy, we want to address inequities and respect diversity so that everyone in Scotland can access the right kinds of palliative care, care around dying and bereavement support for them.

4. Leadership across health and social care systems and with wider delivery partners, including third sector organisations (charities)

Palliative care is planned and delivered in a variety of settings, across a range of sectors, as outlined in Annex B. Within such a wide landscape, clear responsibilities, roles and accountability are essential for effective planning, resourcing, delivery and the monitoring and evaluation of palliative care. Leadership, collaboration and communication are paramount to make sure all partners are involved in a co-ordinated and comprehensive whole system approach to palliative care.

Going forward, the National Care Service (NCS) will provide opportunities to strengthen the delivery of integrated health and social care services, including palliative care, and to ensure greater consistency and quality of services for everyone.

⁷ [Additional paper: Lived Experience and Public Views](#)

Our outcomes

We have developed eight outcomes, each underpinned by a number of actions intended to support the achievement of these outcomes. Taken together, these outcomes are designed to deliver the overarching aims of this strategy.

Outcome 1: People have the understanding, information, skills and confidence to support themselves and others to live well with serious illnesses or health conditions; to plan for the future; and to support each other through dying and bereavement.

Understanding palliative care

Palliative care offers much more than care when adults or children are dying, but many people still think offering palliative care means someone is near death. The Gathering Views consultations carried out by HIS found a range of opinions and misconceptions but confirmed that those with experience of palliative care valued support and care focused on the adult or child's quality of life and wellbeing. People often talked about the importance of feeling cared for, treated as a person, and having their needs met.

“It (palliative care) provides support at a very emotional, stressful and scary time in your life.”

When asked how best to raise awareness of, and promote, a better understanding of palliative care early on in someone's illness, many people said that information should be available around the time of diagnosis and be appropriate to a range of health conditions, cultures and localities. The need for information in many formats in a wide range of places was highlighted, including leaflets; social media; and information in GP surgeries, hospitals, community groups and schools; as well as from health and social care staff.

People have diverse and varying views about the value of talking openly about death and dying and the concept of a 'good' death. It helps to talk openly or comfortably about living with serious illnesses, dying and bereavement, so everyone is more able to give and receive support from others. However, people from different backgrounds may have diverse values, views and ways of coping. Discussions about what matters to adults and children, their families and carers are opportunities to make sure approaches to care and support are personal, respectful and sensitive to individual and cultural preferences. Health and care staff who provide person-centred palliative care without naming it as such could also think about explaining how this type of care can add value to life, health and care for adults and children.

NHS Inform provides a central point of information about palliative care, linked to a much wider range of information from other organisations. Third sector organisations also promote awareness and knowledge through public events, social media, online resources and national and local networks, (e.g. [Good Life, Good Death, Good Grief](#); Demystifying Death Week; and To Absent Friends Festivals).

Wider support

Adults with serious illnesses and children or young people with serious health conditions, their families and carers need support and signposting, through health and social care staff and community support groups, to the right information about how to get practical help with financial benefits and housing or legal matters.

Some groups also need more flexible and tailored approaches to palliative care. For example, people living in insecure housing or who are homeless can often have multiple health problems and wider complex needs aggravated by serious illnesses, and the prison population is ageing, with older prisoners likely to have multiple health conditions and serious illnesses.

Palliative care in prisons

An independent hospice supports prisoners with palliative care needs in local prisons. David*, who had progressive blood cancer, was referred and visited regularly by the hospice community palliative care team providing support and advice to him, his care team and his family. His symptoms and function improved, and he talked about what mattered to him and what the future might hold. Working with the prison staff, social workers, his hospital specialist, chaplains and prison nurses, the hospice team coordinated conferences to plan for care when he was dying. When his health worsened, a planned transfer to the hospice enabled him to die, while still in custody, with his wife and daughter present.

The 'Spectrum of Palliative Care' education tool is improving palliative care for people in prisons across two Health Boards. Prison healthcare staff are trained to identify people who need palliative care and have reported improved confidence in providing it. This approach is now embedded in the prison healthcare programme. Palliative care needs are met earlier and more fully, including future care planning conversations, integration with frailty pathways, better access to rehabilitation and speech and language services, improved management of palliative care by prison nursing teams, and higher quality and more frequent discussions about palliative care at multidisciplinary team meetings.

*Not his real name

Living in poverty leads to earlier ill health with more multimorbidity and a shorter life span, with longer periods of poor health than for those living in more affluent areas. Further to this, we already know that households with a disabled adult or child are at greater risk of poverty, and the *Dying in the Margins* project⁸ highlighted the experiences of people from an urban area who were dying at home and living with financial hardship and deprivation. The Scottish Government is continuing to take action to reduce poverty, with the eradication of child poverty being the Scottish Government's top priority.

The Benefits Assessment Under Special Rules in Scotland (BASRiS) is specifically for adults and children with serious illnesses or health conditions that are 'advanced and progressive and not amenable to curative treatment, and who need additional care and support' in line with the Scottish definition of 'terminal illness.' BASRiS is the only

⁸ [University of Glasgow - Research - Research units A-Z - Glasgow End of Life Studies Group - Our Research - Dying in the Margins](#)

supporting information required when someone is applying for disability benefits under the special rules. It is important for this rapid access to disability benefits to be accessible to everyone entitled to it and for professionals to have clear information about their role and responsibilities.⁹

We also recognise the impacts of other, wider policies and legislation on the experiences of adults with serious or life-threatening illnesses and children with serious health conditions, their families and carers. These must be taken into consideration, with improvements made to the wider support available to people in this situation. This also applies to policies that seek to promote inclusion of communities who may be impacted in different ways.

Community networks and support

Local communities play a key role in supporting adults and children, as well as their families and carers, and their contributions should be better recognised, valued and included in local planning of whole system approaches to palliative care. This includes *Compassionate Communities*, which take a community development approach to supporting local people to take action to improve people's experiences of serious illness, dying, death, loss and care.¹⁰ Local areas often have a wide range of third sector projects which directly or indirectly provide support.

Truacanta Project

This project was based on community led development, with a project manager supporting five projects across Scotland.¹¹ A community asset-based approach allowed projects to grow naturally, with groups exploring for themselves how people can be supported to deal with deteriorating health, death, dying and bereavement. These were non-prescriptive, directed towards local needs, and developed at a pace reflecting local capacity. Being part of a national project with networking events gave groups access to support, peer learning/sharing and a sense of credibility and pride. However, community development approaches were time consuming, did not lend themselves to planning, and progress could feel intangible. There were clear benefits in building grass-roots insights and connections, but the need for ongoing collaboration and compromise brought challenges in terms of decision-making, relationships, action, people and money. Truacanta has left a legacy in all the communities it has touched, and there are plans for many aspects of the project's work to be sustained going forward, including the national network.

There are well-established training and community-led education opportunities covering the basics of providing palliative care and care for dying people. These enable people to be more comfortable and confident in supporting family, friends, neighbours and community members who are dying or bereaved. In Scotland, these include End of Life Aid Skills for Everyone (EASE)¹² and Last Aid¹³. Tailored support and training in managing medicines, medical devices and care equipment also help families and carers.

⁹ [Social Security Scotland - Chief Medical Officer's guidance for clinicians completing a BASRIS form](#)

¹⁰ [How compassionate communities are implemented and evaluated in practice: a scoping review | BMC Palliative Care | Full Text \(biomedcentral.com\)](#)

¹¹ [Truacanta Report.indd \(palliativecarescotland.org.uk\)](#)

¹² [Good Life, Good Death, Good Grief: End of Life Aid Skills for Everyone \(EASE\) \(goodlifedeathgrief.org.uk\)](#)

¹³ [Last Aid | Highland Hospice](#)

As part of the finalisation of the strategy and development of the delivery plan, Scottish Government will work with delivery partners to further develop the following proposed actions, timings and appropriate governance arrangements:

- 1.1. Take forward work across relevant policy areas to improve the wider experiences of people receiving palliative care and care around dying; remove barriers to access; and maximise support, including in areas related to children and young people, equalities, justice, fair work, housing and tackling poverty.
- 1.2. Explore ways to promote access to financial benefits for adults or children with serious illnesses or health conditions and increasing health and care needs under the Benefits Assessment for Special Rules in Scotland (BASRiS) application process through improved public information and professional education and guidance.
- 1.3. Work with agencies and statutory and third sector organisations responsible for housing and services for people who are homeless or vulnerably housed to develop and promote ways to enable adults and children living with serious illnesses or health conditions to access the social, practical and financial assessments and support they need.
- 1.4. Collaborate with NHS 24 and wider partners to make sure the NHS inform website provides relevant, up to date and accessible public information about future care planning, palliative care and care around dying for adults and children, families and carers, including links to support organisations and resources for people from diverse groups and communities.
- 1.5. Support the Scottish Partnership for Palliative Care (SPPC) to provide a sustainable, national infrastructure that enables statutory and third sector organisations palliative care providers, staff, community groups and individuals to work together to promote understanding and awareness of living and dying with serious or life-threatening illnesses and serious health conditions; and to contribute towards empowering people to be more informed and equipped to plan ahead and support each other through serious illness, dying, death and bereavement.
- 1.6. In partnership with the third sector, widen access to community-led public education opportunities which provide knowledge, skills, resources and training, to help more people be comfortable and confident in supporting family, friends and people in their local community when someone is dying, caring or bereaved.
- 1.7. Work with Integrated Joint Boards (IJBs) and Health and Social Care Partnerships (HSCPs) to explore options for their strategic plans for palliative care to recognise, and work collaboratively with, local community groups, networks and projects that offer support for adults with serious illnesses; children and young people with serious health conditions; and their families and carers.

Outcome 2: Leaders, stakeholders and delivery partners will work together in partnership, with clear roles and responsibilities, to make sure there is reliable and effective planning, delivery, accountability and improvement of palliative care services and wider support.

Local leadership and planning

Across Scotland, Palliative Care is delivered within an integrated landscape, with joint working across the NHS, Local Authorities and third and independent sector organisations (annex D provides further information about this). Together, partners aim to deliver joined up palliative care which supports the national health and wellbeing outcomes ([National Health and Wellbeing Outcomes: A framework for improving the planning and delivery of integrated health and social care services](#)).

The aim of strategic planning is to encourage holistic planning as a way to uphold rights; tackle inequalities; and safeguard, support and promote wellbeing, so that people who receive services and support experience this as joined up at all levels. As a minimum this must include all adult social care, adult primary and community health care and a proportion of adult acute services. The process involves assessing and forecasting population need; linking investment to agreed outcomes; planning the nature, range and quality of future services; and working in partnership to put these in place.

Whole system approaches

Leadership at local levels needs to drive the development of whole system approaches with joined up services and, most importantly, clear and co-ordinated pathways of care between services. This will enable the right care in the right place at the right time, and help to ensure that the changing needs of adults, children and their families, and carers, are met, in line with what matters to them. Comprehensive and co-ordinated models will improve delivery through specialist palliative care units, hospices, community hospitals, primary care, care homes, care at home and the third sector, in partnership with families and local communities. This requires Integration Authorities to develop and plan to meet the palliative care needs of their local populations now and in the future.

Local strategies or plans should set out how people with palliative care needs will be identified and assessed; how health and care plans and future care planning will be delivered; and the range of services with pathways into and between them, in order to direct and commission services to meet identified and assessed needs. They also need to set out how specialist and general palliative care will be integrated and co-ordinated across all places of care, in collaboration with delivery partners. This needs to recognise and include the important contributions made by families, carers, volunteers and communities.

Focusing on what matters to people; where they would like to receive their care; and providing treatments of benefit and value to the person, can provide opportunities to redesign services. Service models across health and social care are moving towards better care at home or in a care home, supported by effective unscheduled health and care, and targeted day care; outpatient services; and hospital admissions that are as short as possible.

Independent hospices are also a key delivery partner, providing specialist palliative care in hospices and the community, commissioned by Health Boards and IJBs. They have shared aims to shift the balance of care closer to people's homes, including hospice at home and community outreach services, supporting people to stay in their own homes. They are system leaders, open to working as partners with Integration Authorities to innovate and reconfigure services to meet current and projected population need. Sustainable arrangements for commissioning and funding independent hospice care are essential to enable them to participate as equal partners in the redesign of services to meet future need.

Population-based plans should consider how to leverage current resources to greatest impact so that people can access the services they need more quickly. Local engagement with communities should make sure changes match needs and preferences. Involvement of local community resources should enhance local and compassionate care.

Reconfiguring services to invest in palliative care and integrating systems and budgets can deliver more effective, high-quality care for adults, children, their families and carers, including shared decision making and building a personalised approach to care in the context of innovation and improvement.

End of Life Care Together Programme in NHS Highland

A partnership of organisations, led by NHS Highland and Highland Hospice, found 75% of NHS expenditure for people in the last year of life went on unscheduled hospital care. This meant 1 in 3 emergency admission beds.

A transformation fund to change this is increasing future care planning and coordinated care in the community. There is now a 24/7 Palliative Care Helpline and access to a responsive, dedicated social care service with support from specialist palliative staff. This innovation is improving satisfaction with care while reducing hospital stays and costs.

Service planning should be underpinned by data on current and projected population needs. With increasing numbers of people requiring palliative care, as well as greater complexity as our population ages and more people have multiple health conditions, it will be necessary for partners to work jointly together to identify and analyse local and national population needs.

Services should be reshaped to meet population needs for palliative care more closely now and in the future. This includes making space to innovate and to target resources more effectively by focusing on what really matters to each adult or child and their family.

It is important to learn from HSCPs and Health Boards that have reconfigured services to achieve more collaborative working across a range of services and sectors, in consultation with users of these services.

Service redesign in NHS Fife

An enhanced and integrated approach to palliative care services in Fife means more people now benefit from coordinated palliative care delivered across health and social care and in all places of care.

Key components include a Social Care End-of-Life Care Team delivering personal care; a 24/7 District Nurse Palliative Care Helpline providing prompt support and symptom management; the Marie Curie Nursing Service providing evening and overnight community care; and a 24/7 Single Point of Access for professionals requiring Specialist Palliative Care advice and/or patient assessment.

This 7-day, Specialist Palliative Care Service has been realised through resource reallocation; reducing inpatient specialist palliative care beds to those needed for people with the most complex needs; and establishing an agile, responsive, multidisciplinary Outreach Team.

Fife's Palliative Care Collaborative, comprising health, social care and third sector stakeholders, ensures connectivity at a strategic and planning level and promotes shared learning. Daily clinical collaboration is supported by shared electronic community patient records; twice daily huddles, including District Nursing, Specialist Palliative Care, Social Care and Marie Curie; and multidisciplinary meetings with general and specialist palliative care providers in acute and community settings.

National Care Service

The proposed National Care Service Board (NCSB) is intended to oversee reformed Integration Authorities (NCS Local Boards) and, through them, the delivery of integrated community health, social work and social care services that they direct. It is intended that the NCSB will bring significantly more coherence and collective focus to strategic planning and delivery of integrated health and social care services to:

- ensure close monitoring of performance;
- drive improvement in transparency of delivery, outcomes and spend;
- improve data sharing to support these aims;
- improve collective learning; and
- support improvement where it is required.

It is intended that the NCSB will have a role to set guidance and standards for integrated health and social care and seek delivery assurance on local strategic plans; to monitor system performance; and to ensure visibility of data and information about services. It will also be able to take material action when monitoring indicates that standards are not met, to ensure services improve for people through a progressive support and improvement framework.

The ongoing development of the NCS provides important opportunities to clarify the delegation of responsibility for ensuring equity of access to general palliative care and specialist palliative care services in all places of care.

As part of the finalisation of the strategy and development of the delivery plan, Scottish Government will work with delivery partners to further develop the following proposed actions, timings and appropriate governance arrangements:

- 2.1. Develop guidance with IJBs and Health Boards to support the identification of a clinical and a managerial / executive lead, and to establish a Managed Care Network (MCN), updating previous guidance for Health Boards on MCNs.
- 2.2. Work with Health Boards to establish new requirements for inclusion of integrated specialist palliative care services within annual delivery plans and performance monitoring.
- 2.3. Work with HSCPs and adult independent hospice organisations to develop a national guidance framework to support and improve consistency of local planning and commissioning of independent hospice services.
- 2.4. Work with the Scottish Partnership for Palliative Care (SPPC) to establish a national Palliative Care Innovation Network, where people and teams involved in palliative care delivery; community-led initiatives; improvement and research; or education can come together to share learning and ideas for improvement and innovation.
- 2.5. Continue to engage with palliative care delivery partners on how the proposed NCSB and the reformed Integration Authorities will improve national and local governance, roles, responsibility, commissioning, monitoring and reporting of specialist palliative care services and general palliative care.

Outcome 3: National and local leaders will have access to relevant data to inform planning and delivery of services, and will put in place improved ways to monitor and evaluate the outcomes and experiences of children and adults receiving palliative care, as well as their families and carers.

People's experiences of palliative care

In the past, an indicator of a “good death” has been place of care, with national data collection and service outcomes focussed on this and time spent at home in the final months of life. This is based on the premise that dying at home is what most people would choose. However, while most people say they prefer to be at home or in a homely setting as much as possible, this can often change closer to dying.

Various systems and tools, including Care Opinion, patient-reported experience measures (PREMs) and patient reported outcomes (PROMS), are being used to collect information about people's experiences of palliative care services. National tools, such as the Person-centred Framework, are also in development. However, at present this type of information is not collected and analysed routinely at a national level for palliative care.

We need to understand, measure and learn from people's experiences of palliative care, care around dying and bereavement to improve the quality of outcomes for adults and children, families and carers.

Planning and delivery of services

Having accurate, up to date, readily available data will enable service planners to improve adult, paediatric and neonatal palliative care services now and in the future.

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, as well as on place and causes of death. This data is available through a data dashboard to inform local planning for adult palliative care services.

While we have some data from PHS on location of death and the numbers of children living with serious health conditions from the 2018/19 Children in Scotland Requiring Palliative Care 3 (CHiSP3) study and the strategy paediatric palliative care survey, there is currently no national data collection system for children's palliative care. Data on the needs of individual children, their families and carers, and service provision from general paediatric and specialist paediatric palliative care services, along with activity data, should be collected and reported at a national level.

Few HSCPs or Health Boards report having a dedicated resource for managing, reporting or collecting data on palliative care and care around dying¹⁴. Where HSCPs have analytical support, they can bring together and utilise data with their partners to improve care and experiences across whole systems.

HSCPs and Health Boards report a need to improve the systems for accessing population data, as well as its usefulness for Health Boards and HSCPs. Whilst they use the current

¹⁴ [Additional paper: Service Mapping Survey](#)

national data on palliative care, they need better access to local population data and local analytical support, and more clarity on what data and data sets should be collected for consistency; minimum data sets; quantitative and qualitative data; and how data is reported. This would enable them to plan better how their resources should be used.

As part of the finalisation of the strategy and development of the delivery plan, Scottish Government will work with delivery partners to further develop the following proposed actions, timings and appropriate governance arrangements:

- 3.1. Work with PHS, Health Boards, HSCPs and other key partners, including paediatric palliative care planners and service providers, across all sectors to improve the quality and range of palliative care data collected, analysed and reported. Such data can be used to inform improvement, experiences and delivery of palliative care for adults and children, families and carers. This includes:
 - updating and improving the existing adult palliative care population data reporting systems; and providing access for service planners and health and care staff.
 - developing a national approach to data collection on paediatric palliative care services for babies, children and young people (0 -18 years) and developing a new dashboard that can be accessed by paediatric palliative care service planners and health and care staff.
 - development of a Scottish minimum data set for all adult specialist palliative care services.
 - development of a Scottish minimum data set for all paediatric and neonatal specialist palliative care services and transitions.
 - working with HSCPs and Health Boards to develop a data template that supports them to collect, analyse and report high quality data on general palliative care and specialist palliative care services delivered to adults, children and young people for service planning and improvement, which includes user experiences in all places of care.
- 3.2. Explore evidence based and emerging co-design approaches to hearing and measuring people's experiences of palliative care, care around dying and bereavement support in palliative care for all places of care, and establish a consistent national approach to help improve these experiences.

Outcome 4: Adults with serious or life-threatening illnesses will be identified earlier and be able to access general palliative care and specialist palliative care services whenever and wherever needed.

Identification of palliative care needs

We want all adults living with any serious or life-threatening illnesses to stay as well as possible and to receive the right care and support when their health changes, along with their families and carers.

Many adults will be living with one or more serious illnesses that mean their health fluctuates but gets worse over time. Changes in health can be due to serious illness complications or a new life-threatening illness. This means that what might happen and when is often uncertain and unpredictable. People in this situation can often benefit from palliative care for months or years before they are dying. A majority of these will be older people.

We know that focusing on how long a person might live and difficulties in trying to identify whether they have a 'terminal illness' means people miss out on being offered palliative care and are at risk of receiving health and care which is not of benefit or value to them. Recognising who needs palliative care is a challenging, but important, role for busy health and social care staff. Screening and clinical identification is followed by a review and person-centred assessment, based on what matters to the person and their family or carers.

There are tools to help health and social care staff, teams, organisations and service planners identify more people earlier for palliative care assessment and future care planning. For instance, the [SPICT \(Supportive and Palliative Care Indicators Tool\)](#) is used widely to identify adults in the community, care homes, hospitals, and now in prisons. SPICT has clinical and care indicators for each of the main illnesses associated with palliative care need and general indicators of increasing needs. These include unplanned hospital admissions, poorly managed symptoms and more care and support needs.

Population screening tools search primary health care records to help staff and teams identify and prioritise adults with frailty for clinical review and holistic needs assessment. The [Electronic Frailty Index](#) is in general use, and there are prototype electronic tools that can screen GP practice records to identify more people for palliative care assessment and future care planning.¹⁵

When a person's physical wellbeing and functioning declines, and they need more personal care, that often prompts a review that can include identifying them as likely to benefit from palliative care. Widely used tools are the Australia Modified Karnofsky Performance Status tool¹⁶ and the Barthel Index.

Promoting consistent use of tools is important for all HSCPs and Health Boards to enable staff, people themselves, and others who know the person, to recognise changes over time.

¹⁵ [Computer screening for palliative care needs in primary care: a mixed-methods study | British Journal of General Practice \(bjgp.org\)](#)

¹⁶ [The Australia-modified Karnofsky Performance Status \(AKPS\) scale: a revised scale for contemporary palliative care clinical practice](#)

Understanding the needs of palliative care service users

Primary care teams, GPs and community nurses have a central role in palliative care, including leading improvements in early identification and providing holistic care for people and families. A Key Information Summary (KIS) electronic care record is often used for care planning and coordination.

We know that what makes the most difference is the offer of a review and assessment of holistic needs from the primary care team; a social worker; social care staff at home or in a care home; or another trusted nurse, doctor or staff member. Staff education tools, like the [Spectrum of Palliative Care poster](#), can enable more health and social care staff to offer people earlier general palliative care and/or involve a specialist service.

Some adults identified for palliative care will have multi-dimensional needs, including management or treatment of pain and other symptoms, mental health issues and family and carer support needs. Different health and social care professionals will be involved in holistic reviews and discussions with people depending on their circumstances, problems and place of care. When a person or situation is more complicated, advice or a further assessment may be needed from a palliative care specialist or another specialist or service.

Future care planning may begin with a palliative care review. A palliative care review and assessment is an opportunity for people to talk about their lives, what they hope for and any worries they may have. Treatment and care options and medicines can be reviewed to improve overall health and avoid unnecessary tests, treatments or side effects. This can also include discussion on any practical or social problems that they may need help with.

Palliative care reviews also include exploring people's values, beliefs, faith and cultural practices and preferences, alongside offering spiritual care in line with the [Scottish Spiritual Care Framework](#).

Person-centred palliative care includes the people that are important to the person - particularly carers, family members and close friends. Carers of someone meeting the criteria for a 'terminal illness' in line with BASRiS are entitled to have their own support needs considered and addressed via an accelerated adult carer support plan or young carer statement, in line with the Carers (Scotland) Act.

Health and social care professionals and teams providing palliative care will use review processes and assessment tools suited to their work situation. A key tool for assessing the holistic palliative care needs of adults is the [Integrated Patient Outcome Scale](#), and one that is widely used to guide support for carers of someone receiving palliative care is the [Carer Support Needs Assessment Tool Intervention](#).

Delivery of adult palliative care

Palliative care is delivered in the community, through care at home; in a care home; or in a community hospital by multi-disciplinary teams of primary and secondary health care and social care staff. Many different staff may be involved, including GPs; nurses; community pharmacists; social workers; allied health professionals, including physiotherapists, occupational therapists, and dieticians; care at home staff; and care home staff. Unscheduled NHS services – NHS 24, primary care out-of-hours, Scottish Ambulance

Service, and hospital emergency departments – provide essential urgent palliative care, along with emergency social work and rapid response social care services.

Palliative care in acute hospitals is important at many points in the illness journeys of people admitted with a wide range of serious illnesses and complications. Specialist inpatient and outpatient treatments continue to be important for people who are dying. Many medical, nursing, allied health professional, pharmacy, social work and spiritual care staff and teams provide palliative care as part of their other roles.

Palliative care is relevant for people with many long-term conditions, and should be better integrated with other treatments and introduced well before the final weeks of life. Specialist palliative care review can be prompted by poorly controlled symptoms despite optimal treatment of the underlying health conditions or other holistic needs.

Adult specialist palliative care

Adult specialist palliative care teams offer a wide range of services, including direct care in 14 independent hospices and 7 NHS palliative care units. They may also provide specialist outpatient clinics and day care services.

Specialist palliative care community services deliver expert care, and support primary care teams, social care staff and the many other staff caring for people and their families at home, in care homes and in other places of care, right across Scotland. A core team of specialist nurses is supported by palliative medicine consultants and other specialist medical staff, with access to other palliative care specialists and services where needed.

In hospitals, specialist palliative care services offer expert advice and patient and family assessments, for increasing numbers of people with diverse serious illnesses, or share care with hospital staff from other specialities and teams. Specialist medical and nursing staff enhance delivery of [Realistic Medicine](#), contribute to shortening hospital stays, and help support timely discharge home. For example, people with incurable cancers receiving newer treatments have improved outcomes, but life can include temporary improvements or rapid declines, with persistent symptoms. Complex decision-making and wider concerns are often best addressed by palliative care integrated with cancer care from diagnosis.¹⁷

In addition to specialist palliative medicine consultants; nurse specialists; and other specialist medical staff, specialist palliative care services may include pharmacy; social work; family support; occupational therapy; physiotherapy; lymphoedema services; psychology; hospice at home; telephone advice; spiritual care; and bereavement support. Our survey¹⁸ reported limited funding or allocated time for specialist nurses and many of these other staff. Independent hospice services and NHS specialist palliative services were working hard with other NHS and local authority services to try and address gaps.

Detailed research into patient and family needs and journeys showed that specialist palliative care being provided in the community, hospices and hospitals is complex, highly specialised and cost-effective.¹⁹

¹⁷ [Illness trajectories of incurable solid cancers | The BMJ](#)

¹⁸ [Additional paper: Service Mapping Survey](#)

¹⁹ [A casemix classification for those receiving specialist palliative care during their last year of life across England: the C-CHANGE research programme \(nih.ac.uk\)](#)

We know some adults find it harder to access general and specialist palliative care services, or avoid engaging with them because of personal circumstances, family situation, faith or cultural beliefs and practices.²⁰ This includes people with learning disabilities or mental illness, LGBTQI+ people and people from minority ethnic communities.

Emergency situations and urgent palliative care for adults

Many adults with serious or life-threatening illnesses, and their families and carers, require urgent palliative care because their health and care needs change, sometimes rapidly and unexpectedly. In 2022/23, over 59,000 people visited a hospital emergency department in the last six months of life, and 94% of all hospital admissions were for emergency care during that time.²¹

We know that people depend on timely support from unscheduled healthcare services and rapid response social care. Being identified for palliative care already; having a future care plan; and knowing how to get the right help in a crisis make a big difference to how these services are used and whether they meet people's needs. Local telephone advice lines for people and families are available in some HSCPs and Health Boards, and those who have had access to a special helpline, in addition to NHS 24, rated these highly.²²

Most adult specialist palliative care services across Scotland offer designated professional advice lines to colleagues working in hospitals, the community, care homes and to the Scottish Ambulance Service. These advice lines are staffed by senior specialist palliative care medical and/or nursing staff. This optimises provision of palliative care by specialist teams working in partnership with other teams caring for people in all places of care and with all types of serious illnesses. It is important that this specialist advice is available at all times of the day and night, including at weekends.

Rural and Island communities have adopted innovative approaches to palliative care service delivery in response to their populations and geography. Ongoing challenges are addressed through a range of integrated and joint working with palliative care specialists, who might be based in other Health Boards, and with local health and social care staff working in the community and small hospitals.

Palliative care in NHS Shetland

NHS Shetland cares for a population of 23,000. Most people live in Lerwick, with the rest dispersed throughout rural areas of the mainland and the outer isles.

The Board's unique palliative care service is provided by primary care and community clinicians, social care, care homes and a small Rural General Hospital. The nine residential care homes provide beds for a small number of people needing palliative care, with support from primary care and community staff. Within the Board's nurse led oncology team there are two palliative care clinical nurse specialists, who provide support and input for patients and families with more complex needs. There is an excellent relationship with the Palliative

²⁰ [Additional paper: Lived Experience and Public Views](#)

²¹ [Additional paper: Population Data and Research](#)

²² [Integrating lived experiences of out-of-hours health services for people with palliative and end-of-life care needs with national datasets for people dying in Scotland in 2016: A mixed methods, multi-stage design - PMC \(nih.gov\)](#)

Care Service based at Roxburghe House in NHS Grampian, which provides 24-hour specialist advice as required.

Details of people receiving palliative care are held and shared between out-of-hours primary care clinicians, with direct phone access provided via the hospital switchboard to reduce the burden and provide more support for people, their families and carers.

Though the Board's lack of specialist service may be seen as a disadvantage, working as a team, with support when required, allows general palliative care skills to be maintained and developed to a high standard to provide a bespoke service to the local population.

As part of the finalisation of the strategy and development of the delivery plan, Scottish Government will work with delivery partners to further develop the following proposed actions, timings and appropriate governance arrangements:

- 4.1. Work with Healthcare Improvement Scotland (HIS) to improve guidance and promote improvements in use of evidence-based tools to support proactive identification and review of adults with unmet palliative care needs, their families and carers, by staff and teams working across health and social care in all HSCPs and Health Boards.
- 4.2. Work with NHS National Services Scotland (NSS), HIS and digital science experts to explore further development and implementation of national health records screening tools to improve identification of adults with serious or life-threatening illnesses for earlier palliative care and future care planning.
- 4.3. Explore viable options with NHS 24 and other delivery partners to provide a 24/7 national palliative care advice line (via the 111 system) for patients, families and carers that reduces delays in access to urgent primary care and social care and connects with locally delivered palliative care telephone helplines and services.
- 4.4. Support collaborative working to promote inclusion of palliative care and care around dying in service planning and delivery for people with one or more long term health conditions.
- 4.5. Support innovative models of care and consider options for service developments and partnership working to increase equity of access to adult specialist palliative care, both in-hours and out-of-hours, in all Health Boards and HSCPs, including a specific focus on people who have more barriers to accessing the specialist palliative care they need.
- 4.6. Explore options with Health Boards and HSCPs to make sure there is consistent access at all times (24/7) to specialist clinical care from a consultant in palliative medicine, and from senior nurse specialists, whenever a person is receiving inpatient hospital or community hospital specialist palliative care, including contractual arrangements to support rural and island Health Boards.
- 4.7. Work with Health Boards, HSCPs and third sector organisations to improve access to urgent palliative care services in the community that can reduce avoidable hospital admissions and shorten inpatient stays, and provide more effective, timely admission processes for those needing hospital care. This includes improving access to

specialist palliative care advice in hospital and at home within wider national and local work on unscheduled care and early hospital discharge.

- 4.8. Work with Health Boards, HSCPs and third sector organisations to support improved provision of professional-to-professional specialist palliative care clinical advice lines, ensuring these are available 24/7 in all parts of Scotland, so that other health and care staff providing palliative care, including the Scottish Ambulance Service, can access specialist palliative care advice at all times.
- 4.9. Work with Health Boards, HSCPs, third sector organisations, and other delivery partners and community groups, to improve palliative care, care around dying and bereavement support for people from minority communities and other groups who face barriers to accessing palliative care or who need flexible approaches tailored to their health conditions, situation, personal circumstances, values and preferences.

Outcome 5: Adults living with serious or life-threatening illnesses and children with serious health conditions will be offered person-centred future care planning involving their families and carers, and care plans will be recorded and shared using national digital systems

Future care planning

Future care planning is about supporting adults and children, their families and carers to think and plan ahead for changes in their life, health and care. It can be relevant for anyone whose health or care needs might change due to their health conditions or disabilities, but is particularly helpful for adults with serious or life-threatening illnesses or children with a serious health condition. It is an integral part of palliative care that focuses on each adult or child and what matters for them now and in the future. Future care planning includes, and involves, the people important to the adult or child, such as family, carers, parents and support workers.

Scotland's Future Care Planning Programme aims to improve person-centred care coordination and urgent care across the health and care system in all Health Boards. This is an iterative programme of national work based on consultations and engagement with many stakeholders, including members of the public; service users; health and social care staff; national and third sector organisations for adults and children; and policy makers.

Future care planning differs from anticipatory or advance care planning in important ways. Whilst these were mainly healthcare plans that invited people to express choices and wishes about future loss of capacity, care when dying and cardiopulmonary resuscitation, future care planning accepts and manages the inherent uncertainties of the illness journeys experienced by each adult, child or young person.

Future care planning discussions around what matters to an adult or child in their life, health and care open up wider conversations that include making personalised plans for treatment and care options to guide future decisions. This is particularly important when an adult or child might need urgent help from unscheduled healthcare services or emergency social care, and matters well before they are dying.

Future care planning continues through transitions from children's services into adult health and care. It can include other aspects of life relevant to palliative care, like managing finances; making a will; plans for a pet or property; or digital legacy planning.

It is important for future care planning to be tailored to the individual and to take account of human rights; legal position; and the roles of proxy decision makers, if the person is a child or an adult with impairments that affect their capacity to make health and care decisions now or in the future. These legal proxies include parents and carers with parental responsibility, guardians, and people named in a welfare Power of Attorney.

Digital recording and sharing of care plans are key, whether adults and children are at home; in hospital; in a palliative care unit or hospice; in a care home; or in another place of care.

Future care planning in the community

Future care planning in the community may start when an adult or child is well or stable, but could need urgent support or help in the future, and the plans can change with them over time. Future care planning covers a range of different health and care plans, but our initial focus is on integrated, urgent health and care plans, and draws on existing projects from across Scotland. Many different health and social care staff can contribute to conversations about future care planning if they are supported and trained, reducing workload for GPs. Community groups, third sector organisations and volunteers can offer support and advice too.

A person-centred care plan summarises what matters to the adult or child and anything staff providing urgent or emergency care need to know about them, alongside important clinical advice and social care information provided by experienced staff who usually care for them. Existing care plans inform treatment and care if the adult or child is admitted to hospital, where the focus of care planning shifts to a detailed clinical treatment plan tailored to that admission. Continuity of care on discharge home or to a care home can be improved by updating or starting a community care plan.

Future care plans recorded digitally, using national digital platform technology and different user applications (including a person-held version), can be linked to other health and care records in the community, care homes, hospices and hospitals to enable the person's plans to be recorded, updated and shared with relevant health and social care staff.

Since 2016, the NHS Scotland Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) integrated adult policy²³ and Children/Young People Acute Deterioration Management (CYPADM) guidance have provided a clear, national framework for decision making, communication and recording on standard paper forms. Health and care records are increasingly digital, so the Future Care Planning Group²⁴ will be considering how best to record and share cardiopulmonary resuscitation plans and other emergency treatment measures for adults, children and young people transitioning to adult services via digital systems.

As part of the finalisation of the strategy and development of the delivery plan, Scottish Government will work with delivery partners to further develop the following proposed actions, timings and appropriate governance arrangements:

- 5.1. Support a national partnership programme for future care planning, overseen by the National Future Care Planning Working Group, that is person-centred, inclusive and takes a 'Once for Scotland' and 'digital' approach to development and delivery for children, young people and adults whose life, health or care may change, and which is suitable for all places of care.
- 5.2. Continue to work with NHS Education for Scotland (NES) Digital, and other national organisations and partners, to develop and implement a national electronic urgent and emergency care plan for health and social care, accessible to staff working in the community, NHS unscheduled care services and hospitals in all Health Boards,

²³ [Cardiopulmonary resuscitation decisions - integrated adult policy: guidance - gov.scot \(www.gov.scot\)](https://www.gov.scot/publications/2016-07-27/documents/2016-07-27-dnacpr-integrated-adult-policy-guidance/2016-07-27-dnacpr-integrated-adult-policy-guidance.pdf)

²⁴ [Health: National Future Care Planning Working Group - gov.scot \(www.gov.scot\)](https://www.gov.scot/publications/2016-07-27/documents/2016-07-27-dnacpr-integrated-adult-policy-guidance/2016-07-27-dnacpr-integrated-adult-policy-guidance.pdf)

starting with health care staff and extending to social care staff, care homes and independent hospices.

- 5.3. Continue to work with NES Digital, other national organisations and partners to develop and implement a national electronic hospital urgent care plan to improve treatment and care during a single hospital admission, that connects digitally with community urgent and emergency care plans.
- 5.4. Continue to work with NES, and other national organisations and partners, to develop and deliver national education and implementation resources on future care planning for use across Scotland.
- 5.5. Promote future care planning across all sectors and involve a wide range of stakeholders, including members of the public; adults; young people; families; parents and carers; minority groups; patient support groups; and third sector organisations, in the development and delivery of accessible and inclusive resources and information about future care planning.

Outcome 6: Quality and experiences of care around dying and bereavement support are improved for adults, their families and carers, in all places of care.

What happens when a person dies, and the care and support given, has a big impact on long term experiences of grief. It is important not to over-medicalise dying and to support families and carers through anticipatory grief, and with bereavement after someone has died.

Friends, neighbours, personal networks and local communities have a key role in supporting the person and their family and carers. It is essential that health and social care staff recognise this and work alongside them, and that planners also recognise the wider support available to people and factor this into whole system planning.²⁵

We have used the term ‘care around dying’ to describe all aspects of holistic care for a person who is dying and in the last hours, days and weeks of their life; care after their death; and support with loss and grief for families and carers throughout this time and when they are bereaved. We have not used the older term ‘end of life’ or ‘end of life care,’ as this can be confusing when it refers to variable and uncertain periods of time, given the unpredictable life expectancies and experiences of adults or children who have serious illnesses or health conditions.

Caring for people who are dying involves health and social care staff, teams and services in all places of care. The person who is dying may need to move between different places of care, and it is essential that whole-system approaches provide good co-ordination and communication to enable this to happen as quickly and safely as possible, and in the best interests of the person and their family and carers.

We know that the main priorities for someone who is dying are being comfortable and free from pain and other symptoms; with people important to them; maintaining dignity and self-respect; and being safe and well cared for.²⁶ These are all more important than being at home. While most people say that they would prefer to die at home because this is where they feel most comfortable, people often change their mind due to worsening physical or mental health problems, increasing care needs, or home circumstances. Even when there is a previous plan or wish to be at home, some situations may mean the best option is admission to a hospital, hospice or specialist palliative care unit, or a care home.

The burdens of caring or not having a carer are important too. Carers talked about the demands and challenges of caring, but some gave examples of being resilient and feeling fulfilled in their role. Dignity and respect for a person’s views, wishes, beliefs, faith or religious practices and their culture are all part of person-centred care around dying.

How those close to the person who is dying experience events around the time of death has a big impact on their grief. People who are bereaved need to be well supported before and around the time of dying and feel confident that the person who died was comfortable and received good and compassionate care. Good care of a person who is dying begins with a process of recognising that death is approaching, while acknowledging that there is still uncertainty, and everyone is different.

²⁵ [Lancet Commission on the Value of Death \(thelancet.com\)](https://www.thelancet.com)

²⁶ [Additional paper: Lived Experience and Public Views](#)

The language someone uses when talking with people who are dying, and their families and carers, makes a big difference. It is important to explain in clear and simple terms what is happening with the person's health and to say why they are likely to die soon. It is also important to discuss what often happens when someone is dying and what those around them can do to help care for them. People with different types of illness need care that is tailored to their needs, and decisions about care need to be shared and to include plans for stopping tests, treatments and medicines that will not work or help the person.

Dying at home

Improving the quality of care and offering enough support at home for people who are dying remains a priority and involves a network of people around the person, starting with their families, carers and friends, and extending into local communities. These people provide vital support, alongside social care staff, primary care teams, community pharmacists, allied health professionals, and social workers, supported by palliative care specialists as needed. NHS 24, the Scottish Ambulance Service, primary care out-of-hours, and emergency social work and social care staff all provide essential urgent palliative care by telephone or through direct care.

Knowing who to contact and having a palliative care helpline number helps families and carers feel more confident and secure when someone is dying at home. A key professional to coordinate care also makes a big difference, and this has often been the district nurse.

Scottish Ambulance Service (SAS) Macmillan Palliative Care Programme

This mandatory training programme for all ambulance clinicians equips them to de-escalate crisis situations at home by providing person-centred communication, urgent palliative care assessment and symptom management.

It links to the NES Framework *Enriching and Improving Experience* (NES 2018) and includes self-directed learning and bespoke training in palliative care and clinical communication. New guidance and medicines management systems allows SAS crews to carry and give injectable medicines for urgent symptom management. More people stay at home and experience high quality urgent palliative care, while reducing avoidable and costly transfers to hospital.

Planning for care around dying is an important aspect of well-coordinated care at home. This includes making sure there is a care plan that is regularly reviewed and shared within teams and across services.

Providing care equipment at the right time can be challenging, and people may be reluctant to accept it in advance. Reliable processes to assess changing personal care needs and deliver equipment quickly are essential for care around dying at home. Primary Care Teams and community pharmacists work together to provide support and a supply of 'just in case' medicines for pain and symptom management, or these may be given when someone goes home from hospital. Patients and families with experiences of these medicines spoke of needing clearer information and explanations about what they mean and how they are to be used.

Hospice at home

There is a growing number of rapid response palliative care outreach services available for people who are dying at home. Hospice at home is one such model of care, where staff with palliative care training can visit several times a day and/or stay in the home overnight to provide additional, short-term personal and nursing support to supplement other health and social care. These services are not available in all Health Boards and HSCPs, and often rely on third sector organisations sharing the costs and service management.

Marie Curie Hospice Care at Home

These services operate in many parts of Scotland through partnership arrangements with HSCPs. Expert Marie Curie staff work with district nurses, primary care and local palliative care services to provide planned and urgent support for people at home, tailored to their individual needs and preferences, with a focus on care around dying.

Jim* was referred to Marie Curie Hospice Care by his district nurse to support him to stay at home with Mary*, his wife. Jim's condition was changing quickly, and over the next 10 days he became unable to get out of bed and needed regular medicines for symptom management. It was clear he would die soon. Arrangements were made for Marie Curie Hospice Care staff to be with him in the house overnight that weekend and for several more nights. The Marie Curie staff provided care, comfort, encouragement and advice for the family, and contacted the local specialist palliative care team for additional advice when needed to manage Jim's symptoms overnight.

Mary said afterwards that she would not have coped without the Hospice Care service. Having their support allowed her to be Jim's wife in the last few days of his life and keep him at home, as they both wished. This helped Mary to cope with Jim's death at the time and helps her still. Hospice Care at Home is about all members of the different teams working as one and being around the dying person and their family, day and night.

*Not their real names

Dying in a care home

Care home residents are increasingly frail; many have dementia; and most will be cared for in their care home when they are dying, as highlighted in our [My Health, My Care, My Home](#) – *Healthcare Framework for Adults Living in Care Homes*. Experienced care home staff provide personalised palliative care for residents, with support from a wider multi-disciplinary community team and access to palliative care advice from primary care out-of-hours teams.

It is important for a resident who is dying to be given any palliative care medicines they may need without delay. This requires planning ahead, having the right medicines available, training and support for care home staff and information for residents and families.

Dying in hospital

Hospitals will continue to be a place where people die and there is a need to ensure that there is quality of care around dying, and for this to be monitored as a key service outcome

in every hospital. Improved palliative care in the community, future care planning and timely urgent palliative care can reduce the need for hospital attendances, but people admitted for treatment of serious or life-threatening illnesses may die during that admission or be in a specialist unit when their health deteriorates, and it becomes clear they are dying.

While ward staff and teams provide most of the care to people who are dying, hospital palliative care teams should be available to offer specialist palliative care assessments and advice.

Dying in a hospice or specialist palliative care unit

Referral to a hospice or specialist palliative care unit for care around dying may become necessary when the complexities of the person's pain and symptoms, mental health problems, family situation or personal or home circumstances need the full expertise of a specialist, multi-disciplinary team. Independent hospices and NHS specialist palliative care units are centres of excellence in supporting care around death, as well as many other aspects of specialist palliative care across the health and care system.

Care after someone has died and bereavement support

Bereavement care is the support people need when dealing with grief before and after someone has died. This includes emotional, psychological, practical and financial support. Everyone who experiences a bereavement will have some level of need, which will vary from one person to another, such as the need for acknowledgement and compassion.

Public education about grief helps everyone to understand and support each other better through this time. Some people will need additional support beyond their own networks, and it is important to provide information and signposting for this. Some people will also need additional support, such as counselling, or more intensive or specialist therapeutic support. This is described as a [Pyramid Model of Grief and Bereavement Support](#) by Bereavement Network Europe.

Bereavement care encompasses the support that people of all ages need from their families, friends, places of work or education and communities, as well as from health and social care staff and specialist support and services.

Bereavement will affect everyone at some stage in their life. It has been estimated that around 328,000 people in Scotland are bereaved each year. Bereavement disproportionately affects older people, but children experience care and bereavement more than we might expect. Most children have experienced a bereavement by the age of 8.

People who care for a friend or family member may experience anticipatory grief, which can have effects on their quality of life; their ability to care; and have a long-term impact on mental health. Good bereavement support can have a protective effect on long-term impacts for children, as well as mental health and wellbeing for all, and impacts on work and the economy. This should therefore be offered proactively, as part of palliative care. There are specialist bereavement support services for children and young people, including those delivered by Children's Hospices Across Scotland (CHAS), adult hospices and NHS paediatric palliative care services.

In 2022 the UK Bereavement Commission reported that:

*“Facing a bereavement can be one of the most profound upheavals any one of us experiences. The evidence submitted to the Commission indicated that the impacts of grief are both intense and wide ranging, touching all areas of life. The emotional impacts of grief vary and are changeable over time, often lasting for many months or years in different forms. While most people are able to continue with their existing responsibilities after some time, for some people intense emotional pain does not go away. Grief has physiological impacts, practical impacts on work, school and home life and also people’s longer term economic wellbeing.”*²⁷

Bereavement services are offered through skilled staff working in the NHS, hospices, the care sector, third sector organisations and faith communities. However, it is important that signposting and co-ordination make sure there is equitable access and capacity. Health Boards and HSCPs have a key role to provide information on local support.

It is also important that workplaces and education settings support staff, children and students through times of bereavement. Resources to support this include the [Bereavement Charter for Children and Adults in Scotland](#) and [Good Life, Good Death, Good Grief](#).

Staff involved in palliative care, who are not part of a formal bereavement support or spiritual care service, will be supporting people as part of their everyday role. This includes respecting personal, family, cultural or faith practices. NES’ [Support Around Death](#) provides education and resources for staff across health and social care who need skills and support in dealing with care around dying as a key part of their work.

Staff may, themselves, also need additional support when regularly providing care around dying, as well as when care has been particularly challenging for an individual or the whole team, or when staff experience personal losses or bereavements.

In addition to bereavement support from staff providing palliative care and wider networks of support, everyone who is bereaved should receive information about what to do when someone has died in Scotland through a leaflet called: *When someone has died – information for you*. This includes legal, practical and financial information and wider bereavement support.

People who are bereaved may also need practical financial support, such as the Social Security Scotland Funeral Support Payment, which people on a low income can apply for to contribute towards funeral costs. Awareness periods, such as National Grief Awareness week and Baby Loss Awareness week, are a key opportunity for Social Security Scotland to highlight both the Funeral Support Payment and alternative bereavement support that may be available to clients, through social media, newsletters and website activity.

Work is continuing to ensure that Scottish Government webpages in relation to Funeral Poverty and the Funeral Support Payment signpost clients to other forms of bereavement support available.

²⁷ [UK Bereavement commission report](#)

As part of the finalisation of the strategy and development of the delivery plan, Scottish Government will work with delivery partners to further develop the following proposed actions, timings and appropriate governance arrangements:

- 6.1. Oversee an update to the national guidance on *Care around Death*, and work with Health Boards and HSCPs to make sure it is implemented as best practice in all places of care in Scotland.
- 6.2. Work with Health Boards, HSCPs, primary care teams and pharmacy services to promote timely provision and use of 'just in case medicines' for adults dying at home and residents in care homes, and improve staff education and public information.
- 6.3. Work with HSCPs and Health Boards to promote and develop effective models of urgent palliative care, able to provide rapid access to coordinated health and social care support for adults dying at home, their families and carers.
- 6.4. Work with SAS and NES to ensure palliative care continues to be part of core training and professional development for ambulance clinicians.
- 6.5. Oversee an update to the public information leaflet "*When someone has died – information for you*" with NES and other partners, and promote its use, along with additional local information through Health Board Bereavement Leads, HSCPs and other organisations, including NHS Inform.
- 6.6. Continue to champion, co-ordinate and work in partnership with key stakeholders to ensure compassionate advice, resources and support are available for people experiencing bereavement, following the death of an adult with serious or life-threatening illnesses, or with a child who has a serious health condition, and explore improvements to bereavement care.
- 6.7. Work with NES and other partners to develop a new education and training resource on bereavement care for staff across health and social care, that includes staff support and spiritual care as part of the [Support Around Death](#) resources.

Outcome 7: Babies, children and young people living with serious health conditions, and their families and carers, will experience improved support as their distinctive needs are recognised and addressed by paediatric palliative care, including care around dying, or as they transition into adult services.

It is essential that any child or young person – no matter where they live or their diagnosis – has timely access to high quality palliative care and care around dying, and that their family and carers are also supported.

Parents and carers with parental responsibility say how important it is for them to fulfil their parental role. They need support to do this amongst their caring responsibilities, and to make the most of precious time with their child, creating memories and having space and privacy to be a family. They need to be fully informed, share responsibility for decisions, and advocate for their child's best interests. Palliative care needs to include direct care and emotional support for the parents and wider family, including siblings.

Paediatric palliative care

Paediatric palliative care is provided mainly by specialists from other paediatric specialties, as well as general and community paediatrics. Children with palliative care needs often have unpredictable health, with significant roles for paediatric and neonatal intensive care specialists. While all these clinicians have experience and skills in the delivery of palliative care, it is rarely recognised in their role or job plan. In addition to medical and nursing services, paediatric palliative care draws on a wide range of support from allied health professionals, social work, family support, spiritual care, psychology, play therapy, advocacy, benefits advice, pharmacy and bereavement services.

Specialist paediatric palliative care

Hospital specialist paediatric palliative care is delivered by expert multidisciplinary teams, with a lead consultant in paediatric palliative medicine. There are two hospital-based specialist services in NHS Greater Glasgow and Clyde and NHS Lothian. The teams have expertise in symptom management, future care planning and complex decision-making, as well as coordination and delivery of care around dying across paediatric services.

The specialist staff work alongside other teams involved in a child's care to provide an extra layer of support to both families and professionals where symptoms are hard to manage or where care is highly complex. Specialist paediatric palliative care teams work across hospital and community settings, and in collaboration with other services, including Children's Hospices Across Scotland (CHAS), to support families in their preferred place of care.

Perinatal palliative care

Perinatal palliative care is the delivery of palliative care during pregnancy, birth and neonatal care for babies with serious health or life-threatening conditions. Recognition of the need for palliative care may be from before birth; soon after birth; or further into the postnatal period.

Perinatal palliative care should be delivered by a wide multi-disciplinary team, which may include medical staff, midwives, nurses, allied health professionals and social workers, usually alongside neonatal intensive care teams. This may include additional support from perinatal professionals (nurses and doctors) with a special interest and training in perinatal palliative care. The expertise of specialist paediatric palliative care teams may be required to support some families.

Hospice care

In Scotland, there is one children's hospice provider – CHAS – with two hospices. CHAS provides specialist multi-disciplinary care for children and young people, families, parents and other carers with parental responsibility.

CHAS supports babies, children and young people from pre-birth to 21 years, working in partnership with Health Boards and Local Authorities to provide care and support for the whole family in their own homes, in hospital or in a hospice.

The focus of CHAS' work is to support families through the three critical stages of their child's palliative care journey – learning their child is seriously ill and may die young; living well; and dying well and bereavement.²⁸ CHAS supports the whole family to live well with uncertainty and complexity, and offers holistic care, including activities sessions; sibling support; and advocacy (financial, legal and wellbeing). As a child's health deteriorates, or during periods of crisis (or to prevent crisis), hospices can support care at home through hospice at home services.

Hospice care can be short, planned breaks during periods of stability; crisis/hospital step-down care after a long hospital admission; specialist care when a child's health is more unstable or deteriorating; and care around dying, including a *rainbow room*, which is a cold room where a child who has died can stay until the time of their funeral.

There is ongoing collaboration between CHAS and Health Boards to support the funding and delivery of paediatric palliative care across all settings. CHAS contributes to funding for paediatric palliative care teams in NHS Ayrshire and Arran, NHS Grampian, NHS Greater Glasgow and Clyde and NHS Lothian. This partnership working – together with collaboration with social care and education – supports families to access holistic paediatric palliative care, with the aim of supporting seamless care delivery across all places of care.

Care at home

When a child's condition is unstable, deteriorating, or they are dying, and the family would like care at home, staff and teams strive to support this choice. Care at home can be challenging to provide or sustain, and often relies on bespoke, multi-agency collaboration (hospital, community teams and hospice) and additional input from staff on a 'good will' basis. Children may have symptom management plans and 'just in case' medication boxes, like those for adults.

²⁸ [Children's Hospices Across Scotland Strategic Plan 2024-28](#)

24/7 models of paediatric palliative care

There are a range of service models within and across Health Boards in Scotland for paediatric palliative care, but our paediatric survey found inequities in provision, especially outside standard working hours. This can be improved through a national 24/7 on-call specialist paediatric palliative medical and nursing model.

CHAS and Health Boards are working together to develop a national specialist clinical advisory service with 24/7 access, and a specialist multi-disciplinary team, initially through utilising the current paediatric palliative care medical workforce across CHAS and the NHS. However, further resources will be required to ensure expansion to include specialist nursing advice and support. A national, specialist team can offer an additional level of support and expert advice to colleagues across Scotland.

Identifying children and young people for palliative care

There is a need to consider the use and further development of tools to help staff to identify babies, children and young people with palliative care needs in hospitals and at home. Examples include the Paediatric Palliative Screening Scale (PaPaS Scale)²⁹ and the British Maternal and Fetal Medicine Framework³⁰.

Transition from paediatric to adult services

The move from paediatric palliative care services into adult services can be a distressing time for many young people, as the people and services that they have relied on for care and support for years change or fall away. Those involved in the care of a child or young person as they transition from one service to another need to work together, alongside the young person and their family, to ensure that transition is as smooth and seamless as possible. Adult hospices have a role in the transition and support of individual young people who are living with serious health conditions, and it is recognised that this is a growing area of need to be addressed by wider adult services, including adult specialist palliative care services, which requires relevant processes, training and support.

Children's hospitals and CHAS provide timely transition support to wider adult services, including health and social care (from multi-disciplinary teams); legal (e.g. Power of Attorney, guardianship, advocacy); financial (benefits, self-directed support); and social support (friendships, leisure, further education and access). The age of transition will vary according to individual needs. CHAS work with young people up to the age of 21.

Prince and Princess of Wales Hospice Transition Programme

This adult hospice works collaboratively with CHAS to transition and support young adults from the age of 16, and has developed a transition pathway. There is a specific young adult service, which provides symptom management, future care planning and care around dying, as well as social and education opportunities, carer support, and short break stays.

²⁹ [Paediatric palliative screening scale as a useful tool for clinicians' assessment of palliative care needs of paediatric patients: a retrospective cohort study | BMC Palliative Care | Full Text \(biomedcentral.com\)](#)

³⁰ [BAPM framework on Family Integrated Care | British Maternal & Fetal Medicine Society - BMFMS](#)

Bereavement support

While principles and good practice recommendations for bereavement care and support are relevant when a baby or child dies, loss and grief may have multiple overlapping phases at different times, from diagnosis through survival, to living as well as possible, then dying, death and memory making. Grief reactions affect many individuals and groups, including the child, parents, carers, other children in the family, friends from school and social networks.

The Scottish Government funds a National Hub to review and learn from the deaths of children and young people up to the age of 18, and to improve the support offered to bereaved families and carers. Produced in collaboration with third sector colleagues, its first survey of families and carers in [When a child dies: Learning from the experiences of bereaved families and carers](#) demonstrated that bereavement support, and how it is accessed, varies across Scotland.

In relation to bereavement support for siblings and other family members, a small number of families commented on the support provided by staff in schools; and families and bereaved brothers or sisters had also benefited from support provided by charities and hospices, including telephone support, interactions with play specialists, group support, one-to-one support, and helpful literature. The value of third sector organisations and independent hospices was clearly felt.

Clinical ethics

Health and social care staff providing palliative care to children and young people can face increasingly complex decisions around the care of babies and children within the principles of family-centred care, [Realistic Medicine](#) and inclusion of parental views. This can lead to complex ethical dilemmas. Support for staff in this position may be available through registered chaplains and peer networks.

As part of the finalisation of the strategy and development of the delivery plan, Scottish Government will work with delivery partners to further develop the following proposed actions, timings and appropriate governance arrangements:

- 7.1. Work with key partners to develop a national approach to service planning for all paediatric palliative care, through a multi-agency steering group, to ensure children and families across Scotland have access to the services they need, wherever and whenever these are required, and to ensure that these services are equitable.
- 7.2. Work with CHAS and Health Boards to review current models and develop a national specialist paediatric palliative care service, available at all times (24/7) to meet the needs of children, families and staff across Scotland in all places of care.
- 7.3. Support and develop improved transitions for young people with serious health conditions based on Getting It Right For Everyone (GIRFE) practice model, and the co-designed GIRFE 'team around the person' toolkit for young people in transition from GIRFEC (Getting it Right for Every Child) to GIRFE.

- 7.4. Draw on best practice models to develop and agree paediatric palliative care standards to ensure children and families across Scotland have equitable access to high quality general and specialist paediatric palliative care services wherever and whenever these are required.
- 7.5. Explore options for a national approach to providing ethical clinical review of decision making in paediatric palliative care.

Outcome 8: Employers, professional bodies and education providers will make sure that staff who deliver palliative care are trained, skilled and supported.

It is essential that our workforce is built, trained and sustained so that the multi-agency staff working in primary, community and secondary care and in third sector organisations can deliver palliative care and specialist palliative care for adults and children, including care around dying, and that education, training and up-to-date resources are made available, with protected staff time and full accessibility.

The NES/ Scottish Social Services Council (SSSC) [Palliative Care Education Framework](#) provides a clear and robust structure for education and training, and should continue to form the basis of palliative care education for all health and social care staff in Scotland caring for adults or children.

The [Scottish Palliative Care Guidelines](#) provide practical, evidence based information to support safe and consistent pain and symptom management and clinical decision making by staff providing palliative care throughout Scotland. These are open access and widely used in training and education. It is essential that this clinical guidance continues to be updated in line with emerging evidence and best practice, and that it is widely available as a 'once for Scotland' resource for health and care staff.

There is a wide range of education and training programmes, including online learning; care home collaboratives; undergraduate and postgraduate training; adult specialist palliative care services education and training; and leadership programmes. Palliative care education is also provided within nursing, allied health care professional and medical university and further education college programmes in Scotland.

Project ECHO (Extension for Community Healthcare Outcomes) already provides education from palliative care specialists and other experts for many groups of staff providing adult or paediatric palliative care at local, regional and national levels.³¹ It has a proven role in offering staff support, and facilitates reflective practice and workplace learning. Staff providing general and specialist palliative care in the community and hospitals benefit from national online networks for education, training and development.

Education programmes

There is a need to enable palliative care education to be delivered consistently across Scotland within pre-registration programmes for foundation doctors, nurses and other health and social care professionals, and in further education college programmes. Palliative care education should be included wherever relevant in the curriculum of undergraduate university programmes for doctors, nurses, pharmacists, allied health professionals and other health and social care professionals.

The learning content of NVQs and SVQs is based on the National Occupational Standards in the relevant area. These standards define the skills, knowledge and understanding needed to do a particular job. These qualifications provide training that offers learners an opportunity to develop skills and knowledge on palliative care and care around dying, and an understanding of loss, grief and bereavement.

³¹ [Project ECHO | Highland Hospice](#)

Workforce training in palliative care

Palliative care and care around dying are vital aspects of care provided by health and social care professionals to adults with serious or life-threatening illnesses. Health and social care staff need to have ongoing education and training on the provision of fundamental care for people with palliative care needs relevant to their work roles. This training is key to building the necessary basic knowledge, skills and confidence for health and social care professionals as a baseline for developing interpersonal skills and behaviours related to palliative care. This education is an important underpinning in developing the workforce, and can start with induction training.

There is a need to ensure that palliative care learning resources are well-coordinated and easily accessible, and that staff are aware of the availability of these resources. There is also a need for consistency of approach in the way learning and resources are disseminated and shared across sectors for workforce development.

To ensure a consistent approach in the provision of, and access to, learning and resources across all HSCPs, it is important to consider how they can contribute to the sustainable delivery of consistent and local palliative care training and education across their areas. Similarly, Health Boards need to consider appropriate education and training for hospital staff.

Paediatric palliative care training

Clear training pathways for paediatric palliative care across Scotland are important to enable health and social care staff to have the basic skills and knowledge to deliver palliative care across different settings, relevant to their role. Education resources are currently delivered by a number of key stakeholders, including the Paediatric End of Life Care Network (PELiCaN); the Managed Service Network for Children and Young People with cancer; NES; CHAS; and specialist paediatric palliative care teams.

Paediatric palliative care training should be part of the undergraduate and paediatric pre-registration nursing training curriculum, where relevant, and within the curriculum of postgraduate qualifications in child health. Paediatric staff, as well as medical, nursing (including advanced practice) and specialist practitioners, should have access to a range of relevant opportunities for training and education within paediatric palliative care services.

As part of the finalisation of the strategy and development of the delivery plan, Scottish Government will work with delivery partners to further develop the following proposed actions, timings and appropriate governance arrangements:

- 8.1. Work with HIS to ensure there is sustainable management, updating and extension of the Scottish Palliative Care Guidelines as recommended best practice for symptom management across Scotland on the Right Decision Service; and explore options to develop and include Scottish paediatric palliative care guidelines.
- 8.2. Work with NES to develop a designated online learning space, readily available to all health and social care staff who deliver palliative care to adults, children and young people, that provides a single point of access to relevant training and education resources on palliative care, care around dying and bereavement support.

- 8.3. Work with NES, statutory and third sector organisations, and education providers to support and enable local and national education and training for health and care staff to equip them to have sensitive and effective person-centred conversations with adults or children, families and carers, that are central to future care planning, palliative care, and care around dying, including NES [Having Realistic Conversations](#) resources.
- 8.4. Work with NES and third sector palliative care education providers to promote and develop online learning opportunities and networks for health and social care staff across Scotland, such as Project ECHO.
- 8.5. Work with universities and further education colleges that provide pre-registration courses and undergraduate education programmes to enable all health and social care staff (including doctors, nurses, pharmacists, allied health care professionals and social workers) to receive a level of adult or paediatric palliative care education appropriate to their roles.
- 8.6. Encourage HSCPs and Health Boards to employ palliative care practice educators to support the sustainable delivery of palliative care education and training in line with the NES/SSSC Palliative Care Education Framework, and work collaboratively with adult and paediatric palliative care specialists offering education and training.

Annex A: Terms Used in This Strategy

Allied Health Professionals (AHP)	These healthcare staff include physiotherapists, occupational therapists, dietitians, speech and language therapists, radiographers, paramedics, podiatrists, art therapists, drama therapists and music therapists.
Care around dying	Care around dying means whole person care for an adult or child who is dying, and in the last hours, days or weeks of their life; care after their death; and support with loss and grief for families and carers throughout this time and when they are bereaved.
Compassionate communities	Compassionate communities is a broad term that includes people's own networks of family, friends, neighbours, work colleagues and people they meet in daily life, plus support from communities we live in and are part of. Compassionate communities invest in and promote individual action, group strategies or societal structures or policies that prevent or reduce suffering resulting from experiences of serious illness, death, dying and loss; promoting health and wellbeing, community support and empowerment of community members affected by such experiences; and acknowledge these experiences as natural parts of daily life.
Family and carers	By family and carers, we mean anyone who is close or important to an adult or child, including variable social networks of family, friends and neighbours who are central to the life and care of the adult or child.
Future care planning	Future care planning is about supporting adults and children, their families and carers, to think and plan ahead for changes in their life, health and care.
General palliative care	Palliative care for adults or children that is provided by many different health and social care staff as part of their usual care for people with palliative care needs, and by staff and teams who are specialists in other fields.
Health and Social Care Partnership (HSCP)	HSCPs are organisations formed to integrate services provided by Health Boards and Local Authorities/ Councils in Scotland. Each partnership is jointly run by the NHS and local authority. HSCPs are directed by their area IJBs (see below).

Independent Hospice	Independent hospices are key delivery partners and centres of excellence for specialist palliative care and wider holistic care and support delivered by staff and volunteers within the hospice building, at home or in a care home and, in some cases, specialist services in local hospitals and other places of care. Some units named “Hospice” are not run by specialist palliative care services, but may be staffed in different ways. For example, through primary care, elderly medicine or other services.
Integration Authority	Integration Authorities represent partnerships between Local Authorities and Health Boards for delivering health and social care services and integration of budgets.
Integration Joint Board (IJB)	IJBs are a type of Integration Authority (see above) and are responsible for the planning and commissioning of health and social care services for their areas.
Serious health condition (children)	The term serious health condition is used as a broad term for a wide range of illnesses and health conditions that mean a baby, child or young person can benefit from palliative care and is likely to live for a shorter time, but how long an individual child lives can be very variable.
Life-threatening illness	When an adult or child has a life-threatening illness, we mean they will not recover and may die, although could improve for a short time.
Multi-disciplinary Teams	Multi-disciplinary teams are groups of staff made up of different professional groups in health and social care who work together to provide care and support for adults or children, as well as their families and carers.
Palliative care for adults	Palliative care is holistic care that prevents and relieves suffering through the early identification, assessment and management of pain and other problems – whether physical, mental health, social or spiritual.
Palliative care for children and young people	Palliative care for children and young people is an active and total approach to care, from the point of diagnosis or recognition throughout the child’s life. It includes physical, emotional, social and spiritual elements, and focuses on enhanced quality of life for the child or young person and support for their family.
Serious illness (adults)	A serious illness is an illness which causes an adult’s health to fluctuate over months or years, but to get worse over time. Some people have more than one serious illness.

Specialist Palliative Care Unit	An NHS inpatient unit or beds where adults are cared for by specialists in palliative care. Specialist palliative care units may provide a range of services and be similar to an independent hospice.
Specialist Palliative Care Service (adult or children)	A service which has a single operational management structure that provides a range of specialist services delivered by staff who are experts in palliative care and have advanced training and experience in palliative care.

Annex B: Planning and Delivery of Palliative Care

The way in which health and social care services are planned and delivered across Scotland was changed by the [Public Bodies \(Joint Working\) \(Scotland\) Act 2014](#). This Act provided for the integration of health and social care, with delegation of some of the functions of Health Boards and Local Authorities to Integration Authorities. With the exception of Highland where the Health Board remains responsible as a lead agency for all adult services, all other areas formed 31 Integration Joint Boards (IJBs) which have functions delegated to them from Health Boards and Local Authorities.

How is palliative care for adults planned and delivered?

IJBs are responsible for planning and resourcing adult palliative care in hospitals and their communities. IJBs need to work in partnership with a wide range of independent and third sector organisations within their own area, or through arrangements with other relevant bodies in other areas. Independent hospices are important system leaders working with IJBs.

Health and Social Care Partnerships (HSCPs) are responsible for delivering local health and social care services, as directed by their IJB. All have a common purpose – to deliver better health and wellbeing outcomes for the people of Scotland. This means that across Scotland, palliative care is delivered within an integrated landscape, with joint working across the NHS, Local Authorities and the third and independent sectors.

Most palliative care for adults is provided by a wide range of health and social care staff as part of their usual care for people with palliative care needs, and by staff and teams who are specialists or experts in other fields, whether at home; in care homes; in hospital; or in other places of care. This is referred to as ‘general’ palliative care.

Adult specialist palliative care services are delivered by staff with expertise and specialist training when a person and their family need specialised treatment and support, including for pain and other symptoms, family distress, or complex treatment and care planning.

Adult specialist palliative care services are delivered in all places of care by multi-disciplinary teams of staff and through multi-agency partnerships.

Specialist community palliative care services are available in all HSCPs and there is hospital specialist palliative care provision in each Health Board. This includes some joint arrangements between HSCPs to access services from other HSCPs. Collectively, these arrangements provide access to specialist palliative care across Scotland.

There are 14 independent hospices for adults, serving 7 Health Board areas, and 7 NHS specialist palliative care units, serving 8 Health Board areas.

Specialist palliative care services have a key role in supporting other health and social care staff and teams who are providing general palliative care in the community and hospitals through offering specialist advice, education and training.

How is palliative care for children and young people planned and delivered?

Palliative care for children and young people is an active and total approach to care, from the point of diagnosis or recognition of palliative care needs, throughout the child's life. It embraces physical, emotional, social and spiritual elements, and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks, care around dying and bereavement support.³²

Paediatric palliative care is provided across all places of care (hospital, home and hospice), and is delivered within paediatric services across Scotland by NHS services and one independent hospice provider (Childrens Hospices Across Scotland - CHAS). Children who live with serious health conditions are supported, first and foremost, by their parents, wider families, friends, neighbours, local communities, volunteers and support groups.

Paediatric palliative care services are the responsibility of Health Boards, unless delegated by local arrangement to IJBs. The planning and delivery of palliative care for children and young people also involves multiple sectors and services, including CHAS and other third sector organisations, working in partnership with Health Boards, Local Authorities and IJBs.

IJBs are a statutory partner within Children's Services Planning arrangements, and have a key role in supporting integration across local strategic activity. This includes ensuring the local Children's Services Plan reflects related services (adult services and/or community-based supports) as well as children's services, where these are relevant to i) support provided to a parent or carer which has an impact on child wellbeing ii) provision of holistic whole family support and iii) supporting streamlined transitions for young people as they move between children's and adult services.

³² [TfSL-A-Guide-to-Children's-Palliative-Care-Fourth-Edition-5.pdf \(togetherforshortlives.org.uk\)](https://www.togetherforshortlives.org.uk/TfSL-A-Guide-to-Children's-Palliative-Care-Fourth-Edition-5.pdf)



© Crown copyright 2024



This publication is licensed under the terms of the Open Government Licence v3.0 except where otherwise stated. To view this licence, visit nationalarchives.gov.uk/doc/open-government-licence/version/3 or write to the Information Policy Team, The National Archives, Kew, London TW9 4DU, or email: psi@nationalarchives.gsi.gov.uk.

Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

This publication is available at www.gov.scot

Any enquiries regarding this publication should be sent to us at

The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

ISBN: 978-1-83601-538-3 (web only)

Published by The Scottish Government, October 2024

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS1477498 (10/24)

W W W . g o v . s c o t