



Palliative and End of Life Care

A framework to support the learning
and development needs of the health
and social service workforce in Scotland

*Enriching &
improving experience*



Acknowledgements

Acknowledgements

NHS Education for Scotland and the Scottish Social Services Council acknowledge the contribution made by individuals, groups and organisations from the public, independent and third sectors who engaged with us on this collaborative journey. Their commitment to enhancing the provision and experience of palliative and end of life care for the people of Scotland and strengthening workforce learning and development activity has been instrumental in developing the framework.

We thank those who shared their views and experiences, imparted their knowledge and expertise of palliative and end of life care, learning and development, and integration to help shape the direction, structure and content of the framework.

We also gratefully acknowledge the work of the Education Advisory Group (Appendix 1) for their insight, guidance and support.

The framework

It's all about experience.
Everyone's experience.

The experience of people
requiring palliative and
end of life care and support.

The experience of people
providing palliative and
end of life care and support.

Contents

Contents

Introduction

Appendix 2. Principles of the framework

Introduction

Purpose of the framework

Introduction

Purpose of the framework

All of us at some point will have friends, colleagues and family members who have a progressive and/or advanced condition that is life-limiting or life-shortening. Babies, children, young people and adults with such conditions require palliative and end of life care and support, as do the families and carers who look after them. Importantly, palliative care includes, but is not limited to, end of life care.¹ The challenge we face is enabling people* to live and die well, on their own terms. Care and support focus on improving quality of life and providing timely and effective responses to physical, psychological, social and spiritual concerns,² working with families, communities and carers as equal partners in care.

In the Strategic Framework for Action on Palliative and End of Life Care,² the Scottish Government made 10 commitments towards a national vision that by 2021, everyone in Scotland who needs palliative care and end of life care will have access to it. These commitments are part of wider public service reform, as set out in the Health and Social Care Delivery Plan** which emphasises the importance of ensuring meaningful conversations and puts personal outcomes at the heart of service delivery.

To support the health and social service workforce, NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) were commissioned to develop a new framework that would offer a way of identifying the knowledge and skills required by all workers who might come into contact with people who have palliative and end of life care needs. This document describes the key domains that are integral to palliative and end of life care in all health and social care settings, and outlines the associated knowledge and skills required.

Scotland has a compassionate and committed health and social service workforce, and this palliative and end of life care framework seeks to build on the considerable capacity and expertise that already exists.

*For ease of reading, throughout this framework the words 'people' and 'person' refer to all age groups (babies, children, young people, adults and older adults).

**Scottish Government (2016) Health and Social Care Delivery Plan. Edinburgh: Scottish Government. Available at: <http://www.gov.scot/Publications/2016/12/4275>

Introduction

Development of the framework

Introduction

Development of the framework

We consulted widely with health and social service workers, experts in palliative and end of life care, educators and other partners to promote an integrated and collaborative approach to workforce learning and development. These partners helped us develop, review and refine the framework.

The initial structure and content of the framework developed from evidence gathered through:

- a scoping exercise of existing palliative and end of life care education and development provision
- a rapid review of literature and mapping of existing palliative and end of life care competency and capability frameworks
- focus groups with health and social service workforce representatives
- a NES/SSSC survey of the palliative and end of life care learning needs of the health and social service workforce.

The revised framework was reviewed through an online consultation, with the resultant feedback informing refinement of the final content.

Introduction

Using the framework

Introduction

Using the framework

The framework promotes a consistent, inclusive and flexible approach to learning and development on palliative and end of life care for the health and social service workforce. It is aspirational and values workers' previous learning, and existing knowledge and skills. It acknowledges the place of informal and formal learning in supporting the workforce to develop knowledge and skills, and recognises sector- and discipline-specific standards and frameworks, such as National Occupational Standards³ and the NHS Knowledge and Skills Framework.⁴ The framework's flexibility enables it to be used in different ways to support learning and development at individual, service-provider and organisational levels.

Health and social service workers can use the framework to:

- help them understand the principles, knowledge and skills necessary to fulfil their roles and responsibilities in delivering high-quality palliative and end of life care centred on what matters to people, their families and carers (the framework can be used alongside generic and/or professional frameworks relevant to individual workers)
- independently determine existing knowledge and skills in relation to palliative and end of life care, identify gaps and highlight potential areas for future development
- recognise strengths and identify learning needs in relation to their roles in conjunction with their managers/supervisors, and together take action to address areas for development.

(continued)

Introduction

Using the framework

Introduction

Using the framework

Service providers and organisations can use the framework to:

- ensure workers have the necessary knowledge and skills to support people with palliative and end of life care needs, their families and carers
- map existing learning and development provision, support workforce plans and shape future educational opportunities and learning and development activities to support the health and social service workforce in relation to palliative and end of life care
- consider ways of learning that maximise existing resources and facilitate opportunities for health and social service workers to learn together to promote collaborative and integrated working
- enhance and strengthen sustainable relationships with education and training providers in creating and delivering palliative and end of life care learning and development.

Education and training providers can use the framework to:

- review existing provision, inform the content of education and learning opportunities, and shape the design and delivery of vocational and professional undergraduate and postgraduate education and learning opportunities (the framework takes account of recognised credit and qualifications frameworks)
- maximise opportunities for health and social service workers to learn together to promote collaborative and integrated working
- enhance and strengthen sustainable relationships with health and social services providers and organisations in creating and delivering palliative and end of life care learning and development activity.

Introduction

Principles of the framework

Introduction

Principles of the framework

The framework is underpinned by three sets of principles that promote a person-centred, outcomes-focused, human rights-based approach to palliative and end of life care. The principles are at the heart of integration of health and social care and wider public service reform and are intended to guide health and social service workers to deliver high-quality palliative and end of life care centred on what matters to people, their families and carers. The principles, shown in full in Appendix 2, are as follows.

- **World Health Organization definitions of palliative care⁵**
these universally acknowledged definitions outline the principles and approaches that guide palliative care for children and adults. Palliative care is internationally recognised as a basic human right, promoting person-centred care and support that attends to the specific needs and preferences of people and their families.
- **The PANEL principles (Participation, Accountability, Non-discrimination and Equality, Empowerment and Legality)**
the PANEL principles underpin a human rights-based approach that empowers people to know and claim their rights. Scotland's national action plan for human rights⁶ sets out a programme of co-ordinated activity that envisions everyone living with human dignity, using the PANEL principles to put human rights into practice.
- **The National Care Standards principles⁷**
these are integral to the standards that outline what everyone in Scotland can expect when using health and social care services, and how providers of care should deliver and improve services. They are based on a human rights approach underpinned by the PANEL principles.

Introduction

Structure of the framework

Introduction

These five domains reflect the core knowledge and skills considered integral to the delivery of high-quality palliative and end of life care.

Domain 1

Fundamentals of palliative care



This domain includes the underpinning principles and philosophy of a palliative care approach, and incorporates elements essential to developing and improving palliative and end of life care service provision.

Domain 2

Communication and conversations



Effective communication and conversations are integral to the provision of palliative and end of life care and support. Workers need to be able to have effective conversations with people who may be experiencing distress and uncertainty, provide support and share decision-making. Good communication is also essential to enable effective teamwork in and across teams.

Domain 3

Loss, grief and bereavement



Dealing with loss, grief and bereavement is integral to palliative and end of life care provision for people, their families and carers, and the workforce providing care and support. This domain acknowledges the potential impact of living and working with loss and recognises the importance of appropriate support for self and others.

Domain 4

Care planning and delivery



This domain outlines the importance of working in partnership with the person, their family and carers to promote participation, choice and control, and address their personal outcomes and holistic needs. It involves taking a proactive approach to care by anticipating, assessing and responding in a timely way to incorporate people's needs, personal outcomes and choices, and take account of changing needs, deterioration and uncertainty.

Domain 5

Care in the last days of life



This domain focuses on care in the last days and hours of life, when the team caring for the person agree that death is expected within hours or days and a natural death is occurring, all possible reversible causes having been considered.

(continued)

Structure of the framework

Introduction

Structure of the framework

Introduction

Knowledge and skills

Each domain presents four levels of knowledge and skills that outline what workers need to know and do, depending on their degree of involvement in palliative and end of life care, and their role responsibilities in caring for and supporting people with palliative and end of life care needs, their families and carers. Some of the knowledge and skills are integral to all health and social care, but are applied in this framework in the context of palliative and end of life care.

The levels of knowledge and skills required by workers may differ across the five domains depending on their degree of involvement and role responsibilities. Knowledge and skills at each level are incremental, in that the depth and breadth of knowledge required and the complexity of related skills associated with the domains increase at each level. A worker at enhanced level within a domain will therefore have the knowledge and skills defined at the preceding levels.

This enables the framework to be used flexibly, supporting workers to develop their knowledge and skills at different levels.

The framework does not specify particular roles in relation to the knowledge and skills levels, and the levels are not defined by profession or seniority in an organisation or sector. Individual workers and their employers are best placed to interpret and apply the content and aspirations of the framework to their roles.

Informed level

Informed level outlines the knowledge and skills required by all health and social service workers in relation to palliative and end of life care.

Skilled level

Skilled level outlines the knowledge and skills required by health and social service workers who by virtue of their role and level of responsibility regularly provide care and support to people with palliative and end of life care needs, their families and carers.

Enhanced level

Enhanced level outlines the knowledge and skills required by health and social service workers who by virtue of their role and level of responsibility provide, co-ordinate and manage the care and support of people with palliative and end of life care needs, their families and carers.

Expert level

Expert level outlines the knowledge and skills required by health and social service workers who by virtue of their role and level of responsibility play an expert specialist role in the care and support of people with palliative and end of life care needs, their families and carers.

Structure of the framework



Palliative and End of Life care

A framework to support the learning and development needs of the health and social service workforce in Scotland

*Enriching &
improving experience*

*Search
the framework*

Searching the framework

Domains are colour coded and represented by an icon. Within each domain there are four levels of knowledge and skills.

Scroll over the hexagons opposite and click to access the knowledge and skills levels in each domain.

To return to search again, simply click on the icon at the top left of the screen.

Domain 1

Fundamentals of palliative care



Informed

KNOWLEDGE

Know the meaning and principles of palliative and end of life care, that it is appropriate for all life-limiting conditions across the life-course, and is applicable in all care settings.

Know the meaning of person-centred and family-focused care and support in the context of palliative and end of life care.

Know the range of services, agencies and sources of support and information that may be involved in providing palliative and end of life care.

Know that professional, legal and ethical frameworks exist to protect and promote people's rights and safety.

Know the importance of respecting diversity, culture and beliefs in the context of palliative and end of life care.

Know about attitudes to death, dying and bereavement in society.

SKILLS

Recognise your role as part of a team in palliative and end of life care.

Recognise that palliative and end of life care and support should be centred on what matters to people, their families and carers, including babies, children and young people.

Be receptive to people and signpost them to sources of support and information.

Work within your organisational policies and procedures to protect and promote people's rights and safety in the context of palliative and end of life care.

Treat people with dignity and respect and recognise issues related to diversity, culture and inequality in palliative and end of life care.

Reflect on your attitudes towards death, dying and bereavement and be willing to engage in discussions around these issues.

Domain 1

Informed

Domain 1

Fundamentals of palliative care



Skilled

KNOWLEDGE

Understand the importance of identifying people with palliative and end of life care needs within your care setting.

Knowledge and understanding of the key concepts of a palliative care approach that embraces the interdependence of physical, psychological, social and spiritual needs of the person, family and carers.

Knowledge of the range of services and support available to people, their families and carers, and the contribution each makes to palliative and end of life care and support.

Knowledge of how and when transitions in care and support may arise between and across services, sectors and settings.

Knowledge and understanding of multidisciplinary team-working in palliative and end of life care.

SKILLS

Use appropriate validated tools to identify people with palliative and end of life care needs.

Engage, support and enable people, their family and carers, whatever their individual circumstances, to feel valued and to live and die well.

Adopt a holistic approach to the provision of palliative and end of life care and support.

Work collaboratively with a range of services and agencies in caring for and supporting the person, family and carers.

Listen to and respect the range of perspectives within the care and support team.

Use effective verbal and written communication and documentation.

Recognise what information to share within the multidisciplinary team (while respecting confidentiality) and when it should be shared.

(continued)

Domain 1

Skilled

Domain 1

Fundamentals of palliative care



Skilled

KNOWLEDGE

Knowledge of professional, legal and ethical approaches to protecting and promoting people's rights and safety, such as professional codes of practice, capacity and consent, and ethical principles.

Knowledge and understanding of diversity, cultural beliefs and preferences within the context of providing palliative and end of life care.

Knowledge of approaches to learning and development of self and others.

SKILLS

Take appropriate action (according to organisational policies and procedures) when people's rights or safety may be compromised

Provide care and support that respects individual diversity, cultural practices, beliefs and rituals.

Reflect on your values and beliefs and how this may influence your behaviour, actions and words.

Facilitate and contribute to the learning and development of others to improve care for people, their families and carers.

Reflect on your learning and development needs in palliative and end of life care.

Domain 1

Skilled

Domain 1

Fundamentals of palliative care



Enhanced

KNOWLEDGE

Comprehensive knowledge of inequalities in palliative and end of life care.

In-depth knowledge of working with families and the stages of human development in the context of palliative and end of life care.

In-depth knowledge of the professional, legal and ethical approaches that exist to protect and promote people's rights and safety in the context of palliative and end of life care.

In-depth knowledge of the process and impact of transitions in care and support across services, settings and sectors.

SKILLS

Proactively engage and adapt your practice for people who are less likely to access care and support, and ensure the integration of person-centred approaches.

Engage with the family as a unit to provide care and support for all family members living with the implications of life-limiting illness, giving due regard to the developmental stages of children and young people.

Collaborate with others in the use of professional, legal and ethical frameworks that guide shared decision-making in the context of palliative and end of life care.

Balance autonomous and collaborative practice and decision-making.

Advocate on behalf of people to ensure their needs are identified and measures are taken to address them.

Lead, with others, to ensure that systems and processes enable seamless transitions in care and support.

(continued)

Domain 1

Enhanced

Domain 1

Fundamentals of palliative care



Enhanced

KNOWLEDGE

In-depth knowledge and understanding of team-working and team-development theory.

Comprehensive knowledge and understanding of cultural practices and beliefs in relation to palliative and end of life care.

In-depth knowledge of approaches to mentoring, learning and development.

Comprehensive knowledge and understanding of palliative and end of life care policies, service development and provision.

SKILLS

Co-ordinate and support collaborative and integrated team-working across care settings and services to facilitate palliative and end of life care.

Value the contribution of team members and support effective multidisciplinary relationships.

Take a lead in communication and appropriate information-sharing across teams and services to improve outcomes in palliative and end of life care.

Provide guidance and support in the provision of care that respects individual diversity, cultural practices, beliefs and rituals.

Support others to recognise, reflect on and evaluate their attitudes and behaviours towards death and dying, and how these can impact on the care and support they provide.

Influence, advise and support others to improve care.

Contribute to audit and research in developing and delivering local palliative and end of life care policies and services.

Domain 1

Enhanced

Domain 1

Fundamentals of palliative care



Expert

KNOWLEDGE

Expert knowledge and understanding of legislation, policies, service development and improvement that impact on palliative and end of life care across the health and social services sector.

SKILLS

Lead in the development and delivery of palliative and end of life care to ensure that local policies, systems and processes give people choice and control over their care and support.

Actively engage with service users, carers and stakeholders to plan and commission services, and drive and sustain improvement.

Design, deliver and evaluate services that provide palliative and end of life care, taking account of cultural diversity.

Work collaboratively to reduce inequalities, eliminate discrimination and advance equality when developing, planning and delivering palliative and end of life care.

Articulate and negotiate palliative and end of life care issues at strategic level, recognising competing needs and priorities.

Expert knowledge and understanding of the principles, approaches and practices that promote a person-centred and personal-outcomes approach to palliative and end of life care.

Provide expert advice in implementing evidence-based, person-centred palliative and end of life care to drive continuous improvement.

Lead with others to identify not only the outcomes that matter to people, but also the issues that enable and hinder them in making progress to achieve the outcomes.

(continued)

Domain 1

Expert

Domain 1

Fundamentals of palliative care



Expert

KNOWLEDGE

Comprehensive knowledge of methodology and ethical issues in audit and research involving people with palliative and end of life care needs.

Expert knowledge in supporting learning and development in palliative and end of life care.

Expert knowledge of professional, legal and ethical issues relevant to people with palliative and end of life care needs.

SKILLS

Lead, facilitate and engage with audit, research and practice development in palliative and end of life care.

Identify and respond actively to the learning needs of the workforce, sharing palliative and end of life care knowledge and supporting the provision of evidence-based practice.

Support individuals, teams, services and agencies to enable them to provide palliative and end of life care.

Act as a source of expertise on professional, legal and ethical issues relevant to people with palliative and end of life care needs.

Share expertise in complex situations and dilemmas in palliative and end of life care.

Domain 1

Expert

Domain 2

Communication & conversations



Informed

KNOWLEDGE

Know about effective person-centred communication skills and barriers to communication.

SKILLS

Use effective communication skills to engage with people in an open, honest and sensitive manner.

Modify your approach for people with speech, language and communication needs, for example by using augmentative and alternative communication supports.

Engage with people in a way that respects their wishes, confidentiality, choices, unique strengths and abilities.

Reflect on and recognise your communication skills and limitations and appropriately seek support and feedback.

Know about verbal and non-verbal behaviours that can support someone who is distressed.

Be attentive and recognise, acknowledge and respond to distress to help people feel they have been heard.

Domain 2

Informed

Domain 2

Communication & conversations



Skilled

KNOWLEDGE

Knowledge of effective communication and why this is integral to the delivery of palliative and end of life care.

SKILLS

Engage sensitively and enable conversations to elicit people's understanding of their situation, feelings and expectations.

Support the person, family and carers to identify the information and support they need to live and die well.

Create and sustain trusting relationships that enable people to feel safe and comfortable, and work within the context of distress.

Use verbal and non-verbal skills that show compassion and empathy, and 'be with' people to support them to express their thoughts and feelings.

Reflect on your communication skills and proactively seek feedback to support your learning and development.

Understand barriers to good communication and how challenges can be overcome.

Interact with people, their families and carers in an open and empathic manner, recognising the importance of giving time and using communication aids when there are difficulties with receptive or expressive communication.

(continued)

Domain 2

Skilled

Domain 2

Communication & conversations



Skilled

KNOWLEDGE

Understand cultural and language influences on communication.

Knowledge of approaches to decision-making.

Understand the roles of advocacy and proxy decision-makers in palliative and end of life care.

Understand the issues of uncertainty in life-limiting illness.

Knowledge of helpful strategies to use when sharing information that may cause people distress.

SKILLS

Take account of, and take appropriate measures to address, cultural and language influences in sharing information.

Work with the person, family and carers to maximise their ability to participate in decisions and make choices regarding their care and support.

Acknowledge and communicate uncertainty.

Share sensitive information in a way that supports emotional wellbeing.

Domain 2

Skilled

Domain 2

Communication & conversations



Enhanced

KNOWLEDGE

In-depth knowledge and understanding of communication models and skills.

Working knowledge of shared decision-making approaches.

Comprehensive knowledge of appropriate approaches and techniques for communicating when age, developmental stage or capacity may have implications in a palliative and end of life care context.

Comprehensive knowledge of the support available to address sensory and/or cognitive impairment, cultural and language barriers.

In-depth knowledge of the diversity of communication challenges encountered in palliative and end of life care, including uncertainty, strong emotions, denial, tension and conflict.

SKILLS

Modify your communication approach to address the diversity of communication challenges encountered in palliative and end of life care.

Develop empowering and facilitative relationships with people, their families and carers to support and involve them in decision-making.

Provide information in a sensitive, timely and clear way, having established the information needs and preferences of the person, family and carers.

Share and communicate important information when required in an honest and clear manner.

Assess a person's response to information shared, check understanding and respond appropriately.

Use effective and sensitive communication skills that help people manage the reality and challenges of living with uncertainty.

Proactively role-model effective communication and respond to communication challenges sensitively.

Domain 2

Enhanced

Domain 2

Communication & conversations



Expert

KNOWLEDGE

Expert knowledge of the theories of communication.

SKILLS

Facilitate the learning and development of communication skills within health and social care practice in the context of palliative and end of life care.

Proactively role-model communication skills to support and facilitate learning and development.

Proactively provide and receive feedback to support learning and development within and across teams.

Domain 2

Expert

Domain 3

Loss, grief & bereavement



Informed

KNOWLEDGE

Know that grief is a normal response to loss, and understand the range of thoughts, feelings and behaviours that may be experienced by those living with loss and grief.

Know that people may experience a range of losses in a palliative and end of life care context.

Know about the process of reflection.

Know about the importance of care of self.

SKILLS

Interact sensitively and empathetically with a person who is experiencing loss.

Recognise the personal impact of loss, grief and bereavement and engage with support strategies to build resilience.

Engage in reflection.

Engage in activities to care for yourself, and recognise when additional support is required.

Domain 3

Informed

Domain 3

Loss, grief & bereavement



Skilled

KNOWLEDGE

Knowledge and understanding of theories of loss and grief.

Knowledge and understanding of the significance of stages of human development and capacity, and the impact this may have on responses to loss, grief and bereavement.

Knowledge and understanding of concepts in care of self.

Knowledge of reflective practice.

SKILLS

Recognise anticipatory grief and the impact it may have on people.

Recognise factors that may increase vulnerability and the risk of encountering difficulties in grief, and remain aware of people's strengths and assets.

Respond to the needs of people experiencing loss and assist them to access appropriate support.

Recognise the impact on self of living and working with loss, death and bereavement.

Recognise your strengths, limitations and vulnerabilities when working with loss, death and bereavement.

Engage with reflective practice, support and supervision.

Support other members of the team in dealing with loss, death and bereavement.

Domain 3

Skilled

Domain 3

Loss, grief & bereavement



Enhanced

KNOWLEDGE

In-depth knowledge and understanding of theories and models related to loss, grief and bereavement.

In-depth knowledge of grief reactions, including complicated grief, and use of risk assessment tools.

In-depth knowledge of the support families, children, young people and adults at risk may require when the person is dying.

In-depth knowledge of bereavement support and referral routes to support services.

In-depth knowledge of reflective practice and models of supervision.

SKILLS

Use effective and sensitive communication skills to support and empower those experiencing loss, grief and bereavement.

Assess and manage risk, provide support according to individual circumstances and refer appropriately.

Appreciate the impact of a loss that may not be socially recognised or openly acknowledged and ways in which to address this grief.

Work in partnership with children, young people and adults at risk, and with their parents, guardians and other family members, to prepare and support them for the person's death.

Act as a resource and provide support to others experiencing loss, grief and bereavement.

Recognise the potential impact of a person's death on those who have been living with and caring for them.

Support and facilitate reflective practice, debriefing, support and supervision for individuals and teams.

Domain 3

Enhanced

Domain 3

Loss, grief & bereavement



Expert

KNOWLEDGE

Expert knowledge and application of loss, grief and bereavement policy and research.

Expert knowledge of therapeutic counselling approaches.

Expert knowledge and understanding of policy, service development and provision relating to loss, grief and bereavement.

Expert knowledge of reflective practice and supervision models.

SKILLS

With others, lead and co-ordinate bereavement services and support.

Provide therapeutic support using accredited counselling approaches (when appropriate to role).

Lead in the development and delivery of loss and bereavement care, policies, service development and provision.

Articulate and negotiate loss and bereavement care issues at strategic level, recognising competing needs and priorities.

Provide expert advice in implementing evidence-based person-centred loss and bereavement care to drive continuous improvement.

Demonstrate leadership and collaboration to engage with people and communities to build knowledge and resilience around loss and bereavement.

Provide formal supervision to individuals and/or teams offering loss and bereavement support.

Domain 3

Expert

Domain 4

Care planning & delivery



Informed

KNOWLEDGE

Know the importance of ensuring that the person, family and carers have choice and control in care assessment and planning.

Know about personal outcomes in the context of palliative and end of life care.

Know that carers have a right to their own care and support plan.

Know about the concept of anticipatory care-planning.

SKILLS

Respect people's beliefs, personal outcomes and choices about their care and support.

Recognise that people with palliative and end of life care needs, their families and carers have strengths and assets that can support their wellbeing.

Recognise when it may be appropriate to engage with anticipatory care-planning.

Be able to signpost people to sources of support in relation to anticipatory care-planning.

Domain 4

Informed

Domain 4

Care planning & delivery



Skilled

KNOWLEDGE

Knowledge and understanding of common life-limiting conditions and how they may affect the person.

Knowledge and understanding of the physical, psychological, social and spiritual domains in relation to palliative and end of life care.

Knowledge and understanding of approaches to personal outcomes in the context of palliative and end of life care.

Knowledge of appropriate validated care-planning assessment approaches and tools.

Understand the requirements of formal assessment of capacity under the terms of legislation (Adults with Incapacity (Scotland) Act 2000⁸).

SKILLS

Recognise how a person's physical, psychological, social and spiritual wellbeing can be affected by living with life-limiting illness.

Identify commonly occurring concerns and symptoms that people living with life-limiting conditions may experience.

Anticipate and respond to the holistic needs of people with palliative and end of life care needs in a proactive and timely way.

Engage with the person, family and carers to identify and review the outcomes that matter to them, and put them at the centre of their care and support.

Participate in assessment of physical, psychological, social and spiritual wellbeing, using recognised assessment approaches to care- and support-planning.

Recognise changes and fluctuations in capacity and the impact on consent, choice and decision-making.

(continued)

Domain 4

Skilled

Domain 4

Care planning & delivery



Skilled

KNOWLEDGE

Knowledge of factors that increase risk and the principles of child and adult protection.

*Knowledge of the Carers (Scotland) Act 2016.⁹
Knowledge of carer support resources and organisations.*

SKILLS

Contribute to the protection of children and adults who may be at risk, and contribute to individual plans that protect and promote wellbeing.

*Recognise the expertise, role and value of carers as equal partners in care.
Work collaboratively with people and their carers to enhance health and wellbeing.
Contribute to carer support plans, or young carer statements, recognising that carers' needs and outcomes may differ from those of the cared-for person.
Support, encourage and enable carers in their caring role.*

(continued)

Domain 4

Skilled

Domain 4

Care planning & delivery



Skilled

KNOWLEDGE

Knowledge of the process and value of anticipatory care-planning.

Knowledge of the organisational approach to, and processes for, anticipatory care-planning, including documentation and information-sharing.

Knowledge of the legal status and implications of anticipatory care-planning.

Knowledge and understanding of the duties and powers of the Social Care (Self-Directed Support) (Scotland) Act 2013¹⁰, its underpinning values and principles of choice and control.

Knowledge of current evidence and guidelines that support assessment, symptom management, care-planning and provision.

SKILLS

Engage sensitively to facilitate the development of collaborative anticipatory care plans at an appropriate time and pace for the person, family and carers.

Respond effectively to people who indicate they wish to discuss their future care, and provide support, information and referral to others appropriately.

Acknowledge choice, respecting that some people may not wish to participate in anticipatory care-planning discussions, and refer to others appropriately.

Use anticipatory care plans to support decision-making.

Work with people, their families and carers as equal partners, empowering people to have choice and control over their care and supporting arrangements to achieve the outcomes that matter to them.

Use current evidence in the assessment, planning and delivery of care and support.

Develop an individualised care plan that reflects personal outcomes and is responsive to changing needs.

(continued)

Domain 4

Skilled

Domain 4

Care planning & delivery



Skilled

KNOWLEDGE

Knowledge of non-complex evidence-based interventions to support wellbeing and comfort, including physical, psychological, social and spiritual interventions and support.

SKILLS

Support people with physical care needs, maintaining privacy and dignity.

Participate in the management of symptoms experienced by people with palliative and end of life care needs.

Support people to maintain their important roles and relationships.

Support people to maintain their mental and emotional wellbeing.

Support people to participate in meaningful and pleasurable activity that enhances wellbeing.

Provide support to enable people to participate in the spiritual and cultural aspects of their lives.

Knowledge of approaches to adaptation, reablement, rehabilitation and self-management.

Knowledge of assistive technologies and equipment.

Support people to use their strengths and assets to support adaptation and self-management approaches.

Support and enable people to maintain their independence and manage risk.

(continued)

Domain 4

Skilled

Domain 4

Care planning & delivery



Skilled

KNOWLEDGE

Knowledge of the importance of regular review and observation for changes in condition, signs and symptoms.

SKILLS

Participate in the ongoing delivery, regular review and evaluation of planned care and support, reflecting people's choices and the outcomes that matter to them.

Identify palliative and end of life care issues that require urgent review or emergency response.

Recognise and respond in a timely and effective way to changes in people's wellbeing or circumstances and escalate appropriately.

Knowledge of evaluation of care and support plans.

Participate in evaluation of the effectiveness of interventions on outcomes for the person, family and carers.

Domain 4

Skilled

Domain 4

Care planning & delivery



Enhanced

KNOWLEDGE

In-depth knowledge of the presentation, course and current management of advanced life-limiting illness, within the scope of practice.

Comprehensive knowledge of evidence-based assessment approaches and tools that can be used in assessing palliative and end of life care needs.

In-depth knowledge and understanding of personal-outcomes approaches.

Comprehensive knowledge of intrinsic and extrinsic factors that increase vulnerability and risk and affect palliative and end of life care and support needs.

SKILLS

Incorporate knowledge of conditions and current clinical information into care-planning and decision-making.

Undertake a comprehensive holistic assessment of palliative care and end of life care needs.

Lead and collaborate with others to hold people, their families and carers at the centre of decisions about palliative and end of life care and support.

Elicit, acknowledge and empathise with concerns raised and incorporate the person's views, choices and preferences.

Proactively identify distress and suffering, exploring contributing physical, psychological, social and spiritual factors.

Distinguish between issues that can be addressed by routine measures from those that require more expert intervention.

Assess vulnerability and risk, and incorporate appropriate support to manage risk.

(continued)

Domain 4

Enhanced

Domain 4

Care planning & delivery



Enhanced

KNOWLEDGE

Comprehensive knowledge of legal and procedural requirements of systems in place to protect adults and children at risk of harm.

Comprehensive knowledge of relevant current legislation on capacity, informed consent and confidentiality.

Comprehensive knowledge of carers legislation and requirements for carer support-planning, including end of life plans.

In-depth knowledge of the carer's role and the potential impact of caring on health and wellbeing.

SKILLS

Respond appropriately where safeguarding issues have been identified.

Apply the principles and key provisions of legislation, and support people to understand the implications.

Lead, with others, to co-ordinate the carer support plan or young carer's statement to ensure the needs and outcomes of carer and cared-for person are met.

Take a proactive approach to support and empower carers, recognising the impact of caring in the context of advanced life-limiting illness.

Assess the impact of caring on the health and wellbeing of carers and seek appropriate support for them.

(continued)

Domain 4

Enhanced

Domain 4

Care planning & delivery



Enhanced

KNOWLEDGE

In-depth knowledge of relevant current legislation and organisational policies and guidance that can support people with anticipatory care-planning.

In-depth knowledge of how to apply the principles, duties and powers of self-directed support in practice to ensure that people are equal partners in their care and support decisions.

Comprehensive knowledge of approaches to co-ordinating and managing care and support.

SKILLS

Sensitively engage with people and provide support and information to facilitate anticipatory care-planning.

Engage sensitively and collaboratively to support people, their families and carers to identify their priorities for the future and develop an anticipatory care plan.

Lead, with others, and take responsibility for documenting, appropriately sharing and regularly reviewing anticipatory care plans.

Lead and co-ordinate work with people, their families and carers as equal partners, empowering people to have choice and control over their care and support arrangements to achieve the outcomes that matter to them.

Engage collaboratively and take a lead role in planning, co-ordinating and managing complex care plans to address individual needs, choices and priorities.

Act as a key worker, co-ordinating multi-agency care and support plans across care settings.

(continued)

Domain 4

Enhanced

Domain 4

Care planning & delivery



Enhanced

KNOWLEDGE

In-depth knowledge of evidence-based approaches and interventions for physical, psychological, spiritual and social distress or concerns.

Comprehensive knowledge of main world faith communities, cultures, beliefs and practices relating to illness, death and dying.

Comprehensive knowledge of potentially reversible causes of deterioration and anticipatory approaches to their management.

Comprehensive knowledge of proactive management plans, including prescribing anticipatory medicines.

SKILLS

Draw on, and individually adapt and tailor, a range of approaches to address the complexity of holistic need.

Provide evidence-based interventions and support to address needs.

Take a proactive approach to identify distress or concerns early and signpost to support or refer appropriately.

Integrate the person's spiritual and religious needs into the plan of care, respecting people, families and carers.

Provide opportunities in a respectful and supportive way for people to express spiritual dimensions of their lives.

Implement care and management plans for potentially reversible causes in the event of deterioration in a person's condition.

Adapt care plans and care delivery in response to changes in the person's mental or physical capacity or circumstances.

(continued)

Domain 4

Enhanced

Domain 4

Care planning & delivery



Enhanced

KNOWLEDGE

Detailed local knowledge of resources, services, networks and referral pathways to meet identified needs.

Comprehensive knowledge of health behaviour change and self-management approaches in relation to palliative and end of life care.

In-depth knowledge of evaluation tools and outcome measures that can be used in palliative and end of life care settings, and with populations.

SKILLS

Recognise own limitations and consult and involve others to make appropriate and timely referrals to support complex needs.

Assess motivation and implement tailored self-management and rehabilitation approaches to maintain independence and enhance quality of life.

Implement interventions and evaluate outcomes of care and support plans.

Domain 4

Enhanced

Domain 4

Care planning & delivery



Expert

KNOWLEDGE

Expert condition-specific knowledge to inform assessment and care-planning.

Expert knowledge of anticipatory care-planning.

SKILLS

Contribute expertise to assessment of complex issues in palliative and end of life care.

Undertake comprehensive assessment in complex situations, drawing on and involving other team members as appropriate.

Meet complex needs and provide a leadership role within and across care environments.

Use expert condition-specific knowledge to inform detailed anticipatory care plans.

Lead and take an expert role in promoting and integrating anticipatory care-planning in practice.

(continued)

Domain 4

Expert

Domain 4

Care planning & delivery



Expert

KNOWLEDGE

Expert knowledge of evidence-based approaches and interventions for physical, psychological, spiritual and social distress or concerns.

Expert knowledge of complex symptom management.

Expert knowledge of facilitating family meetings and case conferences.

Expert knowledge of palliative care service models and practice.

SKILLS

Contribute expert support and intervention to care delivery in collaboration with the wider team.

Provide interventions for complex symptoms using recognised evidence or best practice-based approaches (when appropriate to role).

Provide individually adapted evidence-based psychological interventions (when appropriate to role).

Lead and mediate discussions about the planning of care and support to resolve contentious issues, involving other team members as appropriate.

Facilitate multi-agency case reviews and morbidity and mortality reviews of adverse events in palliative and end of life care to identify learning and opportunities for improvement.

Domain 4

Expert

Domain 5

Care in the last days of life



Informed

KNOWLEDGE

Know that dying is part of life, and that uncertainty surrounds how and when someone may die.

Know the importance of considering the choices and preferences of the person, family and carers in the last days of life.

Know that action when a person dies is directed by legislation, policy and guidance.

SKILLS

Respond in a sensitive and empathic manner to people who are dying, their families and carers.

Be respectful of choices, preferences and decisions in the last days of life.

Recognise your role in relation to organisational policies and procedures when a person dies.

Domain 5

Informed

Domain 5

Care in the last days of life



Skilled

KNOWLEDGE

Knowledge and understanding of the dying process and common symptoms in the last days of life.

Knowledge of principles and national and local guidelines on caring for people in the last days and hours of life.

Knowledge of the place of nutrition and hydration in the last days of life.

SKILLS

Working collaboratively with the multidisciplinary team, anticipate, recognise and respond to signs and symptoms that may indicate a person is entering the last days of life.

Communicate observed changes that may indicate a person is entering the last days of life to the appropriate person.

Engage in sensitive and clear communication with the dying person, family and carers in relation to their changing condition and the focus of care.

Support people, families and carers regarding uncertainties of how and when someone may die.

Apply the principles and guidelines when caring or supporting people, their families and carers in the last days and hours of life.

Support the person to eat and drink if he or she wishes and is able to, and monitor for difficulties with eating and drinking.

Offer support to the person, family and carers on the place of food and fluids in the last days of life.

(continued)

Domain 5

Skilled

Domain 5

Care in the last days of life



Skilled

KNOWLEDGE

Knowledge and understanding of the ethical dilemmas that arise in relation to decision-making in the last days of life.

Knowledge and understanding of culture, beliefs and rituals that guide practices before and after death.

Knowledge that policies and processes exist for verification and certification of death.

SKILLS

Participate in shared decision-making to care and support people, their family and carers in the last days of life.

Maintain the respect and dignity of people, their family and carers when providing care and provide support before and after death in the context of their choices, culture, beliefs and rituals.

Provide information and signpost to sources of support for the practical issues that surround death.

Domain 5

Skilled

Domain 5

Care in the last days of life



Enhanced

KNOWLEDGE

In-depth knowledge of the dying process and differentiation from reversible causes of deterioration.

In-depth knowledge in assessing and managing symptoms that arise in the last days of life.

In-depth knowledge and understanding of ethical decision-making around burdens, benefits and futility of interventions in relation to the last days of life.

SKILLS

Recognise and assess reversible causes of deterioration.

Initiate and contribute to multidisciplinary discussion and decision-making on recognition of dying, acknowledging inherent uncertainty.

Initiate and conduct sensitive conversations on choices and preferences with the person, family and carers when death is imminent, and explain what is likely to happen.

Anticipate, recognise and respond to signs and symptoms in the last days of life.

Anticipate and proactively plan to address issues that may arise for the person, family and carers in the last days of life.

Ensure daily review and evaluation of planned care and draw on a range of support and interventions to address unmet needs and distress.

Recognise when to withhold or discontinue interventions and confidently engage with multidisciplinary decision-making processes, supporting and including the person, family and carers.

(continued)

Domain 5

Enhanced

Domain 5

Care in the last days of life



Enhanced

KNOWLEDGE

In-depth knowledge and understanding of the place of nutrition and hydration in the last days of life.

In-depth knowledge of services and resources that can respond quickly to meet care needs in the last days of life.

Knowledge of legal requirements on reporting deaths to Police Scotland and/or the Procurator Fiscal.

SKILLS

Undertake an assessment of nutritional and hydration status, and communicate and document the assessment outcome and agreed decisions.

Recognise and respond promptly to individual choices and preferences in the last days of life, which may require a change of care environment and provision.

Initiate procedures for carrying out verification and certification of death (when appropriate to role).

Engage with organisational policy and procedure to ensure timely verification of death, particularly out of hours.

Domain 5

Enhanced

Domain 5

Care in the last days of life



Expert

KNOWLEDGE

Expert knowledge of evidence-based care in the last days of life.

SKILLS

Provide expert guidance and support to other teams and services providing care in the last days of life where complex issues are identified.

Provide expert care and support to the person, family and carers in the last days of life.

Expert knowledge of team-working theory and techniques/ strategies to support teams in providing care in the last days of life.

Lead and support teams in providing and delivering care in the last days of life.

Domain 5

Expert

References

References

1. Scottish Partnership for Palliative Care (2015). Grasping the Nettle. What Action Can We Take to Improve Palliative and End of Life Care in Scotland/ Edinburgh: Scottish Partnership for Palliative Care
http://www.parliament.scot/S4_HealthandSportCommittee/Inquiries/PCA_Grasping-the-Nettle_SPPC.pdf (Accessed 3 March 2017)
2. Scottish Government (2015). Strategic Framework for Action on Palliative and End of Life Care 2016–2021. Edinburgh: Scottish Government
<http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/SFA> (Accessed 3 March 2017)
3. Skills for Care (undated). National Occupational Standards.
<http://www.skillsforcare.org.uk/Standards-legislation/National-Occupational-Standards/National-Occupational-Standards.aspx> (Accessed 3 March 2017)
4. NHSScotland (undated). NHS Knowledge and Skills Framework Guidance.
<http://www.ksf.scot.nhs.uk/> (Accessed 3 March 2017)
5. World Health Organization (2017). WHO Definition of Palliative Care.
<http://www.who.int/cancer/palliative/definition/en/> (Accessed 3 March 2017)
6. Scottish Human Rights Commission (2013). Scotland's National Action Plan for Human Rights 2013–2017. Edinburgh: Scottish Human Rights Commission
<http://www.snaprights.info/wp-content/uploads/2016/01/SNAPpdfWeb.pdf> (Accessed 3 March 2017)
7. Scottish Government (2016). New Principles for National Care Standards.
<http://www.gov.scot/Topics/Health/Support-Social-Care/Regulate/Standards/NCSreview/NCSPrinciples> (Accessed 6 March 2017)
8. Scottish Parliament (2000). Adults with Incapacity (Scotland) Act 2000. Edinburgh: Scottish Parliament
<http://www.legislation.gov.uk/asp/2000/4/contents> (Accessed 3 March 2017)
9. Scottish Parliament (2016). Carers (Scotland) Act 2016. Edinburgh: Scottish Parliament
<http://www.legislation.gov.uk/asp/2016/9/contents> (Accessed 3 March 2017)
10. Scottish Parliament (2013). Social Care (Self-directed Support) (Scotland) Act 2013. Edinburgh: Scottish Parliament
<http://www.legislation.gov.uk/asp/2013/1/contents> (Accessed 3 March 2017)

Appendix 1

Education Advisory Group representation

The Education Advisory Group includes representation from:

Alzheimer Scotland
Association of Palliative Care Social Workers
Care Inspectorate
Coalition of Carers in Scotland
Council of Deans of Health Scotland
Health and Social Care Alliance Scotland
Healthcare Improvement Scotland
Integration joint boards
Marie Curie Expert Voices Group
NHS Education for Scotland
Scottish Care
Scottish Children and Young People's Palliative Care Executive Group
Scottish Executive Nurse Directors
Scottish Government
Scottish Hospices
Scottish Palliative Care Pharmacists Association
Scottish Partnership for Palliative Care
Scottish Qualifications Authority
Scottish Social Services Council

Appendix 2

Principles of the framework

World Health Organization definition of palliative care⁵

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Appendix 2

Principles of the framework

World Health Organization definition of palliative care for children⁵

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.

- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources.
- It can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

Appendix 2

Principles of the framework

The PANEL principles

Participation

Everyone has the right to participate in decisions that affect them. Participation must be active, free and meaningful and give attention to the issues of accessibility, including access to information in a form and a language that can be understood.

Accountability

Accountability requires effective monitoring of human rights standards. For accountability to be effective, there must be appropriate laws, policies, administrative procedures and mechanisms of redress to secure human rights.

Non-discrimination and Equality

A human rights-based approach means that all forms of discrimination must be prohibited, prevented and eliminated. It also requires the prioritisation of those in the most vulnerable situations who face the biggest barriers to realising their rights.

Empowerment

People should understand their rights and be fully supported to participate in the development of policy and practices that affect their lives. People should be able to claim their rights when necessary.

Legality

The full range of legally protected human rights must be respected, protected and fulfilled. A human rights-based approach requires the recognition of rights as legally enforceable entitlements and is linked to national and international human rights law.

Appendix 2

Principles of the framework

Appendix 2

National care
standard principles

National Care Standards principles

Dignity and respect

- My human rights are respected and promoted.
- I am respected and treated with dignity as an individual.
- I am treated fairly and do not experience discrimination.
- My privacy is respected.

Compassion

- I experience warm, compassionate and nurturing care and support.
- My care is provided by people who understand and are sensitive to my needs and my wishes.

Be included

- I receive the right information, at the right time and in a way I can understand.
- I am supported to make informed choices, so that I can control my care and support.
- I am included in wider decisions about the way the service is provided, and my suggestions, feedback and concerns are considered.
- I am supported to participate fully and actively in my community.

Responsive care and support

- My health and social care needs are assessed and reviewed to ensure I receive the right support and care at the right time.
- My care and support adapts when my needs and choices and decisions change.
- I experience consistency in who provides my care and support and in how it is provided.
- If I make a complaint, it is acted on.

Wellbeing

- I am asked about my lifestyle preferences and aspirations and I am supported to achieve these.
- I am encouraged and helped to achieve my full potential.
- I am supported to make informed choices even if this means I might be taking personal risks.
- I feel safe and I am protected from neglect, abuse or avoidable harm.