



National Service Specification for Wales: Palliative and End of Life Care Services

August 2025



Disclaimer for the National Service Specification for Wales: Palliative and End of Life Care.

The National Programme for Palliative and End of Life Care and NHS Wales Performance and Improvement assume that healthcare professionals will use their clinical judgement, expertise, and knowledge when determining the appropriateness of applying the specification in individual cases.

This document serves as guidance and may not be clinically applicable in every situation. It does not replace the responsibility of healthcare professionals to make decisions based on the specific circumstances of each patient in consultation with the patient, the carer and/or their legal guardian as appropriate.

The National Programme for Palliative and End of Life Care and NHS Wales Performance and Improvement disclaim any liability for outcomes arising from the use or non-use of the specification. It remains the responsibility of service providers, Health Boards and Trusts to ensure compliance with relevant laws, professional standards, and local governance requirements.

Acknowledgements

We extend our sincere gratitude to colleagues and services across Wales and beyond who generously contributed their time, knowledge, and expertise to inform the development of this specification. We would like to thank the members of associated advisory task & finish groups, whose dedication and collaborative efforts were instrumental in shaping significant aspects of this work.

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Foreword

Dr Idris Baker, National Clinical Lead for Palliative & End of Life Care in Wales
Lynda Kenway, National Strategic Programme Lead for Palliative & End of Life Care

Palliative and end of life care is about so much more than the final days of life. It is about enabling people, at any stage of a life-limiting condition, to live as well as possible for as long as possible, and to do so with dignity, comfort, and a sense of control. It is about standing alongside families, friends, and carers during some of life's most challenging moments and ensuring that those providing care have the skills, resources, and confidence to deliver it.

This *National Service Specification for Palliative and End of Life Care in Wales* is the product of months of listening, discussion, and collaboration. It reflects the contributions of people with lived experience, families, clinicians, commissioners, service providers, the voluntary sector, and many others. It sets out, for the first time, an agreed baseline of what high-quality, equitable palliative and end of life care should look like across Wales, regardless of age, diagnosis, or postcode.

We want to be clear: this is a **live document**. The specification marks an important milestone, but it is not the end of the journey. Over the next six months, we will work with health boards, trusts, and service providers to complete a national baseline assessment, identifying where services already meet the specification and where there are gaps. This will lead to a phased implementation plan that recognises the realities of current service landscapes, financial pressures, and capacity for change, while still pressing forward at a pace that makes a meaningful difference.

For **patients and those closest to them**, this specification is a commitment: that care will be compassionate, timely, and person-centred, wherever you are in Wales. For **staff and volunteers**, it is a framework to guide practice, support [NHS Wales Performance and Improvement](#)

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decision-making, and ensure that training and development are aligned to delivering the best possible care. For **service providers**, it is a shared set of expectations and standards that will help align local delivery with national priorities, enable fair commissioning, and support continuous improvement.

We will be developing a new **Governance and Assurance Framework** for PEoLC to monitor progress, agree on measurable outcomes, and ensure transparency and accountability. Alongside this, the *All-Wales Competency Framework for Palliative & End of Life Care* and the *Commissioning Framework for Hospices* will strengthen the foundations for change. Together, these tools will help us build services that are consistently excellent, equitable, and resilient.

We are grateful to every individual and organisation who has contributed to this work so far. Your insight and expertise have shaped a document that is both ambitious and practical. Now, our collective task is to bring it to life, to translate the words on these pages into real improvements in care, comfort, and support for the people of Wales.

We look forward to working alongside you in this next phase.



A handwritten signature in black ink, appearing to read 'I. Baker'.

Dr Idris Baker

National Clinical Lead for Palliative & End of Life Care in Wales

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A handwritten signature in black ink, appearing to read 'Lynda Kenway'.

Lynda Kenway

National Strategic Programme Lead for Palliative & End of Life Care

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Executive Summary

Overview of Key Goals

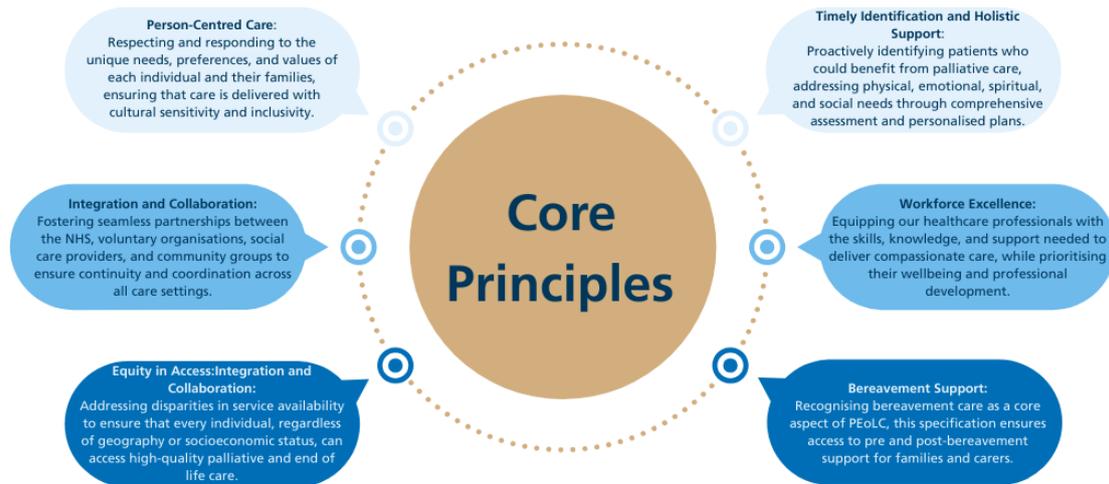
The National Service Specification for Palliative and End of Life Care (PEoLC) and Paediatric Palliative Care (PPC) in Wales reflects a collective ambition to deliver equitable, person-centred, and high-quality care to individuals and families navigating life shortening, life limiting, and in some cases life threatening, conditions. Rooted in the values of compassion, dignity, and respect, this document serves as a roadmap for achieving a consistent standard of care across all regions and care settings in Wales.

As our population ages and the prevalence of chronic and complex conditions rises, the demand for palliative care grows. This specification responds to these evolving challenges by setting clear expectations for the delivery of care, informed by the Welsh Government's [Quality Statement](#)^[1] for PEoLC/PPC and aligned with our broader vision for a [Healthier Wales](#).^[2] It builds on the strengths of our integrated health and social care system and leverages advancements in digital tools, workforce planning, and service innovation.

Core Principles Figure 1:0

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These core principles in **Figure 1:0** have been amalgamated into the [key five service features alongside the two interconnecting core themes](#) below:



Timely and Equitable Access to Palliative Care This ensures that people and their families receive well-coordinated, personalised care when they need it. This characteristic covers the complete journey from identifying when someone might benefit from palliative care, through to taking quick action and ensuring 24/7 access to urgent care when needed.

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Personalised, Holistic and Compassionate Care This ensures that palliative and end-of-life care is tailored to each person's unique needs, wishes and values. It focuses on treating the whole person not just their illness by addressing physical symptoms, emotional wellbeing, spiritual needs, and social support. Care involves specialist teams (including specialist palliative care and other specialties) working together to provide expert support when needed, while ensuring compassionate care during the final stages of life.

Coordinated and Integrated Services This ensures that palliative and end-of-life care is delivered through well-coordinated services that work together seamlessly. It covers care across all settings (home, hospital, hospice, care homes), supports smooth transitions between services, provides comprehensive support for families and carers, and uses modern technology to improve care coordination.

Skilled Workforce and Continuous Learning To ensure all staff have the right skills and knowledge to provide high-quality, age-appropriate care. This means ongoing training and development based on national standards to deliver consistent, evidence-based care.

Leadership, Governance and Quality Improvement This promotes a system-wide approach to delivering high-quality, person-centred palliative and end-of-life care (PEoLC) and paediatric palliative care (PPC) in Wales. It emphasises the importance of strong executive leadership, clear clinical accountability, and robust governance frameworks to support quality, safety, and integrated planning across health and social care. Central to this is the routine use of outcome and experience data including the Core Outcome Set for adult PEoLC, Patient Reported Outcome Measures (PROMs), and Patient Reported Experience Measures (PREMs) to inform service improvement, enhance patient and family experience, and ensure continuous quality improvement at all levels of care.

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Specialist Palliative Care To ensure access to the expertise of adults and Children and young people PEO/LC/PPC specialists' teams and/or professionals who can anticipate, prevent, minimise and manage crises, as well as provide appropriate and responsive care to address holistic and complex needs beyond the capacity of generalist teams. Core specialist multi-professional teams that support care across all environments and cater to all age groups, including antenatal care, children, as well as young people and adults. These teams should function as integrated services across different care settings and be composed of professionals whose primary activity is delivery of specialist palliative care. Staff with appropriate specialist qualifications and training team members working at the relevant national competency levels to ensure high-quality care.

Bereavement and family Support Bereavement is an experience that affects everyone at some point, often multiple times throughout life. Grief, our natural response to loss, is not an illness but a deeply personal process that varies greatly from person to person. While grief is a normal reaction, its impact can be profound and far-reaching. The vision for Wales, as outlined in the [National Framework for the Delivery of Bereavement Care in Wales](#),^[3] is for a compassionate Wales where everyone has equitable access to high quality bereavement care and support to meet their needs effectively at the time they need it. Support is required for individuals both before (anticipatory grief) and following the death of someone significant in their lives. It includes bereavement due to the death of any person, including those who die before birth for any reason and at all gestation ages.

This document also acknowledges the vital contributions of unpaid carers, who often play a vital role in end-of-life care. By providing enhanced support, training,

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and respite services, we aim to ease the emotional and physical burdens faced by these essential caregivers.

Recognising the importance of robust data collection and interrogation is central to accessing service performance and informing service development and improvements. Reliable data enables us to evaluate how well services are meeting the needs of individuals and families, identify areas for improvement, and ensure accountability across all care settings. By integrating comprehensive data systems, we can:

- Monitor patient outcomes and experiences to measure the effectiveness of care delivery.
- Identify gaps or inequities in service provision and address them proactively.
- Inform workforce planning, ensuring resources are allocated effectively to meet demand.
- Support research and innovation, driving evidence-based advancements in PEOC/PPC.

The Last Year of Life Dashboard provides an invaluable tool for understanding patterns in service usage, patient needs, and care outcomes during the critical final years of life. It is critical that appropriate and meaningful dashboards of data are also created where children and young people access PPC services in Wales. By leveraging these dashboards, we can adopt a systems-thinking approach to service development, ensuring that every component of care delivery is interconnected and responsive to patient and population needs. Key benefits include:

- **Holistic Insights:** The dashboard facilitates a comprehensive view of care trends, enabling the identification of systemic inefficiencies and areas for improvement.

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- **Proactive Planning:** Data from the dashboard supports anticipatory planning, ensuring that services are prepared to meet the evolving demands of individuals in their last years of life.
- **Integrated Care Pathways:** Using a systems-thinking lens, we can ensure that care pathways are cohesive, reducing fragmentation and enhancing patient experiences.

We are committed to a cycle of continuous quality improvement, underpinned by the ongoing collection and analysis of data. Through robust monitoring and effective feedback mechanisms, we ensure our services remain responsive, effective, and sustainable.

This specification is not a static document but a dynamic framework, evolving in response to emerging evidence, demographic shifts, and technological advancements. We acknowledge that achieving this vision requires shared responsibility and steadfast collaboration, recognising that not all objectives will be realised immediately, or in the same way. However, by working together across sectors and disciplines, we can transform palliative and end-of-life care in Wales, delivering comfort, dignity, and unwavering support when it matters most. Thank you for your ongoing dedication to improving the lives of patients and families across Wales.

Glossary of Terms/Acronyms

Adults are used throughout this document to refer to those aged 18 years and over.

Advance Care Planning (ACP) see Future Care Planning.

Allied Health Professionals (AHP) make up the third largest professional workforce in the NHS. Representing thirteen distinct professions, they play an integral role in promoting public health and improving the physical, mental, and social well-being of the population.

All-Wales Paediatric Palliative Care (AWPPC) Network brings together statutory healthcare services, both at tertiary and local levels, with third sector providers, notably two children's hospice organisations. The AWPPCN plays a vital role in coordinating care, providing advice, and offering targeted interventions to support both families and the wider health and social care workforce.

Bereavement Care Services All specialist palliative care services should also have access to a range of pre-bereavement and bereavement care services, as outlined in the national bereavement framework and pathway for bereavement services in Wales.

Carers (see unpaid carers).

Charitable Hospices can be a specialised care facility or a service that provides holistic, compassionate support for adults or children, and young people with life-shortening or life-limiting/threatening conditions, and their families. Care can be provided at the hospice itself, in patients' homes, or through community outreach services. Hospices focus on enhancing the quality of life for patients and their families by addressing their physical, emotional, social, and spiritual needs, aiming to maximise comfort and dignity. They are non-profit organisations often utilising donations and fundraising to support their services.

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Continuing Healthcare (CHC) A set of national guidelines that outline the process for assessing and determining eligibility for NHS CHC. [aAA](#) package of care arranged and funded solely by the NHS for individuals aged 18 and over who have significant ongoing healthcare needs. The guidance ensures consistent, fair, and lawful decision making across all health boards.

Children and Young People (C&YP) For the purpose of this document this is defined as people from birth to their 18th birthday.

Data Standards Change Notice (DSCN) is a mandate to NHS and partner organisations and system suppliers to ensure that they are able to support a new or changed data standard.

Digital Technology Innovation and Value (DDTIV) A directorate within NHS Wales Performance & Improvement responsible for leading the development and delivery of digital health and care services, data-driven innovation, and technological solutions that improve patient outcomes, system efficiency, and value for money. DDTIV plays a key role in enabling transformation across NHS Wales.

Enhanced Palliative Care for children (also known as 'wrap-around' care)

There is a sense in which all palliative care for children is 'wrap-around'. The term 'enhanced' care is preferred here because it emphasises the need for families to be able to access services that are highly valued and essential to enable them to live their best lives and reach their full potential but are not typically available through statutory providers. Enhanced care begins from the point that the child is identified as having a life limiting or life-threatening condition (including antenatally) and continues for the life of the child and to support bereaved family members. Enhanced care complements direct specialist medical and nursing care, the primary purpose of which is the management of medical symptoms.

Family is used throughout this document to refer to whoever is close or important to the patient, regardless of the status and nature of their relationship.

Future Care Planning (FCP) an opportunity for an individual to work with health and social care professionals to consider what matters to them in terms of their [NHS Wales Performance and Improvement](#)

wellbeing and explore their wishes for any future care or support that the person may need, in the context of their condition, circumstances and options. Most people value the support of others such as family in doing this. This includes what is sometimes also referred to as Advance Care Planning (ACP) approaches, and conversations with family about the care of people unable to participate in ACP because they lack capacity for the relevant decisions. It has now been adopted to unify terminology used across health and social care (e.g., anticipatory, advance, contingency planning). Written output may include a Record of Best Interests Discussions (RBID), a Lasting Power of Attorney (LPA), an Advance Decision to Refuse Treatment (ADRT), an Advance Statement (of Wishes and preferences, also known as an advance care plan), and other less formal records. It recognises that much of the meaningful value of FCP is in the conversations themselves. This will also include a Paediatric Advance Care (PAC) plan. The use of a PAC-Plan includes options regarding resuscitation and should alert the beginning of a process of discussion and individualised care.

General Practitioner (GP) a medical doctor who works in primary care and provides general healthcare services to patients within the NHS system.

Health Boards (HB) These are responsible for planning, securing, and delivering healthcare services within their respective areas. They work to improve the health and well-being of their populations, reduce health inequalities, and ensure access to a wide range of healthcare services, including primary, community, and secondary care, as well as specialist services.

Health Education and Improvement Wales (HEIW). A Special Health Authority within NHS Wales responsible for the education, training, development, and workforce planning of healthcare professionals. HEIW works to ensure a sustainable, skilled, and resilient workforce across health and care services in Wales, supporting continuous improvement in patient care and service delivery.

Hospice can be a specialised care facility or a service that provides holistic, compassionate support for adults or C&YP with life-shortening or life-

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limiting/threatening conditions, and their families. Care can be provided at the hospice itself, in patients' homes, or through community outreach services. Hospice focuses on enhancing the quality of life for patients and their families by addressing their physical, emotional, social, and spiritual needs aiming to maximise comfort and dignity (Also see Charitable Hospices).

Hospice at Home Services deliver hands on care for adult patients at home at the end of life. They are often procured by the NHS and delivered by charitable sector or NHS services and should work in partnership with community nursing services and other specialist palliative care (SPC) services. Some, but not necessarily all, hospice at home teams will be part of SPC services.

Independent Organisations is used through this document to refer to an entity that operates separately from the National Health Service (NHS) but plays a significant role in delivering or supporting palliative care services. These organisations typically include charitable bodies including hospices, voluntary organisations, social enterprises, or private care providers. They often complement statutory services provided by the NHS and local authorities, addressing gaps, or providing specialised care.

Integrated Palliative care Outcome Scale (iPOS) A validated patient-centred assessment tool used in palliative and end of life care to measure symptoms, concerns, and overall well-being. iPOS supports holistic care planning by capturing physical, emotional, psychological, and spiritual needs from the perspective of patients and carers.

Joint Commissioning Committee (JCC) A formal body that brings together NHS and local authority partners to plan, fund, and oversee the delivery of integrated health and care services. The JCC ensures collaborative decision-making and shared accountability for commissioning priorities and outcomes.

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Key Performance Indicators (KPI) are measurable values used to assess the performance and effectiveness of services, helping to monitor progress, ensure quality, and support continuous improvement.

Life Shortening In this document this is used, particularly for adults, in place of the term 'life-limiting' to emphasise that other aspects of life need not necessarily be limited by the condition if the right care and support are provided.

The term 'life-shortening' is also used to describe a condition that makes it unlikely that a child will survive into adulthood.

Life Limiting/Threatening refers to conditions that are expected to significantly reduce a person's life expectancy compared to the general population. This term alongside life shortening is often used interchangeably but can have nuanced differences based on the context of care.

Local Health Board (LHB) Local health boards are responsible for planning and delivering NHS services in their areas.

Medical Examiner (ME) This is a senior medical doctor trained in legal and clinical elements of the death certification process and taking oversight of all proposed causes of death.

Multi-Disciplinary Team (MDT) For the purpose of this document, this is a group of professionals from various disciplines and sectors who collaborate to coordinate care for patients. These bring together a range of expertise to address complex healthcare needs. Sometimes the members are from different professions, working in a particular specialty such as palliative care. Sometimes they are from different specialties, working together to support the care of people with a particular illness or group of illnesses.

National Institute for Health and Care Excellence (NICE) An independent public body in the UK that provides national guidance and advice to improve health and social care. NICE develops evidence-based recommendations on treatments, care pathways, public health, and resource use to ensure high-quality, cost-effective services across the NHS and wider care system.

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Out of Hours (OOH) Healthcare services provided outside of normal working hours, typically evenings, overnight, weekends, and bank holidays, when regular GP surgeries or clinics are closed. OOH services ensure patients have access to urgent care and advice during these times.

Paediatric Palliative Care (PPC) is a specialised approach to care that focuses on improving the quality of life for children and young people with life-limiting or life-threatening conditions, as well as providing support for their families. It is holistic and family-centred, addressing physical, emotional, social, and spiritual needs from the point of diagnosis through the trajectory of the illness, including end-of-life care and bereavement support.

Palliative and End of Life Care (PEoLC) The care and support of people with progressive life shortening conditions and their families (i.e. whoever is close and important to the person), often but not exclusively those who may be in the last year of life. It includes the various elements often described as palliative care, end of life care or care in the last days of life.

Palliative Care Children's Out-reach in-reach Nursing Service (COINS).

Palliative Rehabilitation is the method of helping individuals who have a progressive, advanced or incurable illness to reach their potential physical, psychological, and social limits that are consistent with physiological and/or environmental limitations and life preferences. This may extend functional independence and improve quality of life.

Patient In the context of a clinical encounter or clinical relationship, a person may be referred to as a patient.

People Throughout this document people includes children, young people, and adults.

Preferred Place of Care (*This is often shortened to PPC but not in this document*) This refers to the location where a person with a life-shortening or life-limiting, life threatening condition wishes to receive their care and support, particularly during advanced illness and at the end of life.

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Proactive Identification Guidance (PIG) The National Gold Standard Framework Centre's guidance for clinicians to support earlier identification of patients nearing the end of life, leading to improved proactive person-centred care.

Preferred Place of Death (PPD) refers to the location where a person chooses to spend their final moments and die, based on their personal values, preference and circumstances.

Patient Reported Experience Measures (PREMs) Tools used to capture patients' views on their experience of receiving care. PREMs help healthcare providers understand what matters to patients, such as communication, involvement in decisions, and dignity, to improve service quality.

Patient Reported Outcome Measures (PROMs) are standardised questionnaires completed by patients to assess their health status or quality of life related to a condition or treatment. PROMs provide insights into the effectiveness of care from the patient's perspective.

Quality Statement Welsh Government high-level statement of intent for what "best" looks like for Palliative and End of Life Care services.

Service Level Agreement (SLA) is a formal contract between service providers and commissioners or partners that defines the scope, standards, performance expectations, and responsibilities for delivering a service.

Specialist Palliative Care (SPC) Specialist palliative care services are those whose core activity is limited to palliative care. These are involved in the care of individuals who can have complex and demanding care needs, and can require a greater degree of specific training, and other resources. It involves assessing need, promoting and preserving choice, predicting problems and planning in the context of a changing and deteriorating disease trajectory (adapted from Palliative Care Competence framework) Includes but is not exclusive to EOL care.

Specialist Palliative Care Children (SPPC) As in adults, specialist palliative care is defined according to the competences of those delivering the service. A specialist in paediatric palliative medicine (also called Level IV) is a paediatrician

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who has completed the competences required for certification of specialist training in Paediatrics/Palliative Medicine and who is expected to work mainly or entirely in PPC. A paediatrician with a special interest in PPC (also called level III) is one who holds a recognised postgraduate qualification in PPC and who has usually spent training time within a specialist PPC team.

Specialist Palliative Care Multidisciplinary Team (SPC MDT) Adult Specialist Palliative Care (SPC) is delivered by a Consultant in Palliative Medicine led Multidisciplinary Team (MDT) with the requisite qualifications, expertise and experience in offering care for people with life shortening, life limiting, or life threatening illness, to support them to live as well as possible during their illness ensuring their comfort and dignity are maintained as they come to the end of their lives. The SPC MDT should be appropriately staffed to deliver the following key, core components of specialist assessment and intervention, education, research, and strategic leadership.

Statutory and Independent Providers in settings like hospice facilities, homes, and hospitals, and includes support for families through respite and bereavement services.

Supportive and Palliative Indicator Tool (SPICT) A clinical tool used by health and care professionals to help identify individuals who may benefit from a palliative or supportive care approach. SPICT supports early recognition of deteriorating health and prompts timely assessment, care planning, and coordination of appropriate support.

Transitional Palliative Care Transition from children to adult services in healthcare is commonly defined as a purposeful, planned process that addresses the medical, psychosocial, and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child and family-centred to adult-oriented healthcare systems. It is a process over a several years rather than a one-off event that occurs when the child turns the legal adult age of 18. It is well known that poorly co-ordinated and planned transition from paediatric to adult services results in poor health outcomes for [NHS Wales Performance and Improvement](#)

young people. Transitional palliative care also applies to those young people who first develop LLC and palliative care needs during the transition age range.

Unpaid Carers (See Carers) are individuals who provide essential, uncompensated care to family or friends unable to manage daily activities due to illness, disability, or ageing. Their support may include personal care, assistance with mobility, managing medication, and coordinating healthcare needs, allowing individuals to remain in their homes and communities. This also includes parents of children with life-shortening conditions whose role in caring for a child may span decades and has far-reaching impacts well beyond the normal commitments that parenting entails.

Verification of Expected Death (VoED) Verification of the fact of death, documents the death formally in line with national guidance. The time of verification is recognised as the official time of death. Doctors call this process 'confirmation of death', and paramedics call this process 'recognition of life extinct

Welsh Government (WG) is the devolved government for Wales. Led by the First Minister, it works across devolved areas that include key areas of public life.

Welsh Ambulance Services University Trust (WAST) is the national ambulance service for Wales, providing emergency and non-emergency patient transport.

Introduction: Purpose and Scope

The National Service Specification for Palliative and End of Life Care (PEoLC/PPC) in Wales sets clear standards for delivering high-quality, person-centred, and equitable care across all settings. It guides Health Boards, Trusts, and independent providers in aligning services to ensure consistent, accessible care for patients of all ages and backgrounds.

Grounded in the principles of value-based health and care and the [Welsh Government's Quality Statement for PEoLC](#) ^[1], [National Clinical Framework](#) ^[4], and [Duty of Quality Guidance](#) ^[5], and [A Healthier Wales](#) ^[2], this specification promotes a whole system approach focused on quality, safety, and dignity at the end of life.

Scope: The specification covers:

- Palliative and end of life care (PPC) for C&YP
- General and specialist PEoLC for adults
- Care delivered by statutory, voluntary, and independent sectors in any setting

It defines key terms and supports a shared understanding across services.

Guiding Principles

- Quality and Safety: High standards and patient safety
- Equity and Prevention: Early intervention and reduced inequalities
- Person-Centred Care: Responsive to individual needs and preferences
- Partnership: Integrated working across all sectors
- Workforce Investment: Ongoing training and development

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Executive leadership within health boards is accountable for effective service delivery. This document supports a unified, high-quality approach to PEOLC/PPC across Wales, with each section tailored to various audiences and levels of care.

Who Should Use the Service Specification?

This specification is intended for all stakeholders involved in planning, delivering, or supporting palliative and end-of-life care (PEoLC/PPC) in Wales, including:

- **Service planners, providers, and commissioners** across hospitals, community services, care homes, hospices, and unscheduled care.
- **Leaders and decision-makers** accountable for aligning PEOLC/PPC services with national standards and local needs.
- **Clinical and non-clinical staff**, including GPs, nurses, allied health professionals, chaplains, counsellors, psychologists, social workers, and specialist palliative care teams everyone who is involved in or responsible for the care people need or receive.
- **Organisations involved in research, education, and workforce development** related to PEOLC/PPC
- **Charities, community groups, and third sector organisations** offering holistic support or any element of PEOLC/PPC (e.g. emotional, psychological, and social care).

Patients, families, and the public may also have an interest in its contents, as it outlines the standards of care they can expect.

Alignment with Welsh Government Health Goals, Frameworks, and National Quality Standards

Health Boards, Trusts, and third sector organisations developing their Palliative and End of Life Care (PEoLC/PPC) services will need to align with key Welsh

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Government policies, strategic frameworks, and nationally recognised standards. This alignment ensures that PEOLC/PPC services across Wales are consistent, of high quality, equitable, and responsive to patient needs. Along with those key documents mentioned above the primary frameworks include:

- [Six Goals for Urgent and Emergency Care](#) ^[6]
- [Improving Health and Social Care: COVID-19 Looking Forward](#) ^[7]
- [The NHS Quality and Safety Framework](#) ^[8]
- [The Bereavement Framework for Wales](#) ^[2]

In addition, PEOLC/PPC services should adhere to relevant standards from the [National Institute for Health and Care Excellence](#) (NICE) ^[9-16], which provide evidence-based recommendations to support high-quality, person-centred care.

Key guidelines

- NICE NG31: *Care of the Dying Adult in the Last Days of Life* – guidance on managing symptoms, including pain, breathlessness, and nausea, to ensure comfort and dignity.^[9]
- NICE NG142: *End of Life Care for Adults* – service delivery recommendations to support consistent, coordinated, and accessible care for adults in the last year of life.^[10]
- NICE QS13: *End of Life Care for Adults* – quality standards on recognising and planning for end-of-life needs, ensuring that individuals receive appropriate care and support.^[11]
- NICE NG61: *End of Life Care for Infants, Children, and Young People* – recommendations to support young people and their families, focusing on symptom management, emotional support, and transition planning.^[12]
- NICE QS144: *Care of Dying Adults in the Last Days of Life* – standards to promote personalised care planning and effective symptom control.^[13]
- NICE QS160: *End of Life Care for Infants, Children, and Young People* – quality standards for paediatric palliative care, addressing multidisciplinary support, symptom management, and grief support for families.^[14]

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- NICE NG197: *Shared Decision Making* – guidelines promoting collaborative decision-making between patients, families, and healthcare professionals to ensure care aligns with patient values and preferences, especially relevant in PEOLC.^[15]
- NICE NG43: *Transition from Children’s to Adults’ Services* – guidance on providing seamless, supported transitions for young people moving from paediatric to adult care, ensuring continuity and responsiveness to their evolving care needs.^[16]

By adhering to these frameworks, standards, and guidelines, PEOLC/PPC services in Wales can deliver consistent, high-quality care that respects the diverse needs and preferences of patients and their families. This adherence ensures accountability, supports continuous improvement, and upholds the values of quality, safety, and person-centred care.

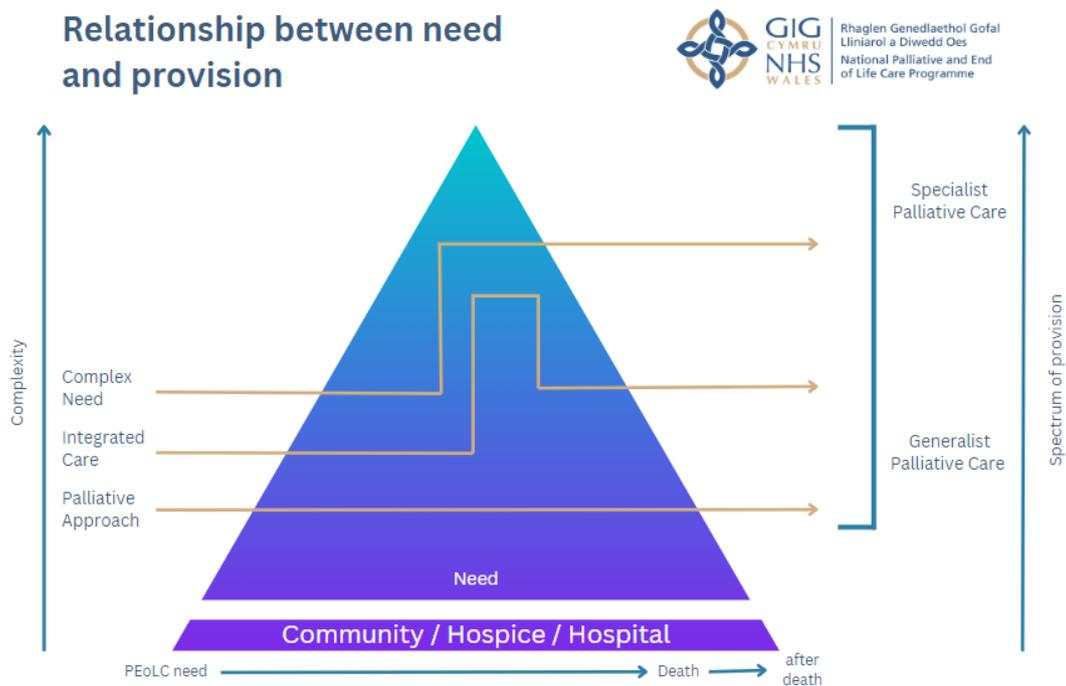
Wales Context for Palliative and End of Life Care

Palliative and End of Life Care (PEOLC/PPC) in Wales is delivered within an integrated health and social care system, relying on collaboration across various clinical disciplines and service providers. This system includes not only palliative care specialists, but all kinds of teams providing care in all settings including hospitals, care homes, hospices, prisons and people’s own homes. There is no clinical specialty in which PEOLC need is not encountered at least sometimes so this range includes urgent and unscheduled care teams, primary care and community teams, every hospital specialty such medicine, surgery, oncology, haematology, care home teams, hospice staff, care agencies, social care, and voluntary and third sector providers. People needing care move between settings, so all these components must work together seamlessly to ensure that high-quality, person-centred care is accessible to everyone who needs it ([See Figure 2.0](#)) for an overview of PEOLC provision in Wales, highlighting complexity, need, and provision.

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Figure 2.0 Outline of the complexity and provision of Palliative and end of life care in Wales



v6

PEoLC/PPC Services in Wales

Palliative care in Wales is intended to be available 24/7, with over 75% of the week falling into out-of-hours (OOH) periods. While there is good access to some elements throughout Wales, and while in some areas there is comprehensive coverage for at least some patient groups, there are important gaps. The task of this service specification is to make clear what should be available so that those gaps can begin to be addressed. Health Boards and Trusts are responsible for delivering both generalist and specialist PEoLC for adults, PPC for children, and young people across all settings, including hospitals, the community, care homes, hospices, homes, and secure environments like prisons.

PEoLC /PPC is embedded within the wider health and social care system, involving GPs, primary and community care, frailty and long-term condition services, local

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authorities, domiciliary care, urgent and emergency services, Welsh Ambulance Service Trust (WAST), the 111 service, and education and research providers.

Typical Arrangements for PEO LC / PPC in Wales

PEoLC/PPC services for adults and children are delivered through various arrangements across Wales, as outlined below:

1. **NHS Statutory Provision:** Some Health Boards provide their own NHS statutory services, including Specialist Palliative Care (SPC) Units, hospice beds, hospice-at-home services, and community SPC services. However, many Health Boards receive these services from voluntary hospice providers or use a combination of in-house and contracted voluntary services.
2. **Cross-Board Collaboration:** Certain Health Boards receive SPC services from other Health Boards or voluntary providers in different geographical areas to meet local demand.
3. **Day Therapy Services:** While day hospice therapy services are not typically contracted for, a few Health Boards with NHS statutory hospices provide day therapy provision as do some hospices.
4. **Cross-Border Services:** Due to geographical considerations, some Health Boards commission hospice beds and community providers in England to provide accessible care for Welsh residents in border areas, delivering a complex, interconnected network crossing organisational and national boundaries, to ensure people can access the care they need, regardless of location.
5. **Specialist Paediatric Palliative Care (SPPC):** The All-Wales Paediatric Palliative Care network (as hosted by Cardiff and Vale University Health Board) is distinct from adult PEO LC. Specialist paediatric palliative care is

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not currently under the remit of the Joint Commissioning Committee unlike most other tertiary paediatric services.

6. **Generalist Paediatric Palliative Care:** Generalist care for children is usually provided by healthcare professionals within a Local Health Board (LHB), including community children's nurses, neonatal teams, and general or community paediatricians.
7. **Enhanced or Wrap-Around Services:** These services, which aim to enhance quality of life, such as respite, are not routinely directly delivered by Health Boards and often rely on charitable funding, though they may be part of broader delivery arrangements with Health Boards.

Regional and Socioeconomic Considerations in PEO LC/PPC - Access to PEO LC/PPC is affected by rurality, deprivation, and demographic factors like age and marital status. Patients in rural areas and socioeconomically disadvantaged communities often face more barriers. Services must be designed to address the effects of these inequalities and respond to local needs. This underscores the need for coordinated service development and workforce planning between organisations and across community, home, hospice, and hospital settings.

Workforce and Policy Requirements - Future PEO LC/PPC delivery depends on a well-supported workforce, especially for out-of-hours care, which covers 75% of the week. Wales aims for a 24-hour response, with a two-hour standard for urgent cases, in line with the National Specification for Community Nursing (2022).^[18] Achieving this requires workforce investment and strong clinical training, guided by the Welsh Government's [Quality Statement](#) for PEO LC ^[1] and in line with the All Wales Competency Framework for PEO LC (2025).^[19]

Enhanced or Wrap-Around Care - Complementary therapies, respite, and psychosocial support, often charity-funded play a key role in holistic PEO LC/PPC but remain unevenly available. Some proven clinical interventions are not provided. Other elements may lack an evidence base but are known to improve

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wellbeing for people with clear preferences for them. There is a clear need to address the inequities in their provision.

Unpaid Carers in PEOLC/PPC - Unpaid carers, including family and friends, provide critical end-of-life support but face emotional, physical, and financial strain. Around 310,000 people in Wales (1 in 10) are unpaid carers.^[19] Many do not self-identify for years, and support is often reactive.^[17] Carers are more likely to be female, older, or retired, though many are working age. Surveys show many lack adequate skills or support, and caregiving can disrupt employment ^[20] Early identification and tailored support including respite and bereavement services are essential, particularly for parents of children with life-shortening conditions.

Current and Projected PEOLC Provision for Adults - Annual adult deaths in Wales are projected to rise from 36,378 in 2022 to 41,937 by 2048, over half among people aged 85+. A large majority of these people have a period of PEOLC need before their death, although that need is often identified late in the illness when significant opportunities to improve their care and their care utilisation have already passed by. A growing proportion have multiple chronic conditions. This growing medical and social complexity, mean that the scale of demand for PEOLC is growing more quickly than the number of people needing it. Dementia and cancer are expected to drive much of this demand. ^[17] Meeting future needs will require investment in both specialist and generalist services, supported by workforce planning and aligned policies, not only to give the right care but also to avoid the unaffordable costs of the alternative unplanned care.

Current and Projected PPC Provision for C&YP - In Wales, around 3,655 C&YP under 18, live with life-limiting or life-threatening conditions most of which result in childhood deaths. The prevalence of LLCs among children increased by nearly 25% between 2009 and 2019.^[21] This number is expected to rise further, with more young people living into adulthood with complex needs. Even with the All-Wales Paediatric Palliative Care network, regional gaps in service provision, especially in North and Mid Wales, highlight the need for better and more

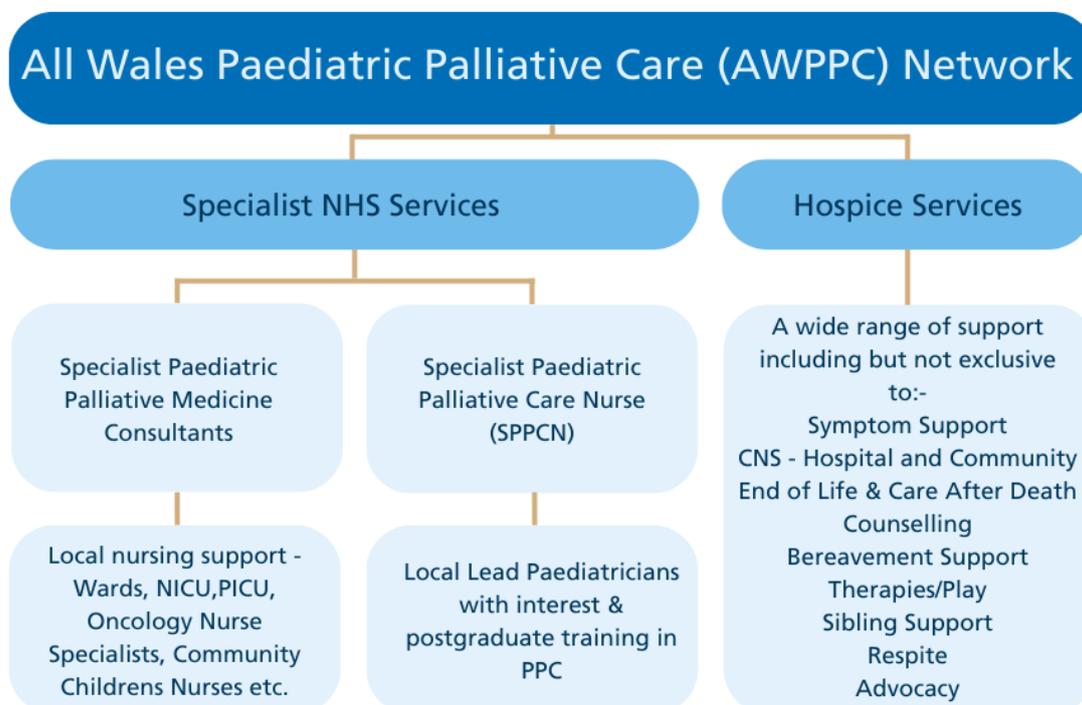
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equitable access, including transitional support to adult care and perinatal palliative care.

Specialist paediatric palliative care in Wales follows a model distinct from that for adults. Much of the palliative care needed by children with LLCs is delivered by unpaid carers and families, alongside local healthcare professionals who specialise in children’s care but may not have specific expertise in palliative care. The All-Wales Paediatric Palliative Care (AWPPC) network aims to equip these local caregivers with the necessary skills and knowledge to manage complex needs, thereby enhancing the quality of life for both children and their families. As children’s care trajectories often span their entire lifetimes, with respite care playing a critical role, this specification recognises the need for a distinct service delivery model for children. However, the core characteristics of palliative and end-of-life care must be preserved consistently across all age groups.

Figure 3.0 The All-Wales Paediatric Palliative Care (AWPPC) Network



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Palliative care for infants, C&YP in Wales encompasses over 300 different life-shortening or life-threatening conditions. Many of these children have severe disabilities, multiple and complex healthcare needs, often without a definitive underlying diagnosis, alongside their palliative care needs. Specialist palliative care may be required at various stages of a child or young person's life, and sometimes at multiple points.

There is a central tertiary team offering specialist support to a local network of paediatricians with an interest, General Practitioners with a special interest and specialist paediatric palliative care nurses (SPPCN), who in turn support general paediatric and primary care colleagues in caring for children with a life-limiting condition and their families. Many children access paediatric services through their GP and hospital paediatricians. Some children with LLC hardly need specialist input because their needs can be met by more generalist services. More often, generalists need to seek advice from the local lead or, as the condition progresses and symptoms become more complex, from the central specialist team. It is not unusual for the PPC specialist to become the child's *de facto* lead paediatrician_ especially in more complex cases or close to end of life.

PEoLC/PPC Services and Future Considerations

Based on current demographic projections, NHS Wales must focus on the following development priorities:

- Community-Based PEoLC/PPC: Expand capacity of community teams to support growing demand for home-based care and ease hospital pressures, as reflected in [A Healthier Wales](#) [2].
- Out-of-Hours Service: Strengthen access to district nurses (DN) /Community children's nurses (CCN) and clinical nurse specialists (CNS) to ensure consistent 24/7 access to palliative care.

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- Sustainable Hospice Funding: Establish sustainable, equitable funding models to ensure reliable hospice access across Wales.
- Specialist PEO LC/PPC Services: Expand provision for patients with complex needs and multiple conditions to address existing gaps where available services fall short of this specification now and as it evolves.
- Allied Health Professionals: Increase access and funding to AHP roles, embedding in teams to support holistic care.
- Digital and Remote Service: Enhance telehealth and remote monitoring to improve access, particularly in rural areas.
- Data requirements: Services are expected to contribute by collecting and using relevant data to help close these gaps. Improving PEO LC/PPC relies on better data collection and use, including activity, cost, outcomes, and experience areas where gaps remain. The National Clinical Programme is developing systems to generate insights across all aspects of PEO LC/PPC, supporting NHS Wales' value-based care goals.

Supporting Functions for PEO LC/PPC

To ensure that investment in PEO LC/PPC translates into measurable improvements in care quality, experience, and outcomes, robust supporting functions must be in place. These underpin the effective delivery and sustainability of services, enabling a coordinated, person-centred approach across settings. Key supporting functions include administrative support, digital infrastructure, data systems, and governance mechanisms.

Administrative and Operational Support

Administrative teams play an essential role in the day today running of PEO LC/PPC services. Their responsibilities include scheduling appointments, managing referrals, coordinating multidisciplinary team (MDT) meetings, and supporting timely and accurate documentation of care plans, including Future care plans

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(FCPs) ^[22] and Paediatric advance care (PAC) ^[23;24] plans. Effective administrative processes ensure continuity of care, facilitate communication, and maintain compliance with audit and governance requirements. With insufficient administrative and operational support, scarce clinicians find their time diverted from the expert care only they can offer.

Digital Infrastructure and Communication

Digital transformation is central to the coordination of PEO LC/PPC services. All professionals involved in PEO LC/PPC, including those in specialist roles and across all care settings, must document the care they provide using appropriate digital systems. Prioritising fit-for-purpose electronic record systems supports timely handovers, shared access to patient information, incident reporting (e.g. via DATIX), referral management, and care planning.

Digital platforms must:

- Enable real-time communication between MDTs.
- Support interoperability across Health Boards, providers, and hospices.
- Offer accessible, user-friendly interfaces for clinicians, administrators, and, where appropriate, patients and families.

Securing and sustaining these functions requires adequate digital workforce.

Data Management and Analytics [\(Appendix 1\)](#)

Improved PEO LC/PPC depends on high-quality data collection and analysis. This includes the routine capture and use of:

- Patient Experience Measures (PREMs) &/or other experience measures.
- Patient-Reported Outcome Measures (PROMs) &/or other outcomes measures.
 - *Outcomes data will help evaluate service impact and tailor personalised interventions.*

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- *Appropriate tools to measure both outcomes and experience are needed for C&YP; for adults the implementation of tools and systems is ongoing at the time of writing.*
- The All-Wales Core Data Set and PEO LC/PPC dashboards to monitor activity and guide improvement.
 - A Data Standards Change Notice (DSCN) for PEO LC will be required to support these data requirements.
- Predictive analytics to support service planning, based on demographic and clinical trends.

Technological Innovation

Innovative technologies offer opportunities to enhance care delivery and efficiency. These include remote monitoring tools to support symptom management at home, virtual consultations to increase access in rural areas, and mobile apps to help patients and carers manage medications, appointments, and resources. These innovations do not replace or replicate the distinct contribution of face-to-face contact but are a useful addition to it.

Education, Training, and Equity

Supporting functions must enable ongoing training in the use of digital tools and data systems. Training should also promote cultural competence and Welsh language accessibility, helping to ensure equitable and inclusive services.

Support for carers both paid and unpaid should include access to reliable information through a range of accessible formats.

Ensuring Equitable Digital Access

All digital tools must meet accessibility standards and be available in Welsh and English. To prevent digital exclusion, services must offer alternatives for those who lack digital literacy or access or who find digital systems harder to use. These systems are there to improve care, not to make some people's access harder.

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Digital Governance and System Readiness

Digital Health and Care Wales (DHCW), Health Boards, and Trusts must ensure that healthcare professionals have secure, real time access to patient records and the tools required to document care. This includes:

- Appropriate devices, network connectivity, and software.
- Structured, accessible clinical records with capacity for cumulative data use.
- Mechanisms for clinicians, including those in independent hospices, to access and contribute to electronic records on equal footing with NHS colleagues.
- Data infrastructure that enables patient feedback and secondary data use for governance, audit, and service planning.

Hospice IT and Digital Readiness

To support equitable digital care, Health Boards must ensure that hospice contracts include robust IT and digital provision. This includes hardware, licensing, and governance frameworks that support seamless and secure access to clinical systems.

Roles and Responsibilities

The following [table 1.0](#) outlines responsibilities of commissioners and providers, respectively. Commissioners are primarily Health Boards, but other organisations may have a commissioning function, for instance where a hospice commissions a service from another provider or where a service is centrally commissioned. Providers include NHS Trusts, hospices, independent or commercial sector organisations, charitable organisations, and health boards.

Where a health board provides care to its resident population, its responsibilities are those of both commissioner and provider. Most of the responsibilities outlined here will therefore fall to each health board.

Table 1.0 Responsibilities of Commissioners and Providers

Category	Commissioners (Including Health Boards in commissioning role)	Providers (Including Health Boards and voluntary organisations in provider role)
Roles and Responsibility	<ul style="list-style-type: none"> - Develop and align services with the Welsh Government’s Quality Statement and National Service Specification. - Ensure adequate funding for workforce, infrastructure, and digital systems. - Plan, commission, and manage local PEoLC/PPC services. - Collaborate with providers and voluntary organisations for integrated care. - Co-design services with patients, carers, and communities. - Ensure equitable access, including bilingual and culturally sensitive care. 	<ul style="list-style-type: none"> - Deliver care in line with this Service Specification, relevant quality standards, and evidence-based pathways. - Address national and local needs. - Collaborate across sectors and with commissioners and other providers to provide integrated, patient-centred care. - Support community engagement and co-design of services. - Ensure equitable care including language and cultural needs.

	<ul style="list-style-type: none"> - Support the recruitment, training, and retention of a skilled workforce. - Use national frameworks to monitor quality, performance, outcomes, and resource use. - Align voluntary sector input with strategic priorities. 	Voluntary organisations may provide specialist or supplementary services to address gaps identified in community engagement.
Category	Commissioners	Providers
Accountability & Insight	<ul style="list-style-type: none"> - Accountable to Welsh Government for PEO LC/PPC policy implementation and resource use. - Maintain governance frameworks to monitor quality, safety, and compliance. - Use audits, evaluations, and risk management. - Monitor performance with PROMs, PREMs, and other relevant measures including clinical outcomes. - Promote transparency through performance reporting. - Convene multi-agency forums to address systemic challenges. 	<ul style="list-style-type: none"> - Accountable to Health Boards for quality of care. - Conduct self-assessments, peer reviews, and patient surveys. - Ensure compliance with legal, professional, and regulatory standards. - Demonstrate transparency in equity of provision, service delivery, and funding <p>Voluntary providers are also accountable to trustees and regulators (e.g., Charity Commission, Health Inspectorate Wales, Care Inspectorate Wales).</p>
Category	Commissioners	Providers
Reporting & Escalation	<ul style="list-style-type: none"> - Receive regular reports from providers (including Health Boards and voluntary organisations). - Refer unresolved matters to Welsh Government and/or to NHS Wales Performance & Improvement via the National Programme for PEO LC, as appropriate. 	<ul style="list-style-type: none"> - Report regularly on outcomes, KPIs, and patient satisfaction. - Submit activity and performance data to Health Boards. - Escalate issues internally or externally as needed. - Participate in incident reviews, improvement plans,

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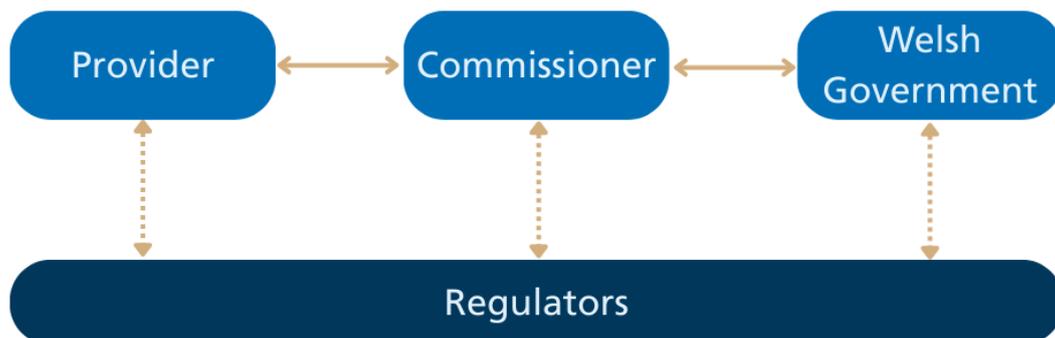
	<ul style="list-style-type: none"> - Convene strategic forums for improvement and innovation. - Publish performance reports for transparency. - Report to regulators as required. 	<p>and in the investigation of and response to complaints and concerns from patients, families and other bodies, cooperating with them as necessary in generating responses.</p> <ul style="list-style-type: none"> - Report to regulators and advocate for system improvements.
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Integrated Oversight and Escalation - Accountability Framework

- **Welsh Government:** Provides overall oversight via policy and funding.
- **National Palliative Care Steering Group:** To be set up and align local delivery with nationally identified priorities.

Figure 4:0 Reporting and Escalation Flow

Providers including hospices, NHS Trusts, health boards and commercial providers report on performance and incidents to **Health Boards Commissioners** (mainly **Health Boards**) escalate systemic issues or non-compliance to **Commissioners** and **WG** as necessary
Commissioners Escalate unresolved or critical matters to **Welsh Government**
All report to regulators as required



Feedback Loops Multi-agency reviews, community input, and patient feedback drive improvement and ensure compliance with national standards.

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Delivering on Key Performance Indicators All service providers delivering Palliative and End of Life Care (PEoLC/PPC) are expected to embed a culture of continuous quality improvement through the collection, monitoring, and utilisation of meaningful data. This includes a commitment to meeting and demonstrating progress against a defined set of Key Performance Indicators (KPIs), which will evolve over time in line with national priorities, emerging evidence, and local need. A DSCN for PEoLC will be required to support data requirements.

These KPIs will reflect the core service features and minimum standards outlined within this specification and are designed to ensure that care is equitable, timely, person-centred, and outcome focused. They will encompass both qualitative and quantitative measures across domains such as access, responsiveness, effectiveness, safety, patient and carer experience, workforce capability, and digital maturity.

Service providers are expected to:

- **Collect and report data** routinely using nationally agreed data sets and reporting frameworks, including the All-Wales PEoLC Dashboard and the Core Data Set.
- **Contribute to national benchmarking** to support transparency, identify variation, and inform service development at a local and national level.
- **Support the development and implementation** of systems to use measures of outcomes and experience, including the deployment of tools to capture the Core Outcome Set for PEoLC and to use those data in clinical care and in service development
- **Act on insights** from performance data, including Patient-Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs), to inform real-time improvements and longer-term planning.

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- **Demonstrate alignment** with the agreed minimum standards across all service features, ensuring that delivery is consistent, high quality, and responsive to the needs of individuals and their families.
- **Engage in audit and evaluation** activities, including national audits and peer review processes, to assess fidelity to service expectations and identify areas for development.
- **Support the development of future KPIs** by contributing data and feedback that reflects the complexity and diversity of PEOLC/PPC delivery across care settings and populations.

As the service evolves, the set of KPIs as part of a governance and assurance framework will be reviewed and refined to incorporate learning, technological advances, and changing population needs. Providers must therefore remain agile and committed to data-informed practice, demonstrating accountability and leadership in driving quality, consistency, and equity in palliative and end of life care across Wales.

Key Service Features Figure 5:0

These set out what end-of-life care services should provide across Wales. They should form an integral part of the PEOLC/PPC delivery model within each Health Board area. They include five core cross-cutting elements, with specialist palliative care and bereavement support as essential, overarching components.

Achieving these will require collaborative arrangements between service providers, with joint delivery approaches established to ensure the full range of services is available. They represent both the expected level of service and areas

for ongoing improvement and will be used to assess how well services are performing.

Each feature applies to adults, C&YP, or both groups, depending on the context. These features must be seen in line with national standards and guidance, some of which are relevant to all features such as:

- [NICE Guidance and/or Quality Standards](#) ^[9-16]
- Welsh Government's [Quality Statement](#) ^[1] for PEOC
- Welsh Government (2022) Wales Five Year Plan 2022-27 [More than just words \(gov.wales\)](#) ^[25]
- Welsh Government (2011) Welsh Language Standards Legislation [Welsh Language \(Wales\) Measure 2011](#) ^[26]

Figure 5:0 Key Service Features



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Timely and Equitable Access to Palliative Care

Adults, Children & Young People

Overview: Timely and equitable access to palliative care ensures that people and their families receive well-coordinated, personalised care when they need it. This characteristic covers the complete journey from identifying when someone might benefit from palliative care, through to taking quick action and ensuring 24/7 access to urgent care when needed.

Purpose: To help healthcare professionals identify patients who could benefit from palliative care as soon as they need it, coordinate thorough assessments that look at all aspects of patient needs (physical, emotional, spiritual, and social), ensure both general and specialist care teams can respond quickly and effectively, and reduce inequities arising from uneven timeliness of identification of PEO LC/PPC need across multiple dimensions of inequality. This includes making sure there are clear pathways for children transitioning to adult services, with planning starting from age 14.

Service Standard General:

- Healthcare professionals in all settings must have essential skills in palliative care, including managing symptoms, sensitive communication, and ethical decision-making, with reference to the relevant competency frameworks.
- Training programmes should be available to staff in all settings to support them in keeping updated on latest practices.
- Specialist teams should have arrangements to support people with face-to-face assessment in any hospital or community setting, including all types of hospitals, patients' own homes (or other people's homes where they are cared for), all types of care homes, hospices, and prisons or young offenders' institutions, without the setting causing delay.
- Services should have clear referral criteria and care needs identification tools readily available.

Assessment and Communication:

- Service providers should conduct thorough assessments to understand all patient needs and support accurate prognosis
- Service providers should ensure smooth communication between all care settings
- Hospital palliative care professionals should add adult patients (and where relevant children) identified in hospital to GP practice palliative care registers

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- Service providers should hold regular team meetings to identify patient needs and coordinate care
- GP practices should have a named contact within their local specialist palliative care team

Timely Action and Referral:

- Frontline clinicians must have capacity to deliver palliative care effectively
- Services should establish quick referral mechanisms that align with patient goals and preferences
- Services should refer to specialist teams when needs are complex (symptoms not responding to treatment, unstable conditions, complex psychosocial needs)

Emergency and Urgent Care:

- Commissioners should ensure provision is available to ensure 24/7 access to palliative care specialists
- Services should have clear referral pathways and communication with emergency services
- Training for emergency staff to support timely identification of palliative care needs should be in place.
- Pathways should be established to enable services to coordinate with ambulance services and out-of-hours GPs to reduce unnecessary hospital admissions

What can patients and families expect: You and your family will receive the care and support you need when you need it wherever you are.

- You will not be left waiting for care because of where you live, the time of day, or your background.
- Health professionals will recognise when palliative care could help you and act quickly.
- You will be able to access urgent advice and support 24/7, including weekends and nights.
- If things change suddenly, you will get a fast response from the right team at home, in hospital, in a care home, or another setting.
- If you are a child or young person, your needs will be picked up early, and you will be supported to move into adult services at the right time, in the right way.

**Adult Palliative Care Requirements:
When to Consider Palliative Care:**

**Paediatric Palliative Care Requirements:
When to Consider Palliative Care:**

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Based on Prognosis (Expected Survival):

- When clinicians would not be surprised if an adult patient died within the next year due to worsening condition
- However, waiting for certainty about prognosis can delay important care

Based on Need:

- When someone with a life-shortening illness has uncontrolled physical pain, emotional distress, spiritual concerns, or social problems
- This support can be provided alongside other treatments and does not mean giving up on recovery
- Identifying needs early helps patients get the right support without delay

Referral Sources for Adults:

[Use All Wales Referral and Discharge Guidance for adult SPCT Wales](#) ^[27] and standardised referral forms

- Routine referrals: first assessment within 14 days; urgent referrals: within 48 hours

Based on Prognosis (expected death in childhood):

For children: when clinicians would not be surprised if the child did not reach age 18 or when an unborn child has been identified with a condition incompatible with survival or expected to result in early childhood death.

Based on need:

- When a C&YP with a life-shortening illness has uncontrolled physical pain, emotional distress, spiritual concerns, or social problems
- This support can be provided alongside other treatments which whilst they may not be curative are designed to increase life expectancy
- Identifying needs early helps C&YP and their families get the right support without delay and increase family wellbeing outcomes

Referral Sources for Children: Will depend on the source of referral but are often made directly to the All-Wales PPC team by:

- General or community paediatricians
- Specialist paediatricians (oncologists, neurologists, intensive care doctors)
- Children's hospices
- Community children's nursing team
- Maternity/Foetal Medicine services (for Antenatal cases)

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It is unusual for a referral to come directly to specialist PPC from primary care as children with LLC all require a lead local paediatrician.

Referrals to the children's hospices are not dependant on the child being referred to/ known to the All-Wales PPC NHS team and referrals to this level of support can be made by any health, social care, or education professional as well as families self-referring. There are service specific pathways in place to support timely response to urgent referrals.

National Standards & Guidance:

- [NHS Wales Urgent and Emergency Care Programme](#) [28]
- [All Wales Referral and Discharge Guidelines for adult SPCT Wales](#) [27]
- All Wales Competency Framework for PEoLC 2025 [19]
- Association for Paediatric Palliative Medicine, Combined Curriculum in Paediatric Palliative Medicine [Combined Curriculum in Paediatric Palliative Medicine \(appm.org.uk\)](#) [29]
- [CPCET-Education-Standard-Framework.pdf](#) [30]
- RCN A career and education framework [Caring for Infants, Babies, Children and Young People Requiring Palliative Care](#) [31]

Supporting Tools/Resources:

- [Gold Standards Framework](#) Proactive Identification Guidance Tool (GSF PIG) [32]
- [Supportive and Palliative Indicator Tool \(SPICT\)](#) to aid early identification of palliative needs, ensuring proactive care planning and timely intervention [33]
- Nationally agreed [Community Health Pathways for Palliative and End-of-Life Care](#) [34]

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- [All Wales Care Decisions for the Last Days of Life Guidance](#) ^[35]
- Welsh language and culture [Care and Comfort in Welsh | Learn Welsh](#) ^[36]
- Care coordination platforms/systems
- Clinical decision support tools for emergency staff
- Patient/family education materials on accessing urgent palliative care

Personalised, Holistic and Compassionate Care

Adults, Children & Young People

Overview: This characteristic ensures that palliative and end-of-life care is tailored to each person's unique needs, wishes and values. It focuses on treating the whole person not just their illness by addressing physical symptoms, emotional wellbeing, spiritual needs, and social support. Care involves specialist teams (including specialist palliative care and other specialties) working together to provide expert support when needed, while ensuring compassionate care during the final stages of life.

Purpose: Person-Centred Approach

Care is designed around what matters most to each person and their family. This includes managing physical symptoms, supporting emotional and mental health, respecting spiritual beliefs, and meeting social needs. Care plans are flexible and can be adjusted based on personal goals, cultural background, and preferred ways of communicating.

Service Standards:

Everyone should be provided with the opportunity to discuss and document their preferences for future care. The provision of personalised care should include consideration of patient and family need for enhanced wraparound support; this is support that sits outside of medical care but can help improve the quality of life for patients and carers. It can include:

- Respite care - giving family carers essential breaks
- Emotional support - counselling and mental health services
- Complementary therapies - massage, aromatherapy, music therapy
- Practical help - assistance with daily tasks and social activities
- Spiritual care - support that respects individual beliefs and cultural needs

Ensuring access to enhanced wraparound care (Adults, C&YP)

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The services outlined above are often the added value services provided by the charitable sector and sit outside of the statutory service offer commissioned or provided by health boards. This does not make them any less important to the overall provision of personalised and compassionate palliative care and as such **commissioners should establish frameworks** for recognising the impact of such services on outcomes for patients and families and the potential effect on demand for more medicalised interventions.

You will be cared for as a whole person not just your illness.

- Your care will reflect your values, wishes, and cultural or spiritual needs.
- You will be supported emotionally, practically, and socially not just medically.
- Care plans will be created with you, not for you, and reviewed as your needs change.
- Support will be available for your family too including respite, counselling, and help with daily life.
- If you are a parent, carer, or loved one, your role will be recognised, and you will not be left to carry everything alone.

Service Requirements:

Future Care Planning (FCP) Adults

- Plans should include conversations about what is important to people including treatment options and where they would like to be cared for.
- Preferences and plans should be discussed at the right time in a sensitive way which recognises that preferences will emerge and

Paediatric Advance Care Planning (PAC) C&YP

- There should be a clear Wales-wide process for advance care planning in children, supported by documentation that is consistent across the country and, where possible, with parallel documentation in England; recognising that some C&YP are cared for in cross border arrangements.
- Plans should be well-designed with children and young people in mind acknowledging the needs and preferences of their families too.

<p>evolve over time so that more than one conversation will be needed.</p> <ul style="list-style-type: none"> • Plans should be regularly reviewed and updated as needed. • Plans should be clearly recorded and shared with relevant healthcare teams. • Plans should be accessible across different care settings. 	<ul style="list-style-type: none"> • Plans should be clearly recorded and shared with relevant health, social care, education teams and be accessible across the different care settings used by the children and young people. • Plans should be regularly reviewed to ensure they reflect any changing needs, deteriorations or improvements in condition and to take account of the child's stage of development and ability to engage in any future care discussions.
<p>Care in the Last Days of Life for Adults</p> <p>During the final days of life, care focuses on:</p> <ul style="list-style-type: none"> • Managing pain and symptoms safely and effectively • Stopping doing things which are no longer helpful • Rapid response to urgent needs • Supporting families through this difficult time • Respecting wishes about where someone wants to die • Ensuring dignified and compassionate care 	<p>Care in the Last Days of Life for C&YP</p> <ul style="list-style-type: none"> • During the final days of life, care focuses on: • Managing pain and symptoms safely and effectively and being clear about non escalation of treatment • Acknowledging wishes about preferred place of care/ death and supporting this preference where service provision means it is safe to do so • Ensuring dignified and compassionate care for child or young person and their family • Ensuring support is available both during standard hours and out-of-hours to provide expert guidance when needed, including clear processes for contacting specialist Paediatric Palliative Care consultants for advice.
<p><u>National Standards & Guidance:</u></p>	

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- [All Wales Referral and Discharge Guidelines for adult SPCT Wales](#) [27]
- [Future Care Planning Resources](#) [22]
- [Paediatric Advance Care Planning in Wales](#) [23;24]
- Sharing and Involving: Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Decisions for Adults in Wales [37]

Supporting Tools/Resources:

- [Supportive and Palliative Indicator Tool \(SPICT\)](#) to aid early identification of palliative needs, ensuring proactive care planning and timely intervention [33]
- [Gold Standards Framework \(GSF\)](#) to support high-quality, personalised PEOLC, fostering early discussions and continuous alignment with patient preferences [32]
- **Patient-Reported Outcome Measures (PROMs)** and **Patient Reported Experience Measures (PREMs)** to capture real-time feedback from patients on their care experience, including enhanced support, guiding service improvements.
- **Local Community Resources** and **Charitable Support Networks** to provide additional practical and emotional support
- **Quality Improvement Frameworks** NACEL indicator Goal 1: Improvement in individualised care plans, ensuring care plans are documented and address psychological, emotional, spiritual, and physical needs [38]
- **Quality Improvement Frameworks** NACEL Goal 3: Improving access to specialist palliative care 8 hours a day, 7 days a week, and a 24-hour advice line [38]
- Standardised pain/symptom assessment tools
- Family caregiver support resources
- Clinical decision support for end-of-life management
- Welsh language and culture [Care and Comfort in Welsh | Learn Welsh](#) [36]
- Resources and guidance on CPR: www.wales.nhs.uk/dnacpr [39]
- [Healthcare Inspectorate Wales review](#) re decision making about DNACPR [40]

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Coordinated and Integrated Services

Adults, Children & Young People

Overview: This characteristic ensures that palliative and end-of-life care is delivered through well-coordinated services that work together seamlessly. It covers care across all settings (home, hospital, hospice, care homes), supports smooth transitions between services, provides comprehensive support for families and carers, and uses modern technology to improve care coordination.

Purpose: To ensure that everyone receiving palliative care gets joined-up, person-centred support that is tailored to their needs recognising those needs change over time. This includes making sure services work together, families get the support they need, and young people moving from children to adult services have a smooth transition.

Service Standards:

Community Nursing Services:

Commissioners will support provider services to:

- Establish and maintain a 7-day-a-week community nursing service, including access to evening, weekend and overnight support
- Ensure community nurses can prescribe medications when appropriate or have pathways in place to ensure access to timely prescribing, particularly out of hours
- Providers will support the development of workforce skills in managing complex symptoms and providing holistic care at home.

Care Coordination:

Commissioners will ensure systems are in place to:

- Offer every patient access to a named care coordinator who acts as their main point of contact.
- Provide 24/7 telephone access through a single point of contact (e.g. "111 press 0") for advice and support for Health and Social Care Professionals and patients and families with a PEoLC/PPC need regardless of if they are known to local SPCT or hospice team.

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- Establish rapid transport services to help people get to their preferred place of care or PPD.

For children and young people:

Commissioners should work with providers to ensure sustainable arrangements to enable timely transfers between hospital, children's hospices and the family home for end-of-life care e.g. working with WAST EOL ambulance provision, paediatric/neonatal transport services, and voluntary WISH ambulance as appropriate.

Partnership Working:

Commissioners will work with providers on:

- Setting up Strategy Groups led by senior clinicians to oversee palliative care services.
- Working in partnership with NHS, social care, voluntary organisations and hospices.
- Ensuring contracts with hospices meet national standards.

Medication Access:

Commissioners will work with providers to:

- Ensure community pharmacies stock essential end-of-life medicines.
- Provide anticipatory medications / "Just in Case" bags medication.
- Enable paramedics to administer end-of-life medications when needed.
- Offer 24/7 medication advice for families and professionals.

Palliative Rehabilitation:

Service providers will:

- Ensure services take account of the need for palliative rehabilitation; this supports individuals in maintaining functional wellbeing and adapting to changing goals throughout fluctuating or declining health. It enables active living from diagnosis to end of life and is integral to care models for adults. ^[41]
- Due to the long-term nature of many of the life-limiting conditions experienced by C&YP the maintenance of functional wellbeing needs to be central to care delivered across a range of settings used by the C&YP.

Preferred Place of Care:

Service providers will:

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- Respect and support patients' and families' choices about where they receive care and where they die.
- Provide fast-track processes for hospital discharge to preferred location.

Provision of palliative care in care homes:

Providers of specialist palliative care will ensure that care homes have:

- Clear procedures for accessing pain relief medications and specialist equipment
- A named contact from the specialist palliative care team
- Support to engage in future care planning so residents' wishes are respected
- Access to appropriate training for care home staff

Provision of palliative care in prisons:

The unique challenges for this group, requires further and ongoing collaboration and development, utilising the [Dying well in Custody Charter](#) as appropriate ^[42]

Provision of palliative care transition pathways:

Commissioners should: ensure that provider services have established pathways in place to support the transition of young people from PPC to the most appropriate adult service provision. This process should begin from age 14 where appropriate. This may not always be to adult specialist palliative care or adult hospice services and may require signposting to other health and social care services.

Service providers should consider:

- Providing flexible arrangements wherever possible, where care is based on individual needs rather than strict age limits.
- Setting up Transition Pathway Clinics to support smooth handovers.
- Nominating adult specialist palliative care leads in each health board to work with children's teams and with the national specialist PPC lead for Transition.

Family and Carer Support:

Commissioners may request providers to offer the following services as non-commissioned services:

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- Provide timely assessments of carers' needs and signpost to appropriate support services.
- Offer training for unpaid carers on essential caregiving skills.
- Ensure access to financial advice and benefits guidance.
- Provide comprehensive bereavement support before and after death.
- Develop public education programmes about death and dying.

Digital and Administrative Support:

Commissioners will expect providers to:

- Use digital systems to share information between all care providers.
- Use of data and digital systems to understand workload, workforce, and caseload, to support project future workforce.
- Ensure all staff can access and update patient records in real-time.
- Provide suitable devices and technical support for all staff.
- Collect feedback from patients and families to improve services.
- Ensure digital systems work in Welsh and English and are accessible to people with disabilities.
- Maintain robust administrative support for scheduling, referrals, and coordination.

Quality and Safety:

Commissioners will expect providers to:

- Implement robust governance frameworks with risk management.
- Investigate incidents promptly and learn from them.
- Support staff wellbeing and provide appropriate training.
- Regularly measure patient and family experiences.
- Ensure cultural competency training for all staff.

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What this means for patients and families: Your care will be joined up across services, so you do not have to repeat yourself or fall through the gaps.

- Everyone involved in your care will talk to each other and share information appropriately.
- You will have one main point of contact who knows your situation and can help you navigate services.
- If you need help in a crisis, there will be a clear pathway to get the right care quickly.
- When moving between services for example, from children's to adult care, or from hospital to home the process will be planned and supported.
- Support for carers will be coordinated too, including practical help and bereavement support.

National Standards & Guidance:

- Refer to the [National Service Specification for Wales Bereavement and family support service feature](#) in this document
- National Continuing Health Care (CHC) Framework (2021) ^[43]
- [Welsh Government Transition Guidance](#) for Health Services ^[44]
- [All-Wales Future Care Planning Standards](#) ^[22]
- [All Wales Paediatric Advance Care Plan \(Pac-plan\)](#) ^[23]
- [Equality Act \(2010\)](#) ^[45] and [Accessibility Standards](#) ^[46]
- [Daffodil Standards for Community Pharmacy](#) ^[47]

Supporting Tools/Resources:

- [National Community Nursing Specification](#) ^[18]
- [Enhanced Community Care Virtual Wards](#) ^[48]
- 24/7 telephone advice line ("111 press 0")
- Rapid transport services for end-of-life care

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- CARiAD model for carer support ^[49]
- Six Steps to Success in End-of-Life Care Care Homes ^[50]
- Carer Support Needs Assessment Tool ([CSNAT](#)) ^[51]
- Remote consultation platforms
- [Dying well in Custody Charter](#) ^[42]
- Palliative rehabilitation interventions in palliative care ^[41]
- Death Literacy Health Boards and Providers should support the improvement of death literacy for unpaid carers to enable and support information on for example, *death as a normal part of life; planning; relieving suffering; final goodbyes*. This will have a similar construction to courses such as [Last Aid](#). ^[52]
- Provide round-the-clock access to **medication advice** 24/7 for professionals, patients, and families (This could include utilising services such as “111 press 0” to provide information on pharmacies, prescriptions, and dispensing of drugs).
- [Carer Aware](#) training programme ^[53]
- [National Bereavement Pathway](#) ^[54]
- Capture and utilise the outcomes and experience of patients and carers, including PROMS and PREMS for palliative and end of life care as part of a value-based approach
- Marie Curie Cymru (2024) Dying in Poverty in Wales 2024 ^[55]
- Carers UK (2022). [Cycles of caring: transitions in and out of unpaid care](#) ^[56]
- Welsh language and culture [Care and Comfort in Welsh | Learn Welsh](#) ^[36]

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Skilled Workforce and Continuous Learning

Adults, Children & Young People

Overview: To ensure all staff have the right skills and knowledge to provide high-quality, age-appropriate care. This means ongoing training and development based on national standards to deliver consistent, evidence-based care.

Purpose: To ensure that all staff involved in delivering palliative and end of life care, from generalist to specialist, and across all settings are equipped with the necessary knowledge, skills, and behaviours to provide safe, effective, age-appropriate, and compassionate care. This includes implementing structured, ongoing education and professional development aligned with national competency frameworks. A strong culture of learning, research, and workforce planning will underpin continuous quality improvement and innovation in service delivery.

Standard: Health Boards should ensure that specialist palliative care services have enough trained staff to meet growing needs

Commissioners should make provision to:

- Lead and support training for all healthcare workers who provide palliative and end of life care, as these are essential skills needed by all staff caring for people with life-limiting, life shortening illness.
- Work with universities and research partners to expand knowledge and improve evidence-based care in all areas of palliative and end of life care.
- Ensure patients and families have fair access to participate in research studies, promoting equal opportunities to contribute to improvements in care.
- Provide training to healthcare workers delivering core palliative care, while also contributing to training programmes for doctors, nurses and other health professionals. This includes offering practical placement opportunities.
- Ensure all healthcare workers providing palliative care have the right training, skills and knowledge to deliver age-appropriate, evidence-based care.
- Secure the collection of nationally agreed workforce data and their use for organisational and system-wide planning.
- Follow national competency standards for palliative and end of life care with relevant professions.

Research: Palliative care services should use current research findings in their practice and ensure adults; children and their families have equal access to well-designed research studies. They should have adequate resources to ensure:

- Sufficient administrative support for Welsh studies that can influence national policies and priorities.
- Adequate administrative support for participation in research projects with centres outside Wales to expand knowledge and evidence in all areas of palliative and end of life care for adults and children.

What this means for patients and families:

- You will be supported by staff who are trained, confident, and compassionate.
- Everyone involved in your care from GPs and nurses to care home staff and volunteers will have the right knowledge and skills.
- Staff will be trained to listen carefully, communicate sensitively, and care for people from all walks of life.
- Training will include supporting children, older adults, people with disabilities, and those with complex needs.
- If English or Welsh is not your first language, or you communicate differently, staff will do their best to support you.
- Services will keep learning from feedback and improving care over time.

Specific considerations re: Verification of Expected Death (VoED) Adults

Services should have proper systems in place to support death verification across all settings, ensuring this is done promptly by properly trained staff. All staff being aware of the role of the medical examiner. They should:

- Establish clear local processes to support timely death verification in all community settings, following HEIW All-Wales VoED guidance ^[57]

Specific considerations re: Verification of Expected Death (Children & Young People)

Verifying and certifying death in children follows the same core principles as adults, but with some specific considerations. Data about all child deaths in Wales informs the Public Health Wales [Child Death Review Programme](#). ^[58] A statutory response is required for unexpected deaths in childhood ([PRUDiC](#)). ^[59] All expected child deaths should be reported to the Medical Examiner (ME) service (as for adults). Expected deaths of children & young people that occur in a hospice setting can be verified by appropriately trained

- Ensure registered practitioners can access and complete All-Wales VoED competency training in all settings, enabling them to verify deaths confidently and according to best practices.

children’s hospice nurses in Wales. Guidance should be developed to replicate this approach within health board community teams to support timely verification of expected deaths of children and young people in all care settings across Wales. [60;61]

National Standards & Guidance:

- [VoED Guidance Adult](#) [57]
- VoED of a Children or Young Person (ABUHB 2021) [60]
- VoED Childrens Hospices (Hope House/Ty Gobaith 2024) [61]
- All Wales Competency Framework for PEO LC 2025 [19]
- [APPM national clinical competences for paediatric palliative care](#) [29]
- [CPCET-Education-Standard-Framework.pdf](#) [30]
- RCN A career and education framework [Caring for Infants, Babies, Children and Young People Requiring Palliative Care](#) [31]

Supporting Tools/Resources:

- HEIW Strategic Nursing Workforce Plan: 2025 – 2030 heiw.nhs.wales/files/strategic-nursing-workforce-plan-2025/ [62]
- HEIW Allied Health Professions Workforce Development Plan (2022) heiw.nhs.wales/files/ahp-workforce-development-plan/ [63]
- HEIW Workforce Planning Resources [Workforce planning resources - HEIW](#) [64]
- Social Care Wales – a workforce strategy for health and social care [A Healthier Wales – a workforce strategy for... | Social Care Wales](#) [65]
- A Healthier Wales: Our Workforce Strategy for Health and Social Care (2020) [A healthier Wales](#) [2]
- Welsh language and culture [Care and Comfort in Welsh | Learn Welsh](#) [36]

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Leadership, Governance and Quality Improvement Adults, Children & Young People

Overview:

This characteristic promotes a system-wide approach to delivering high-quality, person-centred palliative and end-of-life care (PEoLC) and paediatric palliative care (PPC) in Wales. It emphasises the importance of strong executive leadership, clear clinical accountability, and robust governance frameworks to support quality, safety, and integrated planning across health and social care. Central to this is the routine use of outcome and experience data including the Core Outcome Set for adult PEoLC, Patient Reported Outcome Measures (PROMs), and Patient Reported Experience Measures (PREMs) to inform service improvement, enhance patient and family experience, and ensure continuous quality improvement at all levels of care.

Purpose:

This characteristic ensures strong leadership, clear accountability, and a structured, system-wide approach to quality improvement in palliative and end-of-life care (PEoLC) and paediatric palliative care (PPC). It promotes high-quality, person-centred care through data-driven decision making, robust governance, and continuous monitoring of outcomes and experiences.

Health Boards and Trusts must:

- Appoint designated executive and clinical leads (medical, nursing, AHP) with responsibility for PEoLC and PPC.
- Establish quality and safety frameworks to support the delivery of specialist palliative care.
- Support operational leadership through identified lead managers.
- Promote integrated planning, contracting, and performance monitoring across health and social care sectors.
- Ensure systematic collection and use of patient-reported outcomes and experiences to inform service development and address gaps in provision.

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- Engage all PEO LC and PPC services in continuous quality improvement, audit, and evaluation at local, regional, and national levels with an aspiration for Wales to contribute to global palliative care benchmarking and learning.

Service Standard:

- Designated executive and clinical leads for PEO LC and PPC with clearly defined responsibilities
- Implement robust governance structures with regular multidisciplinary oversight of PEO LC and PPC strategy, quality, and safety
- Leadership teams are trained in value-based care and quality improvement methodologies
- Processes established to routinely collect, analyse, and act on outcome and experience data, clinical outcome data, risk/incidents, and mortality reviews
- All staff involved in data collection and analysis for PROMs and PREMs are appropriately trained
- Staff are supported and empowered to use data to drive service improvement
- Actively involve patients and families in co-design, feedback, and evaluation activities

What this means for patients and families:

You can feel confident that your care is safe, effective, and continuously improving because strong leadership and clear accountability are in place at every level.

- There are named leaders in every Health Board who are responsible for making sure care is high quality, well-coordinated, and person-centred.
- Your care will be informed by data, experience, and feedback including your own voice not just clinical guidelines.
- Services will actively listen to patients, families, and carers through surveys, conversations, and co-design activities, and use this feedback to make real improvements.
- Everyone involved in your care from hospital consultants to community team is supported to learn from what works and what needs to change.

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- Services are not just aiming to meet the minimum, but to raise standards across Wales and align with the best examples of palliative care globally.

In short, leadership and governance are not just about policies they are about making sure you and your family receive the best possible care, every time, wherever you are.

National Standards & Guidance:

- All Wales Competency Framework for PEO LC 2025 ^[19]
- [Association for Paediatric Palliative Medicine Combined Curriculum](#) ^[29]
- [CPCET-Education-Standard-Framework.pdf](#) ^[30]
- RCN A career and education framework [Caring for Infants, Babies, Children and Young People Requiring Palliative Care](#) ^[31]
- All-Wales Core Outcome Set and National Core Data Set for PEO LC
- Patient-Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) to capture real-time feedback from patients on their care experience, including enhanced support, guiding service improvements

Supporting Tools/Resources: (see Appendix 1)

- Patient/Family Engagement Platforms and Co-Design Frameworks
- NHS Improvement Clinical Governance Resources
- Feedback System (for capturing PREMs) e.g. CIVICA
- All-Wales PEO LC Dashboard and Core Data Set
- OACC measures (IPOS, Phase of Illness, modified AKPS, Views on Care, Zarit Burden Interview)
- Organisational Performance Dashboards
- Quality Improvement Methodologies (e.g. PDSA cycles, audit tools)
- Digital tools for real-time data collection, analysis, and visualisation
- Training programmes for leaders in value-based care and continuous improvement
- DDTIV Programme (supporting digital integration and data use)

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- HEIW Competency Frameworks refer to individual professional documents
- Welsh language and culture [Care and Comfort in Welsh | Learn Welsh](#) ^[36]

Specialist Palliative Care

Overarching Theme

Adults, Children & Young People

Overview: To ensure access to the expertise of adults and Children PEOC specialists' teams and/or professionals who can anticipate, prevent, minimise and manage crises, as well as provide appropriate and responsive care to address holistic and complex needs beyond the capacity of generalist teams. Core specialist multi-professional teams that support care across all environments and cater to all age groups, including antenatal care, children, as well as young people and adults. These teams core activity should include education and research functions, and they should function as integrated services across different care setting and be composed of:

- Professionals whose primary activity is delivery of specialist palliative care
- Staff with appropriate specialist qualifications and training
- Team members working at the relevant national competency levels to ensure high-quality care
- Sufficient staff in each group to offer genuine access at point of need so that they can offer this high-quality care without finding it compromised by them being too thinly spread ([Appendix 3](#))

Purpose:

Health Boards and providers should engage together and with service users to understand the population requirements, including unmet need, to inform development and delivery of services. SPC should be provided where and when the patient needs it, accessible across a wide range of care settings. Formal arrangements for community Specialist Palliative

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Care are required via a service level agreement (SLA) to overcome challenges of supporting patients where services (including general practice) cross health board boundaries or the border with England. Specialist palliative care services must have mechanisms to engage with, and capture the experiences of patients and carers, including PROMS and PREMS for palliative and end of life care as part of a value-based approach ([Appendix 1](#))

What this means for patients and families: If your needs are more complex, you will have access to expert care.

- You will be able to see or speak to professionals with advanced training in managing pain, symptoms, and emotional needs.
- Specialist teams will work across many areas so you can be supported wherever you are.
- If your care requires a hospice bed or hospice-at-home care, it will be available 7 days a week.
- Children and young people will be cared for by specialists trained in paediatric palliative care.
- These services will be there not just at the end of life, but from the time you need them.

Specialist Adult Palliative Care Standard:

Stage 1: Minimum Provision (Expected Current Standard)

- SPC face-to-face assessment (full service): available from 9am to 5pm on weekdays.
- SPC Urgent Clinical Assessment: face to face clinical assessment prioritising urgent referrals and assessments, available from 9am to 5pm on weekends and bank holidays.
- 24/7 SPC Medicine Telephone Advice: Round-the-clock telephone advice available for healthcare professionals, 24 hours a day, seven days a week.
- Support the provision of 24/7 telephone access through a single point of contact (e.g. "111 press 0") for advice and support for Health and Social Care Professionals and

Specialist Paediatric Palliative Care: Standard

A formal All-Wales Managed Clinical Network is necessary to ensure:

- Clear strategic and operational approaches to SPPC that permit development, delivery and monitoring of SPPC services that are equitable, high-quality, and effective.
- Collaborative working between statutory and third-sector providers of palliative care to children to allow co-production of prioritised strategic and operational delivery plans for palliative care in children.

patients and families with a PEOLC need whether known to local SPCT or not.

Stage 2: Enhanced Provision: In addition to Stage 1, the following should be provided:

- 24/7 SPC Medical Clinician Support: Telephone advice and if necessary face-to-face urgent assessment available from a palliative medicine consultant (+/- other supporting doctor) 24 hours a day, seven days a week, across any care setting. Not every patient needs to see a senior specialist doctor, but those who do must have access to one wherever they are cared for. Virtual assessment using videoconferencing offers more than telephone contact in some situations but does not fully reproduce the benefits of assessment in person.

Stage 3: Comprehensive Provision

Building on Stage 1 and 2, the following enhancements should be included:

- Expanded SPC Face-to-Face Assessment: Increased capacity for face-to-face assessments on weekends and bank holidays, tailored to local needs and determined by the specific models of service delivery in the area.
- Access to a range of additional specialist interventions where these are required, such as advanced anaesthetic and interventional pain techniques.

Progress is expected by the first review of the service specification

- A robust and coherent central mechanism that supports development, delivery and monitoring of palliative care services to children, and facilitates quality improvement where needed to comply with national recommendations such as those from the National Programme for Palliative and End of Life Care and the Welsh Government. [Quality Statement](#).^[1]
- Engagement and partnership with other stakeholders, including other acute and community paediatric specialties and providers of 'enhanced' care, especially children's hospices.
- Commissioners must ensure that senior PPC clinical leadership is in place to inform and support the Network's strategic development of palliative care to children across the country. The clinical leadership in PPC should mirror that of other paediatric specialties.

Specialist Paediatric Palliative Care Multi-Disciplinary Teams (MDTs): Specialist paediatric palliative care staffing for the delivery of those key core components demands a multidisciplinary team. Due to the number and distribution of C&YP with PPC needs in Wales, some professionals are locally embedded within health boards, others will have regional or national PPC

To achieve these standards Commissioners must ensure:

Specialist Adult Multi-Disciplinary Teams (MDTs): to ensure access to a comprehensive range of highly skilled professional advice and management for optimal end of life care.

Commissioners must ensure within a locality, the SPC MDT must have arrangements in place to include input from core professionals with relevant specialist qualifications, skills and experience in palliative care, and must have arrangements in place for input from key professionals with additional specialist training and experience, who may not be engaged full time in specialist palliative care, but with flexibility to input to the MDT when required [See Table 2.0](#) services should take the obvious and achievable step of recording the relevant workforce data.

Specialist Palliative Care Inpatient Beds: In each health board area, there is a need to provide adequate provision of specialist palliative care in-patient beds or hospice beds that meet the needs of the local population and ensures there are enough beds for all individuals who need them. There may be some warranted variation in distance to the inpatient unit, it is essential that the provision is genuinely accessible and not merely available 'in principle'

service responsibilities. [See Table 3.0](#) services should take the obvious and achievable step of recording the relevant workforce data.

To achieve these standards Commissioners must ensure:

- Paediatrician (Level 3) with palliative care expertise and appropriate dedicated time in every Local Health Board.
- Specialist palliative care consultant (Level 4) cover for each of the Local Health Boards across Wales.
- Specialist palliative care consultant (Level 4) and/or nurse based at Cardiff Children's Hospital to link with paediatric and neonatal intensive care units.
- National strategic lead for Transitional Palliative care to ensure appropriate local transition pathways are developed and implemented
- Access to specialist PPC medical advice by frontline local teams seven days a week, ensuring that families and local healthcare professionals receive timely guidance and support.
- Sufficient administrative support is available to the SPPC Network to enable prompt interactions

Hospice at Home dedicated 'Hospice at Home' services, or their equivalent, are available to support core care delivery at home

7-day Clinical Nurse Specialist Service:

- As a minimum provide a clinical nurse specialist palliative care service for adults and children that operates 7 days a week, from 9am to 5pm including Bank Holidays. This service should cover inpatient, community, and hospice settings to ensure comprehensive holistic palliative care support
- Ensure that clinical nurse specialists are available to conduct face-to-face assessment when required, providing timely and personalised care.
- Record outcome data in alignment with national standards to contribute to National PEOC Data Dashboard, ensuring consistent monitoring and evaluation of service effectiveness.

Specialist Palliative Allied Health Professional (AHP)

Provision: Health Boards and Providers should urgently prioritise embedding a core AHP resource and enhancing pathways to AHP provision in their services. Strengthening this resource will enable earlier interventions, with evidence indicating that the greatest benefit is achieved when AHPs are involved with patients for at least a 3-months.

between specialist and local paediatric teams as needed.

Hospice at Home: dedicated 'Hospice at Home' services, or their equivalent, are available to support core care delivery at home.

Commissioners should ensure that:

- Dedicated PPC services are available to support core care delivery at home for children.
- These services should provide 24/7 support where it is needed and should work collaboratively with community nursing and other children's nursing services.
- Locality based Clinical Nurse Specialist support (SPPCNS) should be available in all areas of Wales and resourced to provide a 7-day service to ensure access by families and local healthcare professionals to comprehensive holistic palliative care support.
- Arrangements are in place to provide a "pop up" palliative care model delivering 24/7 nursing support for children at home in the immediate days/weeks before death, in partnership with hospices or informed by evidenced-based models of care, such as the Palliative Care

- Health Boards should work with partners to establish agreed minimum levels of AHP provision, ensuring that services meet the needs of their population effectively.
- The configuration of core AHP resources should be determined at local level, considering factors such as disease prevalence, deprivation index, and population demographics to ensure that services are responsive to the unique needs of each community.

Inpatient Hospice/Inpatient Unit (IPU) Referral: To ensure equitable access and referral and support adults' preferred place of care, collaboration will be required to **achieve the following milestones by the first review of this specification**

- Establish a clear and standardised referral process for admission to adult inpatient specialist units and hospice inpatient units, based on assessed need, ensuring that the process is accessible and transparent
- Develop local arrangement to expand access for urgent hospice admissions, particularly during out-of-hours periods
- Ensure that hospice admission is available a minimum of 7 days a week from 9am to-3pm by 2026 and extend availability to 9am to 5pm by **the first review of this specification**

Children's Out-reach In-reach Nursing Service (COINS) ^[66]

Such support can be delivered in various ways, depending on local arrangements, including:

- Third-sector providers (e.g. Children's Hospices)
- Domiciliary care agency providers
- Statutory sector providers
- A combination of these options.

In-patient beds: as there are no statutory inpatient beds for children requiring palliative care, *commissioners must ensure* that such care is delivered through arrangements with children's hospices who provide beds for SPPC. *Commissioners should ensure* adequate access to SPPC in-patient beds that correspond to the population of children with LLC within their area.

- Guarantee that all adult patients in Wales have access to a SPC inpatient unit (SPCIPU) in a hospice or NHS unit, in addition to access to hospice at home, ensuring comprehensive coverage for all geographical area

Where a nurse or AHP has a leadership role or one with a significant autonomous advisory component (such as in a community, hospital or nurse led clinic) they should be a Clinical Nurse Specialist, Advanced Nurse Practitioner or Nurse /AHP Consultant in Specialist Palliative Care.

For specialist palliative care in-patient units, out-patients and day therapy, such as in hospices, this will also include a range of palliative care nurses (both registered and non-registered) working across the services, including those with additional responsibilities, for example, practice development.

National Standards & Guidance:

All Wales Competency Framework for PEO LC 2025 ^[19]

For children, these competencies should be in line with:

Association for Paediatric Palliative Medicine, Combined Curriculum in Paediatric Palliative Medicine [Combined Curriculum in Paediatric Palliative Medicine \(appm.org.uk\)](#) ^[29]

[CPCET-Education-Standard-Framework.pdf](#) ^[30]

RCN career and education framework [Caring for Infants, Babies, Children and Young People Requiring Palliative Care](#) ^[31]

Children's Out-reach In-reach Nursing Service (COINS) when supporting Infant's, C&YP ^[66]

[All-Wales Future Care Planning \(FCP\)](#) Standards, providing structured guidance on early planning conversations ^[22]

[All Wales Paediatric Advance Care Plan \(Pac-plan\)](#) ^[23]

National Policy [Sharing and Involving: Do Not Attempt Cardiopulmonary Resuscitation \(DNACPR\) Decisions for Adults in Wales](#) ^[37]

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Supporting Tools/Resources:

- [Supportive and Palliative Indicator Tool](#) (SPICT) to aid early identification of palliative needs, ensuring proactive care planning and timely intervention ^[33]
- [Gold Standards Framework](#) (GSF) to support high-quality, personalised PEOLC, fostering early discussions and continuous alignment with patient preferences ^[32]
- [All Wales Referral and Discharge Guidelines for adult SPCT Wales](#) ^[27]
- Patient-Reported Outcome Measures (PROMs) and Patient Experience Measures (PREMs) to capture real-time feedback from patients on their care experience, including enhanced support, guiding service improvements **(Appendix 1)**
- Local Community Resources and Charitable Support Networks to provide additional practical and emotional support services
- Quality Improvement Frameworks NACEL indicator Goal 1: Improvement in individualised care plans, ensuring care plans are documented and address psychological, emotional, spiritual, and physical need **(Appendix 2)**
- Quality Improvement Frameworks NACEL Goal 3: Improving access to specialist palliative care 8 hours a day, 7 days a week, and a 24-hour advice line ^[38]
- Welsh language and culture [Care and Comfort in Welsh](#) ^[36]
- Resources and guidance on CPR: www.wales.nhs.uk/dnacpr ^[39]
- [Healthcare Inspectorate Wales review](#) re decision making about DNACPR ^[40]

Table 2.0 Specialist PEOLC Multi-Disciplinary Teams (MDTs) Core professionals with the requisite specialist qualifications, skills, and experience in SPC	Key professionals with additional specialist training and experience, who may not be engaged full time in SPC
Consultants, Doctors, and appropriate medical clinicians specialising in palliative care	Interventional Pain Specialists
Nurses specialising in palliative care	Medical Ethics and Legal experts
Occupational Therapists specialising in palliative care	Volunteers
Paramedics specialising in palliative care	Welfare Rights Services
Pharmacists specialising in palliative care	Arts Therapists (art, drama, play and music)
Physiotherapists specialising in palliative care	Complementary Therapies Professionals

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Dieticians specialising in palliative care	Bereavement Care Providers
Speech and Language Therapists specialising in palliative care	Education
Social Workers specialising in palliative care	Disease specific specialists, e.g. Oncologist
Psychologists specialising in palliative care	
Faith and Spiritual Care Leaders or practitioners	
In addition, there should be A Lead NHS Operational Manager for the SPC Service alongside administrative and secretarial staff	
Table 3.0 Specialist paediatric palliative care (SPPC) staffing <u>Core</u> professionals with the requisite specialist qualifications, skills, and experience in PPC	Key professionals with additional specialist training and experience, who may not be engaged full time in PPC
Consultants in Paediatric Palliative Medicine (Level 4)	Disease specific specialist paediatricians e.g. Paediatric Oncologist
Specialist Paediatric Palliative Care Nurses/Clinical Nurse Specialists	Condition specific nurse specialists e.g. oncology outreach nurses, respiratory, cardiac, epilepsy, metabolic, neuromuscular
Paediatricians with an interest/expertise in PPC (Level 3) within a health board	Interventional Pain Specialists
General Practitioners with a special interest (e.g., children's hospice medical officer)	Medical Ethics and Legal experts
Paediatric pharmacists with PPC expertise	Paramedic with expertise/lead role in PPC
Paediatric Clinical Psychologists and/or Play Therapists with PPC expertise	Faith and Spiritual Care Leaders or practitioners
Social Work/Advocacy professionals	Paediatric physiotherapists
Play specialists with expertise in PPC	Paediatric speech and language therapists
Bereavement Care Providers	Paediatric occupational therapists
	Paediatric dietitians
	Education professionals
	Arts Therapists (art, drama, play and music)
	Complementary Therapies professionals
In addition, there should be a dedicated All-Wales PPC Network Manager to work with lead NHS Operational Manager and administrative/secretarial staff for the specialist PPC service	

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Bereavement and Family Support

Overarching Theme

Adults, Children & Young People

Overview: Bereavement is an experience that affects everyone at some point, often multiple times throughout life. Grief, our natural response to loss is not an illness but a deeply personal process that varies greatly from person to person. While grief is a normal reaction, its impact can be profound and far-reaching. The vision for Wales, as outlined in the National Framework for the Delivery of Bereavement Care in Wales,^[3] is for a compassionate Wales where everyone has equitable access to high quality bereavement care and support to meet their needs effectively at the time they need it. Support is required for individuals both before (anticipatory grief) and following the death of someone significant in their lives. It includes bereavement due to the death of any person, including those who die before birth for any reason and at all gestation ages.

Purpose: To ensure that good bereavement support is available to everyone who needs it. The National Framework ^[10] defines the responsibilities to ensure that bereavement support is universally available. As part of the framework's implementation a national bereavement pathway for Wales is being developed. It is a multi-disciplinary and multi-agency approach to the bereavement journey and includes a model specification (over-arching pathway) and bereavement specific modules, offering information and guidance to all those involved in providing bereavement support to create a consistent approach to accessing bereavement support across Wales.

Standard:

All staff who encounter bereaved people must have the necessary skills to support them, appropriate to their role.

Bereavement care should be an integral part of palliative and end of life care across all health and social care settings.

Providers must ensure that **staff are skilled and compassionate**, with bereavement awareness training appropriate to their role. Those delivering end of life care should be equipped to offer sensitive, culturally appropriate support. Services should follow a **tiered model of bereavement care**, including universal support from all staff, targeted help for those at risk of complex grief, and access to specialist services where needed.

Providers must offer **timely, accessible information** on grief and support options, including formats in Welsh and Easy Read, and ensure there is **appropriate follow-up** after a death. Care must be **inclusive and equitable**, respecting cultural, language, spiritual, and LGBTQ+ needs, and accessible to all communities.

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Services should be responsive and continuously improved through the **collection of feedback and data** from bereaved individuals

Commissioners must ensure a **coordinated**, clear structure for delivery and referral across all relevant settings.

Investment in **training and workforce development** is essential, ensuring staff in all settings have the skills to support bereaved individuals appropriately. Services must be **inclusive and accessible**, meeting Welsh language requirements and the needs of diverse communities, including those in rural and underserved areas.

Commissioners should **monitor outcomes and service quality**, using data and feedback from bereaved people to drive improvements. Collaboration with the **voluntary sector** is vital to ensure a joined-up and sustainable approach to bereavement care.

What this means for patients and families:

- Support will be available for you and your family before and after someone dies.
- You will not be left alone to deal with grief or loss.
- Support can start before the person dies (anticipatory grief) and continue after.
- Services will offer counselling, peer support, and practical advice tailored to your needs.
- Bereavement care will be available for everyone including parents who lose a child, children who lose a parent, and families experiencing pregnancy or baby loss.
- You will be treated with compassion, and your grief will be respected.

National Standards & Guidance:

- National Framework for the Delivery of Bereavement Care in Wales ^[3]
 - [The UK Commission on Bereavement's Report](#) ^[67]
 - [National Bereavement Pathway](#) ^[54]
- All Wales Competency Framework for PEO LC 2025 ^[19]

Supporting Tools/Resources:

- Welsh language and culture [Care and Comfort in Welsh | Learn Welsh](#) ^[36]
- [VoED Guidance Adult](#) ^[57]

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- VoED of a Children or Young Person (ABUHB 2021) ^[60]
- VoED Childrens Hospices (Hope House/Ty Gobaith 2024) ^[61]

Appendix 1 Quality and Safety

Adult

Specialist palliative care services must have mechanisms to engage with, and capture the experiences of patients and carers, including PROMS and PREMS for palliative and end of life care as part of a value-based approach.

Qualitative Measures:	Quantitative Measures:
PREMS / National PEOLC Patient and Carer Survey	PROMS - Integrated Palliative care Outcome Scale & Support Team Assessment Schedule (iPOS, STAS) ^[68]
Patient Stories	Care Decisions Guidance Case Review Sheets
CARiAD structured de-briefs	CARiAD carer diaries
Bereavement surveys	SPC workforce: (WTEs, Sickness, Retention)
Concerns / Datix incidents /Thank you letters	SPC operational service delivery: <ul style="list-style-type: none"> - Referral activity (numbers and reason) - Response times - Demographic data - Demands and need for service during different times of the day (including 111/999) - Levels of intervention - Palliative care register - Provision of bereavement support
Llais feedback	SPC referral outcomes: <ul style="list-style-type: none"> - Preferred / actual place of death - Rate of readmissions / unscheduled care episodes for SPC patients
Mortality / Medical Examiner feedback	SPC nonclinical activity: <ul style="list-style-type: none"> - Demand for / delivery of PEOLC training and education
Staff survey / feedback (of wider HCPs)	Number of meetings attended by SPC in the health board / organisation
NACEL surveys (staff / bereavement)	% of deaths across all care settings
Evaluation of training and education provided by the SPC service	FCP documentation (number of / communication)
Staff survey (of SPCT MDT members)	Last Year of Life Dashboard

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	NACEL case note reviews / organisational audit / report
	Admission to ED/AMAU for patients with chronic conditions in relation to time of death
	Health economics for SPC models of care (efficiency of cost per intervention /interaction)

Children and Young People

Qualitative/Quantitative Measures	Performance indicators
PROMS Children's Palliative Outcome Scale (C-POS-UK) ^[69]	Percentage of children with LLC in Wales referred to team
'Patient stories' via LHB Patient Experience teams	Percentage of children dying from LLC who are known to the PPM team at the time of death
Feedback from parents while child is alive	Percentage of children dying with LLC who have PAC-Plan (indicator of timely discussion about death)
Patient-reported Experience Measures using the Civica system adapted for paediatrics	Time from referral to PAC plan
Feedback from parents after child's death	Percentage of children dying under the team who were not recognised as 'red' or 'amber'
Feedback from bereavement staff after child's death	Percentage of children dying from LLC in preferred place of death
Feedback from colleagues	Percentage of children dying under the team who had uncontrolled symptoms in the days leading up to death
	Percentage of deaths of children under the team reported to PRUDIC (indicator of timely communication with other services about death)
	Percentage change in symptom severity from baseline

Appendix 2 Governance and Quality Monitoring

The service will adopt NACEL's Healthcare Improvement Plan metrics as a cornerstone for evaluating care quality. Annual quality reports will track progress against the NACEL five improvement goals, such as increasing the proportion of patients with holistic, individualised care plans and improving access to 24/7 specialist palliative care.

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Data collection will follow NACEL's established methodologies, ensuring a robust framework for identifying and addressing areas for improvement.

Data from NACEL's case note reviews, quality surveys, and staff surveys will inform annual reporting and continuous improvement plans. The service will benchmark its performance against NACEL's primary indicators.

Appendix 3 Workforce and Resource Planning

Minimum Staffing Standards

To meet growing and increasingly complex palliative care needs in Wales, updated minimum staffing standards for specialist services will be developed as part of the National Programme future workplan. This work will align with the adult PEOLC competency framework and existing children's frameworks.

Key actions include:

- Analysing current staffing levels against service demands and demographic trends
- Collaborating with clinical experts, workforce planners, and educators to design sustainable staffing models
- Setting clear milestones for implementing updated standards
- Prioritising recruitment, retention, training, and staff wellbeing to support a skilled, resilient workforce

Funding and Support for Charitable Hospices

Hospices in Wales play a crucial role in delivering holistic palliative and end-of-life care across inpatient, community, and at-home settings. They address not only physical health but also emotional, psychological, spiritual, and practical needs, supporting both patients and their families.

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While NHS funding supports some core services, many hospices rely heavily on charitable donations to provide enhanced care such as complementary therapies, emotional support, bereavement counselling, and financial or spiritual guidance, services highly valued by patients and families.

For the children's hospices NHS funding does not currently cover the total costs of providing specialist PPC, including in-patient beds and specialist nursing in the community; the continued provision of these services also often relies on charity funds.

These enhanced services, identified by patients and families as central to the delivery of compassionate palliative care are often not directly delivered by Health Boards, creating additional demand and funding pressures for hospices.

To address this, the National PEOC Programme, in partnership with the Joint Commissioning Committee, is developing an NHS Wales funding framework. This will explore embedding inflationary uplifts, address staff retention, and Agenda for Change issues, and provide clear guidance on service level agreements, supporting sustainable and equitable hospice care.

Future Proofing and Review Cycle

The National Service Specification for Palliative and End of Life Care in Wales must remain responsive, equitable, and sustainable amid changing needs and care advancements. A structured review framework will ensure continuous improvement and alignment with best practice.

Informed by emerging evidence on costs, workforce needs, and demographic trends especially an ageing population and rising complexity of care the framework will also address cultural, linguistic, and socio-economic equity.

Key priorities include:

- Workforce planning focused on recruitment, retention, and upskilling
- Integration of digital tools, AI, and predictive analytics to enhance access and efficiency
- Cross-sector collaboration between NHS, voluntary, and social care providers
- Ongoing feedback from patients, families, and staff to guide service improvement

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Feedback and Review Mechanisms

To ensure continuous improvement, a range of feedback and review processes will be implemented and refined:

Annual Service Monitoring

- Review key indicators: patient outcomes, access, and workforce capacity
- Escalate urgent issues and identify areas for improvement

Comprehensive 3-Year Review

- Assess overall service effectiveness and financial sustainability
- Update the specification based on demographic shifts, evidence, and policy changes

Continuous Quality Improvement (CQI)

Set up of a quarterly Palliative Care Steering Group which will:

- Monitor performance metrics
- Recommend service model updates
- Support cross-sector collaboration

Stakeholder Engagement

- Gather input from professionals, patients, families, and partner organisations to shape service delivery

Research and Innovation

- Integrate national and international evidence
- Pilot new care models, including hospice-at-home and AI-driven tools

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References

- [1] Welsh Government (2022) [Quality Statement](https://gov.wales/quality-statement-palliative-and-end-life-care-wales-html) for palliative and End of Lifecare for Wales. <https://gov.wales/quality-statement-palliative-and-end-life-care-wales-html> (accessed 23/07/25)
- [2] Welsh Government (2021) 'A Healthier Wales' <https://www.gov.wales/sites/default/files/publications/2021-09/a-healthier-wales-our-plan-for-health-and-social-care.pdf> (accessed 23/07/25)
- [3] Welsh Government (2021) Guidance: National framework for the delivery of bereavement care [National framework for the delivery of bereavement care | GOV.WALES](https://gov.wales/national-framework-for-the-delivery-of-bereavement-care) (accessed 23/07/2025)
- [4] Welsh Government National Clinical [Framework](https://www.gov.wales/national-clinical-framework-learning-health-and-care-system) <https://www.gov.wales/national-clinical-framework-learning-health-and-care-system> (accessed 23/07/25)
- [5] Welsh Government (2023) The Duty of Quality Statutory Guidance 2023 and Health and Care Quality Standards 2023 https://www.gov.wales/sites/default/files/publications/2023-04/duty-of-quality-statutory-guidance-2023_0.pdf (accessed 23/07/25)
- [6] Welsh Government (2021) Right care, right place, first time Six Goals for Urgent and Emergency Care [Right care, right place, first time: Six Goals for Urgent and Emergency Care - A policy handbook 2021-2026 \(gov.wales\)](https://gov.wales/right-care-right-place-first-time-six-goals-for-urgent-and-emergency-care-a-policy-handbook-2021-2026) (accessed 23/07/2025)
- [7] Welsh Government (2021) Health and Social Care in Wales – COVID-19: Looking forward [health-and-social-care-in-wales--covid-19-looking-forward_0.pdf \(gov.wales\)](https://gov.wales/health-and-social-care-in-wales-covid-19-looking-forward_0.pdf) (accessed 23/07/2025)
- [8] Welsh Government (2021) Quality and Safety Framework: Learning and Improving Duty of Quality Statutory Guidance. [Quality and Safety Framework: Learning and Improving \(gov.wales\)](https://gov.wales/quality-and-safety-framework-learning-and-improving) (accessed 23/07/2025)
- [9] NICE guideline [NG31] Care of dying adults in the last days of life 2015 (accessed 23/07/25)
- [10] NICE guideline [NG142] End of life care for adults: service delivery 2019 (accessed 23/07/25)
- [11] NICE quality standard [QS13] End of life care for adults 2021 (accessed 23/07/25)

NHS Wales Performance and Improvement

National Service Specification for Wales: Palliative and End of Life Care **V1.2 Final Version**

- [12] NICE guideline [NG61] End of life care for infants, children, and young people with life-limiting conditions: planning and management (accessed 23/07/25)
- [13] NICE quality standard [QS144] NICE QS144: Care of Dying Adults in the Last Days of Life – standards to promote personalised care planning and effective symptom control (accessed 23/07/25)
- [14] NICE quality standard [QS160] End of life care for infants, children, and young people (accessed 23/07/25)
- [15] NICE guideline [NG197] Shared decision making 2021 (accessed 23/07/25)
- [16] NICE guideline [NG43] Transition from children to adults’ services for young people using health or social care services (accessed 23/07/25)
- [17] Office for National Statistics (2023) [Unpaid care by age, sex and deprivation, England and Wales: Census 2021](#) (accessed 23/7/2025)
- [18] Strategic Programme for Primary Care (2022) The Service Specification for Community Nursing; <https://primarycareone.nhs.wales/tools/community-infrastructure-ci-programme/community-infrastructure-ci-programme/national-community-nursing-specification-v1-jan-23pdf/> (accessed 23/07/2025)
- [19] HEIW All Wales Competency Framework for PEoLC (2025)
- [20] Marie Curie (2024) Better End of Life, Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales [beol-2024-time-to-care-report.pdf \(mariecurie.org.uk\)](#) (accessed 23/7/2025)
- [21] Fraser, L., Bedendo, A., & Jarvis, S., (2023) Trends in Prevalence and Complexity Report “Children with a Life-limiting or Life-threatening condition in Wales: Trends in prevalence and complexity” National Programme Board for Palliative and End of Life Care available from <https://www.hopehouse.org.uk>
- [22] Advance & Future Care Planning www.wales.nhs.uk/afcp (accessed 23/07/2025)
- [23] Cardiff & Vale University Health Board (2016) All Wales Paediatric Advance Care Plan (Pac-plan) Policy for Patients Under 18 Years of Age with Life Threatening or Life Limiting Illness cavuhb.nhs.wales/files/policies-procedures-and-guidelines/patient-safety-and-quality/pac-plan-trust-policy-2016-v14-pdf/ (accessed 23/07/25)

NHS Wales Performance and Improvement

National Service Specification for Wales: Palliative and End of Life Care **V1.2 Final Version**

- [24] Together for short Lives (2022) [Care Planning in Advance - Together for Short Lives](#)
- [25] Welsh Government (2022) More than just words gov. Wales Five Year Plan 2022-27 [More than just words \(gov.wales\)](#) (accessed 29/07/2025)
- [26] Welsh Government (2011) Welsh Language Standards Legislation [Welsh Language \(Wales\) Measure 2011](#) (accessed 23/07/2025)
- [27] National Palliative and end of Life Care Programme (2024) Referral and Discharge Guidelines for adult SPCT Wales [Referral and Discharge Guidelines for Adult SPCT Wales.docx](#)(accessed 23/7/2025)
- [28] NHS Wales Urgent and Emergency Care Programme [Urgent and emergency care programme - HEIW](#) (accessed 23/7/2025)
- [29] Association for Paediatric Palliative Medicine [Combined Curriculum in Paediatric Palliative Medicine \(appm.org.uk\)](#) (accessed 23/07/2025)
- [30] Neilson, S., McNamara, K., and Randall, D. (2020) *Children's Palliative Care Education Standard Framework: UK and Ireland*. 1st ed. [CPCET-Education-Standard-Framework.pdf](#).CPCET UK and Ireland Action Group. Available at: <https://www.togetherforshortlives.org.uk> (accessed 23/07/2025)
- [31] Royal College of Nursing (2025) Caring for Infants, Babies, Children and Young People Requiring Palliative Care A career and education framework 3rd Edition
- [32] Gold Standards Framework (GSF) (2022) - Proactive Identification Guidance - 7th edition 2022 [Gold Standard Framework - Proactive Identification Guidance \(PIG\) \(goldstandardsframework.org.uk\)](#) (accessed 29/07/2025)
- [33] University of Edinburgh [Supportive and Palliative Indicator Tool \(SPICT\)](#) The SPICT™ 25 NHS Scotland (accessed 23/07/2025)
- [34] Community Health Pathways Wales [NHS Wales adopts the first nationwide implementation of HealthPathways - Latest Community News \(healthpathwayscommunity.org\)](#) (accessed 29/07/2025)
- [35] All Wales Care Decisions Guidance for the last days of life [All Wales Care Decisions for the Last Days of Life Guidance - NHS Wales Executive](#) (accessed 23/07/2025)
- [36] Welsh language and culture *Care and Comfort in Welsh | Learn Welsh* [Care and Comfort in Welsh | Learn Welsh](#) (accessed 23/07/2025)
- [37] National Palliative and end of Life Care Programme (2024) Sharing and Involving - a clinical policy for Do Not Attempt Cardiopulmonary Resuscitation **NHS Wales Performance and Improvement**

(DNACPR) for adults in Wales' [Sharing and Involving: Do Not Attempt Cardiopulmonary Resuscitation \(DNACPR\) Decisions for Adults in Wales](#) (accessed 23/07/2025)

[38] National Audit of Care at the End of Life (NACEL) (2024) HEALTHCARE IMPROVEMENT PLAN (HIP) 2023 – 2025 Version 1.0 Last updated: 05/02/2024 [Quality Improvement - Documents – National Audit of Care at the End of Life](#) (accessed 23/07/2025)

[39] National Palliative and end of Life Care Programme (2024) Resources and guidance on CPR: www.wales.nhs.uk/dnacpr (accessed 23/07/25)

[40] [Healthcare Inspectorate Wales review](#) (2024) Summary: Review of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Decisions for Adults in Wales (accessed 23/07/2025)

[41] Parola, V., M., Coelho, A., Neves, H., Cardoso, D., Almeida, M., Cruz, A., Apóstolo, J., Palliative rehabilitation interventions in palliative care: a scoping review protocol. JBI Evid Synth. 2020 Nov;18(11):2349-2356. doi: 10.11124/JBIES-20-00024. PMID: 32925394.

[42] [NHS England » Dying well in custody charter and self assessment tool](#) (accessed 08/08/25)

[43] Welsh Government (2021) National Continuing Healthcare (CHC) Guidance Continuing NHS Healthcare. The National Framework for Implementation in Wales [Continuing NHS Health Care](#) (accessed 23/07/2025)

[44] Welsh Government (2022) [The Transition and Handover Guidance February 2022](#) (accessed 23/07/2025)

[45] Equality Act 2010, c. 15. Available at: <https://www.legislation.gov.uk/ukpga/2010/15/contents> [Equality Act 2010](#) (accessed 23/07/2025)

[46] Welsh Government (2024) [Accessibility standards for GOV.WALES | GOV.WALES](#) (accessed 23/07/2025)

[47] Daffodil Standards [The Daffodil Standards \(rcgp.org.uk\)](http://rcgp.org.uk) (accessed 08/08/25)

[48] Strategic Programme for Primary Care (2023) [Enhanced Community Care 'Virtual Wards'](#) Nationally agreed definition, standards, and underpinning quality statements for model of care & support (accessed 23/07/2025)

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[49] Poolman, M., Roberts, J., Byrne, A., Perkins, P., Hoare, Z., Nelson, A., Hiscock, J., Hughes, D., Foster, B., O'Connor, J., Reymond, L., Healy, S., Roberts, R., Wee, B., Lewis, P., Johnstone, R., Roberts, R., Holmes, E., Wright, S., Hendry, A., Wilkinson, C., (2019) CARer-ADministration of as-needed subcutaneous medication for breakthrough symptoms in homebased dying patients (CARiAD): study protocol for a UK-based open randomised pilot trial. BMC

[50] The End of Life Partnership Care Homes [Six Steps Wales - Six Steps](https://eolp.co.uk/SIXSTEPS/six-steps-for-care-homes/six-steps-wales/)<https://eolp.co.uk/SIXSTEPS/six-steps-for-care-homes/six-steps-wales/> (accessed 23/07/2025)

[51] Carer Support Needs Assessment (CSNAT) [Enabling tailored support for carers in everyday practice | Carer Support Needs Assessment Tool Intervention \(csnat.org\)](https://csnat.org) (accessed 23/7/2025)

[52] Bollig, G., Brandt, F., Ciurlionis, M., and Knopf, B., (2019) Last Aid Course. An Education for All Citizens and an Ingredient of Compassionate Communities [Last Aid Course. An Education For All Citizens and an Ingredient of Compassionate Communities - PMC \(nih.gov\)](https://www.nih.gov/last-aid-course) (accessed 23/07/2025)

[53] [Carer Aware Project - What is it? | Carers Trust Wales](https://www.carers-trust.wales/) (accessed 23/7/2025)

[54] Welsh Government (2022) National Bereavement Care Pathway [National bereavement care pathway | GOV.WALES](https://gov.wales/national-bereavement-care-pathway) (accessed 23/7/2025)

[55] Marie Curie Cymru (2024) Dying in Poverty in Wales 2024

[56] Carers UK (2022). [Cycles of caring: transitions in and out of unpaid care](https://www.carersuk.org/cycles-of-caring) (accessed 23/7/2025)

[57] HEIW (2025) All Wales Guidance for Verification of Expected Death Adult

[58] Public Health Wales (Child Death Review programme [Child Death Review - Public Health Wales](https://www.phwales.gov.uk/child-death-review) (accessed 08/8/2025)

[59] Public Health Wales [PRUDiC \(Procedural Response to Unexpected Death in Childhood\) - Public Health Wales](https://www.phwales.gov.uk/prudic) (accessed 08/8/2025)

[60] Aneurin Bevan University Health Board (2021) VoED of a Children or Young Person (ABUHB 2021)

[61] Hope House/Ty Gobaith (2024) VoED Childrens Hospices

[62] HEIW Strategic Nursing Workforce Plan: 2025 – 2030 heiw.nhs.wales/files/strategic-nursing-workforce-plan-2025/ (accessed 08/8/2025)

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- [63] HEIW Allied Health Professions Workforce Development Plan (2022) heiw.nhs.wales/files/ahp-workforce-development-plan/ (accessed 08/8/2025)
- [64] HEIW Workforce Planning Resources [Workforce planning resources - HEIW](#) (accessed 08/8/2025)
- [65] Social Care Wales – a workforce strategy for health and social care [A Healthier Wales – a workforce strategy for Health and Social Care | Social Care Wales](#) (accessed 08/8/2025)
- [66] COINS Children’s Out-reach In-reach Nursing Service (2025) *Guidance to support the management of the Children’s Out-reach In-reach Nursing Service (COINS) when supporting Infant’s, Children and Young People (C&YP) who are at end of life in the community setting.* Hywel Dda University Health Board. July 2025.
- [67] The UK Commission on Bereavement’s Report [Bereavement is Everyone’s Business \(2022\) bereavement-is-everyone-s-business-full-report_1.pdf \(bereavementcommission.org.uk\)](#) (accessed 23/07/25)
- [68] [Palliative care Outcome Scale \(POS\) - POS Background](#)
- [69] Kings College London (2024) [PROMS Children’s Palliative Outcome Scale \(C-POS-UK\)](#)

Bibliography

- Finlay, I., (2008) Report to Minister - Implementation of Palliative Care Report, Palliative care services funding 2008 to 2009 [Microsoft Word - pcpq report final June 08.doc \(ncpc.org.uk\)](#) (accessed 08/08/25)
- Palliative Care Competence Framework Steering Group (2014). Palliative Care Competence Framework. Dublin: Health Service Executive
- Haf Spencer, L., Fern Anthony, B., Davies, J., Pisavadia, K., Gillen, L., Noyes, J., Fitzsimmons, D., Lewis, R., Cooper, A., Hughes, D., Tudor Edwards, R., Edwards, A., (2024) The costs and cost-effectiveness of different service models of palliative care, focusing on end of life care: A rapid review medRxiv 2024.03.06.24303850; doi: <https://doi.org/10.1101/2024.03.06.24303850> (accessed 08/08/25)
- Hospice UK. ‘I just want to be me.’ Trans and Gender Diverse Communities Access to and Experiences of Palliative and End of Life Care. London: Hospice UK; 2023.

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- Marie Curie (2021) A Place for Everyone - What stops people from choosing where they die; A review of the barriers to good end of life care facing diverse groups in the UK
- Marie Curie (2023) Policy Paper Gender & End of Life Care [k399-gender-and-end-of-life-care-internal-research-project-eng-final-lr-v2.pdf \(mariecurie.org.uk\)](#) (accessed 08/08/25)
- National PEOLC Programme Phase 3 interim Report for Welsh Government (2024)
- Pask, S., Davies, J., M., Mohamed, A., Leniz, J., Chambers, R.,L., McFarlane, P., Bone, A., E., Barclay, S., Higginson, I., J., Sleeman, K., E., & Murtagh, F., E., M., (2022) Better End of Life 2022. Mind the gaps: understanding and improving out-of-hours care for people with advanced illness and their informal carers. Research report. London (UK): Marie Curie. [better-end-of-life-report-2022.pdf \(mariecurie.org.uk\)](#)[better-end-of-life-report-2022.pdf \(mariecurie.org.uk\)](#) (accessed 08/08/25)
- Harding, R., and Hammerich, A., (2024) WISH 2024 Forum on Palliative Care Advisory Group [Palliative Care: How Can We Respond to 10 Years of Limited Progress? - WISH](#) (accessed 08/08/25)

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