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NATIONAL STANDARDS FOR PALLIATIVE CARE

with Implementation Guide

MALAYSIA

Ministry of Health Malaysia

NATIONAL STANDARDS FOR PALLIATIVE CARE WITH IMPLEMENTATION GUIDE

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FOREWORD

DIRECTOR GENERAL OF HEALTH, MALAYSIA

It is with great honour that I present the National Standards for Palliative Care, a significant advancement in Malaysia's commitment to reducing health-related suffering and ensuring that all individuals affected by serious illness receive care that is compassionate, holistic, and of the highest quality.

Palliative care is not limited to the final stages of life—it is essential throughout the course of serious health conditions, addressing the complex physical, emotional, psychosocial, and spiritual needs that arise from health-related suffering. These standards are designed to guide the development and delivery of palliative care across all levels of the healthcare system, ensuring consistency, equity, and dignity in care for patients and their families, regardless of diagnosis, age, or care setting.

This document is the result of extensive collaboration among healthcare professionals, policymakers, academics, and representatives from civil society. It uses an evidence-based approach to align with international recommendations, while reflecting Malaysia's cultural values and healthcare realities. The standards provide a structured framework for strengthening services, guiding clinical practice, and promoting the integration of palliative care into mainstream healthcare. It supports continuous service improvement through benchmarking.

The Ministry of Health views palliative care as an essential health service and a core component of universal health coverage. These standards will serve as a foundation for expanding access to quality palliative care and ensuring that people living with serious illness do not suffer needlessly but are supported with care that affirms their dignity and improves their quality of life.

I extend my sincere appreciation to all who contributed to the development of this landmark document. Let it be a testament to our shared vision: a healthcare system that not only treats illness but alleviates suffering in all its forms.

Datuk Dr Mahathar bin Abd Wahab
Director General of Health, Malaysia

FOREWORD

DEPUTY DIRECTOR GENERAL OF HEALTH (MEDICAL), MALAYSIA

The launch of the National Standards for Palliative Care, Malaysia marks an important step forward in our national commitment to delivering high-quality, compassionate care to patients facing life-limiting illnesses.

As the division entrusted with overseeing hospital care services across the Ministry of Health, we recognise the increasing importance of integrating palliative care into mainstream clinical practice. Advances in modern medicine have extended life expectancy, but they have also brought a rising burden of chronic diseases, cancer, and frailty. Patients experience significant health related suffering. In this context, the provision of palliative care which addresses their complex needs and enhances quality of life is an essential component of comprehensive, person-centred healthcare.

These national standards provide a structured and evidence-based framework to support healthcare teams in delivering palliative care that is safe, timely, and culturally appropriate. They address not only the medical dimensions of care, but also the psychosocial and spiritual needs of patients and their families.

I would like to express my sincere appreciation to the dedicated clinicians, institutions, and stakeholders who contributed to the development of these standards. Your efforts reflect a shared vision of healthcare that honours dignity, relieves suffering, and supports families through some of life's most difficult moments.

We remain committed to strengthening hospital-based palliative care services by supporting capacity-building, interdisciplinary collaboration, and integration with primary care services. I encourage all healthcare professionals and administrators to adopt these standards and embed them into everyday practice.

Together, let us ensure that every patient, regardless of diagnosis or care setting, receives the compassion, comfort, and respect they deserve.

Dato' Indera Dr Nor Azimi binti Yunus
Deputy Director General of Health (Medical), Malaysia

FOREWORD

DIRECTOR OF MEDICAL DEVELOPMENT DIVISION, MALAYSIA

It gives me great pleasure to introduce the National Standards for Palliative Care in Malaysia, a landmark document guiding the strategic development of medical services within our public healthcare system. This initiative aligns perfectly with the Ministry of Health's overarching goal of achieving universal health coverage, ensuring every Malaysian receives the care they need, when and where they need it.

Palliative care, as articulated in these standards, is a fundamental pillar of a compassionate and resilient healthcare system. With chronic non-communicable diseases and an aging population, the demand for comprehensive palliative care is growing exponentially. This document provides a vital roadmap for how we, as a Ministry, will systematically embed palliative care principles and practices across all levels of our public healthcare infrastructure – from primary care clinics to major specialist hospitals.

Our focus will be on strengthening KKM units to deliver high-quality palliative care. This involves investing in robust training for medical officers, nurses, and allied health professionals to identify needs early, manage complex symptoms, and facilitate seamless care transitions. We are committed to optimizing access to essential palliative medicines, streamlining processes, and leveraging technology. Fostering strong public-private partnerships will also be crucial for extending vital services.

This document represents our collective aspiration for a future where every Malaysian, regardless of their illness trajectory, can live with dignity and receive compassionate support. It is a testament to the Ministry of Health's dedication to evolving our medical services to meet the complex and evolving needs of our people. I commend all those involved in this meticulous and dedicated effort, and I am confident that these National Standards will serve as a powerful catalyst for transformative change in palliative care delivery throughout Malaysia.

Dato' Dr Mohd Azman bin Yacob
Director of Medical Development Division, Malaysia

FOREWORD

HEAD OF PALLIATIVE MEDICINE SUBSPECIALTY, MALAYSIA

It is with immense pride and a deep sense of commitment that I present the National Standards for Palliative Care, Malaysia. This document marks a pivotal moment in our nation's healthcare journey, reaffirming our dedication to compassionate, high-quality care for all Malaysians facing life-limiting illnesses.

Developed through rigorous Delphi consensus, these Standards reposition palliative care as an integral component of holistic patient care, beginning from diagnosis. Our vision is to elevate clinical excellence and ensure evidence-based care that honours individual needs, values and cultural backgrounds.

Developing these standards has been a truly collaborative effort, involving diverse stakeholders from public and private sectors, and non-governmental organisations. This broad engagement reflects our shared understanding that palliative care is a collective responsibility, requiring seamless coordination and a unified approach. Every voice, from Ministry of Health (KKM) specialists to community care providers and private practitioners, has contributed to shaping an aspirational yet pragmatic framework suited to Malaysia's healthcare landscape.

The indicators are designed to drive continuous quality improvement across all KKM units and beyond. By establishing indicators for timely identification, holistic assessment, coordinated care and patient-centered discussions, we are setting a new paradigm for clinical practice. We are committed to equipping healthcare professionals with the knowledge and skills to deliver a palliative approach to care – ensuring reduced suffering, improved quality of life and dignified support throughout the illness journey.

This document is more than just standards; it is a testament to our unwavering commitment to our patients and their families. It is a promise that clinical excellence in palliative care will be the norm in Malaysia. I extend my heartfelt gratitude to everyone who contributed to this monumental achievement, and I look forward to witnessing the transformative impact of these standards on our national healthcare system.

Dr Fazlina binti Ahmad
Head of Palliative Medicine Subspecialty, Malaysia

ABBREVIATIONS

BAT	Burnout Assessment Tool
BGQ	Brief Grief Questionnaire
CAPC	Centre to Advance Palliative Care
CME	Continuing Medical Education
CNE	Continuing Nursing Education
CSA	Caregiver Self-Assessment
DSM-5-TR	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition, Text Revision
ESAS	Edmonton Symptom Assessment System
ESMO	European Society for Medical Oncology
FAMCARE-2	Family Satisfaction with Advanced Cancer Care (Version 2)
FICA	Faith, Importance, Community, Address (Spiritual Assessment Tool)
FLACC	Face, Legs, Activity, Cry, Consolability Scale (Pain Assessment Tool in Children
HOPE	Hope, Organised religion, Personal spirituality and practices, Effects on care (Spiritual Assessment Tool)
ICD-11	International Classification of Diseases, 11th Revision
IPOS	Integrated Palliative care Outcome Scale

Abbreviation	Definition
MAPPAC	Malaysian Association of Paediatric Palliative Care
MDAC	Medical and Dental Advisory Committee
MDM	Multidisciplinary Meeting
MHPCC	Malaysian Hospice and Palliative Care Council
MOH	Ministry of Health
NEML	National Essential Medicines List
NHS	National Health Service
NGO	Non-Governmental Organization
NURSE	Naming, Understanding, Respecting, Supporting, Exploring (Empathic Communication Tool)
PAINAD	Pain Assessment in Advanced Dementia Scale
PDSA	Plan–Do–Study–Act (Quality Improvement Cycle)
PCOC	Palliative Care Outcomes Collaboration
PGD	Prolonged Grief Disorder
PRN	Pro re nata (Latin: as needed)
RASS	Richmond Agitation-Sedation Scale
REMAP	Reframe, Expect emotion, Map values, Align, Propose (Serious Illness Communication Tool)
REDMAP	Ready, Expect, Diagnosis, Matters, Actions, Plan (Advance Care Planning Framework)

Abbreviation	Meaning
RUG-ADL	Resource Utilization Groups – Activities of Daily Living
RUN-PC	Responding to Urgency of Need in Palliative Care (Triage Tool)
SOP	Standard Operating Procedure
SPICT™	Supportive and Palliative Care Indicators Tool
TWC	Technical Working Committee
VOICES	Views of Informal Carers – Evaluation of Services
ZBI	Zarit Burden Interview (or Inventory)

EXECUTIVE SUMMARY

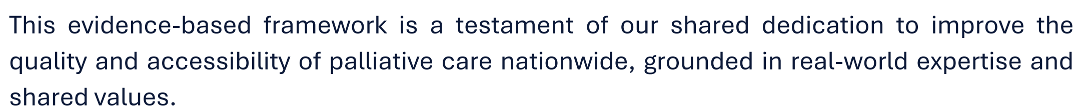
Malaysia is progressing toward an aging population, and with it, a rising burden of non communicable diseases. This demographic shift has created an urgent need for equitable, comprehensive, and sustainable models of palliative care to address the complex needs of patients and their families. This document, comprising the **National Standards for Palliative Care** and a practical **Implementation Guide**, marks a significant milestone in our national commitment to delivering compassionate and dignified care.

Our core vision is to ensure that all Malaysians affected by serious illness receive care that is not only clinically sound but also compassionate, holistic, and dignified. This approach is not limited to the final days of life; it is an integral part of the illness journey from the point of diagnosis. The standards aim to alleviate suffering by addressing the complex physical, psychological, social, and spiritual needs of patients, while also providing vital support to their caregivers and families.

The establishment of these national standards is in direct alignment with the 2019 National Policy and Strategic Development Plan, which identified this as a core strategy for ensuring quality palliative care across diverse healthcare settings. This initiative was born from the need to collaboratively engage a broad range of heterogeneous stakeholders to create a common vision for excellence in palliative care throughout Malaysia, moving beyond previous, often haphazard, models of service development.

This document's development began with a comprehensive literature review of existing published international palliative care standards. The Singapore National Guidelines for Palliative Care (2015) was identified as particularly suitable for the Malaysian context due to cultural similarities and ease of use. We extend our sincere gratitude to our colleagues in Singapore for their generosity and collaborative spirit in granting permission to adapt their framework. Their pioneering work laid a strong foundation for the National Palliative Care Standards Committee to tailor the guidelines to Malaysia's unique healthcare landscape, ensuring both relevance and feasibility.

The resulting standards were further refined and validated through a rigorous Delphi consensus process, which drew on the insights of a broad-based panel comprising generalist and specialist palliative care providers, as well as individuals with lived experience. This inclusive approach ensured strong representation from diverse stakeholders and enabled a robust consensus on indicators that are both contextually relevant and practically feasible in Malaysia.



This evidence-based framework is a testament of our shared dedication to improve the quality and accessibility of palliative care nationwide, grounded in real-world expertise and shared values.

This guide provides a structured approach for enhancing palliative care services across all levels of the healthcare system. It is built on four core domains:

- **Patient Care:** Emphasizing the timely identification of needs, coordinated care, and holistic, patient-centered interventions.

- **Caregiver Support:** Recognizing the crucial role of caregivers and ensuring they have the resources and support they need to cope effectively.

- **Staff and Volunteer Management:** Promoting a resilient and well-trained workforce through ongoing education, self-care, and professional development.

- **Safe Care:** Establishing robust guidelines and processes to ensure the safe, ethical, and effective delivery of all services, including the use of essential medicines.

These standards are intended to be aspirational yet achievable. They are not designed to be punitive but rather to encourage broad adoption and voluntary participation in the continuous pursuit of quality improvement. The implementation of these standards will require a collaborative spirit from all stakeholders, including government bodies, healthcare providers, educational institutions, non-governmental organizations and lived experience experts, working together to overcome existing challenges and build a more integrated and accessible palliative care system.

These National Standards and their accompanying Implementation Guide will serve as a foundational tool for strengthening clinical practice, guiding service development, and building a collaborative culture of continuous quality improvement. We encourage all healthcare providers to embrace this framework as a means of transforming palliative care, ensuring universal access to compassionate, dignified, and high-quality care for every person in Malaysia who need it.

OVERVIEW OF THE NATIONAL STANDARDS FOR PALLIATIVE CARE WITH IMPLEMENTATION GUIDE

The National Standards for Palliative Care, Malaysia—together with its implementation guide—offer a clear, practical framework to support the delivery, evaluation and ongoing improvement of palliative care services nationwide. This integrated document is designed as a working resource for healthcare professionals and organizations, supporting service development, education and training, research and quality improvement efforts in palliative care.

Document Structure

This guide is organized into **4 key domains**, each reflecting a core component of high-quality palliative care. In total, there are **13 standards** articulated across these domains, as detailed in the table below:

Domain	Standards
1: Patient Care	Standard 1: Timely Identification Standard 2: Reducing Barriers to Care Standard 3: Coordinated Care Standard 4: Holistic Assessment Standard 5: Goals of Care Discussions Standard 6: Patient-Centred Care Standard 7: Care in the Last Days of Life
2: Caregiver Support	Standard 8: Caregiver Support Standard 9: Grief & Bereavement Support
3: Staff and Volunteer Management	Standard 10: Trained Staff and Volunteers Standard 11: Staff and Volunteer Self-Care
4: Safe Care	Standard 12: Accessibility and the Use of Opioids Standard 13: Clinical Quality Improvement

How to Understand Each Standard

Each standard in this document begins with a clear statement of the core principles followed by practical implementation details listed according to each indicator. This integrated approach ensures that the objectives and methods are presented together for clarity and ease of use. Each standard is structured as follows:

Standards	
Standard Statement	This is the core principle or desired outcome for a specific aspect of palliative care.
Rationale	This part provides the evidence-based justification for the standard, explaining its importance for ensuring quality care.
Indicators	These are the suggested measurable criteria that demonstrate compliance with standards.
Implementation Guide	
Explanatory Notes	Definitions and explanations of key terms.
Good Practice	Suggestions for effective practices and approaches that providers can adopt to achieve the standard's objectives.
Suggested Indicators	These are measurable evaluation criteria such as audit metrics with numerators and denominators, or existing documentation that demonstrate compliance with standards.
Suggested Tools & Resources for each Indicator	A list of useful tools, methods, and external resources to assist with implementation, assessment, and training. This list is not exhaustive – services may adopt other approaches that suit their local context.

Provider Classifications

To ensure relevance across Malaysia's diverse healthcare landscape, this guide categorizes service providers into three distinct classes, reflecting their respective roles in palliative care:

- **Class A Providers:** These are generalist palliative care providers whose substantive work is not in caring for patients with life-limiting illnesses, but who will encounter them in the course of their work. They are expected to apply a palliative care approach. These include primary care practitioners in the community, and other doctors, nurses and allied health staff in private and public health facilities.

- **Class B Providers:** There are generalist palliative care providers who routinely care for a substantive number of patients with life-limiting illnesses. These may include staff of chronic disease management programmes, intensive care units, specialist cancer units, geriatric units, domiciliary palliative care teams and nursing homes.

- **Class C Providers:** These are specialist palliative care providers who care solely for patients with life-limiting illnesses. These include palliative care teams in private and public hospitals, inpatient hospices and community palliative care services delivering home care.

How to Use This Guide

This document is a tool for continuous quality improvement. Service providers are encouraged to use it by:

1. **Identifying Your Provider Class:** Determine which class (A, B, or C) best describes your service to focus on the most relevant indicators.

2. **Studying the Standards:** Gain a comprehensive understanding of the principles and rationale underpinning quality palliative care.

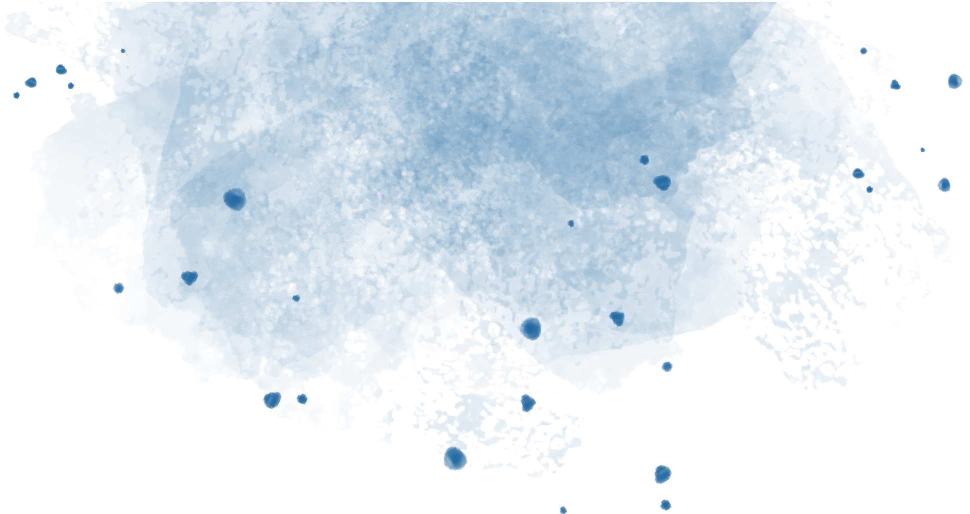
3. **Implementing in Practice:** Use the indicators to guide your practice. We suggest conducting a self-assessment to identify gaps in your services, then prioritizing areas for improvement based on those gaps and what is feasible.

4. **Engaging in Peer Support:** Actively seek opportunities for peer support and shared learning. By connecting with other services, you can share knowledge, exchange resources, and learn from each other's expertise to enhance the quality of care for everyone.

5. **Utilizing Resources:** Take advantage of the recommended tools and resources to support implementation, assessment, and staff development.

6. **Promoting a Collaborative Approach:** Encourage collaboration and seamless care transitions across different settings to ensure all individuals facing a life-limiting illness receive compassionate, dignified, and high-quality care.

By gradually and systematically applying the standards and guidance within this document, services can take meaningful steps toward improving palliative care delivery, helping more Malaysians experience comfort, dignity and support in the face of life-threatening illnesses.



DOMAIN 1:
PATIENT CARE

Standard 1 - Timely Identification People with palliative care needs are identified in a timely manner.	
Rationale	Early palliative care can improve quality of life and reduce unplanned hospital admissions. Timely identification with appropriate needs assessment helps service providers to meet patients' needs and preferences in a more meaningful way.[1-5]

Indicators		
Class A+B	1.1	Healthcare providers should have a systematic approach to identify people with palliative care needs.

Suggested Tools	
1.	Tools to identify Palliative Care Needs:[6] a) Double Surprise Question[7,8] b) Supportive and Palliative Care Indicators Tool (SPICT™)[9] www.spict.org

Implementation Guide

1.1	Healthcare providers should have a systematic approach to identify people with palliative care needs.

Explanatory Notes

Systematic approach	Process in place to identify patients who have palliative care needs.
People with palliative care needs[5]	Individuals living with serious, life-limiting conditions who require holistic care to relieve symptoms, manage pain and enhance quality of life. This care addresses their physical, emotional and psychological well-being. This includes individuals with:[2] • Advanced, progressive, and incurable life-limiting illnesses. • General frailty and multiple health conditions, with a life expectancy of less than 12 months. • Existing chronic conditions that place them at risk of death from an unexpected acute crisis. • Life-threatening acute conditions resulting from sudden catastrophic events. • Those nearing the end-of-life, with death expected within hours or days . A 12-month timeframe serves as a useful guide to identify when individuals with life-limiting conditions may begin to benefit from a palliative approach to their care.

Good Practice

- Class A & B Providers shall identify those with palliative care needs and who require a palliative approach to care.
- This can be done using assessment tools.[6] (See below for examples.)

Suggested Indicators

1. Availability of a guideline or protocol for systematic identification of patients with palliative care needs.

2. Percentage of eligible patients with documentation of a needs assessment:

Numerator	Number of patients with documentation of a needs assessment.
Denominator	Total number of patients during the audit period.

3. Percentage of patients screened using a validated tool:

Numerator	Number of patients screened using a validated tool.
Denominator	Total number of patients during the audit period.

Suggested Tools and Resources

1. Double Surprise Questions– "Would you be surprised if this patient dies within the next 12 months?", or "Would you be surprised if this patient is alive after 12 months?"[7,8]
https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-019-0503-9

2. Supportive and Palliative Care Indicators Tool (SPICT™)[9]
http://www.spict.org.uk/

References:

1. McNamara BA, Rosenwax LK, Murray K, Currow DC. Early admission to community-based palliative care reduces use of emergency departments in the ninety days before death. J Palliat Med 2013;16(7):774-9. doi: 10.1089/jpm.2012.0403. Epub 2013 May 15. PMID: 23676094.

2. Daveson BA, Alonso JP, Calanzani N, Ramsenthaler C, Gysels M, Antunes B, Moens K, Groeneveld EI, Albers G, Finetti S, Pettenati F, Bausewein C, Higginson IJ, Harding R, Deliens L, Toscani F, Ferreira PL, Ceulemans L, Gomes B; PRISMA. Learning from the public: citizens describe the need to improve end-of-life care access, provision and recognition across Europe. Eur J Public Health. 2014 Jun;24(3):521-7. doi: 10.1093/eurpub/ckt029. Epub 2013 Mar 13. PMID: 23487548; PMCID: PMC4032478.

3. Glare PA. Early implementation of palliative care can improve patient outcomes. J Natl Compr Canc Netw. 2013 Mar;11 Suppl 1:S3-9. doi: 10.6004/jnccn.2013.0212. PMID: 23520184.

4. Bandieri E, Sichetti D, Romero M, Fanizza C, Belfiglio M, Buonaccorso L, Artioli F, Campione F, Tognoni G, Luppi M. Impact of early access to a palliative/supportive care intervention on pain management in patients with cancer. Ann Oncol. 2012 Aug;23(8):2016-2020. doi: 10.1093/annonc/mds103. Epub 2012 May 6. PMID: 22565123.

5. Monnery D, Droney J. Early palliative care and its impact on end of life care. Curr Opin Support Palliat Care. 2024 Dec 1;18(4):230-234. doi: 10.1097/SPC.0000000000000729. Epub 2024 Oct 30. PMID: 39351632.

6. ElMokhallalati Y, Bradley SH, Chapman E, Ziegler L, Murtagh FE, Johnson MJ, Bennett MI. Identification of patients with potential palliative care needs: A systematic review of screening tools in primary care. Palliat Med. 2020 Sep;34(8):989-1005. doi: 10.1177/0269216320929552. Epub 2020 Jun 7. PMID: 32507025; PMCID: PMC7388141.

7. Ermers DJ, Kuip EJ, Veldhoven C, Schers HJ, Perry M, Bronkhorst EM, Vissers KC, Engels Y. Timely identification of patients in need of palliative care using the Double Surprise Question: A prospective study on outpatients with cancer. Palliat Med. 2021 Mar;35(3):592-602. doi: 10.1177/0269216320986720. Epub 2021 Jan 11. PMID: 33423610; PMCID: PMC7975860.

8. Veldhoven CMM, Nutma N, De Graaf W, Schers H, Verhagen CAHHVM, Vissers KCP, Engels Y. Screening with the double surprise question to predict deterioration and death: an explorative study. BMC Palliat Care. 2019 Dec 27;18(1):118. doi: 10.1186/s12904-019-0503-9. PMID: 31881958; PMCID: PMC6935168.

9. Mahura M, Karle B, Sayers L, Dick-Smith F, Elliott R. Use of the supportive and palliative care indicators tool (SPICT™) for end-of-life discussions: a scoping review. BMC Palliat Care. 2024 May 16;23(1):119. doi: 10.1186/s12904-024-01445-z. PMID: 38750464; PMCID: PMC11097449.

Standard 2 - Reducing Barriers to Care Palliative care is available for all people based on clinical need, regardless of diagnosis, age, gender, financial means, ethnic and cultural background, and care setting.	
Rationale	All patients with life-limiting illnesses should be cared for by healthcare professionals using a palliative care approach.[1,2.3] Patients with needs that exceed the resource capabilities of the service provider should have access to palliative care services.[4,5] Similarly, where patients require expertise or care outside the scope of the palliative care service, the ability to call upon other services or providers will enhance the care of the patient.[5]

Indicators		
Class A+B	2.1	Patients are referred to palliative care services, should their needs exceed the resource capabilities of the service provider.[4,5,6]
All Classes	2.2	There is evidence of arrangements to ensure that people approaching the end of life, as well as caregivers and families, know who to contact for advice.[7,8,9]
Class C	2.3	The service provider triages and assigns priorities to all initial consult requests and ensures that care is delivered in a timely manner.[10]
	2.4	Patients and family members are able to seek palliative care support at all times, including after office hours.[8,9,11,12]
	2.5	The service provider has protocols for responding to palliative care emergencies or urgent needs.[10]
	2.6	The service provider has access to expert advice and management of patients with specific needs in other fields.

Suggested Tools	
1.	Guidelines for referrals to palliative care, hospice services, or other specialists: a) MHPCC directory of hospice and palliative care services https://www.malaysianhospicecouncil.com/ b) CAPC Palliative Care Referral Criteria https://www.capc.org/documents/download/286/

2.	Information for patients and families on scope of services provided by palliative care or hospice services and referral procedures: a) Malaysian Hospice and Palliative Care Council: Caregiver resources https://www.malaysianhospicecouncil.com/forcaregiver b) Hospice Malaysia. Carer's Guidebook. Kuala Lumpur, Malaysia 2016 https://www.hospismalaysia.org/resources/ c) MAPPAC Care Giver Handbook for Children with Palliative Care Needs https://mappac.org/resources/handbook
3.	Tool to triage consult requests: a) Responding to Urgency of Need in Palliative Care (RUN-PC) Triage Tool https://www.palliativenexus.org/run-pc-triage-tool-calculator
4.	Protocols for responding to palliative care emergencies or urgent needs: a) Handbook of Palliative Medicine in Malaysia, 2nd Edition, 2023 b) SG Pall eBook (Singapore) https://www.duke-nus.edu.sg/lcpc/resources/sg-pall-ebook-disclaimer/sg-pall-ebook/palliative-care-emergencies c) The Global Handbook of Palliative Care 2024 https://static1.squarespace.com/static/62da231748a03c783bb62b04/t/66f1a469112f643c4322ee05/1727112321027/GHPC+Digital.pdf d) Guideline on Suicide Risk Management in Hospitals, MOH https://www2.moh.gov.my/moh/resources/Penerbitan/Rujukan/NCD/Kesihatan%20Mental/guideline_suicide_risk_management.pdf Pharmaceutical Services Programme, Ministry of Health Malaysia. National Essential Medicines List (NEML) 7th edition 2025 – Medicines for Pain and Palliative Care. p. 2. https://pharmacy.moh.gov.my/sites/default/files/document-upload/clean-national-essential-medicines-list-7th-v04_0.pdf

Implementation Guide

2.1 Patients are referred to palliative care services,should their needs exceed the resource capabilities of the service provider.[4,5] **(Class A+B Providers)**

Explanatory Notes	
Needs exceed the resource capabilities of the service provider	Situations where the clinical, psychosocial, or spiritual needs of the patient are beyond the service provider's scope, skills, resources, or available support systems. This includes individuals with:[6] • Poorly controlled pain and/or other symptoms not responding to optimal medical treatment. • Complex psychosocial and/or spiritual issues requiring a multi disciplinary approach. • Goals of care that focuses on comfort or strong wish to avoid hospitalization.

Good Practice

1. All Class A and B Providers should have a list of hospital and community-based palliative care service providers with contact details.
2. Each center should have their own triggers to consider the need for referral that reflects local expertise and available resources.

Suggested Indicators

1. Availability of a documented directory of palliative care providers.
2. Availability of policy or guidelines for referrals to palliative care, hospice services, or other specialists.

Suggested Tools and Resources

1. MHPCC directory of hospice and palliative care services
https://www.malaysianhospicecouncil.com/
2. CAPC Palliative Care Referral Criteria
https://www.capc.org/documents/download/286/

2.2	There is evidence of arrangements to ensure that people approaching the end of life, as well as caregivers and families, know who to contact for advice. **(All providers)**

Explanatory Notes

Approaching the end of life	When a person is likely to die within the next 12 months.[7]

Good Practice

1. All Providers should be aware of available local resources.
2. They should discuss a plan at the end of life that includes how to access care when the need arises and this should be documented in patient notes.[8,9]

Suggested Indicators

1. Documentation of care plans including after hours contact instructions.
2. Availability of communication materials (e.g., info leaflets, discharge checklists, contact cards) which are given to families.

Suggested Tools and Resources

1. Malaysian Hospice and Palliative Care Council: Caregiver resources. https://www.malaysianhospicecouncil.com/forcaregiver
2. Hospice Malaysia. Carer's Guidebook. Kuala Lumpur, Malaysia 2016. https://www.hospismalaysia.org/resources/
3. MAPPAC Care Giver Handbook for Children with Palliative Care Needs. https://mappac.org/resources/handbook

2.3	The service provider triages and assigns priorities to all initial consult requests and ensures that care is delivered in a timely manner.[10] **(Class C providers)**

Explanatory Notes

Palliative care providers should be responsive to referrals from other providers, specialists and institutions.
Timeliness may vary based on the nature and complexity of the referral, but should be guided by defined service timeframes (see below).

Good Practice

1. Services should implement a triage system based on urgency and complexity. Define expected response times for each triage category.
2. There should be an assigned team member to screen and triage incoming referrals daily.
3. Service providers should regularly review timeliness and appropriateness of triage decisions.
4. Triage outcomes and expected timelines are clearly communicated to referring teams and patients.

Suggested Indicators

1. Percentage of new referrals seen/ contacted/ acknowledged within the timeframes stated below:

Numerator	Number of new referrals seen/ contacted/ acknowledged within stated timeframe.
Denominator	Total number of new referrals.

- New inpatient hospital referrals: patients or families should be seen within 1 working day.
- New outpatient hospital referrals: patients or families should be seen within 10 working days.
- New community care referrals: patients or families should be contacted by a member of the clinical team within 2 working days of receiving the referral. This refers to the time period between the date of referral received and first contact by service provider, be it accepted, rejected or pending further information.

- New inpatient hospice referrals: referrals should be acknowledged within 2 working days. This refers to the time period between the date of referral received and acknowledgement of the referral, be it accepted, rejected or pending further information.

	Suggested Tools and Resources
1.	Responding to Urgency of Need in Palliative Care (RUN-PC) Triage Tool https://www.palliativenexus.org/run-pc-triage-tool-calculator

2.4	Patients and family members are able to seek palliative care support at all times, including after office hours.[8,9] **(Class C providers)**

Explanatory Notes

Services should have on-call palliative care support available to patients and families.

The scope of palliative care services available after hours may differ depending on the care setting and available resources. Support may include direct patient care, telephone advice or coordination of referrals.[11,12]

Good Practice

1. Patients and their families are given clear information on how to seek assistance, including numbers for service providers where available.
2. When direct 24-hour coverage is unavailable, coordination with the nearest hospital emergency department or community palliative care team should be established for backup support.

Suggested Indicators

1. Evidence of on-call system (e.g. roster) in place for palliative care.

Suggested Tools and Resources

1. Malaysian Hospice and Palliative Care Council: Caregiver resources
   https://www.malaysianhospicecouncil.com/forcaregiver
2. Hospice Malaysia. Carer's Guidebook. Kuala Lumpur, Malaysia 2016
   https://www.hospismalaysia.org/resources/
3. MAPPAC Care Giver Handbook for Children with Palliative Care Needs
   https://mappac.org/resources/handbook

2.5	The service provider has protocols for responding to palliative care emergencies or urgent needs.[10] **(Class C providers)**

Explanatory Notes

Palliative care emergencies	Unexpected changes to a patient's condition which include the following: • Pain crisis • Stridor • Massive bleed • Intractable seizures • New spinal cord compression • Superior vena cava obstruction • High suicide risk

Good Practice

1. The service maintains written protocols or guidelines for managing palliative care emergencies (e.g.,pain crises, stridor, or massive bleeding) which are easily accessible to all clinical staff.
2. These may be compiled into a departmental guide covering the relevant conditions.
3. All staff involved in patient care are trained and oriented to recognise and respond appropriately to such emergencies.
4. Essential emergency medications and equipment (e.g., midazolam, opioids, suction devices, dark towels for bleeding) are readily available and routinely checked to ensure readiness.

Suggested Indicators

1. Evidence of a response guideline in palliative care emergencies, including pain crisis, stridor, massive bleed, intractable seizures, new spinal cord compression, superior vena cava obstruction, high suicide risk.
2. Evidence of availability of medications for palliative care emergencies.

Suggested Tools and Resources

1. Handbook of Palliative Medicine in Malaysia 2nd Edition
2. SG Pall eBook (Singapore)
   https://www.duke-nus.edu.sg/lcpc/resources/sg-pall-ebook-disclaimer/sg-pall-ebook/palliative-care-emergencies
3. The Global Handbook of Palliative Care 2024
   https://static1.squarespace.com/static/62da231748a03c783bb62b04/t/66f1a46 9112f643c4322ee05/1727112321027/GHPC+Digital.pdf
4. Guideline on Suicide Risk Management in Hospitals, MOH
   https://www2.moh.gov.my/moh/resources/Penerbitan/Rujukan/NCD/Kesihatan%20Mental/guideline_suicide_risk_management.pdf
5. Pharmaceutical Services Programme, Ministry of Health Malaysia. National Essential Medicines List (NEML) 7th edition 2025 – Medicines for Pain and Palliative Care. p. 2.
   https://pharmacy.moh.gov.my/sites/default/files/document-upload/clean-national-essential-medicines-list-7th-v04_0.pdf
6. IAHPC Manual on the Use of Essential Palliative Care Medicines for Adults
   https://iahpc.org/uploads/2025/8/Manual-on-the-use-of-Essential-Palliative-Care-Medicines-for-Adults.pdf

2.6	The service provider has access to expert advice and management of patients with specific needs in other fields. **(Class C providers)**

Explanatory Notes

This may include formal referral pathways, ad hoc expert advice, or established networks, with the goal of providing holistic care that addresses complex symptoms, psychosocial distress, or disease-specific interventions.

Examples of relevant experts include:

- Allied health care, such as social workers, occupational therapists, physiotherapists, dietitians, chaplains.
- Oncologist.
- Interventional Radiologist.
- Pain Specialist.
- Psychiatrist or Clinical Psychologist.
- Others as deemed necessary by individual organisations.

Good Practice

1. The service maintains a current directory of relevant experts who can provide advice or shared care.
2. The service provider ensures its staff are aware of and trained to use referral pathways appropriately.

Suggested Indicators

1. Evidence of a policy or guidelines for referral to relevant experts for patients, when necessary.
2. Evidence of a list of relevant experts who are available for consultation.

References:

1. McVey P, McKenzie H, White K. A community-of-care: the integration of a palliative approach within residential aged care facilities in Australia. Health Soc Care Community. 2014 Mar;22(2):197-209. doi: 10.1111/hsc.12077. Epub 2013 Nov 6. PMID: 24200015.

2. Sawatzky R, Porterfield P, Lee J, Dixon D, Lounsbury K, Pesut B, Roberts D, Tayler C, Voth J, Stajduhar K. Conceptual foundations of a palliative approach: a knowledge synthesis. BMC Palliat Care. 2016 Jan 15;15:5. doi: 10.1186/s12904-016-0076-9. PMID: 26772180; PMCID: PMC4715271.

3. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, Dahlin CM, Blinderman CD, Jacobsen J, Pirl WF, Billings JA, Lynch TJ. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med. 2010 Aug 19;363(8):733-42. doi: 10.1056/NEJMoa1000678. PMID: 20818875.

4. Quill TE, Abernethy AP. Generalist plus specialist palliative care--creating a more sustainable model. N Engl J Med. 2013 Mar 28;368(13):1173-5. doi: 10.1056/NEJMp1215620. Epub 2013 Mar 6. PMID: 23465068.

5.Reville B, Reifsnyder J, McGuire DB, Kaiser K, Santana AJ. Education and referral criteria: impact on oncology referrals to palliative care. J Palliat Med. 2013 Jul;16(7):786-9. doi: 10.1089/jpm.2012.0487. Epub 2013 Mar 19. PMID: 23510168.

6. Hui D, Meng YC, Bruera S, Geng Y, Hutchins R, Mori M, Strasser F, Bruera E. Referral Criteria for Outpatient Palliative Cancer Care: A Systematic Review. Oncologist. 2016 Jul;21(7):895-901. doi: 10.1634/theoncologist.2016-0006. Epub 2016 May 16. PMID: 27185614; PMCID: PMC4943399.

7. Bourmorck D, de Saint-Hubert M, Desmedt M, Piers R, Flament J, De Brauwer I. SPICT as a predictive tool for risk of 1-year health degradation and death in older patients admitted to the emergency department: a bicentric cohort study in Belgium. BMC Palliat Care. 2023 Jun 24;22(1):79. doi: 10.1186/s12904-023-01201-9. PMID: 37355577; PMCID: PMC10290336.

8. Bee PE, Barnes P, Luker KA. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. J Clin Nurs. 2009 May;18(10):1379-93. doi: 10.1111/j.1365-2702.2008.02405.x. Epub 2009 Apr 8. PMID: 18624779.

9. Kreyer C, Stecher B, Pleschberger S, Ewing G. What individual needs do family caregivers have in palliative home care and how are they supported? A qualitative study of a supportive intervention. Support Care Cancer. 2024 Oct 18;32(11):733. doi: 10.1007/s00520-024-08904-6. PMID: 39422785; PMCID: PMC11489160.

10. Le BH, Watt JN. Care of the dying in Australia's busiest hospital: benefits of palliative care consultation and methods to enhance access. J Palliat Med. 2010 Jul;13(7):855 60. doi: 10.1089/jpm.2009.0339. PMID: 20636157.

11. Firth AM, Lin CP, Yi DH, Goodrich J, Gaczkowska I, Waite F, Harding R, Murtagh FE, Evans CJ. How is community based 'out-of-hours' care provided to patients with advanced illness near the end of life: A systematic review of care provision. Palliat Med. 2023 Mar;37(3):310-328. doi: 10.1177/02692163231154760. PMID: 36924146; PMCID: PMC10126468.

12. Goodrich J, Watson C, Gaczkowska I, Harding R, Evans C, Firth A, Murtagh FEM. Understanding patient and family utilisation of community-based palliative care services out-of-hours: Additional analysis of systematic review evidence using narrative synthesis. PLoS One. 2024 Feb 21;19(2):e0296405. doi: 10.1371/journal.pone.0296405. PMID: 38381768; PMCID: PMC10880966.

Standard 3 - Coordinated Care

Care is coordinated between different settings (hospitals, clinics and community) to ensure continuity.

Rationale	As a patient progresses through different stages of their illness, they require care from different healthcare service providers.[1] However, poor coordination between these services lead to undue stress on the patient and their caregivers and suboptimal usage of resources.[2-6] Effective communication and coordination between these services improves quality of life.[1,4,6]

Indicators		
All Classes	3.1	The service provider identifies a lead healthcare provider coordinating the patient's care.[2,3,6,7]
	3.2	Networks are established between different palliative care service providers, to facilitate the provision of seamless care for patients.
	3.3	The patient, caregiver and family are provided with clear written instructions on how to seek help if needed at any time, including after office hours.
	3.4	During transfers between different care settings, necessary patient information is provided to the receiving service provider.
	3.5	A plan is in place for procedures after death, during and after office hours.[8]

Suggested Tools	
1.	Information for patients and families on how and when to seek help: a) Malaysian Hospice and Palliative Care Council: Caregiver resources https://www.malaysianhospicecouncil.com/forcaregiver b) Hospice Malaysia. Carer's Guidebook. Kuala Lumpur, Malaysia 2016 https://www.hospismalaysia.org/resources/ c) MAPPAC Care Giver Handbook for Children with Palliative Care Needs https://mappac.org/resources/handbook

	d) Handbook of Children’s Palliative Care Malaysia. Kementerian Kesihatan Malaysia Handbook_Of_Children’s_Palliative_Care_Malaysia_.pdf
2.	Forms to aid staff in transfer of information: a) Referral forms b) Hand-over forms when organisational boundaries are crossed (e.g. at clinic visits, referral to emergency departments)
3.	Guidance on procedures after death: a) Surat Pekeliling Ketua Pengarah Kesihatan Malaysia Bil. 10/2012, Standard Operating Procedures Of Forensic Medicine Services https://www.moh.gov.my/moh/attachments/6937.pdf b) NHS National End of Life Care Programme - Guidance for staff responsible for care after death (last offices) https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/10/Guidance-for-Staff-Responsible-for-Care-after-Death.pdf

Implementation Guide

3.1	The service provider identifies a lead healthcare provider coordinating the patient's care.[2,3,6,7] **(All providers)**

Explanatory Notes

Lead healthcare provider	All patients should have a primary provider identified to coordinate their care. Transitions of care between providers should be seamless. Lead healthcare provider: • Acute care setting – Primary specialist team or palliative care team. • Inpatient hospice – Palliative care physician or nurse. • Community Palliative Care Service – Community Palliative Care doctor or nurse. The primary provider can change in accordance with a change in care setting. Where possible, the person should be identifiable to the patient and their families.

Good Practice

1.	The lead healthcare provider should be clearly identified in the patient's medical record and communicated to the patient and family.

3.2	Networks are established between different palliative care service providers, to facilitate the provision of seamless care for patients. **(All providers)**

Explanatory Notes

Patients with palliative care needs are often transferred from one health care setting to another (eg. from hospital to home hospice) in the course of their illness. Informal or formal networks between service providers will facilitate provision of seamless and holistic care.

Good Practice

1. There should be established links with service providers in various settings such as hospitals or community hospice services.
2. There should be policies or guidelines for referral between palliative care providers.

Suggested Indicators

1. Evidence of policy or guidelines for referral between palliative care providers.

3.3	The patient, caregiver and family are provided with clear written instructions on how to seek help if needed at any time, including after office hours. **(All providers)**

Explanatory Notes

Patients and caregivers often face new or worsening distressing symptoms, medication-related questions, or sudden changes in condition outside of regular clinic or office hours. Without clear guidance on how to seek timely support, they may experience unnecessary suffering, delays in care, or turn to emergency services inappropriately.

Good Practice

1. The service should provide a simple instruction sheet or name card with phone numbers of whom to contact, including after hours.
2. Instructions should include guidance on what situations warrant seeking help out of hours.
3. This information should be included as part of a patient's discharge planning or discussion of care plans.

Suggested Indicators

1. Evidence of contact instructions available for patients, caregivers and family to seek help if needed, including after office hours.

Suggested Tools and Resources

1. Malaysian Hospice and Palliative Care Council: Caregiver resources
   https://www.malaysianhospicecouncil.com/forcaregiver
2. Hospice Malaysia. Carer's Guidebook. Kuala Lumpur, Malaysia 2016
   https://www.hospismalaysia.org/resources/
3. MAPPAC Care Giver Handbook for Children with Palliative Care Needs
   https://mappac.org/resources/handbook
4. Handbook of Children's Palliative Care Malaysia. Kementerian Kesihatan Malaysia
   Handbook_Of_Children's_Palliative_Care_Malaysia_.pdf

3.4	During transfers between different care settings, necessary patient information is provided to the receiving service provider. **(All providers)**

Explanatory Notes

Written or verbal handovers should be made during transfers between different care settings. The handover content include:

- Case summary including diagnosis and treatment plans.
- Summary of active symptom issues during the episode of care.
- Latest blood and/or imaging results where applicable.
- Information regarding medications such as rationale for drugs used; response to medications; side effects and tolerability; date of dose adjustments.
- Latest discussion and decisions on goals of care.
- Advance care planning discussions where applicable.
- Possible red flags on a case-by-case basis, such as complicated family issues, collusion, delay in diagnosis or treatment, etc.

For Class C Providers Unplanned emergency admissions to hospitals require home care teams to inform hospital palliative care teams for follow-up. Conversely, discharges of patients known to hospital palliative care teams should be handed over to community palliative care teams to ensure continuity of care.

Good Practice

1. Establish a system of handover for palliative care patients transitioning between settings.
2. Particularly in complex cases, both verbal and written communication can be beneficial for both referring and receiving services.

Suggested Indicators

1. Percentage of documented handovers done for expected/planned transfers:

Numerator	Number of documented handovers done.
Denominator	Total number of patients within service transferred to other settings (for expected/planned transfers) in the audit period.

Suggested Tools and Resources
1. Forms to aid staff in transfer of information: a) Referral forms b) Hand-over forms when organisational boundaries are crossed (e.g. at clinic visits, referral to emergency departments)

3.5	A plan is in place for procedures after death, during and after office hours.[8] **(All providers)**

Explanatory Notes

Having a clear plan for procedures after death ensures respectful handling of the deceased, timely certification, and support for grieving families. It prevents delays and distress, especially after hours, and helps maintain dignity and trust in care.

Good Practice

1. There must be a policy / guideline for certification of death during and after office hours.
2. Relevant patient information sheets/pamphlets are available, to be given to caregivers where appropriate.

Suggested Indicators

1. Evidence of a policy or guidelines for certification of death, during and after office hours.

Suggested Tools and Resources

1. Surat Pekeliling Ketua Pengarah Kesihatan Malaysia Bil. 10/2012, Standard Operating Procedures Of Forensic Medicine Services https://www.moh.gov.my/moh/attachments/6937.pdf
2. NHS National End of Life Care Programme - Guidance for staff responsible for care after death (last offices) https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/10/Guidance-for-Staff-Responsible-for-Care-after-Death.pdf

References:

1. Vanbutsele G, Pardon K, Van Belle S, Surmont V, De Laat M, Colman R, Eecloo K, Cocquyt V, Geboes K, Deliens L. Effect of early and systematic integration of palliative care in patients with advanced cancer: a randomised controlled trial. Lancet Oncol. 2018 Mar;19(3):394-404. doi: 10.1016/S1470-2045(18)30060-3. Epub 2018 Feb 3. PMID: 29402701.

2. Mason B, Epiphaniou E, Nanton V, Donaldson A, Shipman C, Daveson BA, Harding R, Higginson I, Munday D, Barclay S, Boyd K, Dale J, Kendall M, Worth A, Murray SA. Coordination of care for individuals with advanced progressive conditions: a multi site ethnographic and serial interview study. Br J Gen Pract. 2013 Aug;63(613):e580 8. doi: 10.3399/bjgp13X670714. PMID: 23972199; PMCID: PMC3722835.

3. Husain A, Barbera L, Howell D, Moineddin R, Bezjak A, Sussman J. Advanced lung cancer patients' experience with continuity of care and supportive care needs. Support Care Cancer. 2013 May;21(5):1351-8. doi: 10.1007/s00520-012-1673-7. Epub 2012 Dec 29. PMID: 23274923.

4. Morita T, Miyashita M, Yamagishi A, Akiyama M, Akizuki N, Hirai K, Imura C, Kato M, Kizawa Y, Shirahige Y, Yamaguchi T, Eguchi K. Effects of a programme of interventions on regional comprehensive palliative care for patients with cancer: a mixed-methods study. Lancet Oncol. 2013 Jun;14(7):638-46. doi: 10.1016/S1470 2045(13)70127-X. Epub 2013 May 9. PMID: 23664708.

5. Engelhardt JB, McClive-Reed KP, Toseland RW, Smith TL, Larson DG, Tobin DR. Effects of a program for coordinated care of advanced illness on patients, surrogates, and healthcare costs: a randomized trial. Am J Manag Care. 2006 Feb;12(2):93-100. PMID: 16464138.

6. Aiken LS, Butner J, Lockhart CA, Volk-Craft BE, Hamilton G, Williams FG. Outcome evaluation of a randomized trial of the PhoenixCare intervention: program of case management and coordinated care for the seriously chronically ill. J Palliat Med. 2006 Feb;9(1):111-26. doi: 10.1089/jpm.2006.9.111. PMID: 16430351.

7. Reeves E, Liebig B, Schweighoffer R. Care Coordination in Palliative Home Care: Who Plays the Key Role? Int J Integr Care. 2020 Sep 28;20(3):15. doi: 10.5334/ijic.5466. PMID: 33041732; PMCID: PMC7528663.

8. Jordhøy MS, Fayers P, Saltnes T, Ahlner-Elmqvist M, Jannert M, Kaasa S. A palliative care intervention and death at home: a cluster randomised trial. Lancet. 2000 Sep 9;356(9233):888-93. doi: 10.1016/s0140-6736(00)02678-7. PMID: 11036893.

Standard 4 – Holistic Assessment Holistic assessment and ongoing care planning for patients and caregivers should respond	
Rationale	A holistic assessment—addressing physical, social, spiritual, and psychological aspects—helps identify the needs of patients requiring palliative care, which can then be addressed by the interdisciplinary team.[1-5] Subsequent on-going assessment and care planning should be proactive and responsive to patients' and caregivers' changing needs.

Indicators		
All Classes	4.1	There is evidence of documented holistic assessments that cover the patient and family's physical, psychological, social and spiritual needs.
	4.2	There is evidence of individualised care plans made after the holistic assessment.
Class C	4.3	Ongoing holistic assessment is supported by the use of assessment tools where appropriate.[6-13]
	4.4	There is evidence of regular assessment of response to treatment and changing needs.
	4.5	There is evidence of ongoing care planning which responds to changing needs.

Suggested Tools	
1.	Holistic assessment tools: a) Edmonton Symptom Assessment System (ESAS)[6] https://www.albertahealthservices.ca/info/Page14546.aspx b) IPOS – Integrated Palliative Care Outcomes Scale[7,8] https://pos-pal.org/ c) Palliative Care Outcomes Collaboration (PCOC) Dataset forms[9] http://ahsri.uow.edu.au/pcoc/forms/index.html d) FICA Spiritual Assessment Tool[10] https://smhs.gwu.edu/gwish/clinical/fica

	e) HOPE Spiritual Assessment Tool[11] f) Distress Thermometer[12,13] https://www.nccn.org/global/what-we-do/distress-thermometer-tool-translations
2.	Examples of care plan templates: a) Queensland Government Palliative Care Patient Information Form https://www.health.qld.gov.au/__data/assets/pdf_file/0029/365492/bspc_pif_paper.pdf

Implementation Guide

4.1	There is evidence of documented holistic assessments that cover the patient and family's physical, psychological, social and spiritual needs. **(All providers)**

Explanatory Notes	
For Class A providers	There should be documentation of screening and management of common symptoms like pain, dyspnoea, other relevant symptoms and assessment of psychosocial needs where relevant.
For Class B+C providers	All patients must have documentation of the following initial assessments: • Pain, dyspnoea and other relevant symptoms. • Psychological Assessment: Mood/coping/ anxiety/ depression Social History: Genogram or case notes documentation of immediate family members and living arrangements. • Spiritual: sources of meaning, beliefs, or existential concerns (may include, but not limited to religion). • Cultural: language preferences, important customs, or practices relevant to care (may include ethnicity).

Good Practice	
1.	Palliative care providers should use validated tools to assess and manage symptoms (e.g., pain, dyspnoea).
2.	Structured templates or forms should be used to ensure consistency and completeness of documentation.
3.	Assessments should be person-centred and culturally sensitive.

Suggested Indicators

1. Evidence of use of a holistic assessment framework. This may include assessment forms or patient reported outcome measures.

2. Percentage of patients with documented physical, psychological, social and spiritual screening:

Numerator	Number of patients with documented physical, psychological, social and spiritual screening.
Denominator	Total number of patients seen over the audit period E.g. of an audit sample: • All patients (or a fixed consecutive number) seen over a 4 week period. • All patient notes within the episode of care*

*An episode of care is a period of contact between a patient and a palliative care service that is provided by one palliative care service and occurs in one setting. An episode of care ends when the setting of care changes.

Suggested Tools

1. Edmonton Symptom Assessment System (ESAS)[6]
   https://www.albertahealthservices.ca/info/Page14546.aspx

2. IPOS – Integrated Palliative Care Outcomes Scale[7,8]
   https://pos-pal.org/

3. Palliative Care Outcomes Collaboration (PCOC) Dataset forms[9]
   http://ahsri.uow.edu.au/pcoc/forms/index.html

4. FICA Spiritual Assessment Tool[10]
   https://smhs.gwu.edu/gwish/clinical/fica

5. HOPE Spiritual Assessment Tool[11]

4.2	There is evidence of individualised care plans made after the holistic assessment. **(All providers)**

Explanatory Notes

Individualised care plan	A care plan which addresses physical, psychosocial and spiritual needs identified through holistic assessment.
For Class A providers	An individualised care plan (including pain and symptom management and psychosocial issues) should be documented after the initial assessment of the patient and family.
For Class B+C providers	In addition to the above, relevant spiritual issues should also be addressed in the individualised care plan.

Good Practice

1. Palliative care providers should develop a written, individualised care plan following the initial holistic assessment.
2. Patients and caregivers are engaged in shared decision-making during care planning.
3. These individualised care plans are accessible to all team members.

Suggested Indicators

1. Evidence of template-guided processes in creating individualised care plans.
2. Percentage of patients with individualised documented care plans at the end of first clinical encounter/initial assessment:

Numerator	Number of patients with individualized documented care plans at the end of first clinical encounter/initial assessment.
Denominator	Total number of newly referred patients over the audit period.

Suggested Tools

2. Queensland Government Palliative Care Patient Information Form https://www.health.qld.gov.au/__data/assets/pdf_file/0029/365492/bspc_pif_paper.pdf

4.3	Ongoing holistic assessment is supported by the use of assessment tools where appropriate. **(Class C providers)**

Explanatory Notes

There must be documentation of regular review of pain and symptom assessment during each episode of care, as well as documentation of regular psychological and spiritual assessment for both patients and families. These assessments can be performed by any member of the palliative care team.

The use of validated assessment tools helps ensure consistency, improves communication within the multidisciplinary team, and improves the quality and completeness of assessments across domains (e.g., pain, dyspnoea, psychological distress, spiritual concerns).

Good Practice

1. Palliative care providers should use validated tools where appropriate to support assessments (see below).
2. Ensure documentation is accessible, timely, and reflects continuity of care across settings and providers.

Suggested Indicators

1. Percentage of patients assessed using validated tools

Numerator	Number of patients assessed using validated tools.
Denominator	Total number of patients during the audit period.

Suggested Tools

1. Edmonton Symptom Assessment System (ESAS)[6]
   https://www.albertahealthservices.ca/info/Page14546.aspx
2. IPOS – Integrated Palliative Care Outcomes Scale[7,8]
   https://pos-pal.org/
3. Palliative Care Outcomes Collaboration (PCOC) Dataset forms[9]
   http://ahsri.uow.edu.au/pcoc/forms/index. html
4. Distress Thermometer[11,12]
   https://www.nccn.org/global/what-we-do/distress-thermometer-tool-translations

4.4	There is evidence of regular assessment of response to treatment and changing needs. **(Class C providers)**

Explanatory Notes

Physical symptoms like pain and dyspnoea must be regularly assessed and monitored in response to evolving clinical conditions, as well as the goals and needs of the patient and family.

Frequency and depth of reassessment may vary based on the care setting (e.g., inpatient, outpatient, home) and the clinical context, but should always be clearly documented.

Good Practice

1. Palliative care providers should conduct routine reassessment of symptoms, including pain and dyspnoea, at each patient encounter.
2. Practice anticipatory care, prescribing treatment for potential complications or deterioration.
3. Use validated tools to monitor treatment response.
4. Document patient response to interventions (e.g. analgesics, oxygen, repositioning) and adjust the care plan as needed.
5. For community settings, reassessment frequency can be guided by changes in condition, visit intervals or caregiver concerns.

Suggested Indicators

1. Percentage of moderate or severe pain episodes (pain score ≥4) improved within 72 hours. Improvement is defined by reduction to no or mild pain (pain score ≤3).

Numerator	Number of patients with moderate or severe pain which improved to no or mild pain within 72 hours.
Denominator	Total number patients with moderate or severe pain (pain score ≥4) during the audit period.

Suggested Tools	
1.	Edmonton Symptom Assessment System (ESAS)[6] https://www.albertahealthservices.ca/info/Page14546.aspx
2.	IPOS – Integrated Palliative Care Outcomes Scale[7,8] https://pos-pal.org/
3.	Palliative Care Outcomes Collaboration (PCOC) Dataset forms[9] http://ahsri.uow.edu.au/pcoc/forms/index. html
4.	FICA Spiritual Assessment Tool[10] https://smhs.gwu.edu/gwish/clinical/fica
5.	HOPE Spiritual Assessment Tool[11]

4.5	There is evidence of ongoing care planning which responds to changing needs. **(Class C providers)**

Explanatory Notes

Care planning should be a dynamic, ongoing process that evolves based on patient and family needs. There should be regular monitoring of the management plan and changes should be made if it is not able to adequately control symptoms.

Good Practice

1. Care plans should be updated following significant clinical changes (eg hospitalisation, deterioration, new goals of care).
2. Practice shared decision-making by involving patients and caregivers.

Suggested Indicators

1. Percentage of cases where there is documentation that the management plan has been reviewed:

Numerator	Number of patients where there is documentation that the management plan has been reviewed.
Denominator	Total number of patients during the audit period.

References:

1. Dudgeon D. The Impact of Measuring Patient-Reported Outcome Measures on Quality of and Access to Palliative Care. J Palliat Med. 2018 Jan;21(S1):S76-S80. doi: 10.1089/jpm.2017.0447. PMID: 29283866; PMCID: PMC5733646.

2. Ahmed N, Ahmedzai SH, Collins K, Noble B. Holistic assessment of supportive and palliative care needs: the evidence for routine systematic questioning. BMJ Support Palliat Care. 2014 Sep;4(3):238-46. doi: 10.1136/bmjspcare-2012-000324. Epub 2014 Jan 10. PMID: 24644199.

3. Hamatani Y, Iguchi M, Ikeyama Y, Kunugida A, Ogawa M, Yasuda N, Fujimoto K, Ichihara H, Sakai M, Kinoshita T, Nakashima Y, Akao M. Comprehensive symptom assessment using Integrated Palliative care Outcome Scale in hospitalized heart failure patients. ESC Heart Fail. 2022 Jun;9(3):1963-1975. doi: 10.1002/ehf2.13907. Epub 2022 Mar 20. PMID: 35307988; PMCID: PMC9065822.

4. Bainbridge D, Seow H, Sussman J. Common Components of Efficacious In-Home End of-Life Care Programs: A Review of Systematic Reviews. J Am Geriatr Soc. 2016 Mar;64(3):632-9. doi: 10.1111/jgs.14025. PMID: 27000336.

5. Puchalski CM. Integrating spirituality into patient care: an essential element of person-centered care. Pol Arch Med Wewn. 2013;123(9):491-7. PMID: 24084250.

6. Hui D, Bruera E. The Edmonton Symptom Assessment System 25 Years Later: Past, Present, and Future Developments. J Pain Symptom Manage. 2017 Mar;53(3):630 643. doi: 10.1016/j.jpainsymman.2016.10.370. Epub 2016 Dec 29. PMID: 28042071; PMCID: PMC5337174.

7. Murtagh FE, Ramsenthaler C, Firth A, Groeneveld EI, Lovell N, Simon ST, Denzel J, Guo P, Bernhardt F, Schildmann E, van Oorschot B, Hodiamont F, Streitwieser S, Higginson IJ, Bausewein C. A brief, patient- and proxy-reported outcome measure in advanced illness: Validity, reliability and responsiveness of the Integrated Palliative care Outcome Scale (IPOS). Palliat Med. 2019 Sep;33(8):1045-1057. doi: 10.1177/0269216319854264. Epub 2019 Jun 12. PMID: 31185804; PMCID: PMC6691591.

8. Lind S, Wallin L, Fürst CJ, Beck I. The integrated palliative care outcome scale for patients with palliative care needs: Factors related to and experiences of the use in acute care settings. Palliat Support Care. 2019 Oct;17(5):561-568. doi: 10.1017/S1478951518001104. PMID: 30841947.

9. Clapham S, Clark K, Draper K, Mastroianni F, Rand J, Redwood L, Currow D. A National Quality Initiative to Improve Palliative Care Outcomes: Identifying Enabling Factors that Drive Quality Improvement. Palliat Med Rep. 2024;5(2):e0092. doi:10.1089/pmr.2024.0092

10. Borneman T, Ferrell B, Puchalski CM. Evaluation of the FICA Tool for Spiritual Assessment. J Pain Symptom Manage. 2010 Aug;40(2):163-73. doi: 10.1016/j.jpainsymman.2009.12.019. Epub 2010 Jul 8. PMID: 20619602.

11. Anandarajah G, Hight E. Spirituality and medical practice: using the HOPE questions as a practical tool for spiritual assessment. Am Fam Physician. 2001 Jan 1;63(1):81-9. PMID: 11195773.

12. Wüller J, Küttner S, Foldenauer AC, Rolke R, Pastrana T. Accuracy of the Distress Thermometer for home care patients with palliative care needs in Germany. Palliat Support Care. 2017 Jun;15(3):288-294. doi: 10.1017/S1478951516000699. Epub 2016 Sep 26. PMID: 27666282.

13. Ohnhäuser S, Wüller J, Foldenauer AC, Pastrana T. Changes in Distress Measured by the Distress Thermometer as Reported by Patients in Home Palliative Care in Germany. J Palliat Care. 2018 Jan;33(1):39-46. doi: 10.1177/0825859717751932. Epub 2018 Jan 14. PMID: 29332504.

Standard 5 – Goals of Care Discussions Patients with palliative care needs should have goals of care discussions.	
Rationale	Patients with palliative care needs, their caregivers and families should have the opportunity to discuss their goals of care. Individuals who have conversations with their healthcare providers about their values, goals, and preferences are more likely to receive the care they want, experience less distress, and report better quality of life.[1,2,3]

Indicators		
All Classes	5.1	There is evidence from documentation that the service provider routinely engages in goals of care discussions with patient, caregiver and family.
Class B+C	5.2	There is regular monitoring of patient care to achieve goal concordant outcomes.

Suggested Tools	
1.	Tools to aid goals of care discussions: a) Serious Illness Discussions[4] https://www.ariadnelabs.org/wp-content/uploads/2023/05/Serious-Illness-Conversation-Guide.2023-05-18.pdf b) REDMAP https://www.spict.org.uk/wp-content/uploads/2025/05/REDMAP-2025.pdf c) REMAP[5] https://www.ethics.va.gov/goalsofcaretraining/REMAP.pdf

Implementation Guide

5.1	There is evidence from documentation that the service provider routinely engages in goals of care discussions with the patient, caregiver and family. **(All providers)**

Explanatory Notes

Goals of care discussion	Discussions about what is most important to the patient, that will help align treatment to patient values and preferences.

Good Practice

1. Palliative care providers should initiate goals of care discussions early in the illness trajectory, and revisit periodically or with any change in clinical condition.
2. Ensure discussions are patient-centred, incorporating the values, beliefs, and preferences of the patient, and where appropriate, the caregiver and family.
3. Use clear, compassionate, and culturally sensitive language.

Suggested Indicators

1. Percentage of patients with documented goals of care discussions:

Numerator	Number of patients with documented goals of care discussions.
Denominator	Number of patients within the audit period.

Suggested Tools

1. Serious Illness Discussions[4]
   https://www.ariadnelabs.org/wp-content/uploads/2023/05/Serious-Illness-Conversation-Guide.2023-05-18.pdf
2. REDMAP
   https://www.spict.org.uk/wp-content/uploads/2025/05/REDMAP-2025.pdf
3. REMAP[5]
   https://www.ethics.va.gov/goalsofcaretraining/REMAP.pdf

5.2	There is regular monitoring of patient care to achieve goal concordant outcomes. **(All providers)**

Explanatory Notes

Goal concordant outcomes[6,7]	This refers to patient care, decision making and clinical outcomes that are aligned with the patient's known goals, values, and preferences and may include: • Decisions about ceilings of care, including resuscitation status, and specific limitations on intubation, feeding tubes, blood transfusions etc. • Decisions about burdensome procedures including. repeated blood draws, imaging, intravenous lines etc. • Preferred place of care. • Preferred place of death.

Good Practice

1. Document changes in symptoms, functional status, or psychosocial circumstances, and ensure these changes are communicated with family members or caregivers as well.
2. If the patient is unable to express goals, ensure a surrogate decision-maker's input is recorded.
3. Reassess and adjust care when there is a significant change in condition (e.g. functional decline, hospitalisation, transition to dying phase).

Suggested Indicators

1. Evidence of a system to measure goal-concordant care (multidisciplinary meetings, mortality/ morbidity reviews, grand ward rounds, etc.).

References:

1. Jain N, Bernacki RE. Goals of Care Conversations in Serious Illness: A Practical Guide. Med Clin North Am. 2020 May;104(3):375-389. doi: 10.1016/j.mcna.2019.12.001. PMID: 32312404.

2. Comer A, Fettig L, Torke AM. Identifying Goals of Care. Med Clin North Am. 2020 Sep;104(5):767-775. doi: 10.1016/j.mcna.2020.06.002. PMID: 32773044; PMCID: PMC7458156.

3. Bernacki RE, Block SD; American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. JAMA Intern Med. 2014 Dec;174(12):1994-2003. doi: 10.1001/jamainternmed.2014.5271. PMID: 25330167.

4. Karim S, Levine O, Simon J. The Serious Illness Care Program in oncology: evidence, real-world implementation and ongoing barriers. Curr Oncol. 2022 Mar 2;29(3):1527–36. doi:10.3390/curroncol29030128. PMID: 35323328; PMCID: PMC8947515.

5. Childers JW, Back AL, Tulsky JA, Arnold RM. REMAP: A Framework for Goals of Care Conversations. J Oncol Pract. 2017 Oct;13(10):e844-e850. doi: 10.1200/JOP.2016.018796. Epub 2017 Apr 26. PMID: 28445100.

6. Ernecoff NC, Wessell KL, Bennett AV, Hanson LC. Measuring Goal-Concordant Care in Palliative Care Research. J Pain Symptom Manage. 2021 Sep;62(3):e305-e314. doi: 10.1016/j.jpainsymman.2021.02.030. Epub 2021 Mar 3. PMID: 33675919; PMCID: PMC9082654.

7. Sanders JJ, Curtis JR, Tulsky JA. Achieving Goal-Concordant Care: A Conceptual Model and Approach to Measuring Serious Illness Communication and Its Impact. J Palliat Med. 2018 Mar;21(S2):S17-S27. doi: 10.1089/jpm.2017.0459. Epub 2017 Nov 1. PMID: 29091522; PMCID: PMC5756461.

Standard 6 – Patient Centred Care

Patients should receive care that is respectful of and responsive to individual preferences, needs and values.

Rationale	Patient's needs are unique and individual. The patient's quality of life is improved by care that is customised to their unique physical, emotional, cultural and spiritual needs.[1,2,3,4]

Indicators		
All Classes	6.1	Each patient's unique cultural and spiritual needs are taken into consideration in the provision of care services.[5,6,7]
	6.2	There is evidence of regular communication of relevant information to patients, their caregivers and families.[8,9,10]
Class C	6.3	Psychological, spiritual, social and physical support services are available when needed or there is an established referral process to such services.[8,9]
	6.4	Where complex ethical cases are identified, there is access to a group of relevant individuals that can provide consultation for complex decision making.

Suggested Tools	
1.	Guides for holistic Palliative Care assessment a) IPOS – Integrated Palliative Care Outcomes Scale[11,12] https://pos-pal.org/ b) FICA Spiritual Assessment Tool[13] https://smhs.gwu.edu/gwish/clinical/fica c) HOPE Spiritual Assessment Tool[14]
2.	Communication guides for healthcare providers: a) Vital Talk Guides https://www.vitaltalk.org/resources/quick-guides/

	b) Serious Illness Discussions[15] https://www.ariadnelabs.org/wp-content/uploads/2023/05/Serious-Illness-Conversation-Guide.2023-05-18.pdf c) REDMAP https://www.spict.org.uk/wp-content/uploads/2025/05/REDMAP-2025.pdf d) REMAP[16] https://www.ethics.va.gov/goalsofcaretraining/REMAP.pdf
3.	Guidance on ethical decision making: a) Jonsen Four Box Model of ethical decision making https://depts.washington.edu/bhdept/ethics-medicine-bioethics-tools/paradigm-4-boxes b) Clinical Ethics Malaysia https://clinicalethicsmalaysia.org/

Implementation Guide

6.1	Each patient's unique cultural and spiritual needsare taken into consideration in the provision of care services. **(All providers)**

Explanatory Notes

Cultural needs	Refers to a body of values, perspectives, beliefs, behaviors, and traditions that are salient within a specific group or for some at the individual level. Race, ethnicity, social class, religion can all intersect to create a person's culture.[5,6]
Spirituality	Can be defined as a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices.[7]

Good Practice

1. All providers should screen for spiritual/psychosocial/cultural needs and concerns at initial consultation and intervals, particularly with changes in disease status.

2. The patient's care plan should reflect support for spiritual/ psychosocial/ cultural needs.

Suggested Tools

1. IPOS – Integrated Palliative Care Outcomes Scale[11,12]
   https://pos-pal.org/

2. FICA Spiritual Assessment Tool[13]
   https://smhs.gwu.edu/gwish/clinical/fica

3. HOPE Spiritual Assessment Tool[14]

6.2	There is evidence of regular communication of relevant information to patients, their caregivers and families. **(All providers)**

Explanatory Notes

All providers should provide updates of a patient's condition to both patient and family on a regular basis: at initial consultation and whenever there are changes in the clinical condition of the patient.

Note: Providers should respect the patient's autonomy and right to know about his/her condition and approach issues of collusion sensitively, understanding the cultural influences and the role of family in decision making.

Good Practice

1. Communication to the patient and family should be performed and documented whenever there are changes in the patient's clinical condition.
2. Communication should anticipate crises or changes in circumstances. Where appropriate, discussions focused on future preparation should be considered.[8,9,10]
3. Communication should be patient-centered, tailoring the content, timing, and approach to meet the needs of the patient and family.[9]
   This includes addressing not only medical therapy, but also the psychosocial, emotional, and practical impact of illness on the patient's life and relationships.[10]

Suggested Tools

1. Vital Talk Guides
   https://www.vitaltalk.org/resources/quick-guides/
2. Serious Illness Discussions[15]
   https://www.ariadnelabs.org/wp-content/uploads/2023/05/Serious-Illness-Conversation-Guide.2023-05-18.pdf
3. REDMAP
   https://www.spict.org.uk/wp-content/uploads/2025/05/REDMAP-2025.pdf
4. REMAP[16]
   https://www.ethics.va.gov/goalsofcaretraining/REMAP.pdf

6.3	Psychological, spiritual, social and physical support services are available when needed or there is an established referral process to such services. **(Class C providers)**
Explanatory Notes	
Support services	Includes care provided by psychologists or counsellors, social workers, physiotherapists, occupational therapists, speech-language therapists, spiritual care providers, volunteer organizations etc.

Good Practice	
1.	Providers should have access to interdisciplinary support services to address the full spectrum of patient and family needs.[8,9]
2.	Close working relationships with support teams should be actively fostered. Interdisciplinary meetings can facilitate care coordination.[8,9]
3.	Support services should be made aware of the unique needs in patients with poor prognosis and deteriorating health.[9]

Suggested Indicators	
1.	Evidence of access to spiritual support, physical, occupational, and speech therapy services etc. This may include a directory or contact list for support services.

6.4	Where complex ethical cases are identified there is access to a group of relevant individuals that can provide consultation for complex decision making. **(Class C providers)**

Explanatory Notes

Ethical dilemma	An ethical dilemma involves the need to choose from among two or more morally acceptable options or between equally unacceptable courses of action, when one choice prevents selection of the other.[17] Examples of Ethical Dilemmas include: • Conflict of ethical principles (e.g. patient's wish to die at home but without adequate support – autonomy vs non--maleficence). • Requests for palliative sedation. • Withdrawing or not providing life-- sustaining treatment.
Group of relevant individuals	An independent advisory panel that may take the form of an Interdisciplinary Ethics Team, Clinical Ethics Committees, Medical and Dental Advisory Committee (MDAC), or an equivalent body for consultation. Institutions may have established ethics committees or form ad hoc panels when complex ethical issues arise.

Good Practice

1. Foster a culture where staff feel safe to raise ethical concerns and seek guidance.
2. Establish and implement a clear protocol for escalating complex ethical cases, including steps for consultation and documentation.
3. Ethical discussions should be documented clearly in the medical record, including values considered, risks weighed, and rationale for the final plan.
4. Train staff regularly to build competence in recognising and navigating ethical dilemmas and embed ethical reflection in routine care.

Suggested Indicators

1. Evidence of a referral system to an Ethics Consultant or Committee for complex ethical cases. For example, Medical and Dental Advisory Committee (MDAC), clinical ethics committees or an equivalent interdisciplinary process that considers multiple perspectives.

Suggested Tools	
1.	Jonsen Four Box Model of ethical decision making https://depts.washington.edu/bhdept/ethics-medicine-bioethics-tools/paradigm-4-boxes
2.	Clinical Ethics Malaysia https://clinicalethicsmalaysia.org/

References:

1. Johnston B, Pringle J, Gaffney M, Narayanasamy M, McGuire M, Buchanan D. The dignified approach to care: a pilot study using the patient dignity question as an intervention to enhance dignity and person-centred care for people with palliative care needs in the acute hospital setting. BMC Palliat Care. 2015 Apr 9;14:9. doi: 10.1186/s12904-015-0013-3. PMID: 25883533; PMCID: PMC4399754.

2. Brännström M, Boman K. Effects of person-centred and integrated chronic heart failure and palliative home care. PREFER: a randomized controlled study. Eur J Heart Fail. 2014 Oct;16(10):1142-51. doi: 10.1002/ejhf.151. Epub 2014 Aug 27. PMID: 25159126.

3. Nkhoma KB, Cook A, Giusti A, Farrant L, Petrus R, Petersen I, Gwyther L, Venkatapuram S, Harding R. A systematic review of impact of person-centred interventions for serious physical illness in terms of outcomes and costs. BMJ Open. 2022 Jul 13;12(7):e054386. doi: 10.1136/bmjopen-2021-054386. PMID: 35831052; PMCID: PMC9280891.

4. Giusti A, Nkhoma K, Petrus R, Petersen I, Gwyther L, Farrant L, Venkatapuram S, Harding R. The empirical evidence underpinning the concept and practice of person centred care for serious illness: a systematic review. BMJ Glob Health. 2020 Dec;5(12):e003330. doi: 10.1136/bmjgh-2020-003330. PMID: 33303515; PMCID: PMC7733074.

5. Crawley L, Koffman J. Ethnic and cultural aspects of palliative care. In: Hanks G, Cherny NI, Christakis NA, Fallon M, Kaasa S, Portenoy RK, editors. Oxford Textbook of Palliative Medicine. 5th ed. Oxford: Oxford University Press; 2015. p. 84–92.

6. UpToDate. Cultural issues in palliative care [Online]. Waltham, MA: Wolters Kluwer; [Accessed 25 June 2025]. Available from:
https://www.uptodate.com/contents/cultural-issues-in-palliative-care

7. Steinhauser KE, Fitchett G, Handzo GF, Johnson KS, Koenig HG, Pargament KI, Puchalski CM, Sinclair S, Taylor EJ, Balboni TA. State of the Science of Spirituality and Palliative Care Research Part I: Definitions, Measurement, and Outcomes. J Pain Symptom Manage. 2017 Sep;54(3):428-440. doi: 10.1016/j.jpainsymman.2017.07.028. Epub 2017 Jul 18. PMID: 28733252.

8. National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care [Online]. 4th ed. Richmond (VA): National Coalition for Hospice and Palliative Care; 2018. Available from: https://www.nationalcoalitionhpc.org/ncp

9. National Institute for Health and Care Excellence (NICE). End of life care for adults: service delivery [Online]. London: NICE; 2019 Oct. (NICE guideline NG142). Available from: https://www.nice.org.uk/guidance/ng142

10. CareSearch. Communication approaches – clinical evidence summaries [Online]. Adelaide (AU): CareSearch; 2024 Dec 5 [Assessed 2 Jul 2025]. Available from: https://www.caresearch.com.au/Evidence/Clinical-Evidence-Summaries/Communication-Approaches

11. Murtagh FE, Ramsenthaler C, Firth A, Groeneveld EI, Lovell N, Simon ST, Denzel J, Guo P, Bernhardt F, Schildmann E, van Oorschot B, Hodiamont F, Streitwieser S, Higginson IJ, Bausewein C. A brief, patient- and proxy-reported outcome measure in advanced illness: Validity, reliability and responsiveness of the Integrated Palliative care Outcome Scale (IPOS). Palliat Med. 2019 Sep;33(8):1045-1057. doi: 10.1177/0269216319854264. Epub 2019 Jun 12. PMID: 31185804; PMCID: PMC6691591.

12. Lind S, Wallin L, Fürst CJ, Beck I. The integrated palliative care outcome scale for patients with palliative care needs: Factors related to and experiences of the use in acute care settings. Palliat Support Care. 2019 Oct;17(5):561-568. doi: 10.1017/S1478951518001104. PMID: 30841947.

13. Borneman T, Ferrell B, Puchalski CM. Evaluation of the FICA Tool for Spiritual Assessment. J Pain Symptom Manage. 2010 Aug;40(2):163-73. doi: 10.1016/j.jpainsymman.2009.12.019. Epub 2010 Jul 8. PMID: 20619602.

14. Anandarajah G, Hight E. Spirituality and medical practice: using the HOPE questions as a practical tool for spiritual assessment. Am Fam Physician. 2001 Jan 1;63(1):81-9. PMID: 11195773.

15. Karim S, Levine O, Simon J. The Serious Illness Care Program in oncology: evidence, real-world implementation and ongoing barriers. Curr Oncol. 2022 Mar 2;29(3):1527–36. doi:10.3390/curroncol29030128. PMID: 35323328; PMCID: PMC8947515.

16. Childers JW, Back AL, Tulsky JA, Arnold RM. REMAP: A Framework for Goals of Care Conversations. J Oncol Pract. 2017 Oct;13(10):e844-e850. doi: 10.1200/JOP.2016.018796. Epub 2017 Apr 26. PMID: 28445100.

17. Ong WY, Yee CM, Lee A. Ethical dilemmas in the care of cancer patients near the end of life. Singapore Med J. 2012 Jan;53(1):11-6. PMID: 22252176.

Standard 7 – Care in the Last Days of Life

Care is taken to fulfil the holistic needs of patients in the last days of life, as well as that of their caregivers and families.

Rationale	Patients entering the dying phase have unique physical, emotional, social and spiritual needs. Important aspects of care include timely identification of the dying phase, effective communication, assessment of values, needs and goals, determining preferred place of care, symptom control, and holistic psycho-social-spiritual care.[1-10]

Indicators		
All Classes	7.1	There is recognition that the patient is transitioning into the dying phase, and this is communicated to patients when appropriate, and to their caregivers and family.
	7.2	The patient, caregiver and family are given the opportunity to discuss and develop an individualized end-of-life care plan that reflects their values, goals and preferences.
	7.3	Symptoms at the end-of-life are assessed and controlled.
Class A+B	7.4	Consultations with specialized palliative care providers are made when there are complex needs at the end-of-life.
All Classes	7.5	Family members and caregivers are given appropriate support and information during the last days of life.

Suggested Tools	
1.	Guidance on recognising and communicating the dying phase: a) Handbook of Palliative Medicine in Malaysia 2nd edition b) Malaysian Hospice and Palliative Care Council: Caregiver resources https://www.malaysianhospicecouncil.com/forcaregiver c) Hospice Malaysia. Carer's Guidebook. Kuala Lumpur, Malaysia 2016 https://www.hospismalaysia.org/resources/ d) MAPPAC Care Giver Handbook for Children with Palliative Care Needs https://mappac.org/resources/handbook

	e) Handbook of Children's Palliative Care Malaysia. Kementerian Kesihatan Malaysia Handbook_Of_Children's_Palliative_Care_Malaysia_.pdf
2.	Guidance on goals of care discussions: a) Serious Illness Discussions[11] https://www.ariadnelabs.org/wp-content/uploads/2023/05/Serious-Illness-Conversation-Guide.2023-05-18.pdf b) REDMAP https://www.spict.org.uk/wp-content/uploads/2025/05/REDMAP-2025.pdf c) REMAP[12] https://www.ethics.va.gov/goalsofcaretraining/REMAP.pdf
3.	Guidance on symptom assessment at the end of life: a) Edmonton Symptom Assessment System (ESAS)[13] https://www.albertahealthservices.ca/info/Page14546.aspx b) Palliative Care Outcomes Collaboration[14] http://ahsri.uow.edu.au/pcoc/forms/index. html c) FLACC assessment tool[15] FLACC pain scale d) PAINAD assessment tool[15] Pain Assessment IN Advanced Dementia Scale (PAINAD) e) Richmond Agitation Sedation Scale (RASS)[16] Richmond Agitation-Sedation Scale-MSD Manual Professional Edition
4.	Directory of palliative care providers: a) MHPCC Directory of Palliative care services MHPCC | Malaysia | Palliative Care | Hospice
5.	Information for family and caregivers at the end of life: a) NURSE acronym Responding to Emotion: Respecting - VitalTalk

Implementation Guide

7.1	There is recognition that the patient is transitioning into the dying phase and this is communicated to patients when appropriate, and to their caregivers and family. **(All providers)**

Explanatory Notes

Dying Phase	This is also referred to as the terminal phase or actively dying phase, typically in the final hours to days of life when death is imminent. Timely recognition is crucial as it has clinical implications for care planning, reducing unnecessary interventions and supporting anticipatory guidance for patients and families. Sensitive end-of-life communication respects patient autonomy, ensures alignment to care preferences and enables patients and families to make meaningful choices at the end-of-life.

Good Practice

1. All healthcare staff should be trained in identifying the signs and symptoms of dying.
2. All healthcare staff should be trained in end-of-life communication skills.

Suggested Indicators

1. Percentage of patients whose transition to the active dying phase is accurately documented:

Numerator	Number of patients whose transition to the active dying phase is documented. Examples of documentation of transition: • Transition to terminal phase. • Initiation of a care plan for the dying.
Denominator	Total number of patient deaths.

2. Percentage of patients whose transition to the active dying phase is communicated to the patient and/or family, where applicable:

Numerator	Number of patients whose transition to the active dying phase is communicated to the patient and/or family, where applicable.
Denominator	Total number of patient deaths.

Suggested Tools

1. Handbook of Palliative Medicine in Malaysia 2nd edition
2. Malaysian Hospice and Palliative Care Council: Caregiver resources https://www.malaysianhospicecouncil.com/forcaregiver
3. Hospice Malaysia. Carer's Guidebook. Kuala Lumpur, Malaysia 2016 https://www.hospismalaysia.org/resources/
4. MAPPAC Care Giver Handbook for Children with Palliative Care Needs https://mappac.org/resources/handbook
5. Handbook of Children's Palliative Care Malaysia. Kementerian Kesihatan Malaysia Handbook_Of_Children's_Palliative_Care_Malaysia_.pdf

7.2	The patient, caregiver and family are given the opportunity to discuss and develop an individualized end-of-life care plan that reflects their values, goals and preferences. **(All providers)**

Explanatory Notes

At the end-of-life, providers should be able to discuss and develop an individualized care plan that reflects the values, goals and preferences of the patient and caregivers. This includes discussions regarding important life goals, preferred place of care, preferred place of death, medical treatment, and comfort measures.

Good Practice

1. All providers should be able to elicit patient and family values, goals and preferences regarding the end-of-life process.
2. All healthcare providers should be equipped to support an individualized end-of-life care plan that considers the patient's values, goals, and preferences, while offering clinical expertise to guide and inform decision making.
3. This includes an awareness of resources available regionally to support end of-life care and skills to facilitate balanced discussions regarding artificial hydration and nutrition at the end-of-life.

Suggested Indicators

1. Percentage of patients with documentation of a discussion to elicit values, goals and preferences at the end of life:

Numerator	Number of patients with a documented discussion to elicit values, goals and preferences at the end of life.
Denominator	Total number of patient deaths.

Suggested Tools	
1.	Serious Illness Discussions[11] https://www.ariadnelabs.org/wp-content/uploads/2023/05/Serious-Illness-Conversation-Guide.2023-05-18.pdf
2.	REDMAP https://www.spict.org.uk/wp-content/uploads/2025/05/REDMAP-2025.pdf
3.	REMAP[12] https://www.ethics.va.gov/goalsofcaretraining/REMAP.pdf
4.	Handbook of Palliative Medicine in Malaysia 2nd edition
5.	Handbook of Children's Palliative Care Malaysia. Kementerian Kesihatan Malaysia Handbook_Of_Children's_Palliative_Care_Malaysia_.pdf

7.3	Symptoms at the end of life are assessed and controlled. **(All providers)**

Explanatory Notes

Symptoms at the end of life

Common symptoms at the end of life include the following:[1,4]

a) Pain
b) Dyspnoea
c) Respiratory secretions/death rattle
d) Terminal delirium/agitation
e) Nausea/vomiting

Good Practice

1. Symptoms at the end of life are assessed and documented, including in non- verbal patients.
2. Symptom reassessment and review of management plans are done at appropriate intervals to ensure ongoing symptom control.
3. Pharmacological and non-pharmacological measures may be used for symptom control.
4. Anticipatory prescribing of PRN medications can support timely symptom control.

Suggested Indicators

1. Percentage of patients whose pain is controlled at the last clinical encounter in the active dying phase. Control is defined as mild or nil pain.

Numerator	Number of patients who had mild or nil pain at the last clinical encounter in the active dying phase.
Denominator	Total number of patients who died.

2. Percentage of patients whose agitation is controlled at the last clinical encounter in the active dying phase. Control is defined as a RASS score of +1 or less.

Numerator	Number of patients whose agitation is controlled at the last clinical encounter in the active dying phase.
Denominator	Total number of patients who died.

3. Percentage of patients for whom anticipatory prescribing is done, which may include PRN medications for pain, dyspnoea, respiratory secretions/death rattle, terminal delirium, nausea/vomiting, where applicable.

Numerator	Number of patients with documented anticipatory prescriptions.
Denominator	Total number of patients who died.

4. Percentage of patients whose bereaved families/caregivers report that physical symptoms were well-controlled in the last days of life. (Caregiver Survey)

Numerator	Number of patients whose bereaved families/caregivers report that physical symptoms were well-controlled in the last days of life.
Denominator	Total number of surveyed bereaved families/caregivers of patients who died.

Suggested Tools

1. Handbook of Palliative Medicine in Malaysia 2nd edition
2. Handbook of Children's Palliative Care Malaysia. Kementerian Kesihatan Malaysia
   Handbook_Of_Children's_Palliative_Care_Malaysia_.pdf
3. Edmonton Symptom Assessment System (ESAS)[13]
   https://www.albertahealthservices.ca/info/Page14546.aspx
4. Palliative Care Outcomes Collaboration[14]
   http://ahsri.uow.edu.au/pcoc/forms/index. html
5. FLACC assessment tool[15]
   FLACC pain scale
6. PAINAD assessment tool[15]
   Pain Assessment IN Advanced Dementia Scale (PAINAD)
7. Richmond Agitation Sedation Scale (RASS)[16]
   Richmond Agitation-Sedation Scale-MSD Manual Professional Edition

7.4	Consultations with specialised palliative care providers are made when there are complex needs at the end-of-life. **(Class A+B providers)**

Explanatory Notes

Complex palliative care needs	Situation when the primary care provider identifies that the needs at the end-of-life exceeds the capacity of the provider.

Good Practice

Class A +B providers:

1. Providers should have a pathway to access available specialised palliative care services.

Suggested Tools

1. MHPCC Directory of Palliative care services
   MHPCC | Malaysia | Palliative Care | Hospice

7.5	Family members and caregivers are given appropriate support and information during the last days of life. **(All providers)**

Explanatory Notes

Last days of life	Refers to the period when death is imminent and expected within hours to a few days. This stage is often marked by significant physical, emotional, and existential changes that can be distressing for families.
Appropriate support and information	Includes addressing emotional needs, supporting practical arrangements—such as letters for compassionate leave, coordination of ambulance services or oxygen—and providing timely, comprehensible information about the physiological changes associated with the dying process, along with pharmacological and non-pharmacological measures to promote comfort.

Good Practice

All Providers:

1. Family members should be given information or directed to resources regarding the signs and symptoms of imminent death on a timely basis.
2. Family members should be given information or directed to resources regarding care practices that can promote comfort, such as repositioning, mouth care, and administration of PRN comfort medications, where appropriate.
3. Clinicians should be sensitive to the emotional needs of family members and able to provide emotional support and communicate empathetically.
4. Clinicians should be aware of practical needs of family members at the end of-life, such as leaves, visitation, spiritual/religious/cultural practices and procedures after death.

Suggested Indicators

1. Evidence that written resources are available for families with information regarding physiological changes in the dying process:
   - Care practices to promote comfort
   - Practical needs
   - Emotional support

Suggested Tools

1. Malaysian Hospice and Palliative Care Council: Caregiver resources
   https://www.malaysianhospicecouncil.com/forcaregiver
2. Hospice Malaysia. Carer's Guidebook. Kuala Lumpur, Malaysia 2016
   https://www.hospismalaysia.org/resources/
3. MAPPAC Care Giver Handbook for Children with Palliative Care Needs
   https://mappac.org/resources/handbook
4. NURSE acronym
   Responding to Emotion: Respecting - VitalTalk

References:

1. Kehl KA, Kowalkowski JA. A systematic review of the prevalence of signs of impending death and symptoms in the last 2 weeks of life. Am J Hosp Palliat Care. 2013 Sep;30(6):601-16. doi: 10.1177/1049909112468222. Epub 2012 Dec 12. PMID: 23236090.

2. Hui D, dos Santos R, Chisholm G, Bansal S, Silva TB, Kilgore K, Crovador CS, Yu X, Swartz MD, Perez-Cruz PE, Leite Rde A, Nascimento MS, Reddy S, Seriaco F, Yennu S, Paiva CE, Dev R, Hall S, Fajardo J, Bruera E. Clinical signs of impending death in cancer patients. Oncologist. 2014 Jun;19(6):681-7. doi: 10.1634/theoncologist.2013 0457. Epub 2014 Apr 23. PMID: 24760709; PMCID: PMC4041673.

3. Lundquist G, Rasmussen BH, Axelsson B. Information of imminent death or not: does it make a difference? J Clin Oncol. 2011 Oct 10;29(29):3927-31. doi: 10.1200/JCO.2011.34.6247. Epub 2011 Sep 12. PMID: 21911715.

4. Heijltjes MT, van Zuylen L, van Thiel GJ, van Delden JJ, van der Heide A. Symptom evolution in the dying. BMJ Support Palliat Care. 2023 Mar;13(1):121-124. doi: 10.1136/spcare-2022-003718. Epub 2022 Nov 21. PMID: 36410945; PMCID: PMC9985713.

5. Berry M, Brink E, Harris J, Sleeman KE. Supporting relatives and carers at the end of a patient's life. BMJ. 2017 Feb 2;356:j367. doi: 10.1136/bmj.j367. PMID: 28154119.

6. End of life care for adults: service delivery. London: National Institute for Health and Care Excellence (NICE); 2019 Oct. PMID: 31633897.

7. Australian Commission on Safety and Quality in Health Care. National consensus statement: Essential elements for safe and high-quality end-of-life care. Sydney: ACSQHC; 2023. Available from: www.safetyandquality.gov.au.

8. Khonsari S, Johnston B, Patterson H, Mayland C. Mechanisms of end-of-life communication contributing to optimal care at the end of life: a review of reviews. BMJ Support Palliat Care. 2024 Jul 2:spcare-2024-004904. doi: 10.1136/spcare-2024 004904. Epub ahead of print. PMID: 38955461.

9. Bhadelia A, Oldfield LE, Cruz JL, Singh R, Finkelstein EA. Identifying Core Domains to Assess the "Quality of Death": A Scoping Review. J Pain Symptom Manage. 2022 Apr;63(4):e365-e386. doi: 10.1016/j.jpainsymman.2021.11.015. Epub 2021 Dec 8. PMID: 34896278.

10. Balasundram S, Holm A, Benthien KS, Waldorff FB, Reventlow S, Overbeck G. Increasing the chance of dying at home: roles, tasks and approaches of general practitioners enabling palliative care: a systematic review of qualitative literature. BMC Prim Care. 2023 Mar 23;24(1):77. doi: 10.1186/s12875-023-02038-0. PMID: 36959553; PMCID: PMC10035229.

11. Karim S, Levine O, Simon J. The Serious Illness Care Program in Oncology: Evidence, Real-World Implementation and Ongoing Barriers. Curr Oncol. 2022 Mar 2;29(3):1527-1536. doi: 10.3390/curroncol29030128. PMID: 35323328; PMCID: PMC8947515.

12. Childers JW, Back AL, Tulsky JA, Arnold RM. REMAP: A Framework for Goals of Care Conversations. J Oncol Pract. 2017 Oct;13(10):e844-e850. doi: 10.1200/JOP.2016.018796. Epub 2017 Apr 26. PMID: 28445100.

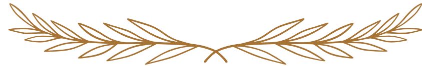
13. Hui D, Bruera E. The Edmonton Symptom Assessment System 25 Years Later: Past, Present, and Future Developments. J Pain Symptom Manage. 2017 Mar;53(3):630 643. doi: 10.1016/j.jpainsymman.2016.10.370. Epub 2016 Dec 29. PMID: 28042071; PMCID: PMC5337174.

14. Clapham S, Clark K, Draper K, Mastroianni F, Rand J, Redwood L, Currow D. A National Quality Initiative to Improve Palliative Care Outcomes: Identifying Enabling Factors that Drive Quality Improvement. Palliat Med Rep. 2024;5(2):e0092. doi:10.1089/pmr.2024.0092

15. Ministry of Health Malaysia. Management of cancer pain. 2nd ed. Putrajaya: Ministry of Health Malaysia; 2023.

16. Bush SH, Grassau PA, Yarmo MN, Zhang T, Zinkie SJ, Pereira JL. The Richmond Agitation-Sedation Scale modified for palliative care inpatients (RASS-PAL): a pilot study exploring validity and feasibility in clinical practice. BMC Palliat Care. 2014 Mar 31;13(1):17. doi: 10.1186/1472-684X-13-17. PMID: 24684942; PMCID: PMC3997822.

DOMAIN 2:
CAREGIVER SUPPORT



Standard 8 – Caregiver Support

Caregivers of patients with life-limiting illnesses face significant stress in their roles, and their own practical and emotional needs need to be supported.

Rationale	Caregivers play a central role in supporting patients with life-limiting illnesses. However, the emotional, physical, and logistical demands of caregiving can negatively impact their health, work, and ability to continue providing care. Providing timely, structured support helps care.[1-5] Addressing caregiver needs can help them provide care more effectively and sustainably. These needs may include practical support such as dressing skills, stoma care and other basic nursing techniques, as well as information about what to expect as the illness progresses, including changes in the patient's condition and care requirements. Psychosocial support is equally important and this includes encouraging self-care, offering reassurance and validation of their caregiving efforts, and providing consistent emotional support, particularly when caregivers experience isolation or distress related to their role.[4,5]

Indicators		
All Classes	8.1	The initial assessment identifies the patient's primary caregiver and main decision-maker.
Class B+C	8.2	The caregiver's practical and emotional needs are assessed and addressed on an ongoing basis.[6,7]
	8.3	The caregiver is provided with education and training on their role, including strategies for self-care and coping with the demands of caregiving.[8-10]

Suggested Tools	
1.	Tools to assess caregiver burden: a) Zarit Burden Index https://wai.wisc.edu/wp-content/uploads/sites/1129/2021/11/Zarit-Caregiver-Burden-Assessment-Instruments.pdf

	b) Caregiver Self Assessment Questionnaire https://www.healthinaging.org/tools-and-tips/caregiver-self-assessment-questionnaire c) MyGovernment Digital Services (resources to apply for government support): https://www.malaysia.gov.my/portal/category/1539 d) Official Portal Mentari Malaysia Ministry of Health Malaysia https://mentari.moh.gov.my/self-test/
2.	Education and self-care resources for caregivers: a) Malaysian Hospice and Palliative Care Council: Caregiver resources https://www.malaysianhospicecouncil.com/forcaregiver b) Hospice Malaysia. Carer's Guidebook. Kuala Lumpur, Malaysia 2016 https://www.hospismalaysia.org/resources/ c) MAPPAC Care Giver Handbook for Children with Palliative Care Needs https://mappac.org/resources/handbook d) CarerHelp, Australia https://www.carerhelp.com.au/ e) Carer Support, National Health Service, United Kingdom: https://www.nhs.uk/conditions/social-care-and-support-guide/

Implementation Guide

8.1	The initial assessment identifies the patient's primary caregiver and main decision-maker. **(All providers)**
Explanatory Notes	
Primary caregiver	Patient's primary carer - often a family member, but sometimes may not be related to the patient (e.g. domestic helper, paid carer or close friend) - who provides practical, emotional, or decision-making support. Caregivers may be formal (paid) or informal (unpaid). In situations where a patient rotates between the homes of different children, caregiving responsibilities may be shared, and a single primary caregiver may not be consistently present throughout the continuum of care.
Main decision-maker	Identifying the decision-maker is also important. This should ideally be someone chosen by the patient and whose role is acknowledged by other family members.

Good Practice

All Providers:

1. Identify the primary caregiver and main decision-maker at the initial assessment.
2. Include caregivers in care planning and discussion of goals of care, where appropriate.

Class B+C Providers:

1. Document the primary caregiver(s) and main decision-maker at the initial assessment, using a genogram where possible.

Suggested Indicators

1. Percentage of patients with a documentation of the primary caregiver:

Numerator	Number of patients with primary caregiver identified at the initial assessment.
Denominator	Total number of patients during the audit period.

2. Percentage of patients with a documentation of the decision-maker:

Numerator	Number of patients with decision-maker identified at the initial assessment.
Denominator	Total number of patients during the audit period.

8.2	The caregiver's practical and emotional needs are assessed and addressed on an ongoing basis. **(Class B+C providers)**

Explanatory Notes

Practical needs	The everyday, practical supports needed by both patients and caregivers, such as help with finances (e.g. transport cost, loss of income), equipment and home care arrangements (e.g. hospital beds, oxygen concentrators) or manpower assistance (e.g. home carers, respite services).
Emotional needs	Caregivers' emotional responses such as anxiety, stress, burnout, anticipatory grief and depression. Assessment and support should be ongoing and revisited at key transitions (e.g., diagnosis, deterioration, discharge, death) or whenever caregiver distress is observed or expressed.[6,7]

Good Practice

Class B+C Providers:

1. Assess caregiver needs early, and regularly, throughout the care process (e.g. ask how they are coping, what support they need, and what challenges they are facing).
2. Incorporate caregiver assessment as part of routine care planning, ideally using simple, validated tools or structured conversations. (e.g. Zarit Burden Inventory (ZBI) , Caregiver self-assessment (CSA) questionnaires).
3. Offer training or guidance in areas relevant to the patient's care (e.g., feeding tube care, mobility assistance).
4. Encourage and normalise conversations around caregiver stress and burnout.
5. Provide emotional support and information/options for respite care. Refer to counselling, social services, or community support services where available.
6. Provide spiritual support for caregivers through compassionate presence, reflective listening, and openness to what gives them meaning and strength.
7. Document caregiver needs and the support provided in the clinical record.

Suggested Indicators

1. Percentage of caregivers with documented needs assessment:

Numerator	Number of caregiver needs assessment documented.
Denominator	Total number of caregivers in the audit sample.

Suggested Tools

1. Zarit Burden Index
   Zarit Burden Interview- assessing caregiving burden
2. Caregiver Self Assessment Questionnaire
   https://www.healthinaging.org/tools-and-tips/caregiver-self-assessment-questionnaire
3. MyGovernment Digital Services (practical resources - facilities, welfare and healthcare)
   https://www.malaysia.gov.my/portal/category/1539
4. Official Portal Mentari Malaysia Ministry of Health Malaysia
   https://mentari.moh.gov.my/self-test/

8.3	The caregiver is provided with education and training on their role, including strategies for self-care and coping with the demands of caregiving. **(All providers)**

Explanatory Notes

Education and training	Structured or informal efforts by healthcare providers to equip caregivers with knowledge and skills relevant to the patient's care, as well as the caregivers' own well-being. This can include :[8-10] • Managing medications and side effects • Non-pharmacological strategies to relieve symptoms • Bed mobility and transfer techniques • Identifying burnout and coping strategies

Good Practice

Class B+C Providers:

1. All providers have access to physical or online caregiver education and training resources.
2. Provide verbal and/or written instructions tailored to the caregiver's role.
3. Share educational materials (e.g. booklets, videos) as well as online caregiver training resources.
4. Document caregiver education and understanding in the patient's record.

Suggested Indicators

1. Percentage of survey respondents who reported receiving education and training.

Numerator	Number of survey respondents who reported receiving education or training.
Denominator	Total number of survey respondents.

Suggested Tools	
1.	Malaysian Hospice and Palliative Care Council: Caregiver resources https://www.malaysianhospicecouncil.com/forcaregiver
2.	Hospice Malaysia. Carer's Guidebook. Kuala Lumpur, Malaysia 2016 https://www.hospismalaysia.org/resources/
3.	MAPPAC Care Giver Handbook for Children with Palliative Care Needs https://mappac.org/resources/handbook
4.	CarerHelp, Australia https://www.carerhelp.com.au/
5.	Carer Support, National Health Service, United Kingdom: https://www.nhs.uk/conditions/social-care-and-support-guide/

References:

1. Kantanis A, Pelantaki M, Fountaki ML, Konstantopoulos V, Paraskevas T, Stavropoulou E, Tsiamaki E, Trimmis N, Plotas P. Stress and Quality of Life in Caregivers of Patients with Multiple Sclerosis. Medicina (Kaunas). 2024 Jun 24;60(7):1033. doi: 10.3390/medicina60071033. PMID: 39064462; PMCID: PMC11278822.

2. Kim Y, Chung ML, Lee H. Caregivers of patients with cancer: perceived stress, quality of life and immune function. BMJ Support Palliat Care. 2025 Feb 26;15(2):195-203. doi: 10.1136/bmjspcare-2021-003205. PMID: 35210302.

3. Hart NH, Crawford-Williams F, Crichton M, Yee J, Smith TJ, Koczwara B, Fitch MI, Crawford GB, Mukhopadhyay S, Mahony J, Cheah C, Townsend J, Cook O, Agar MR, Chan RJ. Unmet supportive care needs of people with advanced cancer and their caregivers: A systematic scoping review. Crit Rev Oncol Hematol. 2022 Aug;176:103728. doi: 10.1016/j.critrevonc.2022.103728. Epub 2022 Jun 1. PMID: 35662585.

4. Hashemi M, Irajpour A, Taleghani F. Caregivers needing care: the unmet needs of the family caregivers of end-of-life cancer patients. Support Care Cancer. 2018 Mar;26(3):759-766. doi: 10.1007/s00520-017-3886-2. Epub 2017 Sep 27. PMID: 28952034.

5. Hall S, Rohatinsky N, Holtslander L, Peacock S. Caregivers to older adults require support: A scoping review of their priorities. Health Soc Care Community. 2022 Nov;30(6):e3789-e3809. doi: 10.1111/hsc.14071. Epub 2022 Oct 17. PMID: 36251430.

6. Bee PE, Barnes P, Luker KA. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. J Clin Nurs. 2009 May;18(10):1379-93. doi: 10.1111/j.1365-2702.2008.02405.x. Epub 2009 Apr 8. PMID: 18624779.

7. Aoun SM, Grande G, Howting D, Deas K, Toye C, Troeung L, Stajduhar K, Ewing G. The impact of the carer support needs assessment tool (CSNAT) in community palliative care using a stepped wedge cluster trial. PLoS One. 2015 Apr 7;10(4):e0123012. doi: 10.1371/journal.pone.0123012. PMID: 25849348; PMCID: PMC4388632.

8. Mollica MA, Litzelman K, Rowland JH, Kent EE. The role of medical/nursing skills training in caregiver confidence and burden: A CanCORS study. Cancer. 2017 Nov 15;123(22):4481-4487. doi: 10.1002/cncr.30875. Epub 2017 Jul 20. PMID: 28727147; PMCID: PMC5673528.

9. Lin X, Moxley JH, Czaja SJ. Caring for Dementia Caregivers: Psychosocial Factors Related to Engagement in Self-Care Activities. Behav Sci (Basel). 2023 Oct 18;13(10):851. doi: 10.3390/bs13100851. PMID: 37887501; PMCID: PMC10604240.

10. Bruening R, Sperber N, Miller K, Andrews S, Steinhauser K, Wieland GD, Lindquist J, Shepherd-Banigan M, Ramos K, Henius J, Kabat M, Van Houtven C. Connecting Caregivers to Support: Lessons Learned From the VA Caregiver Support Program. J Appl Gerontol. 2020 Apr;39(4):368-376. doi: 10.1177/0733464818825050. Epub 2019 Jan 18. PMID: 30658547.

Standard 9 – Grief & Bereavement Support

Families affected by bereavement, grief and loss will be offered support resources appropriate to their needs and preferences in a timely manner.

Rationale	All caregivers and families should be supported through their grief and bereavement process .[1-3] Psychotherapeutic interventions have been found to benefit those who have marked difficulties adjusting to the loss.[4]

Indicators		
All Classes	9.1	Caregivers and families are provided appropriate information on grief and loss.
	9.2	Caregivers and families are provided with practical death related information and resources, including procedures after death.
Class B+C	9.3	There is a screening process for caregivers and families to identify complicated grief.[4-7]
	9.4	There is a process for caregivers and families to be referred to bereavement support services where necessary.[4,8,9]

Suggested Tools	
1.	Information on grief and loss: a) Hospis Malaysia Grief Guide: https://hospismalaysia.org/wp-content/uploads/2017/02/Now-What_-Understanding-Grief.pdf
2.	Death related resources and information: a) Jabatan pendaftaran negara: https://www.jpn.gov.my/my/perkhidmatan/kematian/
3.	Tools to screen for complicated grief: a) Brief Grief Questionnaire (BGQ)[6-7,10] http://www.goodmedicine.org.uk/sites/default/files/assessment%2C%20grief%20brief.pdf

	b) Prolonged Grief Disorder (PG-13-Revised)[4,8-9] https://endoflife.weill.cornell.edu/sites/default/files/file_uploads/pg-13-r_0.pdf
4.	Information on bereavement support services: a) Australian Centre for Grief & Bereavement: Bereavement Support Standards for Specialist Palliative Care Services https://grief.org.au/Common/Uploaded%20files/Bereavement%20support%20standards.pdf b) CareSearch Clinical Evidence Summaries: Grief and Bereavement https://www.caresearch.com.au/Evidence/Clinical-Evidence-Summaries/Grief-and-Bereavement

Implementation Guide

9.1	Caregivers and families are provided appropriate information on grief and loss. **(All providers)**

Explanatory Notes

Appropriate information	Information provided should be clear, culturally sensitive, and suited to the family's level of readiness and literacy. This information could include: • Anticipatory grief and bereavement. • Common emotional and psychological responses to loss • Available support services (e.g., bereavement counselling, peer groups) and how to seek help if grief is prolonged or complicated.

Good Practice

1. Provide information on normal grief responses and where/how to seek help should the need arise.
2. Involve the interdisciplinary team, including social workers, counselors, or chaplains, where available.
3. Make available written resources on grief and loss.

Suggested Indicators

1. Percentage of caregivers who reported receiving bereavement information:

Numerator	Number of survey respondents who reported receiving bereavement information upon death of their family member.
Denominator	Total number of caregiver survey respondents.

Suggested Tools

1. Hospis Malaysia Grief Guide
https://hospismalaysia.org/wp-content/uploads/2017/02/Now-What_-Understanding-Grief.pdf

9.2	Caregivers and families are provided with practical death-related information and resources, including procedures after death. **(All providers)**

Explanatory Notes

Practical death related information and resources	Appropriate practical death-related information should be made available to caregivers and families. Information could include: • What to do when death occurs at home or in hospital. • Documentation required (e.g. medical certificate of cause of death). • Who to contact (e.g. ambulance, police, funeral services). • Financial/legal/housing-related matters. • Execution of will

Good Practice

1. Discuss post-death procedures before death occurs, when appropriate, to reduce distress and uncertainty.
2. Provide written information tailored to the care setting.

Suggested Indicators

1 . Percentage of caregivers who reported receiving bereavement information:

Numerator	Number of survey respondents who reported receiving bereavement information upon death of their family member.
Denominator	Total number of caregiver survey respondents.

Suggested Tools

1. Jabatan Pendaftaran Negara
https://www.jpn.gov.my/my/perkhidmatan/kematian/

9.3	There is a screening process for caregivers and families to identify complicated grief. **(Class B & C providers)**

Explanatory Notes

Prolonged Grief Disorder (PGD)	PGD is considered the same diagnostic entity as Complicated Grief. It is recognised as a mental health disorder in diagnostic guidelines worldwide, including DSM-5-TR and ICD-11. A crucial aspect of the diagnosis is that these symptoms lead to substantial functional impairment in personal, family, social, educational, occupational, or other important areas of functioning. A coherent syndrome of PGD typically has an onset of 6 to 12 months after the death of a close person, and markedly exceeds expected social, cultural, or religious norms for that individual's culture and context setting. The ICD-11 criteria specify symptoms lasting for at least 6 months, while the DSM-5-TR criteria require symptoms to have been present for at least 12 months (or 6 months for children and adolescents). This recognition differentiates atypical grief from normative grief process.

Good Practice

1. There should be a process in place to identify family members with bereavement needs.[4-7]
2. Implement routine follow-up contact with bereaved caregivers/families within an appropriate period post-death.

Suggested Indicators

1. Availability of a protocol for grief screening (e.g. death reviews).
2. Percentage of bereaved caregivers screened for grief risk:

Numerator	Number of caregivers screened for grief.
Denominator	Total number of patients who died.

Suggested Tools	
1.	Brief Grief Questionnaire (BGQ) http://www.goodmedicine.org.uk/sites/default/files/assessment%2C%20grief%20brief.pdf
2.	Prolonged Grief Disorder (PG-13-Revised) https://endoflife.weill.cornell.edu/sites/default/files/file_uploads/pg-13-r_0.pdf

9.4	There is a process for caregivers and families to be referred to bereavement support services where necessary. **(Class B+C providers)**

Explanatory Notes

Bereavement care should be integrated into the entire care process, and not only initiated after death. Services should be tiered based on need.[4,8,9] Examples include:

- Universal support: information, general support available to all.
- Targeted support: for those with moderate needs, e.g. trained volunteer support, chaplaincy, in-house counsellors, etc.
- Specialist intervention: for complicated grief, such as a referral process to mental health services.

Good Practice

1. There should be a process in place to refer family members and caregivers who have difficulty coping for support.[4,8,9]
2. Maintain an up-to-date list of referral options, including community-based, NGO-led, or hospital-affiliated services.

Suggested Indicators

1. Evidence of a process in place to provide or refer family members and caregivers identified as having difficulty with bereavement for support.

Suggested Tools

1. Australian Centre for Grief & Bereavement: Bereavement Support Standards for Specialist Palliative Care Services: https://grief.org.au/Common/Uploaded%20files/Bereavement%20support%20standards.pdf
2. CareSearch Clinical Evidence Summaries: Grief and Bereavement https://www.caresearch.com.au/Evidence/Clinical-Evidence-Summaries/Grief-and-Bereavement

References:

1. Shear MK. Clinical practice. Complicated grief. N Engl J Med. 2015 Jan 8;372(2):153 60. doi: 10.1056/NEJMcp1315618. PMID: 25564898.

2. DiBello KK. Grief & depression at the end of life. Nurse Pract. 2015 May 15;40(5):22 8; quiz 28-9. doi: 10.1097/01.NPR.0000463781.50345.95. PMID: 25839698.

3. Hudson P, Remedios C, Zordan R, Thomas K, Clifton D, Crewdson M, Hall C, Trauer T, Bolleter A, Clarke DM, Bauld C. Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. J Palliat Med. 2012 Jun;15(6):696-702. doi: 10.1089/jpm.2011.0466. Epub 2012 Mar 2. PMID: 22385026; PMCID: PMC3362953.

4. Hudson P, Hall C, Boughey A, Roulston A. Bereavement support standards and bereavement care pathway for quality palliative care. Palliat Support Care. 2018 Aug;16(4):375-387. doi: 10.1017/S1478951517000451. Epub 2017 Jul 13. PMID: 28701233.

5. Prigerson HG, Boelen PA, Xu J, Smith KV, Maciejewski PK. Validation of the new DSM 5-TR criteria for prolonged grief disorder and the PG-13-Revised (PG-13-R) scale. World Psychiatry. 2021 Feb;20(1):96-106. doi: 10.1002/wps.20823. PMID: 33432758; PMCID: PMC7801836.

6. Igarashi N, Aoyama M, Ito M, Nakajima S, Sakaguchi Y, Morita T, Shima Y, Miyashita M. Comparison of two measures for Complicated Grief: Brief Grief Questionnaire (BGQ) and Inventory of Complicated Grief (ICG). Jpn J Clin Oncol. 2021 Feb 8;51(2):252-257. doi: 10.1093/jjco/hyaa185. PMID: 33125072.

7. Ito M, Nakajima S, Fujisawa D, Miyashita M, Kim Y, Shear MK, Ghesquiere A, Wall MM. Brief measure for screening complicated grief: reliability and discriminant validity. PLoS One. 2012;7(2):e31209. doi: 10.1371/journal.pone.0031209. Epub 2012 Feb 14. PMID: 22348057; PMCID: PMC3279351.

8. Bromberg MH, Higginson I. Bereavement follow-up: what do palliative support teams actually do? J Palliat Care. 1996 Spring;12(1):12-7. PMID: 8857242.

9. Ghesquiere A, Bagaajav A, Metzendorf M, Bookbinder M, Gardner DS. Hospice Bereavement Service Delivery to Family Members and Friends With Bereavement Related Mental Health Symptoms. Am J Hosp Palliat Care. 2019 May;36(5):370-378. doi: 10.1177/1049909118812025. Epub 2018 Nov 14. PMID: 30428680; PMCID: PMC6486888.

DOMAIN 3: STAFF AND VOLUNTEER MANAGEMENT

Standard 10 – Trained Staff and Volunteers

Services should have staff and volunteers with the appropriate training and skills to deliver care for those with palliative care needs.

Rationale	Provision of quality palliative care requires a competent and adequate team of healthcare professionals with appropriate on-going training.[1-5] Volunteers with appropriate training may complement the team in the provision of care.[6]

Indicators		
All Classes	10.1	All staff and volunteers should have appropriate palliative care training based on the level of care provided.[1-4]
Class B+C	10.2	Palliative care professionals are appropriately trained in their area of expertise.
Class C	10.3	Adequate staff are available to deliver the care needed.[5]
	10.4	Palliative care teams should consist of an interdisciplinary team of skilled palliative care professionals, including physicians and nurses, and where available, to include pharmacists, physiotherapists, occupational therapists, social workers, counsellors or spiritual care providers. Where these competencies do not exist within a team, there should be clearly defined links to access them if available.[6]
	10.5	Where volunteers are part of the team, there are policies in place to ensure proper screening, recruitment, and on-going training of volunteers.[7]

Suggested Tools	
1.	Information on relevant training: a) List of training available in Malaysia • https://www.malaysianhospicecouncil.com/education-learning • https://hospismalaysia.org/education/ • https://aphn.org/training-and-education/

	• www.openlearning.com/mhpcc • https://ppusmb.usm.my/palliative
2.	Resources for calculating workload: a) RUG-ADL (Resource Utilization Groups – Activities of Daily Living) http://ahsri.uow.edu.au/pcoc/functionalassessment/index.html b) Symptom burden (E.g. Phases/ ESAS/ IPOS) c) Caseloads (E.g. Total new consults cases per month/ Total home visits per month Resources for recommended staffing norms: a) World Health Organisation. Planning and Implementing Palliative Care Services: A Guide for Programme Managers 2016 (pages 20, 22, 29) https://www.who.int/publications/i/item/planning-and-implementing-palliative-care-services-a-guide-for-programme-managers b) National Palliative Care Policy and Strategic Plan 2019-2030 (page 116)
3.	Guidance on developing volunteer policies: a) Surat Pekeliling KPK Bil 252021 - Garis Panduan Perkhidmatan Sukarela Di Fasiliti Kementerian Kesihatan Malaysia https://www.moh.gov.my/index.php/database_stores/attach_download/312/441

Implementation Guide

10.1	All staff and volunteers should have appropriatepalliative care training based on the level of care provided. **(All providers)**

Explanatory Notes	
Staff and volunteers	Refers to those involved in clinical work or with direct patient or caregiver contact.
Appropriate palliative care training	Staff should have relevant training as specified below according to their clinical roles/job descriptions.
Class A & B Providers	• Doctors: Introductory or Basic Palliative Care Courses. • Nurses or Allied Health: Introductory or Basic Palliative Care Courses.
Class C Providers	• Doctors: Malaysian Ministry of Health Subspecialties. Fellowship training in Palliative Medicine, Post-graduate courses in Palliative Medicine. • Nurses or Allied Health: Malaysian Ministry of Health Advanced Diploma in Palliative Care, Post-graduate courses in Palliative Medicine. • Volunteers: In-house training during volunteering/ volunteer training courses or equivalent and Introductory/ Basic Palliative Care Workshops/ Course.

Good Practice	
1.	Class A & B providers should have basic training in palliative care.
2.	Providers are encouraged to adhere to a recognised palliative care training framework and competencies.

Suggested Indicators

1. Percentage of staff (doctors/nurses/ social workers/allied health workers) with palliative care training appropriate to the clinical role:

Numerator	Number of staff (doctors/ nurses/social workers/allied health workers) with palliative care training appropriate to the clinical role.
Denominator	Total number of staff (doctors/nurses/social workers/allied health workers) in the palliative care clinical team.

2. Percentage of volunteers who received palliative care training appropriate to the level of care provided:

Numerator	Number of volunteers who received basic palliative care training appropriate to the level of care they provide.
Denominator	Total number of volunteers involved in clinical work for the past 1 year.

3. Evidence of a system in place to support staff and/or volunteer's supervision and training.

Suggested Tools

1. Examples of training available in Malaysia:
   - https://www.malaysianhospicecouncil.com/education-learning
   - https://hospismalaysia.org/education/
   - https://aphn.org/training-and-education/
   - www.openlearning.com/mhpcc
   - https://ppusmb.usm.my/palliative

10.2	Palliative care professionals are appropriately trained in their area of expertise. **(Class B+C providers)**

Explanatory Notes	
Appropriately trained in area of expertise	Refers to continuous professional development, through attendance of conferences/courses/workshops and structured on the-job training (CMEs/ CNEs/Journal Clubs/assessments) according to their clinical roles.

Good Practice

1. Ensure that newly assigned staff receive orientation or foundational training within a specified timeframe.
2. Regular training needs assessment to be done for all staff.
3. Encourage participation in workshops or continuing professional development (CPD) related to palliative care.
4. Keep records of training where applicable.

Suggested Indicators

1. Evidence of on-going training (CMEs/ CNEs/ Journal Clubs) for staff, such as training schedules and attendance records.

10.3	Adequate staff are available to deliver the care needed. **(Class C providers)**

Explanatory Notes

Adequate Staff	Staffing numbers are based on the patient population served by the service, with reference to recommendations from the following guidelines : World Health Organisation. Planning and Implementing Palliative Care Services: A Guide for Programme Managers (2016).[5]

Good Practice

1. Staffing levels are regularly reviewed to match patient volume and care complexity.

Suggested Indicators

1. Evidence that the service has a workforce planning strategy.

Suggested Tools

1. RUG-ADL (Resource Utilization Groups – Activities of Daily Living) : http://ahsri.uow.edu.au/pcoc/functionalassessment/index.html
2. Symptom burden (E.g. Phases/ ESAS/ IPOS)
3. Caseloads (E.g. Total new consults cases per month/Total home visits per month)
4. Resources for recommended staffing norms:
    a) World Health Organisation. Planning and Implementing Palliative Care Services: A Guide for Programme Managers 2016 (pages 20, 22, 29) https://www.who.int/publications/i/item/planning-and-implementing-palliative-care-services-a-guide-for-programme-managers
    b) National Palliative Care Policy and Strategic Plan 2019-2030 (page 116)

10.4	Palliative care teams should consist of an interdisciplinary team of skilled palliative care professionals, including physicians and nurses, and where available, to include pharmacists, physiotherapists, occupational therapists, social workers, counsellors or spiritual care providers. Where these competencies do not exist within a team, there should be clearly defined links to access them if available.[6] (Class C providers)

Explanatory Notes	
Interdisciplinary Team	A group of healthcare professionals who work collaboratively across disciplines to provide comprehensive care that addresses physical, emotional, social, and spiritual needs of patients and families.[6]

Good Practice

1. Core team includes at minimum a trained physician and nurse with palliative care competencies.
2. Teams should identify gaps in expertise (e.g. psychosocial, pharmacy, rehabilitation) and build referral relationships to access these services.[6]

Suggested Indicators

1. Evidence of interdisciplinary team activity (e.g. multidisciplinary team meetings) consisting of physicians, nurses and other available recommended staff.

Suggested Tools

1. World Health Organisation. Planning and Implementing Palliative Care Services: A Guide for Programme Managers (2016).[5]

10.5	Where volunteers are part of the team, there are policies in place to ensure proper screening, recruitment, and on-going training of volunteers.[7] **(Class C providers)**

Explanatory Notes

Volunteers	Individuals who offer their time and service without financial remuneration. They complement services by contributing to non-clinical roles such as companionship, support for practical needs and bereavement, and administrative tasks.

Good Practice

1. Palliative care services should have policies for screening, recruitment and management of volunteers.
2. Screening and recruitment of volunteers should include interviews by volunteer managers or appointed staff members of the organisation.
3. All regular volunteers with patient or caregiver contact should undergo mandatory volunteer training to ensure patient safety and volunteer wellbeing.

Suggested Indicators

1. Evidence of policies in place to guide volunteer recruitment and management.
2. Evidence of a volunteer management model/workgroup which reviews volunteer management and training.

Suggested Tools

1. Surat Pekeliling KPK Bil 252021 - Garis Panduan Perkhidmatan Sukarela Di Fasiliti Kementerian Kesihatan Malaysia https://www.moh.gov.my/index.php/database_stores/attach_download/312/441

References:

1. Bainbridge D, Bishop V, Myers J, Marshall D, Stajduhar K, Seow H. Effectiveness of Training Programs About a Palliative Care Approach: A Systematic Review of Intervention Trials for Health Care Professionals. J Palliat Med. 2023 Apr;26(4):564 581. doi: 10.1089/jpm.2022.0051. Epub 2022 Nov 15. PMID: 36378898.

2. Sivell S, Lidstone V, Taubert M, Thompson C, Nelson A. Identifying the key elements of an education package to up-skill multidisciplinary adult specialist palliative care teams caring for young adults with life-limiting conditions: an online Delphi study. BMJ Support Palliat Care. 2015 Sep;5(3):306-15. doi: 10.1136/bmjspcare-2013 000595. Epub 2014 Mar 26. PMID: 24670554; PMCID: PMC4552910.

3. Henoch I, Danielson E, Strang S, Browall M, Melin-Johansson C. Training intervention for health care staff in the provision of existential support to patients with cancer: a randomized, controlled study. J Pain Symptom Manage. 2013 Dec;46(6):785-94. doi: 10.1016/j.jpainsymman.2013.01.013. Epub 2013 Jun 10. PMID: 23764108.

4. Kang J, Kim Y, Yoo YS, Choi JY, Koh SJ, Jho HJ, Choi YS, Park J, Moon DH, Kim DY, Jung Y, Kim WC, Lim SH, Hwang SJ, Choe SO, Jones D. Developing competencies for multidisciplinary hospice and palliative care professionals in Korea. Support Care Cancer. 2013 Oct;21(10):2707-17. doi: 10.1007/s00520-013-1850-3. Epub 2013 May 25. PMID: 23708823.

5. World Health Organization. Planning and implementing palliative care services: a guide for programme managers. Geneva: World Health Organization; 2016.

6. Henderson JD, Boyle A, Herx L, Alexiadis A, Barwich D, Connidis S, Lysecki D, Sinnarajah A. Staffing a Specialist Palliative Care Service, a Team-Based Approach: Expert Consensus White Paper. J Palliat Med. 2019 Nov;22(11):1318-1323. doi: 10.1089/jpm.2019.0314. Epub 2019 Jul 26. PMID: 31347940.

7. Monton O, Abou-Zamzam A, Fuller S, Barnes-Malone T, Siddiqi A, Woods A, Patton J, Ibe CA, Johnston FM. Palliative Care Curriculum and Training Plan for community health workers. BMJ Support Palliat Care. 2024 Dec 19;14(e3):e2972-e2976. doi: 10.1136/spcare-2023-004527. PMID: 37679025; PMCID: PMC10918023.

Standard 11 – Staff and Volunteer Self-Care	
Staff and volunteers should have effective self-care strategies and access to support in dealing with psychological stress associated with the work.	
Rationale	As there may be associated emotional and spiritual burden from caring for patients near the end of life, the ability to self-care using effective coping strategies is important.[1-8]

Indicators		
Class B+C	11.1	Education is provided to help staff and volunteers develop effective coping strategies.
	11.2	There are strategies in place to provide situational support, critical incident debriefing and response.

Suggested Tools	
1.	Resources to identify distress and assist in coping: a) Burnout Assessment Tool (BAT)[9,10] https://burnoutassessmenttool.be/start_eng/ b) Palliative Care Australia Self-Care Matters Resources https://palliativecare.org.au/resource/resources-self-care-matters/
2.	Resources for situational support and debriefing: c) Schwartz Rounds https://www.theschwartzcenter.org/programs/schwartz-rounds/ d) Balint Group https://balintsociety.org.uk/balint-groups-and-balint-method

Implementation Guide

11.1	Education is provided to help staff and volunteers develop effective coping strategies. **(Class B+C providers)**

Explanatory Notes

Coping strategies	The specific efforts, both behavioural and cognitive, that people use to master, tolerate, reduce, or minimise stressful events. Two major categories of coping strategies are widely recognized: • Problem-solving strategies (efforts to do something active to alleviate stressful circumstances). • Emotion-focused coping strategies (efforts to regulate the emotional consequences of stressful events).

Good Practice

1. Education initiatives to help staff/volunteers develop effective coping strategies should be present in the institution/organization.
2. Education may be provided within staff/volunteers' induction and orientation programs, or as ongoing training via regular sessions or workshops on self-care, resilience, and emotional wellbeing.

Suggested Indicators

1. Evidence of initiatives to help staff/volunteers develop effective coping strategies, such as:
   - Orientation programs
   - Supervision
   - Mentorship
   - Review of training and developmental needs
   - Professional development programs

Suggested Tools

1. Burnout Assessment Tool (BAT)[9,10]
   https://burnoutassessmenttool.be/start_eng/
2. Palliative Care Australia Self-Care Matters Resources
   https://palliativecare.org.au/resource/resources-self-care-matters/

11.2	There are strategies in place to provide situational support, critical incident debriefing and response. **(Class B+C providers)**

Explanatory Notes	
Situational support	Mechanisms for support include those from both internal and external platforms. Examples of internal mechanisms include (but are not limited to) the use of case conferences, multidisciplinary meetings, mortality rounds, ward rounds and Balint or Schwartz rounds within the institution or service. External mechanisms for support include referrals to support services (e.g. psychiatry services) outside of the institution or service.
Critical incident	Any unexpected or distressing event that has a significant emotional impact on staff or volunteers. In the palliative care setting, this may include: • A sudden or traumatic patient death • Witnessing intense suffering • Conflict with family members or within the team • Medical errors or near misses • Ethical dilemmas
Critical incident debriefing and response	A structured process that allows individuals involved in a distressing event to reflect on what happened, express their emotional responses, and receive support. Strategies may include protocols for escalation, access to trained debriefers, peer support groups, or psychological first aid offered shortly after the incident.

Good Practice

Class B+C Providers:

1. Have access to situational support and resources when required. These could include internet or intranet resource materials on a government or institutional website, or a staff member identified by the institution or service to direct providers to additional support resources when needed.
2. Establish clear protocols for initiating situational support or critical incident debriefing, including identifying and training staff as facilitators.

Suggested Indicators	
1.	Presence of policy/guidelines for situational support for staff during critical events, such as: • Clinical incident reporting. • Records of interdisciplinary meetings (e.g. multidisciplinary meetings, mortality rounds, Balint or Schwartz rounds). • Agreements with external service providers for staff support.

Suggested Tools	
1.	Schwartz Rounds https://www.theschwartzcenter.org/programs/schwartz-rounds/
2.	Balint Group https://balintsociety.org.uk/balint-groups-and-balint-method

References:

1. Cuartero-Castañer ME, Campos-Vidal JF, Hidalgo-Andrade P, Lozano-Montesdeoca K, Bonilla Sierra P. Balancing Compassion and Self-Care: Insights From Palliative Care Professionals and Volunteers. Health & Social Care in the Community; April 2025 doi:10.1155/hsc/5874963

2. Hotchkiss JT. Mindful Self-Care and Secondary Traumatic Stress Mediate a Relationship Between Compassion Satisfaction and Burnout Risk Among Hospice Care Professionals. Am J Hosp Palliat Care. 2018 Aug;35(8):1099-1108. doi: 10.1177/1049909118756657. Epub 2018 Feb 26. PMID: 29482332.

3. Wang C, Grassau P, Lawlor PG, Webber C, Bush SH, Gagnon B, Kabir M, Spilg EG. Burnout and resilience among Canadian palliative care physicians. BMC Palliat Care. 2020 Nov 6;19(1):169. doi: 10.1186/s12904-020-00677-z. PMID: 33158428; PMCID: PMC7648393.

4. Sanchez-Reilly S, Morrison LJ, Carey E, Bernacki R, O'Neill L, Kapo J, Periyakoil VS, Thomas Jde L. Caring for oneself to care for others: physicians and their self-care. J Support Oncol. 2013 Jun;11(2):75-81. doi: 10.12788/j.suponc.0003. PMID: 23967495; PMCID: PMC3974630.

5. Kearney MK, Weininger RB, Vachon ML, Harrison RL, Mount BM. Self-care of physicians caring for patients at the end of life: "Being connected... a key to my survival". JAMA. 2009 Mar 18;301(11):1155-64, E1. doi: 10.1001/jama.2009.352. PMID: 19293416.

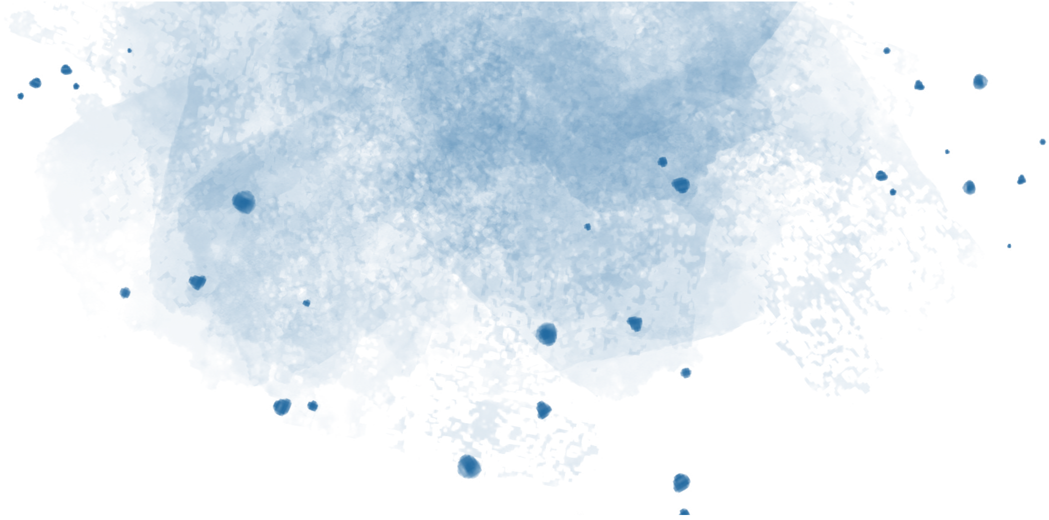
6. Pereira SM, Fonseca AM, Carvalho AS. Burnout in palliative care: a systematic review. Nurs Ethics. 2011 May;18(3):317-26. doi: 10.1177/0969733011398092. PMID: 21558108.

7. Hotchkiss JT, Lesher R. Factors Predicting Burnout Among Chaplains: Compassion Satisfaction, Organizational Factors, and the Mediators of Mindful Self-Care and Secondary Traumatic Stress. J Pastoral Care Counsel. 2018 Jun;72(2):86-98. doi: 10.1177/1542305018780655. PMID: 29914321.

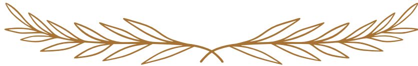
8. Phillips J, Andrews L, Hickman L. Role ambiguity, role conflict, or burnout: are these areas of concern for Australian palliative care volunteers? Pilot study results. Am J Hosp Palliat Care. 2014 Nov;31(7):749-55. doi: 10.1177/1049909113505195. Epub 2013 Oct 3. PMID: 24092764.

9. Schaufeli WB, Desart S, De Witte H. Burnout Assessment Tool (BAT)-Development, Validity, and Reliability. Int J Environ Res Public Health. 2020 Dec 18;17(24):9495. doi: 10.3390/ijerph17249495. PMID: 33352940; PMCID: PMC7766078.

10. Dijxhoorn AQ, Brom L, van der Linden YM, Leget C, Raijmakers NJ. Healthcare Professionals' Work-Related Stress in Palliative Care: A Cross-Sectional Survey. J Pain Symptom Manage. 2021 Sep;62(3):e38-e45. doi: 10.1016/j.jpainsymman.2021.04.004. Epub 2021 Apr 20. PMID: 33864848.



DOMAIN 4:
SAFE CARE



Standard 12 – Accessibility and the Use of Opioids

Patients with palliative care needs should have access to opioids for symptom control, with guidelines and processes in place to ensure safe and effective use.

Rationale	Patients with palliative care needs often require opioids for good symptom management. Opioids should be available and accessible to all patients, including children, in a timely, affordable, and non-burdensome manner. [1-9] Education and guidelines are necessary to ensure optimal symptom control with minimal risks and adverse effects.[10-12]

Indicators		
All Classes	12.1	Service providers caring for patients with palliative care needs should have access to opioids.
	12.2	The use of opioids in the management of symptoms should be evidence-based and administered under guidelines with appropriate monitoring.[7,8,9]
	12.3	There is evidence of patient and caregiver education on the effective and safe use of opioids.[10,11]
	12.4	There is adherence to legal requirements for the prescription, safe storage and transport, dispensing, administration and disposal of opioids in accordance with the Poisons (Psychotropic substances) Regulations 1989 including any subsequent amendments or relevant legislation.[12]

Suggested Tools	
1.	Reference charts/ guidebooks for clinical staff: a) Pharmaceutical Services Programme, Ministry of Health Malaysia. National Essential Medicines List (NEML) 7th edition 2025 – Medicines for Pain and Palliative Care. p. 2. https://pharmacy.moh.gov.my/sites/default/files/document-upload/clean-national-essential-medicines-list-7th-v04_0.pdf

	b) Ministry of Health Malaysia. Management of Cancer Pain Clinical Practice Guidelines 2nd Edition. Putrajaya: MOH; 2023 https://www.acadmed.org.my/index.cfm?&menuid=67 c) Handbook of Palliative Medicine in Malaysia 2nd edition 2023 d) Handbook of Children's Palliative Care Malaysia. Kementerian Kesihatan Malaysia Handbook_Of_Children's_Palliative_Care_Malaysia_.pdf e) Management of cancer pain in adult patients: ESMO Clinical Practice Guidelines 2018 Management of cancer pain in adult patients: ESMO Clinical Practice Guidelines
2.	Educational materials for patients and caregivers: a) Patient information leaflets • https://www.malaysianhospicecouncil.com/forcaregiver • https://www.hospismalaysia.org/resources/
3.	Reference for legal requirements on the handling of opioids: a) Poisons Act 1952, Poisons (Psychotropic Substances) Regulations 1989

ImplementationGuide

12.1	Service providers caring for patients with palliative care needs should have access to opioids. **(All providers)**

Explanatory Notes

Access to opioids	Opioids are listed as essential medication in the National Essential Medicines List (NEML), MOH Malaysia.[1] Service providers must ensure their availability and the capacity to administer them appropriately to patients. The service provider is aware of available resources in order for the patient to gain timely access to opioids including out of hours. Where necessary, this could also be achieved via access to hospitals or home hospice services.

Good Practice

1. Maintain an adequate stock of commonly used opioids (e.g. morphine, fentanyl, oxycodone) at all times, appropriate to the level of care provided.
2. Establish clear SOPs for prescribing, storing, dispensing, and administering opioids, and ensure staff are trained and competent in safe opioid handling and administration.
3. Facilitate timely access to opioids for patients, including during after-hours, via:
    - On-call systems.
    - Access to nearby hospitals, emergency services, or home hospice.

Suggested Indicators

1. Evidence of opioid medications in the service drug formulary.
2. Evidence that the service provider has access to opioids including out-of hours.

Suggested Tools

1. Pharmaceutical Services Programme, Ministry of Health Malaysia. National Essential Medicines List (NEML) 7th edition 2025 – Medicines for Pain and Palliative Care. p. 2. https://pharmacy.moh.gov.my/sites/default/files/document-upload/clean-national-essential-medicines-list-7th-v04_0.pdf

2. Ministry of Health Malaysia. Management of Cancer Pain Clinical Practice Guidelines 2nd Edition. Putrajaya: MOH; 2023 https://www.acadmed.org.my/index.cfm?&menuid=67

3. Handbook of Palliative Medicine in Malaysia 2nd edition 2023

4. Handbook of Children's Palliative Care Malaysia. Kementerian Kesihatan Malaysia Handbook_Of_Children's_Palliative_Care_Malaysia_.pdf

12.2	The use of opioids in the management of symptoms should be evidence based and administered under guidelines with appropriate monitoring. **(All providers)**
Explanatory Notes	
Appropriate monitoring	Monitoring of the correct and safe use of opioids, according to organisational guidelines or SOPs. The service provider is able to recognise a patient's need for opioids and is able to use opioids appropriately when indicated and in accordance with evidence. Patients on opioids are monitored for serious side effects.[7-9]

Good Practice	
1.	There should be organisational guidelines or SOPs in place for safe use of opioids, including monitoring practices for opioid infusions.
2.	Opioids are prescribed in accordance with national/facility guidelines. Indications, dose, route of administration etc. must be documented clearly and completely.
3.	Monitor for and educate about signs of opioid toxicity, especially in the elderly or renally impaired.
4.	Service providers should conduct ongoing review of medication errors.

Suggested Indicators	
1.	Evidence of organisational guidelines or SOPs for safe use of opioids, which include monitoring for signs and symptoms of opioid toxicity.
2.	Evidence that service provider conducts ongoing review of medication errors.

Suggested Tools	
1.	Ministry of Health Malaysia. Management of Cancer Pain Clinical Practice Guidelines 2nd Edition. Putrajaya: MOH; 2023 https://www.moh.gov.my/index.php/pages/view/148
2.	Handbook of Palliative Medicine in Malaysia 2nd edition 2023
3.	Handbook of Children's Palliative Care Malaysia. Kementerian Kesihatan Malaysia Handbook_Of_Children's_Palliative_Care_Malaysia_.pdf
4.	Management of cancer pain in adult patients: ESMO Clinical Practice Guidelines 2018 Management of cancer pain in adult patients: ESMO Clinical Practice Guidelines

12.3	There is evidence of patient and caregiver education on the effective and safe use of opioids. **(All providers)**

Explanatory Notes

All providers who prescribe opioids should routinely provide education and medication counselling to patients and caregivers, particularly for patients newly starting on opioids.

Good Practice

1. All patients newly started on opioids, and their caregivers, should receive appropriate education and medication counselling which cover key areas such as indication, expected effects, common side effects, signs of toxicity, when and how to seek help.
2. Provide written materials where applicable (e.g., MOH leaflets, drug charts/calendars).
3. Document the education provided, including content covered, and recipient (e.g. patient/caregiver).
4. Ensure appropriate language and literacy in communication.

Suggested Indicators

1. Evidence of availability of opioid education materials for patients and caregivers.

Suggested Tools

1. Malaysian Hospice and Palliative Care Council: Caregiver resources https://www.malaysianhospicecouncil.com/forcaregiver
2. Hospis Malaysia. Carer's Guidebook. Kuala Lumpur, Malaysia 2016 https://www.hospismalaysia.org/resources/

12.4	There is adherence to legal requirements for the prescription, safe storage and transport, dispensing, administration and disposal of opioids in accordance with the Poisons (Psychotropic substances) Regulations 1989 including any subsequent amendments or relevant legislation. **(All providers)**

Explanatory Notes

The use of opioids is governed by the Poisons Act 1952 and Poisons Regulations 1989.[12]

Good Practice

All Providers:

1. There should be policies and procedures on receipt, safe storage, transport, prescribing, dispensing, administration, and disposal of opioids.
2. There should be documentation on receipt, prescription, preparation and dispensing/administration of opioids and disposal of opioids according to established protocols.

Class C Providers:

1. Provide staff training and on safe handling, documentation, and disposal of opioids.
2. Conduct regular internal audits of opioid records (eg, stock cards, prescription logs, administration charts).

Suggested Indicators

1. Evidence of policies and procedures on receipt, safe storage, transport, prescribing, dispensing, administration, and disposal of opioids.
2. Evidence of documentation on receipt, prescription, preparation and dispensing/administration of opioids and disposal of opioids according to established protocols.

Suggested Tools

1. Poisons Act 1952, Poisons (Psychotropic Substances) Regulations 1989 .

References:

1. Medical Services Unit. National Palliative Care Policy and Strategic Plan 2019-2030. Ministry of Health Malaysia; 2019. 1-196 p.

2. Caraceni A, Hanks G, Kaasa S, Bennett MI, Brunelli C, Cherny N, Dale O, De Conno F, Fallon M, Hanna M, Haugen DF, Juhl G, King S, Klepstad P, Laugsand EA, Maltoni M, Mercadante S, Nabal M, Pigni A, Radbruch L, Reid C, Sjogren P, Stone PC, Tassinari D, Zeppetella G; European Palliative Care Research Collaborative (EPCRC); European Association for Palliative Care (EAPC). Use of opioid analgesics in the treatment of cancer pain: evidence-based recommendations from the EAPC. Lancet Oncol. 2012 Feb;13(2):e58-68. doi: 10.1016/S1470-2045(12)70040-2. PMID: 22300860.

3. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X, Arreola Ornelas H, Gómez-Dantés O, Rodriguez NM, Alleyne GAO, Connor SR, Hunter DJ, Lohman D, Radbruch L, Del Rocío Sáenz Madrigal M, Atun R, Foley KM, Frenk J, Jamison DT, Rajagopal MR; Lancet Commission on Palliative Care and Pain Relief Study Group. Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: the Lancet Commission report. Lancet. 2018 Apr 7;391(10128):1391-1454. doi: 10.1016/S0140-6736(17)32513-8. Epub 2017 Oct 12. Erratum in: Lancet. 2018 Jun 2;391(10136):2212. doi: 10.1016/S0140 6736(18)30616-0. PMID: 29032993.

4. Integrating palliative care and symptom relief into paediatrics:a WHO guide for health care planners, implementers and managers. Geneva: World Health Organisation; 2018

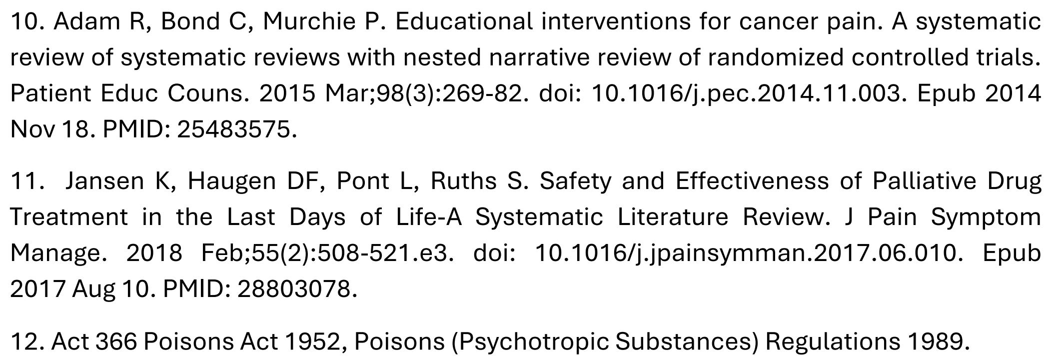
5. Cherny NI, Cleary J, Scholten W, Radbruch L, Torode J. The Global Opioid Policy Initiative (GOPI) project to evaluate the availability and accessibility of opioids for the management of cancer pain in Africa, Asia, Latin America and the Caribbean, and the Middle East: introduction and methodology. Ann Oncol. 2013 Dec;24 Suppl 11:xi7 13. doi: 10.1093/annonc/mdt498. PMID: 24436961.

6. Cleary JF, Husain A, Maurer M. Increasing worldwide access to medical opioids. Lancet. 2016 Apr 16;387(10028):1597-9. doi: 10.1016/S0140-6736(16)00234-8. Epub 2016 Feb 3. PMID: 26852263.

7. Wiffen PJ, Wee B, Derry S, Bell RF, Moore RA. Opioids for cancer pain - an overview of Cochrane reviews. Cochrane Database Syst Rev. 2017 Jul 6;7(7):CD012592. doi: 10.1002/14651858.CD012592.pub2. PMID: 28683172; PMCID: PMC6483487.

8. Barnes H, McDonald J, Smallwood N, Manser R. Opioids for the palliation of refractory breathlessness in adults with advanced disease and terminal illness. Cochrane Database Syst Rev. 2016 Mar 31;3(3):CD011008. doi: 10.1002/14651858.CD011008.pub2. PMID: 27030166; PMCID: PMC6485401.

9. Wiffen PJ, Cooper TE, Anderson AK, Gray AL, Grégoire MC, Ljungman G, Zernikow B. Opioids for cancer-related pain in children and adolescents. Cochrane Database Syst Rev. 2017 Jul 19;7(7):CD012564. doi: 10.1002/14651858.CD012564.pub2. PMID: 28722116; PMCID: PMC6484393.



10. Adam R, Bond C, Murchie P. Educational interventions for cancer pain. A systematic review of systematic reviews with nested narrative review of randomized controlled trials. Patient Educ Couns. 2015 Mar;98(3):269-82. doi: 10.1016/j.pec.2014.11.003. Epub 2014 Nov 18. PMID: 25483575.

11. Jansen K, Haugen DF, Pont L, Ruths S. Safety and Effectiveness of Palliative Drug Treatment in the Last Days of Life-A Systematic Literature Review. J Pain Symptom Manage. 2018 Feb;55(2):508-521.e3. doi: 10.1016/j.jpainsymman.2017.06.010. Epub 2017 Aug 10. PMID: 28803078.

12. Act 366 Poisons Act 1952, Poisons (Psychotropic Substances) Regulations 1989.

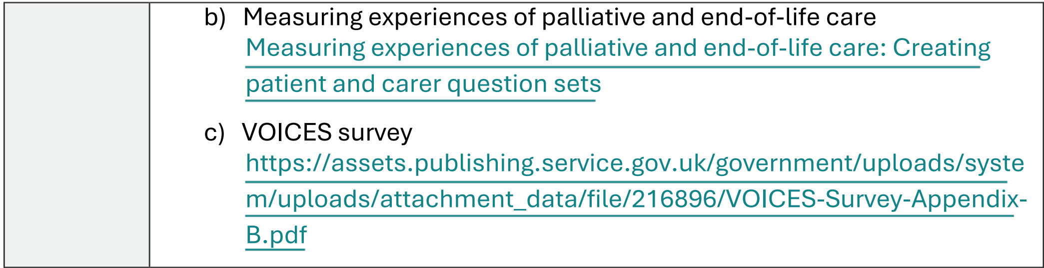
Standard 13 – Clinical Quality Improvement

The service is committed to improvement in clinical and management practices.

Rationale	Commitment to a high quality of care to patients and their families should be an integral part of palliative care services. Services should practice quality improvement activities through regular review, analysis, goal setting and revision of care processes.[1-10]

Indicators		
Class B+C	13.1	Presence of a framework to guide quality improvement, consisting of: a) Evidence of dissemination and incorporation of quality improvement findings into practice. b) A process for identifying and reducing adverse events to patients, caregivers and healthcare providers.
Class C	13.2	There is evidence of the implementation of quality improvement projects to evaluate and develop services.[10-14]
	13.3	There is evidence of evaluation of patients' and families' experience and satisfaction with care, and improvement measures where necessary.[15,16,17]

Suggested Tools	
1.	Resources for Quality Improvement in Palliative Care: a) PCOC Quality Improvement Guide (Australian Health Services Research Institute, University of Wollongong) https://www.uow.edu.au/australasian-health-outcomes-consortium/pcoc/accreditation-standards-quality/
2.	Patient and Carer satisfaction / experience surveys: a) FAMCARE-2 questionnaire (KIV malay / chinese version) Microsoft Word - FAMCARE Guidelines-15Aug12.docx



	b) Measuring experiences of palliative and end-of-life care Measuring experiences of palliative and end-of-life care: Creating patient and carer question sets c) VOICES survey https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216896/VOICES-Survey-Appendix-B.pdf

Implementation Guide

13.1	Presence of a framework to guide quality improvement, consisting of: a. Evidence of dissemination and incorporation of quality improvement findings into practice. b. A process for identifying and reducing adverse events to patients, caregivers and healthcare providers. **(Class B+C Providers)**

Explanatory Notes

Quality Improvement	Quality improvement consists of systematic and continuous actions that lead to measurable improvement in health care services and the health status of patients.

Good Practice

Class B+C Providers:

1. There are policies or guidelines for quality improvement in clinical practice.
2. Quality improvement activities are discussed in team meetings.
3. There is a quality improvement/assurance committee or a person who oversees the quality of care.
4. Death reviews should be completed within 1 month of death, and should ideally cover the domains of symptom control, psychosocial issues, bereavement needs and whether goals of care preferences have been honoured.

Suggested Indicators

1. Evidence of a quality improvement/assurance committee or person to review the quality of care.
2. Percentage of deceased patients with death reviews completed within 1 month of death. Death reviews for Class C Providers should include domains of symptom control, psychosocial issues and bereavement needs.

Numerator	Number of deceased patients with death reviews completed within 1 month of death.
Denominator	Total number of deceased patients.

13.2	There is evidence of the implementation of quality improvement projects to evaluate and develop services. **(Class C providers)**
Explanatory Notes	
Quality improvement projects	Systematic activities that are organised and implemented by an organisation to monitor, assess, and improve its quality of health care. The activities are cyclical so that an organisation continues to seek higher levels of performance to optimise its care for the patients it serves, while striving for continuous improvement.[10-14]

Good Practice	
1.	Use a recognised quality improvement tool/framework (e.g. PDSA) in the implementation of the quality improvement project.

Suggested Indicators	
1.	Evidence of at least one quality improvement project each year.

Suggested Tools	
1.	PCOC Quality Improvement Guide (Australian Health Services Research Institute, University of Wollongong) Quality improvement - University of Wollongong – UOW

13.3	There is evidence of evaluation of patients' and families' experience and satisfaction with care, and improvement measures where necessary.[15,16,17] **(Class C providers)**

Explanatory Notes

Regular feedback from patients and families should include the following domains:

- Symptom control
- Psychosocial support
- Communication
- Bereavement Care

Good Practice

1. Use a validated tool to evaluate patient and caregiver experience and/or satisfaction.

Suggested Indicators

1. Evidence of routine use of a patient and family satisfaction survey.
2. Evidence of improvement measures implemented as a result of survey findings.

Suggested Tools

1. FAMCARE-2 questionnaire (KIV malay / chinese version)
   Microsoft Word - FAMCARE Guidelines-15Aug12.docx
2. Measuring experiences of palliative and end-of-life care
   Measuring experiences of palliative and end-of-life care: Creating patient and carer question sets
3. FVOICES survey
   https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216896/VOICES-Survey-Appendix-B.pdf

References:

1. De Roo ML, Leemans K, Claessen SJ, Cohen J, Pasman HR, Deliens L, Francke AL; EURO IMPACT. Quality indicators for palliative care: update of a systematic review. J Pain Symptom Manage. 2013 Oct;46(4):556-72. doi: 10.1016/j.jpainsymman.2012.09.013. Epub 2013 Jun 26. PMID: 23809769.

2. Lau BD, Aslakson RA, Wilson RF, Fawole OA, Apostol CC, Martinez KA, Vollenweider D, Bass EB, Dy SE. Methods for improving the quality of palliative care delivery: a systematic review. Am J Hosp Palliat Care. 2014 Mar;31(2):202-10. doi: 10.1177/1049909113482039. Epub 2013 Mar 26. PMID: 23532404; PMCID: PMC4696032.

3. Dy SM, Kiley KB, Ast K, Lupu D, Norton SA, McMillan SC, Herr K, Rotella JD, Casarett DJ. Measuring what matters: top-ranked quality indicators for hospice and palliative care from the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association. J Pain Symptom Manage. 2015 Apr;49(4):773-81. doi: 10.1016/j.jpainsymman.2015.01.012. Epub 2015 Feb 16. PMID: 25697097.

4. Woitha K, Van Beek K, Ahmed N, Jaspers B, Mollard JM, Ahmedzai SH, Hasselaar J, Menten J, Vissers K, Engels Y. Validation of quality indicators for the organization of palliative care: a modified RAND Delphi study in seven European countries (the Europall project). Palliat Med. 2014 Feb;28(2):121-9. doi: 10.1177/0269216313493952. Epub 2013 Jul 16. PMID: 23861161.

5. Leemans K, Cohen J, Francke AL, Vander Stichele R, Claessen SJ, Van den Block L, Deliens L. Towards a standardized method of developing quality indicators for palliative care: protocol of the Quality indicators for Palliative Care (Q-PAC) study. BMC Palliat Care. 2013 Feb 8;12:6. doi: 10.1186/1472-684X-12-6. PMID: 23394401; PMCID: PMC3600663.

6. Higashi T, Nakamura F, Saruki N, Sobue T. Establishing a quality measurement system for cancer care in Japan. Jpn J Clin Oncol. 2013 Mar;43(3):225-32. doi: 10.1093/jjco/hyt001. Epub 2013 Feb 6. PMID: 23390306.

7. De Lima L, Bennett MI, Murray SA, Hudson P, Doyle D, Bruera E, Granda-Cameron C, Strasser F, Downing J, Wenk R. International Association for Hospice and Palliative Care (IAHPC) List of Essential Practices in Palliative Care. J Pain Palliat Care Pharmacother. 2012 Jun;26(2):118-22. doi: 10.3109/15360288.2012.680010. PMID: 22764847.

8. Raijmakers N, Galushko M, Domeisen F, Beccaro M, Lundh Hagelin C, Lindqvist O, Popa-Velea O, Romotzky V, Schuler S, Ellershaw J, Ostgathe C; OPCARE9. Quality indicators for care of cancer patients in their last days of life: literature update and experts' evaluation. J Palliat Med. 2012 Mar;15(3):308-16. doi: 10.1089/jpm.2011.0393. Epub 2012 Feb 10. PMID: 22324541.

9. World Health Organization. Assessing the development of palliative care worldwide: a set of actionable indicators [Internet]. Geneva: WHO; 2021 [cited 2025 Jun 19]. Available from: https://iris.who.int/bitstream/handle/10665/345532/9789240033351-eng.pdf.

10. Garralda E, Benítez E, Montero Á, Sánchez-Cárdenas M, Tripodoro V, Centeno C. Enhancing Global Development of Palliative Care: Insights from Country Experts on ATLANTES Observatory's Role. J Palliat Med. 2023 Dec;26(12):1709-1714. doi: 10.1089/jpm.2023.0169. Epub 2023 Oct 16. PMID: 37843901; PMCID: PMC10714114.

11. Agar M, Luckett T. Outcome measures for palliative care research. Curr Opin Support Palliat Care. 2012 Dec;6(4):500-7. doi: 10.1097/SPC.0b013e32835a66ca. PMID: 23080308.

12. Hanson LC, Rowe C, Wessell K, Caprio A, Winzelberg G, Beyea A, Bernard SA. Measuring palliative care quality for seriously ill hospitalized patients. J Palliat Med. 2012 Jul;15(7):798-804. doi: 10.1089/jpm.2011.0471. Epub 2012 Jun 11. PMID: 22687268.

13. Penrod JD, Pronovost PJ, Livote EE, Puntillo KA, Walker AS, Wallenstein S, Mercado AF, Swoboda SM, Ilaoa D, Thompson DA, Nelson JE. Meeting standards of high quality intensive care unit palliative care: clinical performance and predictors. Crit Care Med. 2012 Apr;40(4):1105-12. doi: 10.1097/CCM.0b013e3182374a50. PMID: 22202706; PMCID: PMC3307856.

14. Ministry of Health Malaysia. Patient Safety [Internet]. Putrajaya: Ministry of Health Malaysia; [cited 2025 Jun 19]. Available from:
https://patientsafety.moh.gov.my/v2/?page_id=56

15. Weissman DE, Morrison RS, Meier DE. Center to Advance Palliative Care palliative care clinical care and customer satisfaction metrics consensus recommendations. J Palliat Med. 2010 Feb;13(2):179-84. doi: 10.1089/jpm.2009.0270. PMID: 19922199.

16. NHS England. Measuring experience in care in end of life care: An overview [Internet]. Leeds: NHS England; 2018 [cited 2025 Jun 19]. Available from:
https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/06/Measuring_experience_in_care_in_end_of_life_care_-_An_overview.pdf

17. Ananth P, Mun S, Reffat N, Kang SJ, Pitafi S, Ma X, Gross CP, Wolfe J. Refining Patient-Centered Measures of End-of-Life Care Quality for Children With Cancer. JCO Oncol Pract. 2022 Mar;18(3):e372-e382. doi: 10.1200/OP.21.00447. Epub 2021 Oct 6. PMID: 34613797; PMCID: PMC8932486.

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