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30 October 2015

Australian Commission on Safety and Quality in Health Care
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To whom it may concern

RE: Consultation on Version 2 of the National Safety and Quality Health Service (NSQHS) Standards

Thank you for the opportunity to comment on the draft version of the NSQHS Standards. These Standards were reviewed by Palliative Care Australia (PCA) and the Palliative Care Australia Standards Working Group (membership of which is attached for your information).

PCA and the PCA Standards Group are of the view that overall, these proposed Standards are a step forward from the current Standards, and the Commission is to be congratulated for their development. The expansion of scope of the Partnering with Consumers in their own care is a welcome change, as is the addition of a new Standards on Comprehensive Care.

PCA expects that the inclusion of more explicit actions about palliative and end of life care will support practice improvement in these areas. Minor amendments to these actions are suggested in the attachment that aim to clarify the requirements of health services and support the development of clear resources to support their implementation.

As previously discussed with members of the Commission one of PCA's main concerns relates to the definitions used, including: end of life; advance care plan; approaching the end of life and specialist palliative care. PCA proposes working with stakeholders and the Commission to develop a resource that will support health services understand these terms so that they are clear on the expectations in the Standards. It is also important to be as clear as possible within the Standards.

Comments on a selection of proposed actions are attached, including some recommendations about what could be included in resources, to support health services in the implementation of the Standards.

PCA looks forward to working with the Commission to support implementation of the Standards, including on development of resources to support the Standards. If you have any queries about the content of this submission please direct them to Philippa Kirkpatrick, National Policy Manager on philippa@palliativecare.org.au or phone 02 6232 4433.

Yours sincerely

A handwritten signature in black ink, appearing to be 'Liz Callaghan', with a horizontal line extending to the right.

Liz Callaghan
Chief Executive Officer
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Membership of PCA Standards Working Group

Andrew Allsop, Chair

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Judi Greaves

Kerri-Anne Dooley

Enyonam Glover

Philippa Kirkpatrick

Liz Callaghan

Proposed changes to the actions are in red.

Item	Wording of actions	Comments
GS 1 Governance and strategic leadership	GS1.1 The highest level of governance: a. Endorses safety and quality goals developed for the organisation b. provides leadership to promote a safety culture in the organisation c. provides leadership on partnering with consumers d. receives reports and monitors progress on safety and quality performance and culture e. provides direction on safety and quality actions taken by the health service organisation	Resources should refer to Element 6 of the End-of-life Consensus Statement
	GS1.2 Where Aboriginal and Torres Strait Islander people receive care in the organisation, the highest level of governance ensures that the safety and quality goals address the specific health needs of these people	In resources refer to Action 1.3 and 7.7 of End-of-life Consensus Statement. The Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013-2023 states that PM&C will support work across Australian Government agencies to build strong governance in organisations providing services to ATSI peoples. This action should support that work and link to any resources or activities developed.
GS4 Policies and procedures	GS4.2 The health service organisation has systems to ensure compliance with legislation and regulation, and to meet jurisdictional requirements	Legal and ethical requirements relating to advance care plans and directives
GS10 Feedback systems	GS10.1 The health service organisation seeks regular feedback from consumers: a. about their experiences and outcomes	Resources could identify that the NSAP program has a family evaluation component.

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	<ul style="list-style-type: none"> b. to use this information to improve safety and quality systems, and their performance 	
<p>GS 11 Healthcare records systems</p>	<p>GS 11.1 The health service organisation has healthcare records systems that:</p> <ul style="list-style-type: none"> a. make the healthcare record available to clinicians at the point of care b. comply with security and privacy regulations c. enable systematic audit of clinical information d. integrate multiple information systems, where they are in use 	<p>Resources should identify that this needs to capture advance care plans and directives.</p>
<p>GS12 Safety and quality training</p>	<p>GS 12.1 The health service organisation:</p> <ul style="list-style-type: none"> a. assesses its safety and quality training needs b. provides access to training to address its safety and quality training needs 	<p>Refer to training available on end of life and palliative care e.g. PCC4U and PEPA. If resources are developed that are relevant to residential aged care then this should also refer to the Palliative Approach toolkit. The PalliAged app is targeted to GPs but may be useful to clinicians across the health sector.</p> <p>Refer to actions 7.1-10 and actions 8.1 and 8.2 of the End-of-life Consensus Statement</p>
	<p>GS 12.2 Where Aboriginal and Torres Strait Islander people receive care in the organisation, the health service organisation has strategies to improve the cultural awareness and competency of the workforce</p>	<p>The Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013-2023 indicates that by 2018 training needs of health sector staff working with Aboriginal and Torres Strait Islander peoples will have been identified and addressed including the development and delivery of new training programs. It is suggested the Commission speak with the lead</p>

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		entities for this activity to ensure it is reflected in the resources.
GS 17 Safe environment for the delivery of care	<p>GS 17.1 The health service organisation:</p> <ul style="list-style-type: none"> a. designs the environment to maximise safe and high-quality care within the constraints of the existing facilities, where relevant b. provides a quiet and safe environment when it is clinically required c. protects consumers, the workforce and visitors from violence and other forms of abuse 	There should be a requirement for health services organisations to identify spaces suitable for dying patients and for family members following the death of a patient.
PC2 Quality improvement	<p>PC 2.1 The health service organisation and workforce use the organisation-wide quality improvement systems to:</p> <ul style="list-style-type: none"> a. monitor the effectiveness of the systems for partnering with consumers b. take action to improve the systems and their performance for partnering with consumers c. report on effectiveness and outcomes 	Resources should identify the Palliative Care Outcomes Collaborative (PCOC) assessment tools that are available to support quality improvement activities.
PC4 Information that is easy to understand and use	<p>PC 4.1 The health service organisation provides information about health and health care that is tailored to the diversity of the consumers who use its services and, where relevant, the local population</p>	<p>Resources should refer to multilingual brochures available on the Palliative Care Australia website. The Caresearch website also has resources available in different languages including videos.</p> <p>The Standards or their resources should make explicit reference to providing access to interpreter services, and making use of such services whenever appropriate.</p>
	<p>PC 4.2 Clinicians provide consumers with information about health and health care that:</p>	Resources should link to the Health Literacy documents developed by the Commission.

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	<ul style="list-style-type: none"> a. is easy to understand and use b. is in a format that meets their needs c. includes information about treatment and options, risks and benefits, the care plan, what they need to do after leaving the organisation, and managing their medicines, where relevant 	
PC 5 Healthcare rights and informed consent	PC5.2 The health service organisation ensures that its informed consent systems comply with legislation and best practice	
	PC5.3 The health service organisation has systems to identify the capacity of a consumer to make decisions about their own care and provide informed consent	<p>The resources for this action need to also identify the need to respect decisions previously made by the consumer about their plan for care and training of the workforce to identify the ethical and legal aspects of determining if a previously made care plan (specifically identifying advance care plans and directives as an example) should be implemented if it conflicts with family, carer or health professionals' preferences for the consumers care.</p> <p>Refer also to RR7.1</p>
	PC5.4 The health service organisation has systems to identify a substitute decision maker if a consumer does not have the capacity to make decisions for themselves	<p>Resources should identify the relevant legislative requirement such as the Guardianship Acts in states and territories as well as local policy. The health service organisation should be required to have training and education of clinicians on their responsibilities regarding taking into consideration or acting upon the wishes expressed by a substitute decision maker. This also needs to</p>

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		<p>consider how this works in the paediatric setting, and how children may build toward supported decision making through to independent decision making.</p> <p>Link also to PC6.3 as the system to identify a substitute decision maker should consider any preferences previously expressed by the consumer.</p>
<p>PC 6 Working together to share decisions and plan care</p>	<p>PC 6.1 Clinicians work with consumers to plan, communicate, set goals and make decisions about their care</p>	<p>This action needs to be about facilitating shared decision making about the goals of care and the plan for care. It needs to be clear that the consumer and their carer or substitute decision maker may change their wishes and that this needs to be taken into account when providing care. The action needs to make it clear that the plan discussed under this action needs to be document and available at the point of care. This requires linking to CC6.1.</p>
	<p>PC 6.2 Clinicians work in partnership with consumers or substitute decision makers to discuss and document preferences and goals for future care when the consumer is experiencing a mental illness, experiencing cognitive impairment or approaching the end of life</p>	<p>See comment on ‘approaching the end of life’ in the definitions. Is this action intended to cover when consumers have reduced decision-making capacity? If so, it may be clearer to say this in the action and use the mental illness, cognitive impairment or dying as ways that reduced decision-making capacity can occur.</p>

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	<p>PC6.3 The health service organisation has systems to identify any support people a consumer wants involved in communications and decision making about their care</p>	<p>The resources for this action should refer to providing advice about consumer advocates that can provide supported decision making services.</p>
	<p>PC 6.4 The health service organisation has systems to ensure that carers are supported to participate in the provision of health care in accordance with the wishes of the consumer and the carer, and to support the carer in their role as advocate for the consumer</p>	<p>The resources for this action should identify that carers may need psychosocial, spiritual or other support to manage the responsibility of making decisions about the consumers care. The role of the health service organisation in providing support to carers should be clear. It should refer to the Clinical Practice Guidelines for the Psychosocial and Bereavement Support of Family Caregivers if appropriate.</p>
	<p>PC 6.5 The health service organisation builds the capacity of the workforce to form partnerships with consumers in their own care</p>	<p>Resources should refer to training programs available</p>
<p>CC2 Quality improvement</p>	<p>CC2.1 The health service organisation and workforce use the organisation-wide quality improvement system to:</p> <ul style="list-style-type: none"> a. monitor the delivery of comprehensive care b. take action to improve systems and their performance of comprehensive care c. report on effectiveness and outcomes 	<p>Resources should refer to the NSAP program which offers a self-assessment and action planning process relating to provision of quality end of life care. This resource could be adapted and identified in the resources to support implementation of the Standards.</p>
<p>CC3 Designing systems to deliver comprehensive care</p>	<p>CC3.1 The health service organisation has systems identify the most appropriate available clinical setting for their care needs and to support them to receive care in that setting</p>	<p>Given the Standards need to refer to actions within the control of the health service, is this more about identification of the most appropriate clinical setting rather than actual matching. Is it better combined with Action CC3.3?</p>

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		<p>Is this action intended to cover the most appropriate setting within the hospital? If it is, resources should identify that clinicians need to consider the care plan when making such decisions. For example, it may not be appropriate to transfer a patient who is dying to the ICU, depending on the care plan and expressed wishes.</p>
<p>CC4 Collaboration and teamwork</p>	<p>CC3.3 The health service organisation has systems for timely referral and transfer of consumers with specialist healthcare needs to appropriate services</p>	<p>This action needs to strongly link with CS4.1. It is not just about transfer out, but about engaging with external organisations to seek to provide continuity of care when the most appropriate service or setting is not available within the health service organisation.</p>
	<p>CC4.1 The health service organisation defines how clinicians responsible for coordinating a consumer's care and clinicians with decision-making authority will work collaboratively to deliver comprehensive care</p>	<p>It needs to be clear within this is coordination within the health service organisation, or whether it also covers coordination between health service organisation.</p>
	<p>CC4.2 The health service organisation has systems that:</p> <ol style="list-style-type: none"> a. identify a clinician who can make definitive decisions about a consumer's care at all times b. clearly define the roles and responsibilities of each clinician working in a team c. support clinicians to work and communicate in a coordinated, accountable, multidisciplinary way 	<p>Point a may apply to cases where urgent care is required. However, in other cases shared decision making between the team of clinicians and the consumer may be more appropriate.</p>
<p>CC5 Screening and assessment of risks</p>	<p>CC5.1 The health service organisation has systems for integrated and timely screening, assessment and risk identification relevant to the consumers who use its services</p>	<p>The resources for this action should refer to triggers to recognise people approaching the end of their life (Element 4 of the End-of-life Consensus Statement)</p>

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	<p>CC5.4 Clinicians comprehensively assess:</p> <ul style="list-style-type: none"> a. conditions and risks identified through the screening process b. where relevant, risks associated with: <ul style="list-style-type: none"> ○ pressure injuries ○ falls ○ malnutrition and dehydration ○ cognitive impairment and delirium ○ identification of consumers requiring end of life care ○ the adverse outcomes associated with end-of-life care ○ challenging behaviours and self-harm 	<p>All items on this list are adverse outcomes except for end of life care. Suggest it is changed to the adverse outcomes associated with end of life care.</p> <p>The resources for this action should refer to responding to concerns about end of life care (Element 5 of the End-of-life Consensus Statement) as well as all other aspects of providing high quality end of life care.</p>
	<p>CC5.5 Clinicians document the findings of the screening, risk identification and assessment processes, including any relevant alerts, in the healthcare record</p>	<p>Link to GS11.1 about making the healthcare record available at the point of care.</p>
<p>CC6 Comprehensive care planning</p>	<p>CC6.1 Clinicians develop and document an integrated and individualised care plan that includes:</p> <ul style="list-style-type: none"> a. consideration of the consumer’s preferences, personal circumstances and information from carers b. strategies and actions for managing identified clinical risks c. clearly articulated goals for the consumer’s episode of care d. the treatment plan and actions to be taken to achieve the goals e. a discharge plan that is commenced at the beginning of the episode of care. The discharge 	<p>The resources for this action need to refer to RH7.2 which requires the advance care plan to be available at the point of care. Is there a gap about making all care plans available at the point of care (this is required for the advance care plan, and for the healthcare record, but I can’t find it for the care plan)?</p> <p>Also link to (or merge with) PC6.1</p>

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	<p>plan should incorporate the needs of families and carers.</p>	
<p>CC7 Use of the care plan</p>	<p>CC7.1 Clinicians work in partnership with the consumer, and their family and carers to:</p> <ol style="list-style-type: none"> a. implement the comprehensive care plan in a timely way b. use the plan as the basis for ongoing care c. monitor the effectiveness of the plan d. reassess the consumer's needs if changes in diagnosis, behaviour, cognition, mental state or physical condition occur e. review and adapt the plan if it is not meeting the consumer's needs 	<p>Link to RH7.2 ensuring it is clear that where it refers to implementation of the 'comprehensive care plan' it also refers to implementation of the 'advance care plan'.</p>
<p>RH7 End-of-life care</p>	<p>RH7.1 Where end-of-life care is provided, the health service organisation has systems to identify people who are approaching the end of life</p>	<p>It is suggested that all the following actions on end of life care better fit within the comprehensive care standard.</p> <p>It needs to be clear that health service organisations need to identify people with a life-limiting illness and provide end of life care, and also to identify people at risk of dying within this admission.</p> <p>Reference End of Life Consensus Statement Element 4. PCA may work with the Commission to identify more specific triggers for common chronic diseases.</p>

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	<p>RH7.2 Where end-of-life care is provided, the health service organisation has systems to ensure that advance care plans:</p> <ul style="list-style-type: none"> a. can be received from consumers b. are documented in the healthcare record c. are easily available at the point of care d. are considered and reviewed as outlined in CC7.1 	Needs to link to PC4.1 which will cover development of an advance care plan.
	<p>RH7.3 Where end-of-life care is provided, the health service organisation has systems that:</p> <ul style="list-style-type: none"> a. define the criteria and processes for clinicians to access help when managing end-of-life issues b. provide access to specialist palliative care advice that is readily available c. provide access to supervision and support for clinicians delivering end-of-life care d. support organ and tissue donations e. review the safety and quality of end-of-life care that is provided against the planned goals of care 	<p>This action appears to include items that support the clinician in providing the care (a and b), provide psychosocial and spiritual support to clinicians that are having difficulty coping with a dying patient (c), supervision of clinicians (c), organ donation (d) and assessment of the quality of provision of end of life care (e). While these are all important, it they do not fit well under a single action.</p> <p>Proposed changes are below. These could replace this action.</p>
	<p>Where end-of-life care is provided, the care aligns with the essential elements described in the National Consensus Statement: Essential Elements for Safe and High-quality End-of-life Care</p>	Refer to the End-of-life Consensus Statement in resources, and in particular. The evidence workbook (or equivalent) could refer to Action 9.5 of the End-of-life Consensus Statement which identifies measures of the safety and quality of end-of-life care.
	<p>Where end-of-life care is provided, provide systems to access specialist palliative care advice and consultation</p>	Specialist palliative care needs to be defined

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		Refer to the Decision Assist Advisory Line as a resource available to support this action and the other existing networks that exist across states and territories. It is suggested that the requirement be that the health service organisation have a policy or procedure that outlines how this support is to be provided.
	Where end-of-life care is provided, the health service organisation has systems that supports organ and tissue donations.	Organ and tissue donation needs to be part of the discussion about goals of care. It is suggested this is incorporated into those requirements in addition to this action.
	The health service organisation makes available support (including psychosocial and spiritual support) to clinicians and other members of the health care team providing end of life care	Refer to elements 8.3 and 8.4 of the End-of-life Consensus Statement Refer to GS12.1 re training and support
	Proposed new action: The health service organisation provides access to grief and bereavement support for the families and carers of people at the end of their life.	This is a gap in the proposed actions and is important to the provision of high quality palliative care.
CS3 Communication systems	CS3.1 The health service organisation has systems to: <ul style="list-style-type: none"> a. identify the clinical communication needs of the organisation b. address these communication needs 	
CS4 Application of communication systems in the local service context	CS4.1 Clinicians apply organisation-wide systems for communication to the local service context to enable communication, collaboration and coordination between	

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	clinicians and between organisations, to ensure continuity of care	
CS5 Clinical handover	CS5.1 The health service organisation has systems for structured clinical handover, at times when all or part of the care of a consumer is transferred between organisations, within the organisation and between clinicians	Resources should refer to the need to ensure that the patient's wishes as well as any advance care plans and directives (including updates to these) are effectively communicated between health services at transitions of care (refer to Action 10.4 and 10.5 of the End-of-life Consensus Statement.
CS6 Communicating critical information	CS6.1 The health service organisation has systems to communicate new critical information and clinical concerns or risks about a consumer's care in a timely manner to clinicians who can make decisions about care	
	CS6.2 Clinicians use the systems to communicate new or critical information, and clinical concerns to clinicians who can make decisions about care, the consumer, and family and carers identified as support people	
CS7 Documentation of information	CS7.1 The health service organisation has systems to contemporaneously document information in the healthcare record when: <ul style="list-style-type: none"> a. new critical information and clinical concerns or risks are identified b. changes occur in the care plan 	
MS10 High risk medicines	MM10.1 The health service organisation: <ul style="list-style-type: none"> a. identifies high risk medicines used within the organisation b. has a system to store, prescribe and administer high-risk medicines safely 	Additional component to this action suggested, to align with Action 10.2 of the End of Life Consensus Statement.

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	<p>c. Ensures access to essential palliative medicines 24 hours a day and 7 days a week.</p>	
<p>RR3 Recognising acute deterioration</p>	<p>RR3.1 The health service organisation has systems for clinicians to:</p> <ul style="list-style-type: none"> a. document individualised plans outlining the monitoring requirements for consumers b. document any limitations on medical treatment that have been agreed c. monitor consumers as required by their individualised plan (which may include mental, cognitive and other criteria to indicate acute deterioration) d. graphically document and track changes in agreed observations to detect acute deterioration over time, as appropriate for the consumer e. escalate care as required, based on agreed criteria f. include acute suffering that is not able to be managed using available treatment as a criterion for escalating care g. include worry or concern about acute deterioration as a trigger for escalating care h. recognise and provide appropriate care for consumers who may die in this admission. 	<p>Resources relating to implementation of item b should refer to the advance care plan (RH7.2).</p>
<p>RR4 Escalating care</p>	<p>RR4.1 The health service organisation:</p> <ul style="list-style-type: none"> a. provides the workforce with mechanisms to escalate care and call for emergency assistance b. has escalation protocols that include criteria for triggering a call for emergency assistance 	<p>Ensure that care escalation aligns with the patient's wishes including as documented in the care plan, advance care plan or directives(RH7.2)</p>

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	<p>RR4.2 Clinicians take action to escalate care when agreed triggers that indicate acute deterioration are breached or when they are concerned about the condition of a consumer</p>	<p>Resources should refer to Element 5 of the End-of-life Consensus Statement</p>
<p>RR5 Escalation by consumers</p>	<p>RR5.1 The health service organisation has systems that:</p> <ul style="list-style-type: none"> a. provide consumers, family members and carers with a mechanism to directly escalate care b. monitor and improve consumers' experiences of using the escalation systems 	<p>Resources should refer to Element 5 of the End-of-life Consensus Statement</p>
<p>RR6 Responding to deterioration</p>	<p>RR6.1 The health service organisation has systems that enable clinicians to provide an initial response to episodes of acute deterioration and suffering in a timely way, as appropriate for their role</p>	<p>Ensure that the response aligns with the patient's wishes including as documented in the care plan, advance care plan or directives (RH7.2)</p>
	<p>RR6.2 The health service organisation has systems to ensure rapid access:</p> <ul style="list-style-type: none"> a. at all times to at least one clinician, either on-site or in close proximity, who can deliver advanced life support b. to appropriate services for definitive management of the acute deterioration 	
<p>RR7 Advance care plans</p>	<p>RR7.1 If consumers are unable to participate in decision making about their care, clinicians use existing advance care plans, treatment-limiting orders, the consumer's previously expressed preferences, and other relevant documentation to guide decision making when responding to deterioration</p>	<p>This action should refer to the requirements relating to substitute decision makers PC5.4 and PC6.2</p> <p>There should be policies and procedures in place to assist clinicians to understand the legal and ethical requirements relating to implementation of advance care plans and directives, and the actions that should occur when it is unclear of the legal</p>

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		standing of a document that is presented to the clinical team.

Current definition

end of life: the period when a consumer is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of consumers with chronic or malignant disease, or very brief in the case of consumers who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.

Proposed Resource

There is different use of terms between resources available. It should align with the Consensus statement definition. The period of end of life care and the period of end of life should be the same.

advance care plan: a plan that states preferences about health and personal care, and preferred health outcomes.

Comment

The definition does not link this document to the planning at the end of life.
It is proposed this is changed to:

Advance care planning provides an opportunity for people to think, discuss and plan for the medical treatment they would prefer if they became too ill in the future to express their wishes. An advance care plan is the documentation of these wishes.

It is suggested there is also the need to define 'care plan' and possibly state that the advance care plan may be part of the care plan that is specifically designed to cover the patient's wishes relating to their end of life care.

PCA to work with the Commission to develop a fact sheet on terminology and the different intentions of the words end-of-life, palliative care, specialist palliative care etc.

Approaching the end of life: there is no definition for this term (used in PC6.2). If the definition of end of life is the entire period someone is living with a fatal condition, then it may not be possible to determine when they are approaching this. Is this intended to mean when it is possible or likely they will die in this admission?

Specialist palliative care: this needs to be defined. The definition from the National Standards for providing quality palliative care for all Australians (4th ed) is:

Specialist palliative care provider is a medical, nursing or allied health professional, recognised as a specialist by an accrediting body (or who primarily works in palliative care if an accrediting body is not available) who provides consultative or ongoing care for patients with a life limiting illness, and support for their caregiver/s and family. Specialist palliative care builds on the palliative approach adopted by primary care providers, and reflects a higher level of expertise in complex symptom control, loss, grief and bereavement. Specialist palliative care providers work in two key ways: first, by providing direct care to referred individuals and their families; and second, by providing a consultancy service to primary care providers and therefore supporting their care of the patient and family.