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Integrative Review for Identifying Patients Appropriate for End-of-Life Care Interventions by

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Integrative Review for *Identifying* Patients Appropriate for End-of-Life Care Interventions by
Using the Gold Standards Framework and Prognostic Indicator Guidance Tool with Surprise
Question: A Presentation with Resource Packet for Primary Care Providers and Staff

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Abstract

Background: End of life is defined as the last 12 months before a person dies, with 1% of the total population passing each year. Primary care providers can predict end of life and implement interventions. Early identification of patients for palliative care prevents crises, meets the needs of patients and families, and reduces the cost of healthcare. Screening for end-of-life care needs in primary care using the Gold Standards Framework (GSF) and the Prognostic Indicator Guidance (PIG) tool/surprise question will minimize risk of missed interventional opportunities.

Purpose: This educational intervention served to increase provider knowledge of the GSF and PIG, and supplied providers with resources for screening patients for end-of-life care needs.

Presentation and Toolkit: An educational presentation of this integrative review and resource packet was given to providers and staff in a primary care clinic. The packet contained current evidence, statistics, references, and resources available for patients and providers. The DNP student created an end-of-life care screening algorithm and an adapted screening tool, both of which were embedded in the resource packet.

Outcomes/Discussion: The DNP student successfully met the desired outcomes. Pre- (100%) and post-presentation (73%) surveys revealed a 100% increase in provider knowledge regarding the GSF, PIG, surprise question, and available resources. Respondents (100%) said they would use the packet and felt confident doing so. The algorithm was deemed helpful, easy to use and satisfied the providers desire for guidance in this process.

Implications/Conclusion: Implications for future practice include the effective and efficient use of the resource packet for early identification of end-of-life patients in primary care. The DNP student is available to consult and assist with implementation of the packet into practice.

Keywords: Gold Standards Framework, palliative care, end of life, surprise question

Introduction and Background

Whether one defines end of life as the last moments of being alive or as the decline in the ability to carry on physical life, identification of patients in this phase of the life cycle is imperative to meeting their healthcare needs (Aldridge, Canavan, Cherlin, & Bradley, 2015; Kirolos et al., 2014; McCusker et al., 2013; Registered Nurses' Association of Ontario [RNAO], 2011). As a nation, we are not providing the best available care for patients at the end of life (National Hospice and Palliative Care Organization [NHPCO], 2015). The human body provides observable indications of decline as it approaches the end of life. Healthcare providers have the knowledge and ability to identify this change; however, many providers find the timing and initiation of this conversation challenging, while patients and their loved ones often do not have the insight to see the change. Resources that can facilitate the provider's ability to identify these patients will assist to fill this gap in the healthcare cycle.

In 2009, Medicare, the health insurance of most older adults in the US, spent \$12.1 billion dollars, with an average increase of \$1.1 billion per year in costs associated with palliative care (Centers for Medicare and Medicaid Services [CMS], 2016). If palliative care were fully integrated nationwide, a savings of \$6 billion per year would result (Healy, 2011). The magnitude of the number of people this affects is substantial. In 2013, there were 1.3 million palliative care patients in the US (CDC). The Medicare benefit introduced in 2014 allows patients with specific chronic illnesses to receive both palliative care and curative services and can be used by most older adults in the US (Cleary, 2016). The healthcare environment and potential economic benefit demand that we mitigate the problem of unidentified end-of-life patients by intervening early and planning appropriately.

The life expectancy of every person is variable, a fact that makes it hard to predict when a person's end of life is approaching. The National Institutes of Health (NIH; 2016) defines the end of life as the time when the goals of care transition from curative measures to comfort and quality of life. This transition requires a change in how healthcare is delivered to these patients. Determining how much time is left in a patient's life is part of the practice of medicine and the art of nursing. No definitive answer exists, but resources are available to help increase the accuracy of prediction. This accuracy is important when assisting patients in making plans for their future and determining the extent and type of beneficial healthcare interventions they need. Predictions based on science that are shared with patients can help to ease their anxiety, as well as improve the provider's ability to plan for their end-of-life care needs. Patient satisfaction is a vital measure of quality healthcare, and a major indicator of meaningful end-of-life care has been defined as the ability of the patient to die in their preferred place—at home or in a facility (Bowers, 2012). The identified reasons that patients do not die in their preferred place are these: a lack of discussion about their wishes, ineffective symptom control, and the inability of patients or caregivers to cope with the dying process alone (Bowers, 2012). To prevent this failure, we must intervene for the right patients at the right time. Early identification of patients at this point in the life spectrum is the first and most important step in the goal of improving end-of-life care interventions.

Problem Statement

Healthcare providers too infrequently use the Gold Standards Framework (GSF) and Prognostic Indicator Guidance (PIG) tool with surprise question to identify patients' palliative care needs in primary care settings due to a lack of knowledge of the screening tool's efficiency and effectiveness, which results in missed interventional opportunities for patients who qualify

for end-of-life care. Patients at the end of life and with chronic illness or multiple comorbidities would benefit from this intervention. This integrative review provided the information and evidence necessary to guide primary-care providers to effectively and efficiently identify patients appropriate for end-of-life care interventions.

Integrative Review of the Literature

A review of the literature was conducted using OVID, Cumulative Index of Nursing and Allied Health Literature (CINAHL), and Public Medline (PubMed), along with the Centers for Disease Control (CDC), Centers for Medicare and Medicaid Services (CMS), and the National Guidelines Clearinghouse. The search terms used were *gold standards framework*, *palliative care*, *end of life*, and *surprise question* and the results were limited to 2011–2017.

A total of 27 articles and two practice guidelines were selected for review and inclusion. Excluded were those articles that were not available in full text, were limited to children, conference aspects, or were focused on hospice patients already in end-of-life care, and those not available in English. Of those articles selected for inclusion there were two evidence based guidelines, seven qualitative analysis and descriptive studies, three cross sectional analysis studies, one systematic review, one structured review, two descriptive surveys, one retrospective descriptive exploratory study, one grounded theory study, one case study, one prevalent cohort study, one practice development guide, two cluster randomized controlled trials, one prospective longitudinal comparative study, one issue brief, one discussion paper, and one secondary analysis using data from a longitudinal observational study.

The John Hopkins Nursing Evidence-Based Practice tool was used to analyze the validity of the chosen research and the studies referenced are of IB, IIIB, and IVB values indicating that

these studies are of moderate strength and good quality and should be considered reliable when taken into consideration with each other, but not necessarily independently reliable.

Problems, Challenges, and Expectations

Many healthcare providers feel unprepared for the task of identifying patients in need of end-of-life care interventions (Jors et al., 2016). The process of identifying exactly when patients have reached the last year of their life and how to communicate that information to them and their families is difficult for many providers (Jors et al.). Those patients most readily identified at the end of life are cancer patients (Okon, 2015). When these patients have experienced treatment failure and/or refuse to continue treatment, we can safely say that they are approaching the end of life. These indications are not as easy for non-cancer patients, which serves as a challenge for many providers (Okon). Focusing on this gap in the healthcare cycle, gathering the necessary information for improvement and change, and disseminating it to those who need it is crucial for this very special population (Jors et al., 2016).

In addition to providers' valid concerns about the timing and accuracy of this conversation, we must acknowledge that patients and their families also have a variety of concerns to be addressed during this stressful discussion. Families are often given masses of medical information and data at one time (at diagnosis, times of change, or times of crises) that are substantial, in depth, and difficult to understand (Izumi & Son, 2016). It is necessary for medical providers and staff to state specifically that the end of the patient's life has approached (Izumi & Son). Providers and staff must sit down and discuss with patients in detail their preferences for the end-of-life transition and process (Izumi & Son). Without this discussion, families will often find themselves caught off guard at emergent times and be forced into making decisions that don't fall in line with their loved one's wishes (Izumi & Son). With proper

planning, this can be avoided and families can, as surrogates, experience less decision-making conflict and distress (Center to Advance Palliative Care [CAPC], 2016).

Most patients have preferences for how they want to be treated and how their affairs are settled (Aldridge et al., 2015; Karakari-Martin, McCann, Hebert, Haffer, & Phillips, 2012; World Health Assembly, 2014). Patients should have the opportunity to outline their wishes while the capacity to do so remains. The patient's perception of how their care is handled is of the utmost importance (Richards, Gardiner, Igleton, & Gott, 2014). Outlining a patient's prognosis and allowing them to plan activities within their disease trajectory gives them control of their remaining life and is a strategy beyond measure to ensure patient satisfaction (Richards et al.). A laid-out path and plan to address end-of-life care can prevent a trigger event in the patient's life that can lead to a rapid decline (Izumi & Son, 2016). This event may not appear as the "final straw," but it could be the beginning of the end and, without appropriate end-of-life care interventions, would lead to a series of very expensive emergency room visits, hospital admissions, doctors' visits, and increased caregiver stress (Izumi & Son). These moments of rapid health change often force families to make hasty emergent decisions that might not coincide with patient wishes, all of which could be avoided with prior end-of-life care discussions and planning (Izumi & Son).

It is important to keep in mind that addressing these issues at the time of initial diagnosis or with bad news is inappropriate (Richards et al., 2014). Allowing patients the time to grieve and come to terms with their situation while gently guiding them to make important end-of-life decisions is beneficial to successful end-of-life interventions (Richards et al.).

Patient care in all settings is driven by a high set of standards, legal guidelines, and moral obligations. End-of-life requires the very best care possible during this difficult time, keeping in

mind that this *time* could be anywhere from 24 hours to 6 months or more (Aldridge et al., 2015). Legal guidelines protecting the rights of the patient to autonomy and individual decision-making should be referenced carefully by providers (Brown & Vaughan, 2013).

Two evidence-based practice guidelines—*Palliative Care for Adults* and *End-of-Life Care During the Last Days and Hours*—provide information for direction and guidance of end of life (McCusker et al., 2013; RNAO, 2011). The authors of both guidelines stress the importance of early identification of patients who would benefit from end-of-life care interventions using clinical expertise, disease indicators, and validated tools. Communication between providers, patients, and caregivers is essential to address continuously changing physical, emotional, psychological, cultural, emotional, and spiritual needs of those involved (McCusker et al.; RNAO). Early intervention is recommended by both guidelines to allow patients to speak for themselves, vocalize their expectations, and set the limits for future situations. A patient's wishes must be documented legally through the creation of a Medical Order for Life-Sustaining Treatment (MOLST) and/or Physician Order for Life-Sustaining Treatment (POLST) to ensure clarity and decrease the risk of miscommunication (McCusker et al.; RNAO). Though these documents might have different titles in different states, each document is a necessary part of advanced care planning and should be completed for all patients with chronic illnesses and multiple comorbidities.

An early end-of-life discussion prevents loved ones from being forced to make emergent decisions later in the dying process without knowing what the patient would have chosen for him/herself (Izumi & Son, 2016). Great Britain and 13 other countries worldwide have found success using the Gold Standards Framework (GSF) and Prognostic Indicator Guidance (PIG) tool to identify patients at the end of life and provide thorough, competent, and effective end-of-

life care. The PIG tool provides easy identification of patients who are terminally ill with a prognosis of 12 months or less to live or in the downward decline of disease processes (CMS, 2016; O’Callaghan, Laking, Frey, Robinson, & Gott, 2014). The GSF and PIG will help prevent failures in care. The GSF has been accepted as best practice, and its use has been supported by providers in Great Britain (Laycock, 2011).

Two broad challenges exist in all end-of-life discussions: (a) difficulty predicting prognosis and (b) communicating with patients to plan care (Laycock, 2011). The GSF and PIG can assist with both challenges, and the introduction of these tools to primary care providers and staff is imperative to reaping their benefits. These tools give providers and staff access to powerful knowledge that when shared with patients can assist in making effective and efficient healthcare decisions.

Gold Standards Framework (GSF)

End-of-life care interventions should be driven by an established framework. The GSF has been found to be effective especially when used in conjunction with the PIG in identifying the opportunity for advanced care planning and implementing a systematic approach to addressing palliative care needs (Gunaratna & Limaye, 2014; O’Callaghan et al., 2014).

The GSF was developed by Kerri Thomas in 2000 to meet the needs of patients at the end of life, particularly to identify those who need care and to enhance the care they receive. Seven key tasks comprise the GSF: communication, coordination of care, control of symptoms and ongoing assessment, continuing support, continued learning, caregiver and family support, and care in the final days (National Gold Standards Framework Centre [NGSFC], 2011). The framework has been utilized in various inpatient, outpatient, short-, and long-term care settings throughout Great Britain and 13 other countries with the focus on successfully improving quality

of life for the patient (NGSFC). The seven tasks of the GSF guide patient care and interprofessional collaboration to meet healthcare goals. The GSF and PIG together provide a solution to the end-of-life care issues (NGSFC).

The GSF provides guidance to address identification, assessment, and planning for end-of-life care (Thomas, Walton, & GSF Team, 2011). Providers can use the guidance and direction given to address and work through this difficult process. While end of life is often a taboo topic that many providers shy away from, the GSF provides a thoughtful, thorough, and complete process for them. The PIG tool allows for easy identification of those patients who meet the criteria via a systematic review of their health status (Thomas et al.). The study of the GSF and PIG conducted by O'Callaghan et al. (2014) found that the effective, efficient use of the PIG in identifying those patients who needed intervention, coupled with the successful application of the framework in establishing their care, led to profound care improvement for this population.

Individuals assessed and identified as having end-of-life care needs early in the dying process are more likely to receive the necessary care to satisfy their needs and expectations (Aldridge et al., 2015; Karikari-Martin et al., 2012). Early identification can decrease the risk of late-stage emergent hospital admissions due to absence of a treatment plan. Kinley et al. (2014) found that implementation of the GSF in nursing homes substantially improved residents' end-of-life care. The GSF effectively decreased out-of-hours hospital admissions, allowing for patient's end-of-life wishes to be granted by their caregivers (Kinley et al.). Planned end-of-life care is key to helping patients have peaceful deaths with managed symptoms and the support of healthcare professionals. The healthcare industry needs to take these decision-making opportunities out of the hospital during acute crises, and move them into primary care settings for preventative planning and early intervention (World Health Assembly, 2014).

Healthcare providers need a solid understanding of end-of-life decision-making processes with chronic conditions and unpredictable disease trajectory (Izumi & Son, 2016). To fully appreciate the medical possibilities with chronic illness, it is important to ensure that the process includes end-of-life care planning (Glaudemans, Charante, & Willems, 2015). Providers and staff must initiate the discussion of end-of-life wishes to address the patient's priorities, beliefs, values, and choices regarding treatment in potential situations (particularly change in health status and end of life), and these discussions must be documented via a MOST (or other similar form based on geographic location). This should become the standard of care (Glaudemans et al.). The preferences and plans that are identified should be patient driven, but the conversation needs to be provider initiated (Laycock, 2011).

Early screening and identification of end-of-life care needs are critical to providing appropriate and timely interventions directed at the specific care level required by the patient and their family (Anderson et al., 2013). Patients with serious or life-threatening illnesses who received end-of-life care interventions reported improved physical and psychological symptoms, better quality of life, and better family caregiver well-being and preparedness (Anderson et al.). Timely referrals to palliative care increase a patient's quality of life by reducing suffering and distress for both patients and families (Torres, Lindstrom, Hannah, & Webb, 2016). A delay in referral to palliative care has been linked to the provider's continued lack of thorough and complete communication, explanation of prognosis, and avoidance of goal setting (Torres et al.).

Terminal patients desire all necessary information regarding their health and medical care to make educated decisions about their diagnosis and prognosis (Macpherson, Walshe, O'Donnell, & Vyas, 2013). Patients want more discussion with providers and staff, increasing their involvement in decisions about their treatment and plan of care (Macpherson et al.).

Patients desire advanced care planning as a repeated process that is revisited and revised as necessary, thereby preventing the creation of a one-time decision-making document (Macpherson et al.). People are continually changing, and it is imperative that we take this into consideration and understand that change can affect end-of-life care decisions.

Prognostic Indicator Guidance Tool (PIG)

The PIG tool is the crux of the GSF, and it begins with the provider asking the surprise question “Would you be surprised if this patient were to die in the next year?” (NGSFC, 2011). The next step is to assess for general indicators of decline and then to identify if the patient has specific clinical indicators of decline (NGSFC). This flow effectively guides assessment for decline of health and disease. The provider may initiate referral to palliative care based on the answers at the end of the process (NGSFC). The PIG outlines in detail the general and specific clinical decline indicators of various chronic illnesses and general degradation in health status (NGSFC). Without this identification to prompt for subsequent planning, there are often repeated emergency room visits and hospital admissions (Izumi & Son, 2016). The culmination of critical indicators of health decline should be maintained in the patient’s file, wherein continued reassessment and tracking of changes can provide the opportunity to review the patient’s wishes (MacPherson et al., 2013).

End-of-life care decisions are often difficult due to the unexpected trajectory from diagnosis to death (Izumi & Son, 2016). These decisions are dependent on the awareness of approaching death by the patients, families, and providers (Izumi & Son). In the Squire et al. (2016) study, 93% of providers felt that the surprise question is an appropriate trigger to identify those patients nearing the end of life. A correlation between actual health status and perceived health status in patients with life-limiting conditions has been discordant and led to a delay or

lack of end-of-life care planning (Cleary, 2016). The surprise question was discovered to be more predictive of patient death than cancer type, age, cancer stage, or time since diagnosis (Vick, Pertsch, Hutchings, Neville, & Bernacki, 2016). The surprise question is a very useful tool to initiate the systematic identification of patients at a high risk of death (Vick et al.).

To avoid missing the opportunity to make plans, end-of-life care discussions should be had early in the disease course (patient preference) not later (provider preference; Cleary, 2016). Using the PIG tool enables providers to identify if the patient is appropriate for end-of-life care interventions and to ensure that the right care is delivered at the right time (NGSFC, 2011). The PIG's detailed information helps to identify a patient's indicators exactly, which is very helpful to the tool's successful application. Each step aids the provider in making the best decision for their patient. This ability to prioritize needs among patients can help ensure that limited resources are applied first to those most in need (patients with years to live may not need palliative care as soon as those with days to live and, conversely, those with years left may need interventions before those with only days remaining). In the US, this care is not provided from a national health registry, but instead by either the patient's primary care provider or a palliative care/hospice team. As such, identification of appropriate timing is even more essential to ensure that patients are not lost in the shuffle or left without care. End-of-life care planning will help to ensure that patients endure less pain and other suffering, avoid readmissions, are subject to fewer nonbeneficial interventions, and receive treatment congruent with their wishes (CAPC, 2016).

The timing of the end-of-life conversation is imperative for its success. While providers should assess every patient's appropriateness for end-of-life care interventions, it is not always appropriate with every patient to initiate the conversation about death and dying (Hannon, Lester, & Campbell, 2012). Providers using the indicators found in the PIG tool will be able to

better identify those patients with whom the conversation can be had (Hannon et al.). Accurate identification of when the end-of-life conversation should be initiated is beneficial to providers and patients (Hannon et al.). Clinical examination and evaluation of conditions such as renal dysfunction, cardiac cachexia, escalating diuretic doses, recurrent episodes of decompensation despite optimally tolerated therapy, or changes in biochemical markers are all measurable triggers of end-of-life care discussions (Johnson & Gadoud, 2011). These measurable indications of decline in disease status prompt the provider to know that it is time to discuss end-of-life care preferences and wishes with patients and their families.

Fenning et al. (2012) compared results of the PIG tool and the Global Registry of Acute Coronary Events (GRACE) in identifying patients at the end of life, and found the PIG had 4% higher accuracy. When utilized in inpatient settings, the PIG was less effective (perhaps due to acute exacerbations of chronic illnesses), further emphasizing that the tool is best utilized in the primary care and other outpatient settings (Gardiner et al., 2013). Strout, Haydor, Han, and Bond (2015) discovered that when modified for a time frame of 30 days, the surprise question was a significant predictor of in-hospital mortality.

Moroni et al. (2014) detailed the outcome of general practitioners using the surprise question for their advanced cancer patients, and they found that the accuracy of survival prognosis correlated significantly with survival at 1 year. The surprise question is also useful for short survival (7 to 30 days) as well as the last year, but it has fewer false positives when used as intended for longer time durations (Hamano et al., 2015). And the simplicity of using the surprise question makes it a very important tool for predicting end of life (Strout et al., 2015).

State-Required Advanced Care Planning Tools

The DNP student created an algorithm to guide provider and staff decisions regarding patient status during visits. This algorithm helps to identify the appropriate time to facilitate advanced care planning and end-of-life care discussions. For the state of Texas (where this project was conducted), the Medical Order for Scope of Treatment (MOST) is the accepted and legal documentation of a patient's wishes regarding end-of-life care, spanning a wide scope of issues that include resuscitation, nutrition, and care needs. Each state has a different form that is required, although the name of the document is not always the same. The MOST is part of the resource packet as an imperative part of planning for end-of-life care (advanced care planning).

Specialty Population Tools

Also included in the resource packet are three specialty population tools that are valuable for providers and staff regarding end-of-life care. They are tools adjunct to the algorithm and screening tool, which many providers find beneficial when dealing with elderly patients who are without specific comorbidities as listed in the screening tool, or for patients who have been on palliative care services in the past.

The Eastern Cooperative Oncology Group (ECOG) Performance Status and the Karnofsky Performance Scale (KPS) are two tools used primarily in the oncology world as standard criteria to measure how the disease is impacting a patient's daily living abilities (ECOG-ACRIN, 2016). They are both used to measure a patient's level of functioning in terms of ability to care for themselves, daily activity, and physical ability to guide planning for treatment and changes in treatment and care (ECOG-ACRIN).

The Palliative Performance Status (design and copyright by Victoria Hospice Society) is an 11-point scale designed to measure patient's performance status based on five observable

parameters (Victoria Hospice, 2017). The five parameters are ambulation, ability to do activities, self-care, food and fluid intake, and consciousness level. This tool is for those patients who are currently receiving palliative care or hospice services. As a patient's health status changes, the appropriateness of these services can also change, making it possible for a patient to be on and off palliative and hospice services.

The final special population tool is the Adelaide Activities Profile. This tool is used as a measurement of the lifestyle activities of the elderly in the four domains of domestic chores, household maintenance, service to others, and social activities (Clark & Bond, 1995). This tool was included to help gauge levels of more active elderly patients beyond those of the other tools, an assessment that can be completed by the patients themselves. The insight derived from this assessment could be beneficial to providers and staff.

Provider Benefits

Some providers, after spending their lives and careers devoted to preventative and curative patient care, tend to feel that screening and implementation of end-of-life care translates to giving up hope and admitting defeat (Torres, Lindstrom, Hannah, & Webb, 2016). On the contrary, those providers who are actively using the GSF to provide patient care and have administrative support from their facilities produce the best outcomes (Kinley et al., 2014). Active engagement, education, and use of the GSF enable practices to provide effective and desired end-of-life outcomes for their patients (Kinley et al.).

The GSF is effective in guiding care for the end of life to help patients, caregivers, and families manage the dying process (Kinley et al., 2014; Nash & Fitzpatrick, 2015). All programs have limitations, and multiple studies have revealed that consistent education, support, and implementation for staff is imperative to success with the GSF (Kinley et al.; Nash &

Fitzpatrick). Adopting the GSF but not actively educating, reinforcing, and adapting the framework as needed to fit individual circumstances is a waste of time and a great disservice to staff and patients. Those health systems that implement the GSF without continuing support and education find its effectiveness declines quickly, and with it patient care (Kinley et al.; Nash & Fitzpatrick). Successful implementation of process changes must align with the current needs and values of patients and providers, be easy to use, and produce observable positive results (Torres et al., 2016).

Badger et al. (2010) discovered that in nursing homes using the GSF, the communication between nurses, physicians, and specialists is more enhanced and open than in those not using the framework. The interactive work environment, common goals, and collaboration ensure a positive environment for providers and patients. The improved communication enhances the relationship between primary care providers and individuals providing the day-to-day care (Badger et al.). Providing care during this complex time in the life cycle is not easy and can be emotional and taxing on staff.

All people could benefit from healthcare interventions at some point in their life. The need and demands for healthcare often exceed the availability and sometimes ability of providers. To meet this need, providers and staff must step up and work harder, find innovative solutions, and increase their efforts to meet the various needs of a diverse patient population. The GSF and PIG tool fill this call for extra efforts. The increased workloads for those providers and staff using the GSF and PIG for the improved communication, coordination, and documentation is worth the improved care outcomes (Walshe, Caress, Chew-Graham, & Todd, 2008). This increased workload allows us to satisfy the requirements of dying patients and their families. Staff will need to be educated on how to use the GSF and PIG tool and have access to the

available resources. This increase in workload for providers and staff is for a good reason and with proper evidence and education, providers and staff will go the extra mile.

Theoretical Framework

Theory-guided practice gives direction for nursing care and patient interactions (Zaccagnini & White, 2011). Kurt Lewin's theory of change (Appendix A) is most applicable to the intent of the DNP project. Lewin's change theory occurs in three stages: unfreezing, change, and refreezing (Lewin, 1951). For the theory to be successful, we must look at the driving and restraining forces that have an impact on the ability for change to happen. Focusing on practice effects alone does not bridge the science-to-practice gap in changes in healthcare (Manchester et al., 2014). Regarding early identification of patients appropriate for end-of-life care interventions, the healthcare industry is moving further toward ensuring that we are providing exceptional care and utilizing resources available for these patients. The use of the surprise question is becoming more commonplace in inpatient settings, and the drive to move this screening intervention to the primary care setting is increasing rapidly. The need to improve patient care at the end of life is the driving force behind the need for this change in practice; however, providers identify limited appointment times and lack of an effective and efficient screening tool as the restraining forces preventing this change. The DNP project provided education and knowledge enhancement to further build the driving forces, and provided a resource packet with an easy-to-use algorithm and screening tool to counter the restraining forces. With the appropriate patients and integration of the resource packet, the change in screening for end-of-life care interventions by primary care providers and staff will benefit our healthcare population. Through education and resources, we can create driving forces to overcome the restraining forces, thereby causing an unfreezing in how providers practice,

facilitate a change, and refreeze the results for improved patient care and experiences. The use of Lewin's change model by education evaluators and organizational planners can assist in the preparation, planning, and execution of this change (Manchester et al.).

Goals, Objectives, and Expected Outcomes

The overarching goal of the DNP project was to improve provider and staff knowledge regarding the GSF, the PIG tool, surprise question, and end-of-life screening in primary care through the creation of a PowerPoint presentation and resource packet. The additional goals included completion of an integrative review of the most up-to-date and salient findings of the same material. After completing the integrative review, the goals were to create a resource packet and PowerPoint presentation for providers and staff. Following the creation of these products, the goal was to present the PowerPoint and resource packet to providers and staff and to evaluate for an increase in knowledge regarding the GSF, PIG, surprise question and end-of-life screening.

Table 1

Goals, Objectives, and Expected Outcomes

Goals	Objectives	Expected Outcomes
1. Complete integrative review.	Appropriately search, select, review, and analyze available studies, evidence, research, and data regarding GSF, PIG, surprise question, and end-of-life screening.	Integrative review successfully completed based on objectives with best available evidence-based practice guidelines and available research synthesized for support of providers and staff in end-of-life screening.
2. Create Resource Packet for providers and staff based on relevant findings from integrative review.	Creation of resource packet based on available information and research from integrative review findings. Resource packet tailored to Dallas, Texas	End-of-life screening resource packet created and all objectives met.

	area for chosen clinic (can be adapted for any geographic location).	
3. Create PowerPoint presentation for providers and staff.	Creation of PowerPoint presentation providing education regarding the integrative review and exploring the resource packet for provider and staff use.	PowerPoint presentation created with resource packet embedded within presentation. Softcopy created for distribution to providers and staff.
4. Pre-presentation survey for provider and staff knowledge assessment prior to presentation.	All participants participate in pre-presentation survey.	100% of providers and staff in attendance participated in pre-presentation survey to establish baseline knowledge assessment.
5. Present PowerPoint and distribute resource packet to providers and staff at primary care clinic.	Coordinate presentation with practice manager. Present PowerPoint with embedded resource packet to providers and staff of primary care clinic. Effective explanation and summarization of integrative review and resource packet. Effective articulation of best use of resource packet and review of resources available for patients and providers. Effective demonstration of use of resource packet by providers and staff.	Presentation coordinated and met all objectives. Resource packet distributed to providers and staff.
6. Administer post-presentation evaluation survey and evaluate effectiveness of educational presentation and value of resource packet based on response from survey.	All participants will complete post-presentation survey.	The presentation increased provider and staff knowledge regarding the GSF, PIG, surprise question, and end-of-life screening in primary care by 100%. The resource packet was evaluated as a beneficial improvement and usable resource to increase end-of-life care screening.

Project Designs and Methods

The Doctor of Nursing Practice (DNP) quality improvement project incorporated an integrative review process investigating the GSF, the creation of an algorithm, and an adapted version of the PIG tool with surprise question into a presentation and resource packet. The DNP student used both qualitative (informal focus groups) and quantitative (surveys) methods for data collection and analysis resulting in successful completion of set goals and objectives.

Population, Settings, and Resources

The primary care providers and staff were in a large primary care clinic in Dallas, Texas. Dallas has an estimated population of 1.3 million with 8.8% of persons 65 and older in age (United States Census Bureau, 2016). Per the 2014 American Community Survey Results, 24% of the population is living below poverty level (City of Dallas, 2016). The CDC (2012) reports that in 2011 both the national average and the state of Texas use of hospice care was 28 patients per 1,000 persons aged 65 and older. This primary care clinic sees many patients each year with a total of 40 providers. Exact numbers were not available to the DNP student.

Facilitators and Barriers

The project setting has recently moved to a larger facility and will be expanding their provider base and patient population. The providers and staff were all very supportive and open to discussion and participation with the DNP student; however, the nature of end-of-life screening prevented this DNP project from being implemented as it cannot be predicted when or if patients are appropriate or willing to participate. Given the timelines available and the delicate nature of palliative care, the project should be considered part of the preparation for a larger long-term project to improve end-of-life screening.

Presentation and Resource Packet Implementation Plan Summary

An integrative review was completed regarding the GSF, PIG tool, surprise question, and end-of-life screening in primary care. After completion, a resource packet was created based on the findings of the integrative review. The GSF and PIG had been found as best practice for end-of-life screening in primary care. Due to the nature of the healthcare system as discussed previously, an adapted version of the PIG was created and included in the resource packet. An algorithm was developed by the DNP student to guide the decision-making process for providers and staff. As a new provider, the DNP student could identify resources and tools that would be most beneficial for providers who are not comfortable with initiating the subject or are not routinely screening patients for end-of-life care interventions.

Resource Packet Development

The DNP student created a resource packet (Appendix B) for providers and staff. The table of contents includes hyperlinks allowing for easy navigation through the entire packet. Each section begins with a title page and a quick link to take users back to the table of contents at the touch of a button. The packet includes an overview of the GSF, background and statistics regarding the issues surrounding end-of-life care, an algorithm created by the DNP student to guide decision-making (with hyperlinks to necessary resources within the packet), the adapted screening tool, and a plethora of resources for providers, staff, and patients. Also included in the packet are the evidence-based practice guideline and research supporting the efficacy and efficiency of the GSF, PIG, and surprise question.

Presentation

A presentation utilizing PowerPoint slides (Appendix C) was developed by the DNP student as an overview of the integrative review with a thorough explanation of the DNP project

and reason for the creation of the resource packet. This was presented to providers and staff for review and knowledge improvement. The resource packet was embedded into the PowerPoint presentation to allow for easy transition during the presentation. A complete explanation and example of using the resource packet was utilized during the presentation to allow providers and staff to see the utility of the resource packet firsthand.

Evaluation

Prior to the presentation, a survey was conducted asking attendants if they had ever heard of the GSF, PIG tool, or surprise question (Appendix D). Attendants were also asked if they screened routinely for end-of-life care intervention appropriateness and the reasons they did or did not screen. A six-question survey (Appendix E) was dispersed post-presentation for completion by the attendants, and a focus group was conducted with the four nurse practitioners in attendance.

Outcomes/Interpretation

Prior to presentation of the DNP project, six goals and expected outcomes were identified (see Goals, Objectives, and Expected outcomes section). Below are the same goals with discussion of the DNP project's actual outcomes and interpretation of those outcomes. The goals were met and the project was a success and stands to serve as the first step in a larger project that could be completed to further facilitate improvement in this area of healthcare.

1. Complete integrative review. The first goal of the DNP project was to complete an integrative review of the most up-to-date and salient findings regarding the GSF, PIG tool, surprise question, and end-of-life screening in primary care settings. The DNP student completed this goal, and the review is culminated in this paper.

2. Create resource packet for providers and staff based on relevant findings from integrative review. The second goal was the creation of a resource packet for providers and staff based on relevant findings from the integrative review. The resource packet provided an easy-to-use and intuitive one-stop shop for end-of-life care screening and available resources for patients and providers. The resource packet was provided electronically to the participants for their use after the completion of the DNP project.

3. Create PowerPoint presentation for providers and staff. The third goal was the creation of a PowerPoint presentation for providers and staff to share the findings of the integrative review. The PowerPoint and verbal presentation served to educate providers and staff on the salient findings of the integrative review and the best way to utilize the resource packet and associated tools and information. This presentation provided the DNP student with an opportunity to educate the providers and staff on the GSF, PIG, surprise question, and the importance of early identification of patients appropriate for end-of-life care interventions.

4. Pre-presentation survey for provider and staff knowledge assessment prior to presentation. The fourth goal was a pre-presentation survey to assess provider and staff knowledge prior to the presentation. The survey provided the DNP student an opportunity to assess the baseline knowledge of the participants regarding the GSF, PIG, surprise question, and end-of-life screening in primary care. The pre-presentation survey indicated all 15 members in attendance were interested in learning more about palliative care screening. The respondents were not aware of any one-stop place they could access to gather all the necessary tools and information regarding end-of-life screening. Additionally, only one of the nurse practitioners in attendance felt confident that she knew when to refer patients to palliative care, and the other 14

individuals in attendance were not sure of the best/appropriate time or clinical indications for referral.

5. Present PowerPoint and distribute resource packet to providers and staff at primary care clinic. The fifth goal was to present the PowerPoint and verbal presentation and distribute the resource packet to providers and staff at a primary care clinic. The presentation provided an opportunity for the DNP student to share all findings from the integrative review and demonstrate the use of the resource packet. The packet was thoroughly explained and a demonstration was provided by the DNP student, who elaborated on how to use the packet and its full capabilities (hyperlinks to resources, websites, and further information). Additionally, the presentation created an opportunity for providers and staff to ask any questions they may have had and to make any suggestions for improvement and provide feedback regarding the resource packet and integrative review information.

6. Administer post-presentation evaluation survey and evaluate effectiveness of educational presentation and value of resource packet based on response from survey. The sixth and final goal for the DNP project was the administration of a post-presentation evaluation survey. The survey was created to determine the effectiveness of the educational presentation and the value and ability to use the resource packet in primary care. The survey also allowed for participants to provide feedback regarding the project, the presentation, or the resource packet. Post-presentation survey results indicated that 11 of the 15 respondents felt that the resource packet was an excellent all-inclusive resource to find everything they needed to provide end-of-life care screening measures. Post-presentation survey results indicated all 11 of the respondents felt confident they could use the resource packet, associated algorithm, and screening tool to help identify those patients appropriate for end-of-life care interventions. All 11 respondents felt that

the resource packet was a great idea and a valuable resource for providers and staff. The five nurse practitioners in attendance said they would consider using the resource packet with the right patient population but that they felt a shortened version of the packet would be beneficial for experienced providers. As such, the DNP student created an abbreviated provider handout (Appendix G) consisting of the primary pieces of the resource packet (algorithm, screening tool, resource list).

Discussion

This DNP project provided a succinct and abbreviated collection of data from the integrative review, a useful algorithm for identifying when to screen patients in primary care, and an adapted screening tool for identifying patients at the end of life. A PowerPoint presentation and a resource packet with all the above data were given to providers and staff at a primary care clinic in Dallas, Texas. The results of that presentation culminated in the addition of an abbreviated provider handout for experienced providers and the satisfactory feedback regarding the excellent resource packet and its applicability for new providers and staff or those who need more information. Providers and staff agreed that given the opportunity (via an appropriate patient) they would use the algorithm and screening tool to facilitate identification and tracking of palliative care needs. All respondents agreed that the easy access of available resources provided in the resource packet will allow for easy referral and information gathering by staff and providers. Management in attendance were thankful for the resources provided and admitted to not knowing so many avenues were available for patients and providers.

Ethics and Human Subjects Protection

The University of Massachusetts Amherst Internal Review Board (IRB) approval was obtained prior to initiating the DNP project (Appendix F). This presentation and resource packet

increased provider and staff knowledge of end-of-life care screening and available resources. The project did not require any interaction with patients, patient records, or patient families. Evaluation surveys were collected from the respondents with the responses aggregated and confidentiality maintained.

Conclusion

Mother Nature dictates that as humans we cannot live forever. Science has given healthcare providers the ability to improve quality of life for patients who seek medical care. As providers in the healthcare industry, we have an obligation to help provide the best care possible and the best quality of life possible for our patients to live out their last years as they desire. As primary care providers, giving patients a voice in how they will live out their final days while they have the capacity to do so is the best intervention we can produce. The DNP student created, presented, and evaluated an educational PowerPoint presentation and resource packet that included an easy-to-follow interactive algorithm with adapted screening tool, state-mandated advance care planning forms, and special population screening tools in addition to various resources for providers and patients. Providing easy-to-use tools to facilitate end-of-life screening in primary care is the first step in a larger process to improve end-of-life care for all patients. Identification of those patients who meet the requirements for end-of-life care interventions will provide the starting point to improving end-of-life care for all patients driven by the providers who know them best—their primary care providers.

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Appendix A
Lewin's Change Theory

Kurt Lewin Change Model



Figure 1: Lewin's Model for Change, adapted from Lewin, 1951.

Appendix B
Resource Packet

IDENTIFYING PATIENTS AT THE END OF LIFE

Resource Packet

Designed and shared to distribute information and resources to effectively and efficiently screen patients for end of life care interventions by primary care providers and staff.

For Primary Care Providers and Staff

Primary care involves patients from conception to death.

**Embrace it,
Plan for it.**

*Life and death are but phases of the same things. ...
Death is as necessary for Man's growth as life itself.
-Mahatma Gandhi*

Early end of life conversations and advance care planning are necessary for all patients.



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Disclaimer: The End of Life Resource Packet was created by Melissa Ellis, DNPc. Components of the resource packet were created by authors as cited, other sources are documented, authored works of public record.

Introduction

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Advanced Care Planning

Advanced care planning should include discussing a patient's code status (would they want to be resuscitated in the event that their heart stops, would they want to be intubated in the event they become unable to breath on their own, would they want to be given nutrition artificially in the event they became unable to eat or drink, as well as the necessity for Advanced Directives, Living Wills, Medical Power of Attorney, and documentation of those wishes with their primary care provider, family, and if necessary, an attorney. The state of Texas accomplishes a large portion of this planning via a Medical Order for Scope of Treatment (MOST).

Guidance

This resource packet will provide easy access to tools and resources for provider and staff. While it cannot be all encompassing to meet every provider's needs, it has information and resources to various places in which further information and guidance can be obtained. Please see the reference list for all resources used in the creation of this resource packet. Additionally, there are hyperlinks used throughout the resource packet to make it easier to use and navigate.

Development and Purpose

This resource packet was created as a Doctorate of Nursing Practice Family Nurse Practitioner Capstone project with the intent to take evidenced based practice information and resources for implementation into practice for the purpose of improving patient care and filling an identified gap. Routine screening of patients for end of life care interventions is not routinely done in primary care settings. The culmination of an integrative review on the Gold Standards Framework and associated Prognostic Indicator Guidance tool led to the adaptation and development of this resource packet.

Special Thanks and Consideration

My sincerest gratitude to my husband and three children, who tirelessly survived on take-out food, a messy house, and limited quality time so that I could truly dedicate myself to this project. A special thanks to my husband for my being my rock and support, thank you for never giving up on me (and for picking up the slack while I finished school). A heartfelt thank you to the rest of my family and friends who understood that I while I focused on school they remained loved and important.

My gratitude and immeasurable thanks to my advisor, chair, and cheerleader Dr. Jean DeMartinis for never giving up on me, for truly teaching me to *trust the process*. Thank you to Dr. Terri Black for your input, ideas, patience, and efforts to make this project successful. And a great big thank you to Dr. Pamela Aselton for always having my back and for your endless efforts with Dr. D ensuring we could all contribute to our profession, hold our heads high, and graduate, I have faith we will all make you proud.

-Melissa A. Ellis, DNPc, BSN-RN



Background

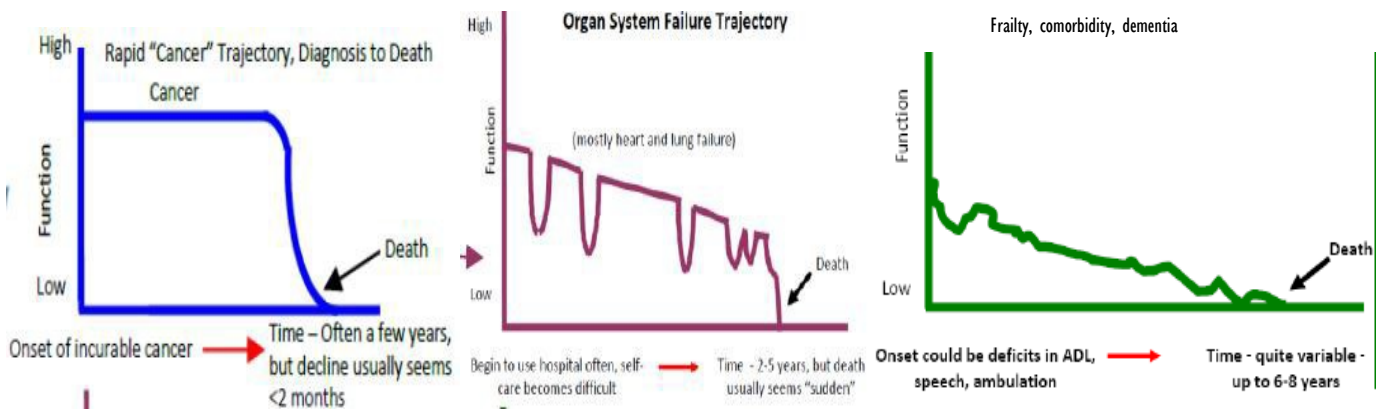
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- Primary care providers are ideal to implement end of life care discussion.
- The answers to when and why a person dies cannot always be manipulated, but sometimes we can address and plan for how and where a person dies.
- Initiating advance care planning discussions to benefit the patient and their family, and to assist the provider to facilitate end of life wishes can be standard practice.




- End of life care discussions are necessary for all patients. Chronic illness disease trajectories and comorbidities increase the appropriateness of palliative care interventions at the end of life for cancer and non-cancer patients alike.

Varying Disease Trajectories



- Focusing these conversations on how to improve end of life for the patient and elaborating on what care they want provided and how it will be provided, will ensure quality care for their passing.
- Patients should choose where they will spend their final days and have control over symptom management.
- Making these wishes known well beforehand increases compliance.

"End of life decisions should not be made at the end of life."

@AtCase.org

Statistics

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Statistics

People

- About 1% of the population dies each year and many of those are seen by a primary care provider in their last year of life
- In 2012, the national and Texas state average use of hospice care was 28 patients per 1,000 persons aged 65 and older.
- In 2013, there were 1.3 million hospice patients in the US.

Economics

- In 2009, Medicare alone spent \$12.1 billion on hospice care.
- In 2013, there were 4,000 hospice agencies in Texas.

Patient Care

- In 2016, the Veteran's Administration and Medicare both made advance care planning a mandatory part of annual wellness visits and added a requirement for advance care planning (beginning with the surprise question).
- End of life is considered to be the last 24 hours to one year of a person's life.
- The top 12 non-cancer diagnosis in hospice care for 1998-2009: Parkinson's Disease, Alzheimer Disease, Non-Alzheimer Dementia, Non-infectious respiratory diseases, Heart disease, Congestive Heart Failure, Failure to thrive, Debility, Pneumonias, Cerebral Vascular Accident/Stroke, Chronic liver disease, and Chronic kidney disease.

Evidence Based Guidelines at a Glance

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Evidence Based Guideline at a Glance

Guideline summary: Palliative care for adults.

In: National Guideline Clearinghouse (NGC) [Web site]. Rockville (MD): Agency for Healthcare Research and Quality (AHRQ); 2013 Nov 01. [cited 2017 Feb 15]. Available: <https://www.guideline.gov>

Major recommendations:

- Educate providers on philosophy and structure of palliative care
- Increase identification of patients in the early stages of serious illness who would benefit from palliative care
- Improve effectiveness and comfort level of primary care providers in communicating necessity and benefits of palliative care with patients who have a serious illness
- Improve percentage of patients identified in early stages of serious illness who have a care plan identified and/or documented
- Improve ongoing reassessment and adjustment of patient's care plan as condition warrants
- Increase completion of documentation and ongoing utilization of advance directives for patients with serious illness

National Guideline Clearinghouse (NGC) Guideline: Caring for dying adults in the last days of life.

****this guideline is not addressed in this integrative review and only referenced in the resource packet as the goal is to intervene appropriately before this late in the life continuum**.**

Integrative Review Findings

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Integrative Review Findings

The integrative review revealed exceptionally positive results from the use of the Gold Standards Framework (GSF) and the Prognostic Indicator Guidance (PIG) tool in the United Kingdom and several other countries with socialized healthcare systems. The United States does not have a healthcare system that would support the design of the GSF, however the research and positive effects of the PIG tool is applicable. Its efficacy is applicable to all patients with chronic illness or multiple comorbidities and can be efficiently used in primary care settings to initiate the process of advanced care planning and facilitate a roadmap for disease trajectory, palliative care interventions, and open discussion between patients and providers/staff.

Research and continued follow up from the Gold Standards Framework Centre found that use of the Prognostic Indicator Guidance (PIG) tool continually increased the number of patients identified as being in the last year of life which allowed for early interventions to improved quality of end of life care for their patients. Providers and staff who routinely use the PIG are able to provide better continuum of care for their patients, are more engaged in patient care, have better patient quality survey outcomes, and have improved end of life care experiences reported by patients and their loved ones.

There are additional tools that can be used effectively for cancer or geriatric patients, however the Prognostic Indicator Guidance (PIG) tool is the only tool found to be applicable to all patients. The cornerstone of the PIG is the surprise question “would you be surprised if this patient died in the next year?”. If your answer is no, then that should be the indication that an intervention is necessary.

Providers and staff were found to be uncomfortable initiating end of life care conversations out of fear of taking hope away from the patient, being unsure where to start, and simply not having enough time. The facts are that every patient is somewhere in the dying process and it is the providers who have the best opportunity to not say “you are dying in so many days/months” but to say, “here is the trajectory of your illness and the anticipated effects, let’s talk about how you want to handle this process, what your wishes are when things become advanced, and here is some very helpful information”. **Providers are the gateway to access care beyond our local pharmacy, serving as an effective gatekeeper while maintaining the watch over disease progression is an immeasurable responsibility and one that can be made a bit easier with the right tools and resources.**

Online Resources

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Resources

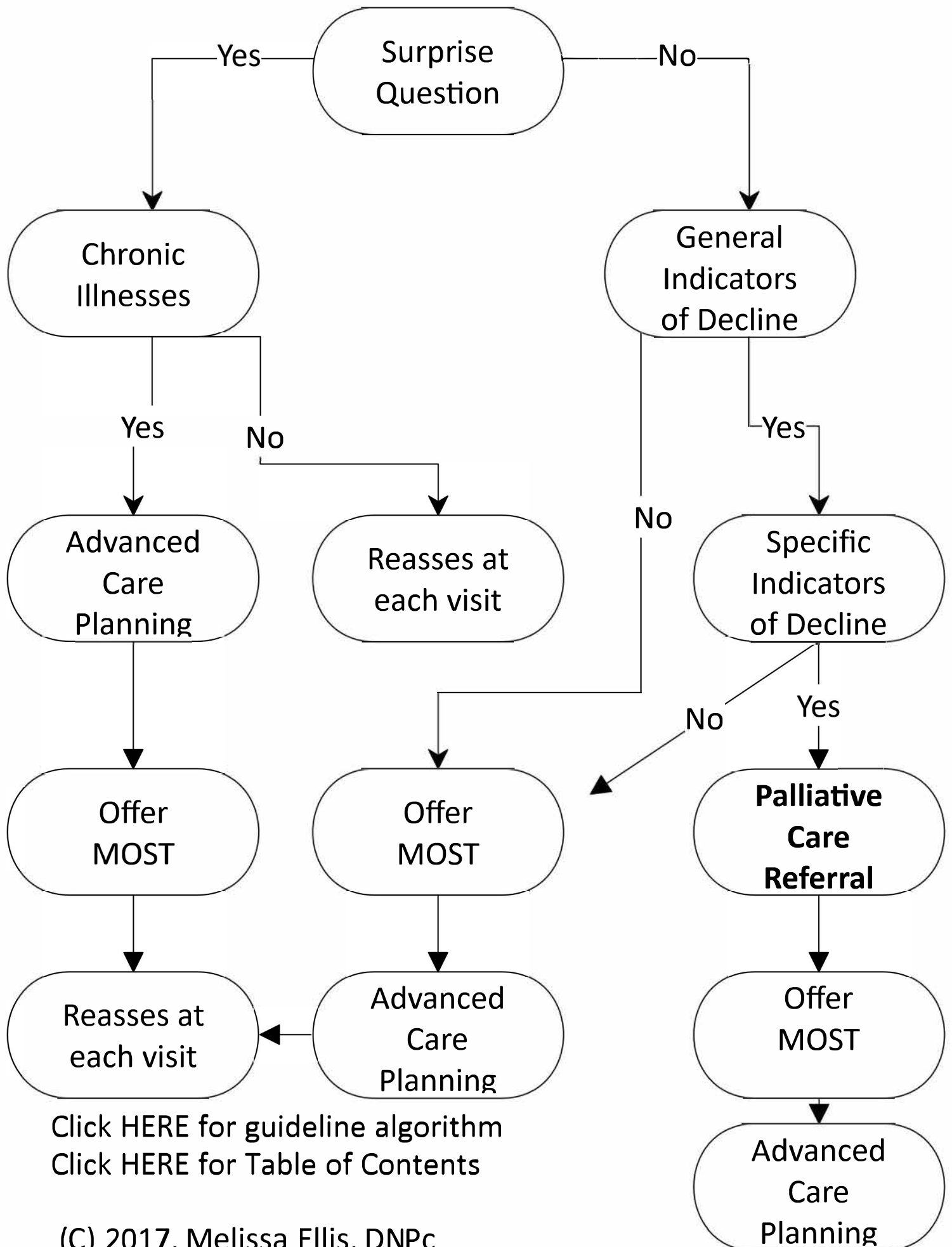
Gold Standards Framework Centre.....www.goldstandardsframework.org.uk
Center to Advance Palliative Care.....www.capc.org
Agency for Healthcare Research and Quality.....www.ahrq.gov
American Academy of Hospice and Palliative Medicine.....www.aahpm.org
American Hospital Association.....www.aha.org
Compassion and Support.....www.compassionandsupport.org
Education on Palliative and End of Life Care.....www.epec.net
National Consensus Project for Quality Palliative Care.....Click [HERE](#)
The Joint Commission.....www.jointcomission.org
Vitaltalk.....www.vitaltalk.org
National Hospice and Palliative Care Organization.....www.nhpco.org
Get Palliative Care.....www.getpalliativecare.org
Hospice Action Network.....www.hospiceactionnetwork.org
Centers for Medicare and Medicaid.....www.cms.gov
Texas and New Mexico Hospice Organizations.....www.txnmhospice.org
North Texas Respecting Choices.....www.northtexasrespectingchoices.com
Texas Academy of Palliative Medicine.....www.tapm.org
Care Planning Council of Texas.....www.caretexas.net
North Texas Veterans Administration.....www.northtexas.va.gov/services/hospice.asp
Dallas Area Chapter of Hospice and Palliative Care Nurses Association.....Click [HERE](#)
Palliative Care for Adults Guideline.....Click [HERE](#)
Baylor Scott & White Palliative Care.....Click [HERE](#)
Methodist Health System Palliative Care.....Click [HERE](#)
UT Southwestern Medical Center Palliative Care.....Click [HERE](#)
Texas Health Presbyterian Palliative and Hospice Services.....Click [HERE](#)
Care of Dying Adults in the Last Days Guideline.....Click [HERE](#)

Algorithm for Early Screening

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End of Life Care Screening Algorithm



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Screening Tool

Adapted from Gold Standards
Framework Prognostic Indicator
Guidance Tool.

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Thomas, K. (2011). Prognostic Indicator
Guidance, 4th Edition. The Gold
Standards Framework Centre In End of
Life Care CIC.

Screening Tool

Guidance for providers and staff to facilitate earlier identification of patients nearing the end of life who could benefit from a hospice palliative care approach

Why is it important to identify people nearing the end of life?

About 1% of the population dies each year. Although some deaths are unexpected, many more in fact can be predicted. This is inherently difficult, but if we were better able to predict people in the final year of life, whatever their diagnosis, there is good evidence that they are more likely to receive well-coordinated, high quality care.

This Screening Tool aims to help primary care providers and staff in earlier identification of those patients nearing the end of life who could benefit from a hospice palliative care approach to care.

The tool has been adapted from the Gold Standards Framework (GSF) Prognostic Indicator Guidance¹ tool developed by the GSF Centre in the UK. The UK has been using the tool along with a comprehensive education program to support providers and staff in various setting in identifying patients and placing them on a register to help trigger specific support.

Three steps that indicate patients could benefit from a hospice palliative care approach

1. **The Surprise Question: 'Would you be surprised if the patient were to die in the next year?'**
 - ****this is often the most important indicator! Trust your instinct. ****
2. **General indicators of decline: deterioration, advanced disease, decreased response to treatment, choice for no further disease modifying treatment.**
3. **Specific clinical indicators related to certain conditions.**

Definition of Hospice Palliative Care³

Hospice palliative care is a philosophy of care that aims to relieve suffering and improve the quality of living and dying. It strives to help individuals and families to:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears;
- prepare for and manage self-determined life closure and the dying process;
- cope with loss and grief during the illness and bereavement;
- treat all active issues;
- prevent new issues from occurring;
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

1. Thomas.K et al. *Prognostic Indicator Guidance, 4th Edition*. The Gold Standards Framework Centre In End of Life Care CIC, 2011.

Screening Tool

Guidance for providers and staff to facilitate earlier identification of patients nearing the end of life who could benefit from a hospice palliative care approach

More details of indicators – the intuitive surprise question, general decline and specific clinical

The Surprise Question

For patients with progressive life-limiting illness – Would you be surprised if the patient were to die in the next year?

The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

General Indicators of Decline

Are there general indicators of decline and increasing needs?

- Advancing disease – unstable, deteriorating complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Choice of no further disease modifying treatment
- General physical decline
- Declining functional performance status (e.g. Palliative Performance Scale⁴(PPS) ≤ 60 , reduced ambulation, increasing dependence in most activities of daily living)
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- Weight loss - >10% in past six months
- Repeated unplanned/crisis hospital admissions
- Sentinel event, e.g. serious fall, bereavement, retirement on medical grounds
- Serum albumin <25g/l

Specific Clinical Indicators

Flexible criteria with some overlaps, especially with those with frailty or other co-morbidities

a. Cancer - rapid or predictable decline

- Metastatic cancer
- More exact predictors for cancer patients are available e.g. PPS, ECOG
- The single most important predictive factor in cancer is performance status and functional ability - if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less

b. Organ failure - erratic decline

- | | |
|---|---|
| Lung Disease (COPD) (at least 2) | <ul style="list-style-type: none">• Disease assessed to be very severe (e.g. FEV1 <30% predicted⁵)• Recurrent hospital admissions (≥ 3 in last 12 months due to COPD)• Fulfills long term oxygen therapy criteria• MRC grade 4 to 5 – dyspnea after 100m on the level or confined to house• Signs and symptoms of right heart failure• More than 6 weeks of systemic steroids for COPD in preceding 6 months |
| Heart Disease (CHF) (at least 2) | <ul style="list-style-type: none">• CHF NYHA Stage 3 or 4 - shortness of breath at rest on minimal exertion• Repeated hospital admissions with heart failure symptoms• Difficult physical or psychological symptoms despite optimal tolerated therapy |

1. Thomas.K et al. *Prognostic Indicator Guidance, 4th Edition*. The Gold Standards Framework Centre In End of Life Care CIC, 2011.

Screening Tool

Guidance for providers and staff to facilitate earlier identification of patients nearing the end of life who could benefit from a hospice palliative care approach

Renal Disease (CKD)	Stage 4/5 Chronic Kidney Disease (CKD) with deterioration plus 2 of these: <ul style="list-style-type: none">• Patients choosing the 'no dialysis' option or discontinuing dialysis (by choice or due to increasing frailty, co-morbidities)• Patients with difficult physical/psychological symptoms despite optimal tolerated renal replacement therapy• Symptomatic Renal Failure – nausea/vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload
Liver Disease	<ul style="list-style-type: none">• Advanced cirrhosis with one or more complications in past year:<ul style="list-style-type: none">• diuretic resistant ascites, hepatic encephalopathy, hepatorenal syndrome, recurrent variceal bleeds⁶• Liver transplant contraindicated⁶• Child-Pugh Class C
Neurological Diseases	<p>General</p> <ul style="list-style-type: none">• Progressive deterioration in physical/cognitive function despite therapy• Symptoms which are complex and too difficult to control• Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure• Speech problems: increasing difficulty in communications and progressive dysphasia <p>Motor Neuron</p> <ul style="list-style-type: none">• Marked rapid decline in physical status• First episode of aspirational pneumonia• Increased cognitive difficulties• Weight Loss• Significant complex symptoms and medical complications• Low vital capacity (below 70% of predicted using standard spirometry)• Dyskinesia, mobility problems and falls• Communication difficulties <p>Parkinson's</p> <ul style="list-style-type: none">• Drug treatment less effective or increasingly complex regime of drug treatments• Reduced independence, needs ADL help• The condition is less well controlled with increasing "off" periods• Dyskinesias, mobility problems and falls• Psychiatric signs (depression, anxiety, hallucinations, psychosis)• Similar pattern to frailty- see below <p>Multiple Sclerosis</p> <ul style="list-style-type: none">• Significant complex symptoms and medical complications• Dysphagia + poor nutritional status• Communication difficulties e.g. Dysarthria + fatigue• Cognitive impairment notably the onset of dementia

1. Thomas.K et al. *Prognostic Indicator Guidance, 4th Edition*. The Gold Standards Framework Centre In End of Life Care CIC, 2011.

Screening Tool

Guidance for providers and staff to facilitate earlier identification of patients nearing the end of life who could benefit from a hospice palliative care approach

c. Frailty/Dementia - gradual decline

- | | |
|-----------------|---|
| Frailty | <ul style="list-style-type: none">• Multiple co-morbidities with significant impairment in day to day living and:• Deteriorating functional performance status• Combination of at least three of the following symptoms: weakness, slow walking speed, significant weight loss, exhaustion, low physical activity, depression |
| Dementia | <ul style="list-style-type: none"><input type="checkbox"/> Unable to walk without assistance and<input type="checkbox"/> Urinary and fecal incontinence, and<input type="checkbox"/> No consistently meaningful verbal communication and<input type="checkbox"/> Unable to do self- care without assistance<input type="checkbox"/> Reduced ability to perform activities of daily living <p>Plus any of the following:</p> <ul style="list-style-type: none">• Weight loss, urinary tract Infection, severe pressures sores (stage 3 or 4), recurrent fever, reduced oral intake, aspiration pneumonia |
| Stroke | <ul style="list-style-type: none"><input type="checkbox"/> Persistent vegetative or minimal conscious state or dense paralysis<input type="checkbox"/> Medical complications<input type="checkbox"/> Lack of improvement within 3 months of onset<input type="checkbox"/> Cognitive impairment / post-stroke dementia |

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1. Thomas.K et al. *Prognostic Indicator Guidance, 4th Edition*. The Gold Standards Framework Centre in End of Life Care CIC, 2011.
2. Lunney JR, Lynn J, Foley DS, Lipson S, Guralnik JM. *Patterns of functional decline at the end of life*. JAMA 2003; 289:2387-92.
3. Ferris, F. et al. *Model to Guide Hospice Palliative Care*. Canadian Hospice Palliative Care Association, 2002.
4. *Palliative Performance Scale (PPSv2) version 2*. Medical Care of the Dying, 4th ed.; p. 121. ©Victoria Hospice Society, 2006.
5. O'Donnell DE et al. *Canadian Thoracic Society recommendations for the management of chronic obstructive pulmonary disease – 2007 update*. Canadian Respiratory Journal, 2007:14 (Suppl B).
6. *Supportive and Palliative Care Indicators tool (SPICT)*. NHS Lothian and The University of Edinburgh Primary Palliative Care Research Group, 2013.

1. Thomas.K et al. *Prognostic Indicator Guidance, 4th Edition*. The Gold Standards Framework Centre In End of Life Care CIC, 2011.

Medical Orders for Scope of Treatment

The First Step in Advanced Care Planning

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TEXAS MEDICAL ORDERS FOR SCOPE OF TREATMENT (MOST) [TXMOSTCoalition2-26-16]

First Name:	Last Name:	Follow this MOST and patient preferences first, then contact a physician. Any section not completed implies full treatment for that section and does not invalidate the form. Send this MOST with the patient for all transfers between treatment sites. Comfort care and dignity will be provided to all patients.
Date of Birth:	Date Form Prepared:	

A	Check ONLY one	PHYSICIAN RESUSCITATION ORDER: If patient does not have a pulse and is not breathing: <input type="checkbox"/> Attempt Resuscitation (CPR) Place tube in the windpipe, electrical shocks to the chest, chest compression, and IV tubes for fluids/medications. <input type="checkbox"/> Do Not Attempt Resuscitation/Allow Natural death (DNAR/AND) Provide physical comfort, emotional, and respectful spiritual support to patient and family. <input type="checkbox"/> Out-Of-Hospital-Do-Not-Resuscitate Form completed If patient is not in cardiopulmonary arrest, follow orders found in Sections B and C
----------	----------------	---

B	Check ONLY one	MEDICAL INTERVENTION SCOPE: If patient is unstable, has pulse and is breathing: <input type="checkbox"/> FULL INTERVENTIONS: <u>Transfer to a hospital, and if necessary to ICU.</u> Use comfort and selective measures, and may add medically appropriate ICU interventions like, but not limited to, intubation/ventilator support, ICU-only medications, and dialysis. <input type="checkbox"/> SELECTIVE INTERVENTIONS: <u>If necessary, transfer to a hospital.</u> In addition to comfort measures, may add interventions like intravenous antibiotics, non-invasive breathing support (BiPAP/CPAP), and fluid resuscitation. <input type="checkbox"/> COMFORT INTERVENTIONS ONLY: <u>Avoid hospitalization unless needed to provide comfort care.</u> Focus on symptom control, dignity, and allowing gentle, natural death should it occur. Use comfort interventions like oral, subcutaneous, or intravenous medications (e.g., opioids), comfort foods/liquids, oxygen, and emotional/spiritual support. ADDITIONAL ORDERS: _____
----------	----------------	--

C	Check ONLY one	MEDICALLY ASSISTED NUTRITION/HYDRATION Offer nutrition and hydration by mouth at all intervention levels if feasible. <input type="checkbox"/> No medically assisted nutrition. <input type="checkbox"/> Unless medically contra-indicated*, defined trial of medically assisted nutrition. Length of trial _____ Goal _____ <input type="checkbox"/> Long-term medically assisted nutrition. <small>*In some circumstances including, but not limited to, heart, lung, liver or kidney failure, assisted nutrition or hydration may increase suffering or hasten death, and is therefore medically contraindicated.</small>
----------	----------------	--

DOCUMENTATION OF DISCUSSION AND SIGNATURES:				
Discussed with: <input type="checkbox"/> Patient (Patient has capacity) <input type="checkbox"/> Health Care Agent or Decision Maker: _____ <input type="checkbox"/> Court Appointed Guardian _____ (Relationship, Name) <input type="checkbox"/> Others in Attendance: _____ (Relationship, Name)			Rationale for these orders: (Choose all that apply) <input type="checkbox"/> Living Will (Directive to Physicians and Family or Surrogates) <input type="checkbox"/> Medical Power of Attorney <input type="checkbox"/> Other: _____	
Physician Signature: My signature certifies both the order and preferences above and the basis for them.				
X	Physician Signature:	Print Physician Name:	Date:	Phone Number:
Patient or Patient's Surrogate Signature:				
X	Patient or Surrogate Signature:	Print Patient or Surrogate's Name, if signing:	Date:	Phone Number:

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED	
Organization or Facility Identifier:	

Patient Last Name:		First Name:		DOB:	
Facilitator Information: If someone other than patient's physician is facilitating this conversation:					
Facilitator Last Name:		Facilitator First Name:		Credentials:	Phone Number:

Instructions for MOST Form

What is MOST?

MOST stands for Medical Orders for Scope of Treatment. It is a physician order set and care planning tool based upon patient treatment preferences that travels with the patient from one site of treatment to another.

Intent or Purpose of MOST: The MOST form is intended to promote patient centered health care and improve communication about that health care between hospitals, nursing facilities and other sites of care. The order and treatment preferences should be based upon:

- The patient's medical condition as determined by a physician; and
- The patient's preferences as directly expressed by the patient, the Living Will, or by the patient's surrogate (patient representative) if the patient can't communicate and lacks a Living Will.

Section A: Translates patient preferences regarding resuscitation into a physician order. It applies when a patient does not have a pulse and is not breathing. If a patient is not in cardiopulmonary arrest, then go to Sections B, C, D. At all times, health care professionals should remember that a DNAR/AND order does not mean that other health problems should go untreated.

Information Regarding Cardio-Pulmonary Resuscitation (CPR): CPR is sometimes helpful but other times can be harmful. It is most effective when a patient dies unexpectedly. CPR is rarely effective in advanced cancer, organ failure, other advanced illness, or advanced age when death would not be a surprise. CPR started in the nursing home almost never leads to survival. If CPR is initially successful in resuscitating a patient, the patient will be on a breathing machine in the ICU. Patients should discuss with their physician the potential to benefit from CPR based on their medical condition.

Section B and C: Provide guidance for more specific orders which a treating physician may issue according to the patient's medical condition, medical appropriateness, and local medical and nursing facility policy. These sections apply when a patient has a pulse and is breathing.

Is MOST a Valid Physician Order for Non-EMS Personnel? Yes. MOST is a valid order for health care personnel in an out of hospital setting other than Emergency Medical Services professionals, as stated in Section 166.102 of the Texas Health and Safety Code: PHYSICIAN'S DNR ORDER MAY BE HONORED BY HEALTH CARE PERSONNEL OTHER THAN EMERGENCY MEDICAL SERVICES PERSONNEL. (a) ...a licensed nurse or person providing health care services in an out-of-hospital setting may honor a physician's do-not-resuscitate order.

Is MOST a Valid Physician Order for EMS Personnel? NO. If EMS comes to a patient in arrest, they will attempt CPR unless a completed (8 signatures) Texas-Out-of-Hospital DNR is present.

What Should Health Care Professionals (Other than EMS) Do With This Form? Make the form a part of the patient's medical record in your facility. Honor the order to attempt or not attempt CPR and patient treatment preferences in accordance with the standard of care in your community. If patient is transferred to any other medical facility, send the form with the patient.

Living Will, MPOA, and OOH-DNR Order: MOST is vital but does not replace these documents. EMS should honor and execute an OOH-DNR order or device [Tex. H&S Code, 166.102(b)] Although this MOST conveys important information about a patient's treatment preferences, it does not replace a Living Will, MPOA, or OOH-DNR Order. A patient's Living Will, MPOA, or OOH-DNR Order controls over this MOST. Health care professionals should be aware that when responding to a call for assistance, EMS personnel shall honor only a properly executed or issued OOH-DNR Order or identification device. [Tex. H&S Code, §166.102(b)].

Copy of MOST and HIPAA: A copy of a completed MOST is as valid as the original, and HIPAA permits disclosure of a completed MOST to other health care providers as necessary for treatment purposes. The complete MOST and associated documents will also be available to your treating physicians electronically via a secure local health information exchange.

Review: Physicians and patient/surrogate should review this form yearly or upon change in care setting, medical condition, or patient treatment preferences. If no changes, physician may simply initial the date of review in the boxes above. If changes are desired by the patient or surrogate, create a new form!

Date of Review								
Physician Initials								

SEND the MOST FORM ON ALL TRANSFERS BETWEEN HEALTHCARE SITES

Supportive Tools for Special Populations

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Eastern Cooperative Oncology Group (ECOG)

Developed by the Eastern Cooperative Oncology Group, Robert L. Comis, MD, Group Chair.*

GRADE	ECOG PERFORMANCE STATUS
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours
3	Capable of only limited self-care; confined to bed or chair more than 50% of waking hours
4	Completely disabled; cannot carry on any self-care; totally confined to bed or chair
5	Dead

*Oken M, Creech R, Tormey D, et al. Toxicity and response criteria of the Eastern Cooperative Oncology Group. *Am J Clin Oncol.* 1982;5:649-655.

Karnofsky Performance Scale

The Karnofsky Performance Scale Index allows patients to be classified as to their functional impairment. This can be used to compare effectiveness of different therapies and to assess the prognosis in individual patients. The lower the Karnofsky score, the worse the survival for most serious illnesses.

Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead

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FAST FACTS AND CONCEPTS #125
THE PALLIATIVE PERFORMANCE SCALE (PPS)
L. Scott Wilner, MD and Robert Arnold, MD

The **Palliative Performance Scale (PPS)** uses five observer-rated domains correlated to the Karnofsky Performance Scale (100-0). The PPS is a reliable and valid tool and correlates well with actual survival and median survival time for cancer patients. It has been found useful for purposes of identifying and tracking potential care needs of palliative care patients, particularly as these needs change with disease progression. Large validation studies are still needed, as is analysis of how the PPS does, or does not, correlate with other available prognostic tools and commonly used symptom scales.

PALLIATIVE PERFORMANCE SCALE (PPS)

% Ambulation	Activity Level Evidence of Disease	Self-Care	Intake	Level of Consciousness	Estimated Median Survival in Days			
					(a)	(b)	(c)	
100	Full	Normal <i>No Disease</i>	Full	Normal	Full	N/A	N/A	108
90	Full	Normal <i>Some Disease</i>	Full	Normal	Full			
80	Full	Normal with Effort <i>Some Disease</i>	Full	Normal or Reduced	Full			
70	Reduced	Can't do normal job or work <i>Some Disease</i>	Full	as above	Full	145		
60	Reduced	Can't do hobbies or housework <i>Significant Disease</i>	Occasional Assistance Needed	as above	Full or Confusion	29	4	
50	Mainly sit/lie	Can't do any work <i>Extensive Disease</i>	Considerable Assistance Needed	as above	Full or Confusion	30	11	41
40	Mainly in Bed	as above	Mainly Assistance	as above	Full or Drowsy or Confusion	18	8	
30	Bed Bound	as above	Total Care	Reduced	as above	8	5	
20	Bed Bound	as above	as above	Minimal	as above	4	2	6
10	Bed Bound	as above	as above	Mouth Care Only	Drowsy or coma	1	1	
0	Death	-	-	-	--			

(a) See Virik and Glare, reference below. Survival post admission to inpatient palliative unit.

(b) See Anderson, reference below. Days until inpatient death following admission to an acute hospice unit, diagnoses not specified.

(c) See Morita, reference below. Survival post admission to inpatient palliative unit, cancer patients only.

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Anderson F, Downing GM, Hill J. Palliative Performance Scale (PPS): A New Tool. *Journal of Palliative Care*. 1996; 12(1); 5-11.

Adelaide Activities Profile

N	Question			
1	How often have you prepared a main meal?			
	Never	Less than once a week	1-2 times a week	Most days
2	How often have you washed the dishes?			
	Less than once a week	1-2 days a week	Most days	Every day
3	How often have you washed the clothes?			
	Never	About once a month	About once a fortnight	Once a week or more
4	How often have you done light housework?			
	Never	Once a fortnight or less	About once a week	Several days a week
5	How often have you done heavy housework?			
	Never	About once a month	About once a fortnight	Once a week or more
6	How many hours of voluntary or paid employment have you done?			
	None	Up to 10 hours/week	10-30 hours/week	More than 30 hrs/week
7	How often have you cared for other family members?			
	Never	About once a month	About once a fortnight	Once a week or more
8	How often have you done household shopping?			
	Never	About once a month	About once a fortnight	Once a week or more
9	How often have you done personal shopping?			
	Never	Once in three months	About once a month	Once a fortnight or more
10	How often have you done light gardening?			
	Never	About once a month	About once a fortnight	Once a week or more
11	How often have you done heavy gardening?			
	Never	About once a month	About once a fortnight	Once a week or more
12	How often have you done household and/or car maintenance?			
	Never	Once in three months	About once a month	Once a fortnight or more
13	How often have you needed to drive a car or organise your own transport?			
	Never	Up to once a month	Up to once a fortnight	Once a week or more
14	How often have you spent some time on a hobby?			
	Never	About once a month	About once a fortnight	More than once a week
15	How many telephone calls have you made to friends or family?			
	None	Up to three calls/week	4-10 calls/week	Over 10 calls/week
16	How often have you invited people to your home?			
	Less than once/fortnight	About once a fortnight	About once a week	More than once a week
17	How often have you participated in social activities at a centre such as a club, a church or a community centre?			
	Less than once/month	About once a month	About once a fortnight	More than once a week
18	How often have you attended religious services or meetings?			
	Never	About once a month	About once a fortnight	Once a week or more
19	How often have you participated in an outdoor social activity?			
	Never	About once a month	About once a fortnight	Once a week or more
20	How often have you spent some time outdoor participating in a recreational or sporting activity?			
	Never	About once a month	About once a week	More than once a week
21	How often have you walked outdoors for 15 minutes or more?			
	Once/month or less	About once a fortnight	About once a week	Most days

Reference:
Clark & Bond, 1985

Patient Resources

Educational Handouts for Patients

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Palliative Care

What You Should Know

To learn more about palliative care, go to getpalliativecare.org

Palliative Care (pronounced pal-lee-uh-tiv) is specialized medical care for people with serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

1 WHERE DO I RECEIVE PALLIATIVE CARE?

Palliative care can be provided in a variety of settings including the hospital, outpatient clinic and at home.

2 DOES MY INSURANCE PAY FOR PALLIATIVE CARE?

Most insurance plans, including Medicare and Medicaid, cover palliative care. If costs concern you, a social worker from the palliative care team can help you.

3 HOW DO I KNOW IF PALLIATIVE CARE IS RIGHT FOR ME?

Palliative care may be right for you if you suffer from pain, stress or other symptoms due to a serious illness. Serious illnesses may include cancer, heart disease, lung disease, kidney disease, Alzheimer's, HIV/AIDS, amyotrophic lateral sclerosis (ALS), multiple sclerosis, Parkinson's and more. Palliative care can be provided at any stage of illness and along with treatment meant to cure you.

4 WHAT CAN I EXPECT FROM PALLIATIVE CARE?

You can expect relief from symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping. Palliative care helps you carry on with your daily life. It improves your ability to go through medical treatments. It helps you better understand your condition and your choices for medical care. In short, you can expect the best possible quality of life.

5 WHO PROVIDES PALLIATIVE CARE?

Palliative care is provided by a team including palliative care doctors, nurses and other specialists.

6 HOW DOES PALLIATIVE CARE WORK WITH MY OWN DOCTOR?

The palliative care team works in partnership with your own doctor to provide an extra layer of support for you and your family. The team provides expert symptom management, extra time for communication about your goals and treatment options and help navigating the health system.

7 HOW DO I GET PALLIATIVE CARE?

You have to ask for it! Just tell your doctors and nurses that you would like to see the palliative care team.

Palliative Care Facts and Stats

- Approximately 90 million Americans are living with serious illness, and this number is expected to more than double over the next 25 years with the aging of the baby boomers.
- Approximately 6,000,000 people in the United States could benefit from palliative care.
- Palliative care is the medical specialty focused on improving quality of life for people facing serious illness.
- Palliative care provides relief from the symptoms and stress of a serious illness.
- The goal is to improve quality of life for both the patient and their family.
- Palliative care is provided by an interdisciplinary team of palliative care specialists, including doctors, nurses, social workers and others who work with a patient's other doctors to provide an extra layer of support.
- Palliative care is appropriate at any age and at any stage in a serious illness, and it can be provided together with curative treatment.
- According to a 2010 study reported in the New England Journal of Medicine, lung cancer patients receiving early palliative care had less depression, improved quality of life and survived 2.7 months longer.
- Illnesses most commonly treated by palliative care are heart disease, cancer, stroke, diabetes, renal disease, Parkinson's and Alzheimer's disease.
- Approximately 68% of Medicare costs are related to people with four or more chronic conditions—the typical palliative care patient.
- If palliative care were fully penetrated into the nation's hospitals, total savings could amount to \$6 billion per year.
- Palliative care growth in hospitals has been exponential. Due largely to the work of CAPC, the number of teams has increased by 164% over 12 years. To date, there are more than 1700 hospitals with a palliative care team.
- Approximately 61% of all hospitals with more than 50 or more beds have a palliative care team today.
- Where you live matters when it comes to access to hospital palliative care. (See the palliative care national and state-by-state report card at capc.org/reportcard).
- According to a 2011 poll conducted by Public Opinion Strategies, once informed about palliative care:
- 95% of poll respondents agreed that it is important that patients with serious illness and their families be educated about palliative care. 92% of poll respondents said they would be likely to consider palliative care for a loved one if they had a serious illness. 92% of poll respondents said it is important that palliative care services be made available at all hospitals for patients with serious illness and their families.

Palliative Care

Frequently Asked Questions

What is palliative care?

Palliative care, or palliative medicine, is the medical specialty focused on people living with serious illness. It provides relief from the symptoms and stress of a serious illness—whatever the diagnosis or prognosis. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a team of specialists who work together with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

Who can benefit from palliative care?

Palliative care is appropriate for anyone suffering from a serious illness (e.g. cancer, cardiac disease, respiratory disease, kidney failure, Alzheimer's, AIDS, amyotrophic lateral sclerosis (ALS) and more.)

When is palliative care appropriate?

You can receive palliative care from the point of diagnosis. It is not dependent on prognosis.

What do you gain from palliative care?

Specially trained to deal with complex pain and symptoms, as well as communication about serious illness, palliative care helps with a wide range of

issues, including pain, depression, anxiety, fatigue, shortness of breath, constipation, nausea, loss of appetite and difficulty sleeping.

It also helps people gain the strength to carry on with daily life. It improves their ability to tolerate medical treatments. And it helps them have more control over their care by improving their understanding of treatment options and matching their goals to those options. It also helps support family caregivers and provides practical support.

Can you have palliative care together with curative treatment?

Yes. You can always have palliative care along with curative and life-prolonging treatment.

Do you have to give up your own doctor?

No. Palliative care teams work together with the primary doctor.

How do you pay for palliative care?

Palliative care is treated in the same way as other medical services (e.g. cardiology). Most insurance plans, including Medicare and Medicaid, cover all or part of palliative care.

How do you get palliative care?

You should ask your doctor for a referral to receive palliative care.

About CAPC

The Center to Advance Palliative Care (CAPC) is a national organization dedicated to increasing the availability of quality palliative care services for people facing serious illness. As the leading resource for palliative care development and growth, CAPC provides health care professionals with the training, tools and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings.

CAPC has taken early innovation in the field of palliative care to scale and transformed it from a “radical concept” promoted by a handful of pioneers to a must-have service. Until a little over a decade ago, palliative care services were only available to those enrolled in hospice. Rarely was it available to people living with a serious illness. Today, due largely to the work of CAPC, palliative care teams are found in over 61% of all U.S. hospitals with more than 50 beds.

As the nation’s leader in providing palliative care training and implementation support, our approach has a proven, fifteen-year track record. Major health care organizations and leaders in the field know CAPC and turn to us for effective training, technical assistance and access to peer organizations.

Growing evidence of palliative care’s impact on both quality of care and health care system sustainability is driving interest from senior health care leaders and organizations. But improving access to palliative care for all seriously ill people requires that every clinician have basic skills

and that patients be able to find high quality palliative care wherever they happen to be—at home, in a nursing home, a cancer center or a dialysis unit. It is CAPC’s clinical and operational training and technical assistance, metrics and dissemination of best practices that help make this possible.

CAPC is a member-based organization open to all healthcare organizations, including hospitals, hospices, payers and community health organizations. Funding is provided through membership fees and the generous support of foundations and private philanthropy. CAPC is affiliated with the Icahn School of Medicine at Mount Sinai in New York City.

CAPC is led by Diane E. Meier, MD, Catherine Gaisman Professor of Medical Ethics and Director of the Center to Advance Palliative Care. Dr. Meier is a leading pioneer in the field and was named a MacArthur Fellow in 2008.

To learn more about CAPC and its mission, please visit capc.org and getpalliativecare.org.

Advance Care Planning – Selected Resources for the Public

The following resources represent a broad array of materials to assist the public in better understanding advance care planning and related topics such as hospice and palliative care, caregiving, cognitive impairment, and legal issues. While extensive, this list is by no means exhaustive and other quality resources are also available.

Guidance on Completing an Advance Directive

Caring Conversations Workbook

Published by the Center for Practical Bioethics, guide helps individuals and their families share meaningful conversations regarding end-of-life decisions
<http://www.practicalbioethics.org/documents/caring-conversations/Caring-Conversations.pdf>

Five Wishes

Guide on advance care planning available in 26 languages
<http://www.agingwithdignity.org/five-wishes.php>

Consumer's Tool Kit for Health Care Advance Planning

Developed by the American Bar Association Commission on Law and Aging
http://apps.americanbar.org/aging/publications/docs/consumer_tool_kit_bk.pdf

The African American Spiritual and Ethical Guide to End of Life Care - What Y'all Gon' Do With Me?

Guide prepared by Heart Tones addressing historical, cultural and spiritual factors that influence African-Americans' decisions about end-of-life care and planning
<http://www.hearttones.com/resources.php>

CRITICAL ConditionsSM

A community education program helping people understand the importance of planning for their end-of-life medical care, this comprehensive advanced care planning program developed by Georgia Health Decisions includes the *CRITICAL ConditionsSM Planning Guide*

<http://georgiahealthdecisions.org>

Thinking Ahead: My Way, My Choice, My Life at the End

Workbook and video created by California advocates with developmental disabilities
<http://www.dds.ca.gov/ConsumerCorner/ThinkingAhead.cfm>

Loving Conversations

Produced by American Health Lawyer Association, follows fictional family through difficult process of making decisions for loved one who did not have advance directive
<http://www.healthlawyers.org/hlresources/PI/InfoSeries/Pages/LovingConversations.aspx>

Respecting Choices

Internationally-recognized, evidence-based program established in 2000 addressing process of advance care planning

<http://respectingchoices.org/>

Advanced Care Planning: Resources for Caretakers and Health Care Professionals Providing Aging Counseling

Online course developed by Carolina Geriatric Education Center that provides evidence-based and culturally-competent geriatrics education and training

<http://clipper.med.unc.edu/acp/>

For Health Care Proxies/Agents: Making Decisions for Someone Else: A How To Guide

Guide published by American Bar Association Commission on Law and Aging

http://www.americanbar.org/groups/law_aging.html

“Good to Go” Toolkit and Resource Guide

Guide published by Compassion and Choices

<http://community.compassionandchoices.org/document.doc?id=425>

Growth House, Inc.

Offers free access to over 4,000 pages of educational materials about end-of-life care, palliative medicine, and hospice

http://www.growthhouse.org/radio_channel_education.html

National Healthcare Decisions Day – April 16

Initiative encouraging individuals to express their wishes regarding health care; provides variety of resources, including materials for public, media kits, and suggested activities

<http://www.nhdd.org/>

Senior Connection

Offers several videos on death and dying that provide information to help seniors and their caregivers help themselves.

<http://www.seniorconnection.org/video.htm>

More on Advance Directives

“Speak Up” Video

Highlights the value of advance care planning and provides helpful information on Health Care Decisions Day on April 16

<http://www.youtube.com/watch?v=Bar0qZTUGdw>

U.S. Living Will Registry

Electronically stores advance directives and makes available to health care providers 24 hours a day via secure Internet or telephone-facsimile; also stores organ donation

<http://www.uslivingwillregistry.com/>

State Specific Advance Directive Form

Free downloadable advance directive forms and information from state bar associations and other reputable state groups.

<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>

Medline Plus

Website of the National Library of Medicine (a part of the National Institutes of Health) offers easy-to-understand information on advance directives

<http://www.nlm.nih.gov/medlineplus/ency/patientinstructions/000472.htm>

Advance Directives and Cancer

Fact sheet providing cancer patients and their families with outline for thinking about end-of-life care issues and guidelines for discussion with doctors, family members, and loved ones

<http://www.cancer.gov/cancertopics/factsheet/support/advance-directives>

Hospice and Palliative Care:**National Association of Home Care and Hospice (NAHCH)**

Nation's largest trade association representing the interests and concerns of home care agencies, hospices, and home care aid organizations.

<http://www.nahc.org/>

National Hospice and Palliative Care Organization (NHPCO)

Represents hospice and palliative care programs and professionals in the United States and works to expand access to hospice care and improve end-of-life

<http://www.nhpc.org/templates/1/homepage.cfm>

Caregivers and Health Care Surrogates:**Family Caregiver Alliance (FCA)**

Addresses needs of family members and others providing long-term care at home; offers programs at the national, state and local levels to support and sustain caregivers

<http://www.caregiver.org/caregiver/>

National Family Caregivers Association (NFCA)

Educates and supports more than 65 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age <http://www.thefamilycaregiver.org/> and

<http://www.familycaregiving101.org/>

AARP Caregiving Resource Center

Caregiving Resource Center offers helpful tools, work sheets and tips on how to plan, prepare and succeed as a caregiver

<http://www.aarp.org/content/aarp/en/home/relationships/caregiving.html>

Administration on Aging's National Family Caregiver Support Program

Provides grants to states and territories to fund range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible

http://www.aoa.gov/aoaroot/aoa_programs/hcltc/caregiver/index.aspx

Cognitive Impairment:

End-of-life Decisions: Honoring the Wishes of the Person with Alzheimer's Disease

Brochure from the Alzheimer's Association addresses issues a family may face when the person with dementia nears the end of life

http://www.alz.org/national/documents/brochure_endoflifedecisions.pdf

Facts and Figures

Annual report of Alzheimer's Association detailing burden of Alzheimer's disease and dementia on individuals, families, state and local governments, and the health care system

http://www.alz.org/alzheimers_disease_facts_figures.asp?type=homepage

Legal Issues:

The National Legal Resource Center

Collaborative effort of the Administration on Aging that provides legal support to aging advocacy network and highlights resources on medical decision making

<http://www.nlrc.aoa.gov/>

Patient Self Determination Act (PL 101-508)

Requires hospitals, nursing homes, home health agencies, hospice providers, and other institutions to inform patients of their rights on decisions about their medical care

<http://www.gpo.gov/fdsys/pkg/GAOREPORTS-HEHS-95-135/pdf/GAOREPORTS-HEHS-95-135.pdf>

Legal Guide for the Seriously Ill: Seven Key Steps to Get Your Affairs in Order (2009)

Prepared by the American Bar Association Commission on Law and Aging for the National Hospice and Palliative Care Organization

http://www.healthcarechaplancy.org/userimages/Legal_Guide_for_the_Terminally_Ill.pdf

Making Medical Decisions for Someone Else: A Florida Handbook

Based on a handbook created in 2006 by the American Bar Association's Commission on Law and Aging, this booklet helps one adult make health care choices for another

<http://med.fsu.edu/index.cfm?page=innovativecollaboration.publicationspresentations>

Five Big Myths of Advance Care Planning and How to Stay Anchored in Reality

Podcast slides address five biggest myths regarding advance care planning and how to make advance care planning more effective

http://www.americanbar.org/groups/health_law/resources/podcast0410_advance_dir.html

Gold Standards Framework Overview

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Gold Standards Framework

United Kingdom
www.goldstandardsframework.org.uk



Overview of the Gold Standards Framework

Identify

Identify those patients that meet criteria for inclusion into the palliative care program.

Assess

Assess the patient's status, their care needs, and how to achieve their end of life goals.

Plan

Through careful planning and cooperation develop a plan of care to provide the patient and their families with the best support and care possible.

The Gold Standards Framework Centre is the foundation and authority for the Gold Standards Framework. Established in 2000 by Dr. Keri Thomas to meet the needs of dying patients particularly to identify these patients and enhance the care they receive from providers and staff.

The Gold Standards Framework is in various settings (primary care, acute care hospitals, care homes, community hospitals) and has been deemed the solution to England's End of Life Care Strategy to meet the needs of dying patients.

Success

The Gold Standards Framework has been successful in England for over a decade successfully implemented in 13 countries. The program is supported by training and education programs available in person and online through the Gold Standards Framework Centre. The experts at the Centre will help to train providers and staff on the aspects of the framework and how to utilize it in various practice settings. The Centre has created a certification program allowing maximum training and implementation of the framework with recognition by peers and patients, as well as to set an exemplary standard of care that is regulated through both the Centre and the National Healthcare System of the United Kingdom.

Key Tasks

There are seven key tasks to the Gold Standards Framework that help to ensure that the best care possible is provided by the healthcare team to the patient. Those tasks are:

- Communication
- Coordination of Care
- Control of Systems and Ongoing Assessment
- Continuing Support
- Continued Learning
- Caregiver and Family Support
- Care in the Final Days

Evidence Based Information and Resources

Evidence Based Practice Guidelines and
Full Guidance with Updates for Using
the Gold Standards Framework.

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ICSI Institute for Clinical Systems Improvement

Health Care Guideline Palliative Care for Adults

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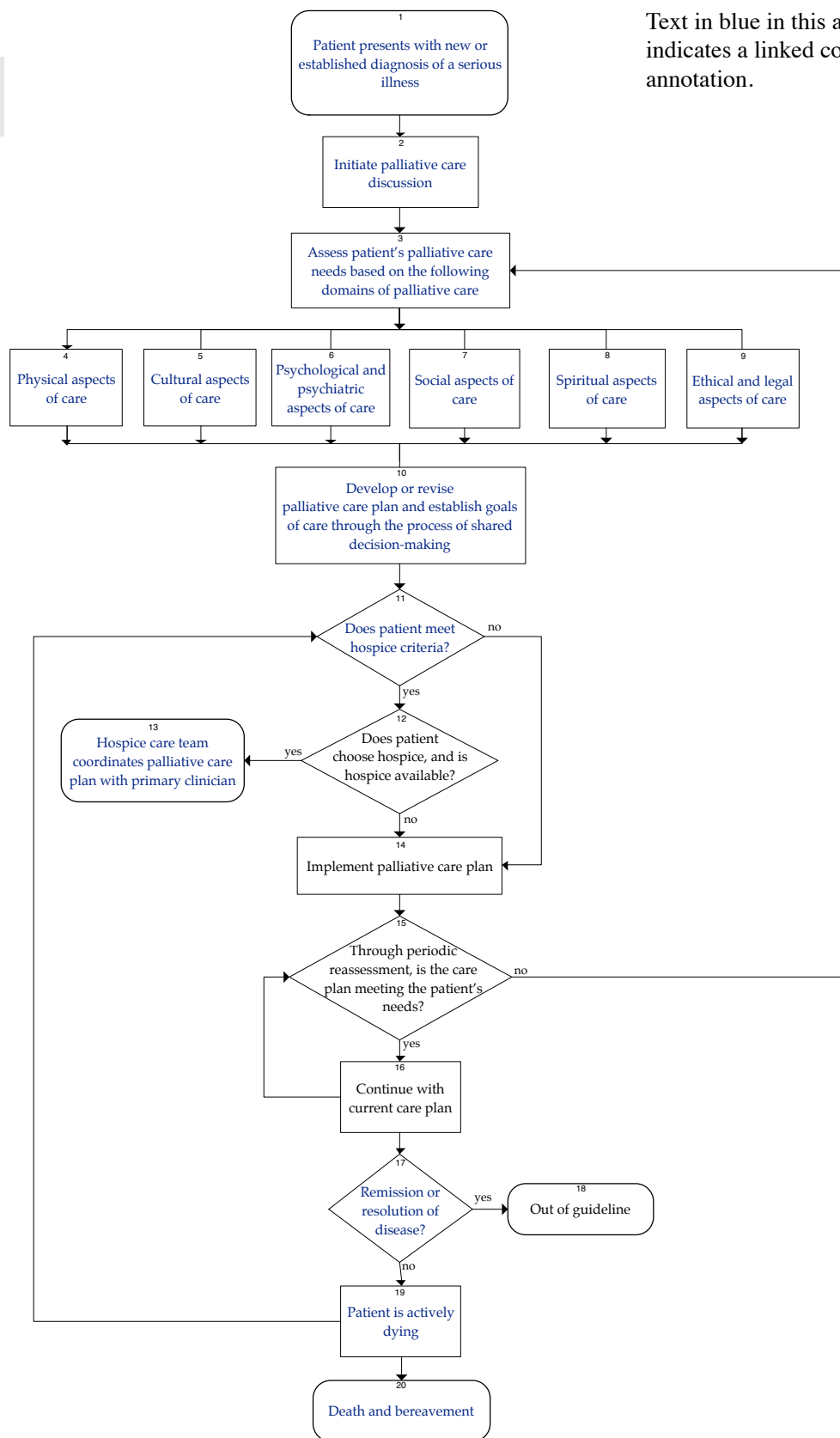


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Evidence Grading

Literature Search

A consistent and defined process is used for literature search and review for the development and revision of ICSI guidelines. The literature search was divided into two stages to identify systematic reviews (stage I) and randomized controlled trials, meta-analysis and other literature (stage II). Literature search terms used for this revision are end-of-life care, advance directives, cultural and ethnic aspects in palliative care, cost and affordability of palliative care, and include literature from July 2011 through July 2013.

GRADE Methodology

Following a review of several evidence rating and recommendation writing systems, ICSI has made a decision to transition to the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system.

GRADE has advantages over other systems including the current system used by ICSI. Advantages include:

- developed by a widely representative group of international guideline developers;
- explicit and comprehensive criteria for downgrading and upgrading quality of evidence ratings;
- clear separation between quality of evidence and strength of recommendations that includes a transparent process of moving from evidence evaluation to recommendations;
- clear, pragmatic interpretations of strong versus weak recommendations for clinicians, patients and policy-makers;
- explicit acknowledgement of values and preferences; and
- explicit evaluation of the importance of outcomes of alternative management strategies.

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Evidence Grading

Category	Quality Definitions	Strong Recommendation	Weak Recommendation
High Quality Evidence	Further research is very unlikely to change our confidence in the estimate of effect.	The work group is confident that the desirable effects of adhering to this recommendation outweigh the undesirable effects. This is a strong recommendation for or against. This applies to most patients.	The work group recognizes that the evidence, though of high quality, shows a balance between estimates of harms and benefits. The best action will depend on local circumstances, patient values or preferences.
Moderate Quality Evidence	Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.	The work group is confident that the benefits outweigh the risks but recognizes that the evidence has limitations. Further evidence may impact this recommendation. This is a recommendation that likely applies to most patients.	The work group recognizes that there is a balance between harms and benefits, based on moderate quality evidence, or that there is uncertainty about the estimates of the harms and benefits of the proposed intervention that may be affected by new evidence. Alternative approaches will likely be better for some patients under some circumstances.
Low Quality Evidence	Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change. The estimate or any estimate of effect is very uncertain.	The work group feels that the evidence consistently indicates the benefit of this action outweighs the harms. This recommendation might change when higher quality evidence becomes available.	The work group recognizes that there is significant uncertainty about the best estimates of benefits and harms.

Choosing Wisely®

As part of a grant from the ABIM Foundation, ICSI is supporting the national *Choosing Wisely®* Campaign. The campaign's goal is to help physicians and patients talk about medical tests and procedures that are often used but may not be necessary and may in some cases cause harm.



The *Choosing Wisely* logo will appear in this document whenever a recommendation from a medical specialty society participating in the *Choosing Wisely* Campaign is in alignment with ICSI work group recommendations.

Permission to use the *Choosing Wisely* logo is granted by the ABIM Foundation.

For all current *Choosing Wisely* recommendations, see [Appendix A, "Choosing Wisely Recommendations Regarding Palliative Care."](#)

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Evidence Grading

Recommendations Table

The following table is a list of evidence-based recommendations for Palliative Care.

Note: Other recommendation language may appear throughout the document as a result of work group consensus, but is not included in this evidence-based recommendations table.

Topic	Quality of Evidence	Recommendation(s)	Strength of Recommendation	Annotation Number	Relevant References
Actively dying patients	Low	Clinicians should discuss the likelihood of disease progression to death with patients and/or their families.	Strong	19	<i>Lamont, 2001;</i> <i>Brody, 1997;</i> <i>SUPPORT, 1995</i>
Advance care plans	Low	Clinicians should initiate or facilitate advance care planning for all adult patients and their families with regular review as the patient's condition changes.	Strong	9	<i>Weissman, 2011;</i> <i>Gries, 2008;</i> <i>Balaban, 2007;</i> <i>Block, 2006;</i> <i>Sinclair, 2006;</i> <i>Lee, 2002;</i> <i>Vandekieft, 2001</i>
Assessment tools	Low	Clinicians should use a validated assessment tool to assess palliative care needs.	Strong	3	<i>Moro, 2006;</i> <i>Chang, 2000;</i> <i>Phillip, 1998</i>
Care conferences	Low	Care conferences with the patient, family and an interdisciplinary health care team are recommended on an ongoing basis to discuss patient's condition, course of illness, treatment options, goals and plan of care.	Strong	3	<i>Gries, 2008;</i> <i>Money maker, 2005;</i> <i>McDonagh, 2004;</i> <i>Curtis, 2001</i>
Care of the dying patient	Low	Clinicians should engage in ongoing communication with the patient and/or family regarding the dying process and the treatment plan.	Strong	19	<i>Brody, 1997</i>
Cultural aspects	Low	A cultural assessment should be an integral component of the palliative care plan.	Strong	5	<i>Kemp, 2005;</i> <i>Searight, 2005;</i> <i>Kagawa-Singer, 2001</i>
Early intervention	Low	Palliative care should begin at the time of diagnosis of a serious condition and continue through cure, or until death and then into the bereavement period.	Strong	1	<i>Temel, 2010;</i> <i>Kass-Bartelmes, 2004;</i> <i>Morrison, 2004;</i> <i>Steinhauser, 2000</i>
Ethical and legal aspects of care	Low	Clinicians should recognize those patients who are receiving non-beneficial, low-yield therapy.	Strong	9	<i>Schneiderman, 2003</i>

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Evidence Grading

Topic	Quality of Evidence	Recommendation(s)	Strength of Recommendation	Annotation Number	Relevant References
Informed consent	Low	Informed consent should be obtained for any treatment or plan of care from either a patient with decision-making capacity or an appropriate surrogate decision-maker.	Strong	9	<i>Silveria, 2010;</i> <i>Arnold, 2006</i>
Integral physical aspects of care	Low	The physical aspects of the patient's serious illness should be an integral component of the palliative care plan.	Strong	4	
Interpreters	Low	Clinicians should follow the established best practices of utilizing professional medical interpreters when English is not a patient's first language or when there are gaps in understanding English.	Strong	5	<i>Norris, 2005;</i> <i>Searight, 2005</i>
Psychological and psychiatric status	Low	A psychological assessment should be an integral component of the palliative care plan.	Strong	6	<i>Bakitas, 2009;</i> <i>Chochinov, 2006;</i> <i>Werth, 2002;</i> <i>Block, 2000</i>
Referral to palliative care specialists	Low	Palliative care discussion or referral should be considered whenever the patient develops a serious illness. Palliative care discussions should be included whenever a patient with a life-limiting or life-threatening illness presents, including the hospital ICU or emergency department.	Strong	2	<i>Strand, 2013;</i> <i>Weissman, 2011</i> <i>Quest, 2013</i>
Social assessment	Low	A social assessment should be an integral component of the palliative care plan.	Strong	7	<i>Gries, 2008;</i> <i>Morrison, 2004;</i> <i>Curtis, 2002</i>
Spiritual needs	Low	A spiritual assessment should be an integral component of the palliative care plan.	Strong	8	<i>Pulchaski, 2000;</i> <i>Post, 2000;</i> <i>Reed, 1987</i>
	Low	Clinicians should utilize clinically trained chaplains as members of the interdisciplinary health care team to provide patient-centered spiritual care and support.	Strong	8	

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Foreword

Introduction

Palliative care is both a philosophy of care and spectrum of care delivery ranging from primary care to specialized teams. The World Health Organization (2002) defines palliative care as "an approach that improves the quality of life for patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." The Center to Advance Palliative Care (CAPC) expanded this definition by emphasizing the need for specialized interdisciplinary care focused on symptoms and quality of life for people of any age and at any stage of a serious illness. The word "palliate," derived from the Latin word *palliatu*s, means to "cloak or cover." Thought of in this way, it is meant to convey care that wraps the patient with another layer of comfort and support.

Clinicians provide palliative care through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient and family needs, values, beliefs and culture(s) (*Lorenz, 2008 [Systematic Review]*). The National Consensus Project (2013), National Quality Forum (2012) and The Joint Commission (2012) have outlined systematic components of palliative care services to support these outcomes. This guideline aims to help clinicians understand the philosophy and structure of palliative care, as well as provide aims and measures to operationalize palliative care services.

Implicit in this definition is the assertion that palliative care may be provided as the primary focus of treatment, or concurrently with other medical interventions at any stage of a serious illness. By intervening at the onset of a serious illness, health care professionals can assure that appropriate interventions are offered to meet the goal of reducing the burden of disease and maximizing the quality of life.

History and evolution of palliative care

Historically, the majority of health care was palliative. Since the discovery of penicillin in 1928, however, new therapies to cure and extend life have provided great promise as well as posed increasingly challenging ethical dilemmas about the appropriateness and effectiveness of use. In the 1960s, the hospice movement began to develop a model of end-of-life care for individuals facing terminal illness. Nevertheless, there was a growing awareness that individuals living with serious illness also had substantial symptom management and support needs much earlier than at the very end of life. Early palliative programs emerged in hospitals like the Cleveland Clinic and Medical College of Wisconsin. The landmark SUPPORT study (1995) documented the scope and nature of challenges associated with seeking to provide effective, comprehensive care for individuals facing serious illness. A series of reports from the Institute of Medicine (1998; 2002; 2003) provided further documentation of how the burdens of disease and treatment were not being adequately addressed.

Early supportive evidence emerged from these hospital-based programs demonstrating it was possible to concurrently provide disease-directed therapies and palliative care. Palliative care teams could facilitate effective communication, identify patient-centered goals, align these with appropriate treatments, improve quality of life for the patient and family, reduce symptom burden and reduce costs (*Morrison, 2008 [Cost Effectiveness Analysis]*). These results supported the ongoing growth of hospital-based palliative care programs, which can be found in more than 60% of all U.S. hospitals, and in more than 85% of hospitals with 300 or more beds (<http://www.capc.org>).

There has been conflicting data on the influence of advance directives on health care spending. In a study using Health Retirement Study data – including Medicare claims data and interviews of relatives of decedents, as well as information on regional health care spending from the Dartmouth Atlas – evidence showed that in high health care spending regions, individuals with an advance directive limiting treatments at end of

life were less likely to die in a hospital, more likely to receive hospice care, and generated lower Medicare end-of-life care costs (*Nicholas, 2011 [Low Quality Evidence]*). Studies have shown that those who die at home and those enrolled in hospice programs have improved quality of life and symptom control. This suggests that for individuals who wish to limit treatments at the end of life, it is particularly important to document those preferences, if one's wishes vary considerably from the norms in one's area of residence.

Outpatient palliative care services evolved to address needs earlier in the disease process. Early palliative care, including outpatient services, could improve quality of life, reduce symptoms, support patient-centered goals and promote increased survival (*Temel, 2010 [Low Quality Evidence]*). These results have supported recommendations from the American Society of Clinical Oncology (*Smith, 2012 [High Quality Evidence]*) to recommend combined oncology and palliative care for any patient with metastatic disease and/or high symptom burden.

With this historical context, the provision of palliative care services is uniquely positioned in the broader scope of health care in the U.S. Palliative care supports health system efforts to work toward the "Triple Aim" of improved patient experience, improved population health, and reduced per capita costs of health care (*Berwick, 2008 [Low Quality Evidence]*). The comprehensive, systematic approach to serious illness aligns palliative care with efforts to reduce avoidable rehospitalization, facilitate transitions between settings of care, and identify patient- and goal-directed services within the purview of collaborating accountable care organizations. As this guideline shows, the strengths and benefits of palliative care services apply in various settings and specialties.

Generalist and specialty palliative care

Nearly all health care professionals offer palliative care to their patients in some manner. Indeed, there is a presumption that providers will all be able to provide a primary level of palliation for symptoms commonly encountered in their respective practices. More challenging cases of distressing symptoms or complicated communication systems would be appropriate for referral to specialty palliative care services with a multidisciplinary team that includes board-certified specialists where available. These specialists are also responsible for teaching other providers and building systems to guarantee the highest possible level of palliative care expertise for a population of patients.

Palliative care and hospice care: similarities and differences

In America, "palliative care" and "hospice care" are terms often used interchangeably. That is not only incorrect, but it also limits access to appropriate services early in the course of illness and treatment. Hospice care is a philosophy of care with health care benefits under most insurance payers. It is designed for patients with a limited life expectancy of six months or less (according to Medicare hospice coverage criteria) and is chosen by patients who want comfort rather than life-prolonging care. Hospice is a defined CMS benefit with explicit enrollment criteria, interdisciplinary practice guidelines, and quality assurance and performance improvement requirements. The majority of the medical community is not well versed in this. See [Appendix D, "Medicare Hospice Benefit: Eligibility and Treatment Plan,"](#) for further details.

HOSPICE: The patient has *both*

- a limited life expectancy (specifically six months or less);
- **and** the goals for care are exclusively to achieve and maintain comfort, regardless of the symptom burden.

PALLIATIVE CARE: The patient has *either*

- a limited life expectancy (regardless of symptom burden or goals for care),
- **or** a significant symptom burden (regardless of prognosis or goals for care) **or** goals for care exclusively to achieve and maintain comfort (regardless of prognosis or symptom burden).



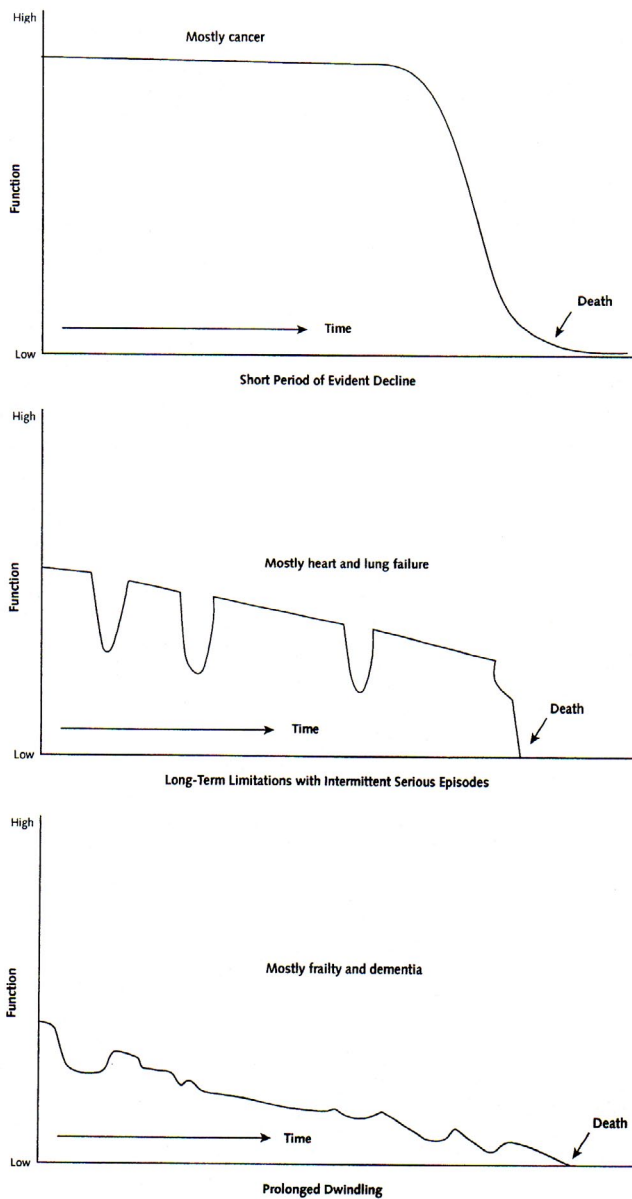
All hospice is palliative care, but not all palliative care is hospice.

By defining appropriate evaluations and outcomes, this guideline attempts to assist the clinician with the appropriate discussions, clinical interventions, and utilization of palliative care and hospice expertise when necessary. As illness progresses and the need for interdisciplinary approaches to the relief of suffering increases, the intensity of palliative interventions will also increase. Due to escalating burden, ongoing communication and reassessment are critical to achieving satisfactory outcomes. Early recognition of serious or life-limiting illness by clinicians and an understanding of disease progression by patients and families are both critical to consider appropriate interventions and use of this guideline. As illness progresses and the need for interdisciplinary approaches to the relief of suffering increases, the intensity of palliative interventions will also increase. Due to escalating burden, ongoing communication and reassessment are critical to achieving satisfactory outcomes.

Trajectories of late-life illness (see following graphs)

The natural history of most cancers, without treatment, is generally marked by a period, which may be prolonged, where patients enjoy good functional status and symptoms are readily treated. At some point, as the disease advances, function begins to decline, and from there the trajectory of the illness tracks steadily downward. It was this model that informed the inclusion of a limited life expectancy as a criterion for hospice services. Other chronic medical conditions, however, manifest different patterns. Patients with conditions such as congestive heart failure and chronic obstructive pulmonary disease have periodic exacerbations where they may become quite ill, and even pre-morbid. Medical treatment may successfully improve their status, although functional recovery may not return quite to the pre-episode level. A graph would show a sawtooth pattern, with the sharp downward inflections marking the acute illnesses, during which death may occur, with an overall slow downward slope in the curve. Progressive neurologic illnesses, such as Parkinson's and Alzheimer's diseases, generally show a slow overall decline in slope, which may occur over years, with occasional downward spikes marking episodes of infection (e.g., pneumonia) during which a patient might die (*Lorenz, 2008 [Systematic Review]*).

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Scope and Target Population

This guideline will assist primary and specialty care providers in identifying and caring for adult patients with a serious (potentially life-limiting, life-threatening or chronic, progressive) illness who may benefit from palliative care. This guideline is appropriate for patients who still desire curative or life-prolonging treatments, or patients who are best served by active end-of-life management. It will outline key considerations for creating a plan of care to meet patient, family and other caregivers' needs throughout the continuum of care.

This guideline will not assist providers in the identification or care for pediatric patients with life-threatening or chronic progressive illness. See [Appendix C, "Pediatrics,"](#) for a brief overview of consideration for pediatric patients.

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Aims

1. Increase the identification of patients who are in the early stages of a serious illness who would benefit from palliative care. (*Annotations #1, 2*)
2. Improve the effectiveness and comfort level of primary care clinicians in communicating the necessity and benefits of palliative care with those patients with a serious illness. (*Annotation #2*)
3. Improve the assessment of the identified patient's palliative care needs, utilizing the domains of palliative care. (*Annotations #3, 4-9*)
4. Increase the percentage of patients in the early stages of a serious illness who have a care plan identified and/or documented. (*Annotations #3, 10*)
5. Improve the ongoing reassessment and adjustment of the patient's plan of care as the condition warrants, utilizing the domains of palliative care. (*Annotations #3, 4-9*)
6. Increase the completion, documentation and ongoing utilization of advance directives for patients with a serious illness. (*Annotations #3, 9*)

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Clinical Highlights

- Planning for palliative care should begin early in the patient's journey of a serious illness. (*Annotations #1, 2; Aim #1*)
 - Where palliative care consultation is available, referral to this service should be considered early on in the patient's care if there are complex needs. Primary care clinicians should begin palliative care planning early through palliative care conversations with their patients. (*Annotations #1, 2; Aim #1*)
- Health care providers should complete a systematic review of patients' palliative care needs and document patients' goals for care and advance directives. (*Annotations #3, 4-9; Aims #3, 6*)
- Suffering is common in this patient population. It commonly presents itself in physical symptoms; thus, controlling symptoms to maximize patient comfort is a cornerstone function of palliative care. Also important are the recognition, assessment and management of non-physical areas of suffering that are important to the patient. These include cultural, psychological, social, spiritual, financial, ethical and legal issues. Where available, consultation with palliative care specialists should be considered for all of these symptoms. (*Annotations #4-9; Aim #3*)
- The ability to address these issues depends on the quality of communication with patients and families. Setting realistic goals of care and providing realistic hope are essential. Engaging patients in decisions about their care increases their involvement and satisfaction. Shared Decision-Making (SDM) is one method to engage patients. (*Annotations #2, 3, 10; Aim #2*)
- Palliative care is compatible with all other medical treatments. (*Introduction*)
- Health care providers play an important role in the grief and bereavement processes by supporting the patient and family throughout the course of illness and following the patient's death. (*Annotation #19*)

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Implementation Recommendation Highlights

The following system changes were identified by the guideline work group as key strategies for health care systems to incorporate in support of the implementation of this guideline.

- Develop a process to provide education to clinicians, patients and families regarding the elements and appropriateness of palliative care. It is important to address the difference between palliative care and hospice.
- Develop a process that will allow clinicians to identify and assess patients who would benefit from palliative care services. This process should include the use of a screening tool that utilizes the domains of palliative care.
- Develop scripts for health care professionals that will assist them in initiating and discussing palliative care services.
- Develop a process for timely referral to palliative care consultation for patients with a serious illness.

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Related ICSI Scientific Documents

Guidelines

- [Assessment and Management of Chronic Pain](#)
- [Heart Failure in Adults](#)
- [Major Depression in Primary Care](#)
- [Management of Chronic Obstructive Pulmonary Disease \(COPD\)](#)

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Definition

Clinician – All health care professionals whose practice is based on interaction with and/or treatment of a patient.

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Algorithm Annotations

1. Patient Presents with New or Established Diagnosis of a Serious Illness

Recommendation:

- Palliative care should begin at the time of diagnosis of a serious condition and continue through cure, or until death and then into the family's bereavement period (*Low Quality Evidence, Strong Recommendation*) (Temel, 2010; Kass-Bartelmes, 2004; Steinhauser, 2000; Morrison, 2004).

Both clinicians and patients generally don't recognize early on those individuals who would benefit from palliative care planning. Early identification of patients with conditions that would benefit from palliative care can be accomplished by considering conditions and symptoms that are appropriate for palliative care services.



An initiative of the ABIM Foundation The following *Choosing Wisely*[®] recommendation from the American Academy of Hospice and Palliative Medicine is in alignment with the above ICSI Palliative Care guideline recommendation:

Don't delay palliative care for a patient with serious illness who has physical, psychological, social or spiritual distress because they are pursuing disease-directed treatment. Numerous studies – including randomized trials – provide evidence that palliative care improves pain and symptom control, improves family satisfaction with care and reduces costs. Palliative care does not accelerate death, and may prolong life in selected populations.

<http://www.choosingwisely.org/doctor-patient-lists/american-academy-of-hospice-palliative-medicine/>

General considerations clinicians should use to identify patients who would benefit from palliative care include:

- disease progression, especially with functional decline;
- pain and /or other symptoms not responding to optimal medical treatment; and
- need for advance care planning.

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Algorithm Annotations

Conditions that may prompt the initiation of palliative care discussions include these (this is not intended to be an all-inclusive list):

Debility/Failure to Thrive	<ul style="list-style-type: none"> • Greater than three chronic conditions in patient over 75 years old • Functional decline • Weight loss • Patient/family desire for low-yield therapy • Increasing frequency of outpatient visits, emergency department visits, hospitalizations
Cancer	<ul style="list-style-type: none"> • Uncontrolled symptoms due to cancer or treatment • Introduced at time of diagnosis – if disease likely incurable • Introduced when disease progresses despite therapy
Heart Disease	<ul style="list-style-type: none"> • Stage III or IV heart failure despite optimal medical management • Angina refractory to medical or interventional management • Frequent emergency department visits or hospital admissions • Frequent discharges from implanted defibrillators despite optimal device and antiarrhythmic management
Pulmonary Disease	<ul style="list-style-type: none"> • Oxygen-dependent, O₂ sats less than 88% on room air • Unintentional weight loss • Dyspnea with minimal to moderate exertion • Other pulmonary diagnoses, e.g., pulmonary fibrosis, pulmonary hypertension
Dementia	<ul style="list-style-type: none"> • Refractory behavioral problems • Feeding problems – weight loss • Caregiver stress – support needed • Frequency of emergency department visits • Increased safety concerns
Liver Disease	<ul style="list-style-type: none"> • Increased need for paracentesis for removal of ascitic fluid • Increased confusion (hepatic encephalopathy) • Symptomatic disease
Renal Disease	<ul style="list-style-type: none"> • Dialysis • Stage IV or Stage V kidney disease
Neurologic	<ul style="list-style-type: none"> • Stroke • Parkinson's • ALS – amyotrophic lateral sclerosis • MS – multiple sclerosis

Many residents in long-term care facilities and patients with poor social support have these symptoms and should be assessed for palliative care.

Unfortunately, accurately predicting death can only be identified by retrospective measures. Multiple studies have shown that physicians overestimate prognosis by a factor of two or more. The medical literature also shows that patients with terminal illness often don't recognize that they are dying, or are unable to acknowledge the fact even to themselves until very late. Life-limiting illness is usually defined as the question "*Would you be surprised if your patient died within the next two years?*" This definition significantly broadens the identified population associated with hospice care to those who would benefit from palliative care. Appropriate medical interventions need to address suffering that occurs due to pain, and other physical symptoms, and psychological issues. Other domains that should be addressed by an interdisciplinary team include cultural, spiritual, ethical, legal and social issues. The care plan created includes the caregivers and family (*National Consensus Project, 2009 [Guideline]; National Quality Forum, 2012 [Guideline]*). Palliative care can occur simultaneously with curative therapies, or may be the sole focus of care.

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2. Initiate Palliative Care Discussion

Recommendations:

- Palliative care discussion or referral should be considered whenever a patient develops a serious illness (*Low Quality Evidence, Strong Recommendation*) (Strand, 2013; Weissman, 2011).
- Palliative care discussions should be included wherever a patient with a life-limiting illness presents, including the intensive care unit and the emergency department (*Low Quality Evidence, Strong Recommendation*) (Quest, 2013).

While all patients who develop a serious illness can benefit from a palliative care approach, currently work-force shortages and resource constraints present barriers to meeting all needs. In some diseases like cancer, involving palliative care at the time of diagnosis is becoming a measure of clinical excellence. Efforts are also underway in several areas to regularly initiate advance care planning at age 50 (See Resources, Honoring Choices Minnesota). For many patients, a hospital admission is a common trigger to consider a palliative care discussion or referral. A recent consensus panel convened by the Center to Advance Palliative Care developed primary and secondary criteria for two checklists – one upon admission and one for daily rounds – to be used to screen patient for unmet palliative care needs (Weissman, 2011 [*Low Quality Evidence*]). The hope is that a checklist approach combined with educational initiatives and other system-change work will allow hospital staff and clinicians engaged in day-to-day patient care to identify and begin to address palliative care needs themselves while reserving specialty palliative care services for more complex problems.

A proactive approach to communication with patients and family members can lead to decreased length of stay, increased team and family consensus on goals of care and high levels of family satisfaction (Strand, 2012 [*Low Quality Evidence*]). While each care setting may come with its own unique challenges, early communication with a palliative focus will greatly increase the quality of care (Quest, 2013 [*Low Quality Evidence*]).

*Criteria for a Palliative Care Assessment at the Time of Admission

A potentially life-limiting or life-threatening condition and . . .

Primary Criteria^a

- The “surprise question”: *You would not be surprised if the patient died within 12 months or before adulthood*
- Frequent admissions (e.g., more than one admission for same condition within several months)
- Admission prompted by difficult-to-control physical or psychological symptoms (e.g., moderate-to-severe symptom intensity for more than 24–48 hours)
- Complex care requirements (e.g., functional dependency; complex home support for ventilator/antibiotics/feedings)
- Decline in function, feeding intolerance, or unintended decline in weight (e.g., failure to thrive)

Secondary Criteria^b

- Admission from long-term care facility or medical foster home
- Elderly patient, cognitively impaired, with acute hip fracture
- Metastatic or locally advanced incurable cancer
- Chronic home oxygen use
- Out-of-hospital cardiac arrest
- Current or past hospice program enrollee
- Limited social support (e.g., family stress, chronic mental illness)
- No history of completing an advance care planning discussion/document

^aPrimary Criteria are global indicators that represent the minimum that hospitals should use to screen patients at risk for unmet palliative care needs.

^bSecondary Criteria are more-specific indicators of a high likelihood of unmet palliative care needs and should be incorporated into a systems-based approach to patient identification if possible.

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***Criteria for a Palliative Care Assessment During Each Hospital Stay**

A potentially life-limiting or life-threatening condition *and* . . .

Primary Criteria^a

- The “surprise question”: *You would not be surprised if the patient died within 12 months or did not live to adulthood*
- Difficult-to-control physical or psychological symptoms (e.g., more than one admission for same condition within several months)
- Intensive Care Unit length of stay ≥ 7 days
- Lack of Goals of Care clarity and documentation
- Disagreements or uncertainty among the patient, staff, and/or family concerning . . .
 - major medical treatment decisions
 - resuscitation preferences
 - use of nonoral feeding or hydration

Secondary Criteria^b

- Awaiting, or deemed ineligible for, solid-organ transplantation
- Patient/family/surrogate emotional, spiritual, or relational distress
- Patient/family/surrogate request for palliative care/hospice services^c
- Patient is considered a potential candidate, or medical team is considering seeking consultation, for:
 - feeding tube placement
 - tracheostomy
 - initiation of renal replacement therapy
 - ethics concerns
 - LVAD^d or AICD^e placement
 - LTAC^f hospital or medical foster home disposition
 - bone marrow transplantation (high-risk patients)

^aPrimary Criteria are global indicators that represent the minimum that hospitals should use to screen patients at risk for unmet palliative care needs.

^bSecondary Criteria are more-specific indicators of a high likelihood of unmet palliative care needs and should be incorporated into a systems-based approach to patient identification if possible.

^cThese matters are included based on a consensus panel opinion.

^dLVAD = Left ventricular assist device.

^eAICD = Automated implantable cardioverter-defibrillator.

^fLTAC = Long-term acute care hospital.

* Used with permission from Mary Ann Liebert, Inc. Publishers, 2013.

Many clinicians believe they lack confidence and experience in discussing with patients the issues and decisions that come with having a serious illness – specifically recommendations about palliative care and hospice services. This may involve delivering “bad news,” as well as answering questions that may not have specific answers. A useful definition of “bad news” is information that “results in a cognitive, behavioral, or emotional deficit in the person receiving the news that persists for some time after the news is received” (*Ptacek, 1996 [Low Quality Evidence]*). Another definition of bad news is “any news that drastically and negatively alters the patient’s view of her or his future” (*Buckman, 1984 [Low Quality Evidence]*). Implicit in these definitions is that a terminal diagnosis is not the only form of bad news; it may also refer to disclosing the diagnosis of a serious chronic condition such as multiple sclerosis, ultrasound-verified fetal demise to a pregnant woman, and other scenarios.

In the absence of more formal education, the more a clinician prepares for discussions surrounding palliative care and puts that preparation into practice, the more skilled and comfortable that clinician can become in this aspect of medical care.

There are several excellent mnemonics available to help clinicians increase their knowledge, practice examples of these discussions, and generally obtain a better understanding of the emotions, questions and problems that may arise with patients and families at this time in their lives.

One mnemonic found useful for this guideline includes:

- ABCDE (Advance preparation, Build a therapeutic environment/relationship, Communicate well, Deal with patient and family reactions, Encourage and validate emotions) (*Vandekieft, 2001 [Low Quality Evidence]*)

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Algorithm Annotations

Advance preparation: Obtain the patient's medical information and test results, if possible, so that you are fully aware of the situation. Mentally rehearsing the way you wish to present the information and options can give you a sense of how the conversation may go. Remember to individualize your approach for each patient and family based on how much they know at that point and how they prefer to receive information. Make sure that you have an appropriately private location in which to have the discussion, and that the session will be free of interruptions, including setting the pager to silent or leaving it with a colleague.

Build a therapeutic environment/relationship: Try to find out how much the patient and family understands, how they want to be told (bluntly, gently, etc.), and how much they want to know at that time.

- "If this condition turns out to be something serious, are you the kind of person who likes to know what is going on?"
- "Would you like me to tell you the full details of the diagnosis?"
- "If your condition is serious, how much would you like to know?" If the patient indicates that he/she does not want any information, it is important to "leave the door open." For example you may say, "That's OK. If you change your mind, at any time, please feel free to talk to me or one of my colleagues."
- Have family members or friends present as per the patient's preference, and take time to learn names and relationships of each support person present. Use touch and humor where appropriate, taking into consideration your relationship with the patient. Reassure the patient of your availability, set up follow-up appointments, and contact other clinicians about the situation where appropriate.

Communicate well: Ask the patient for any questions. Speak truthfully but compassionately and avoid using medical terms or euphemisms. Say the words "cancer," "dying," "death," etc. Although a care clinician may be uncomfortable with these terms, they help with clarity of communication and accurate understanding by the patient and family of what is being said.

Adapt the communication style to the education level and personal preference of the patient and family. For example, if the patient is a company executive who is used to calling the shots, this person may benefit more if provided with several different options to choose from rather than being told what to do. If the education level and preferred style are unknown, a good rule of thumb is to present information at a sixth through eighth grade level.

Don't rush the process; allow time for silence, tears and questions. This allows the patient and family (if present) time to react to the news and to discuss concerns of the patient, and allows the patient to receive the news at his or her own pace (*Ellis, 1999 [Low Quality Evidence]*). Remember that the patient may not retain much of the information given beyond that of the diagnosis or prognosis, and may have to wait to "digest" what information can be absorbed. Strong emotions elicited in difficult conversations may distract the patient from hearing the full communication. Repeat important points, write things down and periodically assess the patient's understanding of the information and reactions to what was heard. Think out loud; help the patient and family feel they are part of the team. Visual aids, written question prompts (suggesting possible questions that a patient or family may want to ask), and the provision of audio tapes of the conversations may aid communication and recall of important points.

Communicate any bad news to the patient and family. The clinician may want to deliver a "warning" statement prior to the bad news itself to prepare the patient (and family if present) for the communication that follows. For example, "I'm afraid I have (difficult/bad) news to share on (your/his/her) condition." Additionally, it may be advisable to ask a few open-ended questions prior to delivering the actual bad news to assess what the patient and family already know and their readiness to hear the news (*Baile, 2000 [Low Quality Evidence]*).

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Algorithm Annotations

The following questions are examples of inquiries that should be utilized in every palliative assessment to ensure cultural awareness:

- "Some people want to know everything about their medical condition, and others do not. What is your preference?" (Identifies preferences regarding disclosure of information)
- "Do you prefer to make medical decisions about future tests or treatments for yourself, or would you prefer that someone else make these decisions for you?" (Identifies locus of decision-making)
- "What do you think caused this illness to happen?" "Why do you think it started when it did?" (Identifies perspectives on death, suffering and grieving)
- "What do you fear about this sickness?" (Identifies perspectives on death, suffering and grieving)
- "What kind of treatment would you prefer to receive at this point?" (Perspectives on physical care)
- "What are the most important results you hope to receive from this treatment?"
- "Do you have other hopes or fears related to your illness?"

Deal with patient and family reactions: Be sensitive to the emotional reactions of the patient and family. Recognize that denial, blame, intellectualization, disbelief and acceptance may be present to varying degrees and time frames. Watch for signs of depression and suicidality in subsequent visits. Be empathetic. Crying may occur but make sure that your tears are empathic in nature and not reflective of personal issues on your part. There may be anger from the patient and family about care received from you or another colleague; resist becoming defensive or argumentative about these issues. Try to deal with that particular patient's and family's cultural and ethnic norms.

- "I was probably raised differently than you. Can you tell me how your family deals with these situations?"

Encourage and validate emotions: During the discussion, periodically ask the patient and family how and what they are feeling, and respond with empathy. If the patient (and family if present) is ready, discuss treatment options and arrange for follow-up to put those options into action. Talk with the patient about what this means for him/her, and what needs outside of the traditional medical scope he/she may have. It is important that the patient and family do not lose their sense of hope. Offer realistic hope. Communicating hope, even though a "cure" may not be possible, may be done by redirecting the focus of hope to keep the patient comfortable and as symptom-free as possible. Reassure the patient that every effort will be made to promote comfort, dignity and quality of life as defined by the patient.

- "I know this is not what you were hoping to hear."
- Don't say, "*There is nothing more we can do*"; instead say, "What we are going to focus on now is ___ (comfort, pain relief, etc.)" (*Baile, 2000 [Low Quality Evidence]*).

Additional considerations pertaining to the initial discussion between clinician, patient and family (based on expert consensus) include the following:

- Discussing prognosis is a difficult issue, and little attention is given to this issue in most training programs, leaving clinicians relatively unprepared to handle this task. The prognosis for a patient is based on multiple factors with complex interactions, including diagnoses, medications and therapeutics, social issues, functional status, patient preferences, and clinician knowledge and experience. The communication of prognosis should be individualized to the needs and desires of the particular patient and family. As mentioned elsewhere, clinicians tend to significantly overestimate prognosis, which may lead to delays in palliative treatments in favor of unnecessary curative or invasive treatments. Clinicians may build additional trust by acknowledging limitations in providing a prognosis. It may be best to provide a range of dates or times, or tie prognoses to hypothetical situations.

- Encourage continual communication for status updates, to assess comprehension of information, and to respond and empathize with new emotions as they come up.
- Coordination of communication is essential among clinicians, especially when there is a change in care setting or a transfer to another facility such as skilled nursing or home care, as patient preferences may not be known to the clinicians in the new setting.
- Document details of all discussions in the medical record.

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3. Assess Patient's Palliative Care Needs Based on the Following Domains of Palliative Care

Recommendations:

- Clinicians should use a validated assessment tool to assess palliative care needs (*Low Quality Evidence, Strong Recommendation*) (Moro, 2006; Chang, 2000; Phillip, 1998).
- Care conferences with the patient, family and an interdisciplinary team are recommended on an ongoing basis to discuss patient's condition, course of illness, treatment options, goals and plan of care (*Low Quality Evidence, Strong Recommendation*) (Gries, 2008; Moneymaker, 2005; McDonagh, 2004; Curtis, 2001).

Perform a thorough assessment based on the domains of palliative care and address needs, values and resources of the patient and family.

It is important, especially in the development of recommendations for care of patients' palliative care and end-of-life needs, that there is recognition of patient autonomy in choosing care. One goal of this annotation is to discuss how clinicians can create an environment in which the needs of the patient, based on a comprehensive assessment, are fully considered. Only then can a reasonable determination be made of what services are required to meet the physical, psychological, social, cultural, legal/ethical and spiritual needs of patients and their families. Clinicians recognize that assessment of these domains of care is important to a patient's care but, in a busy practice, may find it difficult to address all domains. The work group recognizes this and suggests that clinicians could incorporate key aspects of palliative assessment with existing assessment processes. They also encourage using a team approach. Routine assessment has been shown to identify symptoms that may otherwise have been overlooked or unreported, facilitate treatment and treatment planning, and enhance patient and family satisfaction.

For patients to make informed choices regarding palliative care, it is important for both patient and clinicians to have a realistic understanding of the options available. The patient must have the capacity to understand the choices available, especially when some of the choices are not likely to benefit the patient to any great extent. Further, it should be recognized by clinicians and communicated to patients that the realistic choices available for care may change as the patient's medical condition changes. Accordingly, assessment of palliative care needs will necessarily be ongoing and may require at some point, if the patient's decision-making capacity is impaired, the assistance of family or other well-informed surrogates to provide the information needed to assess the patient's ever-changing palliative care needs. The role of surrogate for assessment of patient condition and expression of patient wishes should be anticipated at the time of initial assessment and care planning. Bringing together, as much as possible, those who may impact decision-making should be integral to the initial plan of care development. Careful clarification for all present at initial care planning will help anticipate and prevent discord as the patient and surrogate(s) make future care choices. The initial meeting for care planning is also useful for identifying availability and limitations of caregivers and other resources for meeting patient needs in implementing the plan of care.

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When discussing goals of care or a patient's end-of-life wishes, the "ask – tell – ask" model provides a useful and effective structure for such conversations. In this model, clinicians begin by asking patients and/or family members what they already know about the clinical situation (e.g., "What have the doctors told you about your illness?"). Clinicians can then add additional clinical information as needed or clarify any misconceptions, remembering to use plain, everyday language instead of "medicalese" (e.g., say "The cancer has spread" rather than "The cancer has metastasized"). Clinicians should always assume patients and family member have questions instead of asking whether they do (e.g., don't ask "Do you have any questions?" but rather ask "What questions do you have?") Finally, clinicians should ask the patient and/or family to restate the information discussed to assess their understanding. This can be normalized by saying "To make sure I did a good job explaining everything, can you tell me, in your own words, what we just talked about (or decided)?" (*Smith, 2009*) [*Low Quality Evidence*].

Patient and family expectations, goals for care and for living (quality of life), understanding of the disease and prognosis, as well as preferences for the type and site of care should be assessed and documented. This assessment needs to be reviewed on a regular basis, with consideration given to the patient's capacity to represent himself/herself. Also see [Annotation #10, "Develop or Revise Palliative Care Plan and Establish Goals of Care Through the Process of Shared Decision-Making."](#)

Among the available assessment tools, it was the decision of this work group to recommend the Edmonton Symptom Assessment System (ESAS) because it is thorough yet simple in clinical application, it has a robust evidence-based foundation for validation in various clinical settings, and is readily available via the Internet.

As patient and clinician conditions change, there may be need for change of site or clinicians of care. It is helpful in care planning if the community has a uniform system to communicate patient wishes so that the continuity of care makes a smooth transition between clinicians in these circumstances. In this regard, communitywide agreement on recognition of particular advance directive forms and Clinician/Provider Orders for Life-Sustaining Therapy (POLST) enhances the quality of care available. See [Annotation #9, Ethical and Legal Aspects of Care.](#)

See the Quality Improvement Support "[Implementation Tools and Resources Table](#)" section for the POLST and ESAS Web sites.

Documentation of the goals of care, patient preferences and advance directive in an electronic medical record promotes accessibility and portability across care settings.

Clinicians should be aware of their individual state, provincial or national forms and requirements.

Care conferences

Patient and family meetings or care conferences allow the treatment team an opportunity to meet with the patient and/or family to discuss the patient's diagnosis, condition, course of illness and treatment options and to answer questions and establish both the goals and plan of care. The level of formality of these conferences is likely to vary depending on the focus or goals. These conferences may involve the primary clinician and part of the care team or the entire team.

Most guidelines for care conferencing are based on expert recommendations. Family counseling literature and studies of giving bad news and end-of-life discussions form the basis for these expert recommendations.

A step-by-step model for care conferences outlines four goals for a family meeting or conference. These goals focus on:

- gaining knowledge of the person experiencing the illness and understanding this person's goals,
- promoting communication between the care team and patient/family,

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- decreasing stress and suffering by reviewing realistic goals and establishing a realistic plan that aligns with these goals, and
- establishing trust and support to work with the patient/family throughout the course of illness.

Incorporating time for this assessment can be done in either the inpatient, outpatient or home settings. In the inpatient setting, this assessment may be done by the palliative care team or by the clinician during daily rounds. In the outpatient setting, this assessment can be accomplished over a series of visits or during an extended visit. In the home setting, this can be accomplished in one or more home visits.

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4. Physical Aspects of Care

Recommendation:

- The physical aspects of the patient's serious illness should be an integral component of the palliative care plan (*Low Quality Evidence, Strong Recommendation*).
- The *Choosing Wisely*[®] campaign includes recommendations regarding the care of patients who have a serious illness. See [Appendix A, "Choosing Wisely Recommendations Regarding Palliative Care."](#)

The control of physical symptoms is an important part of the palliative care plan. Common symptoms include, but are not limited to, pain, anorexia and cachexia, constipation, delirium, diarrhea, dyspnea and secretion, fatigue, agitation, nausea and vomiting, cough, fever, gastroesophageal reflux disease, hiccups, ascites and pleural effusions, skin and wound care, pruritus, sleep disturbances and insomnia, urinary incontinence and urinary retention.

Each patient should be frequently evaluated for these issues. Therapy should be individualized for each patient's unique circumstances.

The work group recognizes that there is not a single order set that covers all patient situations. Multiple sources are available to assist in symptom management. Some possible resources include but are not limited to:

The Institute for Palliative Medicine: <http://www.palliativemed.org>

http://www.stoppain.org/palliative_care/content/symptom/pain.asp

Fast Facts: <http://www.EPERC.mcw.edu/EPERC/FastFactsandConcepts>

Pain

Control of pain in order to improve quality of life is an important aspect of palliative care. However, the approach toward pain management in palliative care is different from those of chronic pain and acute pain management. While cures of underlying disease may still be possible, they may no longer be the primary goal, because of life-limiting illness. Disease progression may necessitate increased dosing of opioids to control pain; this should not be confused with "tolerance." In fact, when a patient with previously well-controlled pain develops the need for increasing opioid doses to achieve comfort, advancing illness is almost always the cause (*Emanuel, 1999 [Low Quality Evidence]*).

Pain is a subjective symptom; there is no test to measure pain. Pain is what the patient says it is, and it needs to be addressed adequately in order to improve quality of life. The patient, along with family members, should be actively involved in establishing the goals of palliative pain management.

Opioid rotation, especially for patients with cancer, should be considered when opioid side effects are difficult to manage or if inadequate analgesia is present. If symptoms of delirium and confusion are present and are attributable to opioids, a switch to a different opioid may be advisable.

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5. Cultural Aspects of Care

Recommendations:

- A cultural assessment should be an integral component of every palliative care plan (*Low Quality Evidence, Strong Recommendation*) (Smith, 2009; Kemp, 2005; Searight, 2005; Kagawa-Singer, 2001).
- Clinicians should follow the established best practices of utilizing professional medical interpreters when English is not a patient's first language or when there are gaps in understanding English (*Low Quality Evidence, Strong Recommendation*) (Norris, 2005; Searight, 2005).

Culture has been defined as "the learned and shared beliefs, values, and life ways of a designated or particular group which are generally transmitted inter-generationally and influence one's thinking and action modes" (Leininger, 1985 [*Low Quality Evidence*]). The cultural assessment promotes patient/family-centered decision-making as well as offers the opportunity to identify care preferences. Cultural decisions affecting palliative care also include attention to gender, age, generation, education level, diet/food and ritual. Clinicians should ask the patient/family about these considerations, and keep in mind that every patient conversation is a *cultural conversation*.

For many individuals seeking health care, the vocabulary, structure and process of decision-making in medicine is complex to understand and integrate. Clinicians may underestimate the striking differences between the culture of medicine and the distinct beliefs and traditions that patients may value.

As palliative care providers, clinicians must evaluate their services, policies and procedures to maximize cultural and linguistic accessibility and responsiveness to changing multicultural populations (*National Consensus Project, 2013 [Guideline]*). Seeking input and integrating changes in how care is delivered are two of the most responsible actions we can do as well-meaning health care providers.

Core principles of the cultural aspects for care:

- Culture plays a significant role in shaping the way people make meaning of illness, suffering and dying. Culture helps guide decisions about what kind of care a patient chooses to receive, who it should be provided by and under what conditions. It is important to avoid stereotyping. There are, in fact, wide variations in beliefs, attitudes and behaviors within and between every cultural group (Smith, 2009 [*Low Quality Evidence*]).
- Literacy plays a critical role in cultural competency. Many individuals do not read or write in their spoken language. Therefore, simply translating materials into another written language is of little value for individuals who have never learned to read or write in their spoken language. Using easily understood videos with clear verbal messages and actions is often more effective when confronting literacy barriers.
- Among many populations, factors outside of medical technology such as a divine plan and personal coping skills, may be more important for survival than physician intervention (Smith, 2009 [*Low Quality Evidence*]). Identifying current spiritual or other leaders to help navigate patient/family beliefs and values is often helpful when exploring culture-based decision-making. Conversations with these trusted individuals may help give perspective and bridge gaps in trust between the medical community and the patient/family.

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Guidelines for multicultural patient/family communications

The following recommendations are suggested for clinicians in patient/family communications:

- Use non-verbal forms of education such as drawing, showing pictures or easily understood videos.
- Understand that not all tools (such as pain scales) are universal and that clinicians should use terms that are culturally relevant.
- Avoid using jokes or humor because they may be misunderstood or considered offensive.
- Be sensitive to the roles that gender, age, generation and education play in patient-to-clinician communications.
- Always ask if there are other family/extended family members who should be included in the conversation. It's important to have the necessary people present in health care discussions.
- Address adults formally (Mr., Mrs. or Miss) rather than by their first name. This action demonstrates respect. Individuals can later ask you to use their first name if they prefer.
- Ask open-ended questions that engage and provide clues about patient beliefs and understanding. "Tell me what you believe about your illness" vs. "Do you have any questions about your illness?"
- Review patient education materials for cultural diversity and awareness. Do resources include professionals and persons of color? Are persons of different generations included? Are extended families depicted that include members other than a simplistic "nuclear" family?
- Address dietary/food preferences.
- Address preferences regarding physical care of the deceased, including funeral and burial rituals.

Guidelines for using professional medical interpreters

The following recommendations are suggested for clinicians utilizing professionally trained medical interpreters:

- Meet briefly with interpreters prior to and after delivery of bad news or difficult discussions to help prepare the interpreter and to allow the interpreter to provide information about the patient, family and culture.
- Establish with the interpreter, patient and family members at the outset of a conversation or care conference that everything spoken will be translated word for word.
- After making a complete statement, clinicians should pause to allow for the translation.
- Clinicians should speak to and look at the patient/family rather than the translator. "Where is your pain?" rather than "Can you ask him where he hurts?"
- Consider meeting with the interpreter after health care discussions to allow for any necessary debriefing.
- Establish a strong working relationship with professional medical interpreter companies.

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6. Psychological and Psychiatric Aspects of Care

Recommendation:

- A psychological assessment should be an integral component of the palliative care plan (*Low Quality Evidence, Strong Recommendation*) (Bakitas, 2009; Chochinov, 2006; Werth, 2002; Block, 2000).

It may seem obvious to say psychological and emotional issues are present near the end of life, but too often these issues and their symptoms go undetected and untreated. For example, anxiety disorders in terminally ill cancer patients range from 15 to 28%, and approximately 25% of all cancer patients will experience severe depressive symptoms, with increasing symptoms as the disease progresses. This further burdens patients and may prolong suffering and undermine their quality of life. Routine ongoing assessment of a patient's psychological status is critical to provide quality palliative care.

Pain and other physical symptoms are commonly the initial focus of treatment. Psychosocial issues are more difficult to evaluate and address if the patient has distressing or poorly controlled physical symptoms (Strickland, 2004 [*Low Quality Evidence*]).

Patients come to advanced illness with issues of worry, insomnia, panic, anxiety, nervousness, paranoia and lack of energy. Psychological symptoms may also present as physical symptoms such as pain, constipation, nausea and vertigo. Difficulty in improving physical symptoms should lead one to look at psychological or other causes. Clinicians must be aware of psychological symptoms of depression and anxiety. Use of standardized assessments to diagnose (e.g., PHQ-9) may be helpful; however, no screening tool for depression has been validated for palliative care. Questions like "How are you coping?" "What are you doing to cope?" "Are you having trouble thinking?" "Are you depressed?" "Do you think about ending your own life?" or "Do you feel your situation is hopeless?" are good questions. Refer to the ICSI [Adult Depression in Primary Care](#) guideline for more information about depression and the depression assessment tool (PHQ-9).

Affective disorders such as anxiety and depression are common in seriously ill patients, and they adversely affect their quality of life. Not only they can cause physical symptoms such as nausea, dyspnea and insomnia, but conversely, experiencing such symptoms can exacerbate anxiety, as well. Under treated pain can exacerbate psychological distress. Some recent data suggest that depression is associated with a higher risk of death in cancer patients, as well as decreased treatment adherence, longer hospital stays, reduced quality of life and requests to hasten death.

Anxiety can contribute to suffering and decreased quality of life. The anxiety may be due to medications, social, psychological or unidentifiable reasons, fears or pain. Anxiety may result in insomnia, gastrointestinal upset, dysphagia, fatigue, palpitations, diaphoresis, fear and isolation, and may escalate as disease progresses. Patients with a history of panic disorder, phobia, obsessive-compulsive disorder or other anxiety disorders will have an increased risk of symptoms of anxiety. Causes of anxiety should be identified and treated if possible. Physical and emotional issues should be addressed. Social and spiritual resources should be utilized. Frank discussions of fears may help alleviate anxiety.

It is important to differentiate grief from depression. Grieving can be an appropriate response to loss, but persistence of the symptoms mandates consideration of depression. Simply asking a patient, "Are you depressed?" can be a useful screening tool and provides a reasonably sensitive and specific assessment of depression in patients with terminal illnesses. This may be preceded by educating the patient about the difference between clinical depression and appropriate reactive feelings to the situation.

The clinicians must inquire if the patient is at risk for suicide. There is no evidence that asking the patient about suicide increases the risk that the patient will carry out his or her plan.

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More information can be found in the following Fast Facts at the Web site <http://www.eperc.mcw.edu>. #07 Depression in Advanced Cancer, #59 Dealing with the Angry Dying Patient, #145 Panic Disorders at the End of Life, and #186 Anxiety in Palliative Care – Causes and Diagnosis provide up-to-date, easy-to-access references for psychological aspects of palliative care.

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7. Social Aspects of Care

Recommendation:

- A social assessment should be an integral component of the palliative care plan (*Low Quality Evidence, Strong Recommendation*) (Gries, 2008; Morrison, 2004; Curtis, 2002).

The comprehensive assessment should include family structure and geographic location; relationships and family dynamics; lines of communication and need for counseling for self and family; existing social and cultural network; perceived social support; medical decision-making/advance directives and quality of life; work and school settings; finances including filing for disability and ability to pay for medications and treatments; sexuality; intimacy; living arrangements; caregiver availability; access to transportation, medications, needed equipment and nutrition; community resources; and legal issues.

The impact of a chronic progressive disabling disease extends beyond the patient to the "family," defined in its broadest sense. Children, spouses, parents, co-workers, friends, neighbors, employers and even health care clinicians are all affected by an individual patient's condition. Financial concerns, caregiver coping, communication with family and friends, and discussion/decision-making on advance treatment plans all fall under the domain of social aspects of care. Lack of knowledge about the social aspects of care influencing the patient can frustrate clinicians regarding decisions or lack thereof that the patient makes. Poor communication among patient, family and clinicians undermines effective decision-making.

The interdisciplinary team of professionals including social workers should have patient-population specific skills in assessment and development of a social care plan. Often the social worker is involved in coordinating the care conference and its attendees. In situations where loved ones are making decisions regarding withdrawal of life support for patients, there are reports that suggest that family members feel more satisfied and supported in the decision-making process where there is a family conference exploring the patient's wishes, clinician's recommendations for withdrawing life support, and assessment of the spiritual care needs of family members. Further information and documents of support can be found at <http://www.capc.org/>. Also see Annotation #3, "Assess Patient's Palliative Care Needs Based on the Following Domains of Palliative Care."

- Make referrals to meet identified social needs and to remove barriers to care. This includes but is not limited to transportation for treatment and appointments, caregiver service options to meet patient's needs at home, counseling, financial resources and community clubs/services for support.
- Understand that advance care planning is rarely fixed in time with specific treatment decisions but rather a dynamic process emerging from the clinical context of the disease and the social context of the patient (Prendergast, 2001 [*Low Quality Evidence*]). Clear and honest communication, trust over time, and working within the patients' most important relationships are needed to improve the quality and outcome of this process.

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8. Spiritual Aspects of Care

Recommendations:

- A spiritual assessment should be an integral part of the palliative care plan (*Low Quality Evidence, Strong Recommendation*) (Post, 2000; Pulchaski, 2000; Reed, 1987).
- Clinicians should utilize clinically trained chaplains as members of the interdisciplinary health care team to provide patient-centered spiritual care and support (*Low Quality Evidence, Strong Recommendation*) (Zhang, 2012; Balboni, 2007).

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred. Given this broad definition, it can be said that everyone is spiritual in one form or another.

Illness and the prospect of dying can impact the meaning and purpose of a person's life. Thus, illness and dying have a spiritual dimension and are often perceived by patients as spiritual experiences. As people face serious illness or death, they often ask questions of meaning, value and relationships such as:

Meaning:

- Why is this happening to me? Why now?
- What is the meaning of my illness, my suffering, my death?
- What will happen to me after I die?

Value:

- Do I still have value despite changes in my appearance, productivity, independence?
- Is there anything valuable about me that will persist beyond death?

Relationships:

- Do I need to forgive or be forgiven by anyone?
- Am I loved? By whom?
- Will I be remembered after I die? Will I be missed?

Other spiritual issues and concerns encountered in palliative care include life review, assessment of hopes and fears, meaning, purpose, beliefs about afterlife, guilt, forgiveness, legacy, and life completion tasks.

It is important for clinicians to attend to patients' spirituality – especially any spiritual concerns, questions or distress. Patients often draw on their spirituality as they make health care decisions and to help them cope with illness and the experience of dying (Balboni, 2007 [*Low Quality Evidence*]). Support of patient's spiritual needs at end of life is associated with better quality of life, increased hospice use and decreased use of intensive care (Zhang, 2012 [*Low Quality Evidence*]; Balboni, 2009 [*Moderate Quality Evidence*]). At times, spiritual and religious beliefs can also at times create distress and increase the burden of illness. Attending to a patient's spirituality can deepen the relationship between patient and clinician, and build trust (Ehman, 1999 [*Low Quality Evidence*]).

All palliative care patients should receive a simple spiritual screening on admission. Spiritual screening is a quick determination of a patient's spiritual resources and concerns. Models of spiritual screening use a few simple questions that can be asked in the course of an overall patient and family interview. Examples of such questions include "Are spirituality or religion important in your life?" and "How well are those resources working for you at this time?" Based on information from the spiritual screening, clinicians can

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identify the presence of spiritual issues (including spiritual distress or spiritual resources of strength) and make the appropriate referrals to chaplains in the inpatient setting or to other spiritual care clinicians in an outpatient setting.

There are a number of spiritual assessment tools created for use by clinicians in the clinical setting. Some of these tools include:

- H:** Sources of hope, meaning, comfort, strength, peace, love, connection
- O:** Member of an organized religion?
- P:** Personal spirituality, practices
- E:** Effects of beliefs on medical care and end-of-life issues

(Anandarajah, 2001 [Low Quality Evidence])

- F:** Do you have spiritual beliefs or faith that has helped you cope with difficult times in the past?
- I:** Are these beliefs important to you, and how do they influence the way you care for yourself?
- C:** Are you involved in a spiritual or religious community or church?
- A:** How would you like your health care clinicians to help you address spiritual issues and concerns?

(Puchalski, 2000 [Low Quality Evidence])

- S:** Spiritual belief system
- P:** Personal spirituality
- I:** Integration with a spiritual community
- R:** Ritualized practices and restrictions
- I:** Implications for medical care
- T:** Terminal events planning

(Maugans, 1996 [Low Quality Evidence])

In addition, clinicians can attend to patient's spiritual needs and concerns in the following ways:

- Offer compassionate presence – strive to be present with and attentive to patients. Relate to patients not only as a professional expert but also as a fellow human being.
- Listen to the patient's fears, hopes, pain and concerns – listening is a powerful healing tool.
- Asking about hope and peace can be a simple, brief, yet effective way to assess spiritual concerns. *(Steinhauser, 2006 [Low Quality Evidence])*
 - Do you have hope?
 - Where does your hope come from?
 - What are you hoping for now as you look ahead?
 - Are you at peace with the care decisions you've made?
 - Do you feel at peace – in your heart, your spirit?
 - Where does peace come from for you?
 - Does that peace come from a spiritual or religious source?

Utilize clinically trained chaplains as members of the interdisciplinary health care team – chaplains are experts in spiritual care. They offer interfaith support to all who are in need and have specialized education

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to mobilize spiritual resources to help patients cope more effectively (*VanderCreek, 2001 [Low Quality Evidence]*). Working with and making referrals to these spiritual care clinicians are important aspects of holistic care.

Clinicians should always be respectful of a patient's spiritual beliefs, should keep spiritual discussions patient centered and should never proselytize or impose beliefs onto a patient.

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9. Ethical and Legal Aspects of Care

Recommendations:

- Clinicians should initiate or facilitate advance care planning for all adult patients and their families with regular review as the patient's condition changes (*Low Quality Evidence, Strong Recommendation*) (*Weissman, 2011; Gries, 2008; Balaban, 2007; Block, 2006; Sinclair, 2006; Lee, 2002; Vandekrift, 2001*).
- Informed consent should be obtained for any treatment or plan of care from either a patient with decision-making capacity or an appropriate surrogate decision-maker (*Low Quality Evidence, Strong Recommendation*) (*Silveria, 2010; Arnold, 2006*).
- Clinicians should recognize those patients who are receiving non-beneficial, low-yield therapy (*High Quality Evidence, Strong Recommendation*) (*Schneiderman, 2003*).

The patient's goals, preferences and choices should form the basis for the plan of care. They should be respected within the limits of applicable state and federal laws. Informed consent for any treatment or plan of care requires a patient with decision-making capacity or an appropriate surrogate decision-maker. Informed consent is based on the principle that patients should be allowed to make decisions for themselves. When a patient lacks this ability, a surrogate is needed.

Note: **Competency** is a legal term referring to a decision made by a judge, although a clinician's opinion carries a large amount of weight in a competency hearing. In contrast, **decision-making capacity** (aka decisional) refers to a clinician's determination, based on clinical examination, whether a patient is able to make medical decisions relative to the discussion for themselves. Most state power of attorney for health care documents require a clinician to document that a patient has lost decision-making capacity for the surrogate to become the legal agent for medical decisions.

To be deemed **decisional**, a clinician must be satisfied that a patient is able to:

- receive information (e.g., must be awake, but not necessarily oriented);
- evaluate, deliberate and mentally manipulate information; and
- communicate a treatment preference (i.e., the comatose patient by definition is not decisional).

Decision-making capacity is:

Understanding. Does the patient truly understand the information about the risks, benefits and alternatives of what is being proposed? The patient does not have to agree with your interpretation but should be able to repeat what you have said. Ask, "**Can you repeat to me the options for treatment I have just discussed with you?**" "**Can you explain to me why you feel that way?**"

Task specific. Deciding if the patient is decisional means weighing the degree to which the patient has decision-making capacity against the objective risks and benefits to the patient. Some decisions are more complex than others, requiring a higher level of decision-making capacity. Thus, a moderately demented

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patient may be able to make some decisions (e.g., antibiotics for pneumonia) but not others (e.g., chemotherapy for colon cancer). This sliding scale view of decisionality holds that it is proper to require a higher level of certainty when the decision poses greater risk.

Logical. Is the logic the patient uses to arrive at the decision "not irrational"? One wants, as much as possible, to make sure the patient's values are speaking, rather than an underlying mental or physical illness. Note: Severe depression or hopelessness may make it difficult to interpret decisionality; consult psychiatry for assistance with this or other complex cases.

Time specific. When encephalopathic, a patient may not be decisional, while after treatment, decisionality may be regained.

Consistent. Is the patient able to make a decision with some consistency? This means not changing one's mind every time one is asked. Is the decision consistent with the patient's values? If there is a change in the patient's values, can the patient explain the change?

(Arnold, 2006 [Guideline])

Advance Care Planning

There has been conflicting data on the influence of advance directives on health care spending. In a study using Health Retirement Study data – including Medicare claims data and interviews of relatives of decedents, as well as information on regional health care spending from the Dartmouth Atlas – evidence showed that in high health care spending regions, individuals with an advance directive limiting treatments at end of life were less likely to die in a hospital, more likely to receive hospice care and generated lower Medicare end-of-life care costs (*Nicholas, 2011 [Low Quality Evidence]*). Studies have shown that those who die at home and those enrolled in hospice programs have improved quality of life and symptom control. This suggests that for individuals who wish to limit treatments at the end of life, it is particularly important to document those preferences, if one's wishes vary considerably from the norms in one's area of residence.

While the process of advance care planning often results in the completion of a written health care directive, the main focus of advance care planning is on the discussion between the patient and health care agent regarding the patient's wishes. Written advance directives are legal in every state; however, laws and forms vary from state to state. See the [Implementation Tools and Resources Table](#) for additional information regarding advance directives. It is important to remember that travelers should be aware of differing laws in whichever state they plan to travel, and bring a copy of their document with them so that they may present their health care directive to a facility where they intend to receive medical care.

Advance care planning always consists of conversations among patient, family and clinician about who should make decisions if the patient is unable, and what type of care the patient desires. It is recommended to document that plan with a legal advance directive and/or POLST.

Legal advance directive consists of:

- Designation of a **health care agent** (aka durable power of attorney for health care, health care agent, etc.) – The patient appoints someone to make decisions about his/her medical care if he/she cannot make those decisions. Ongoing communication between the patient and his/her health care agent is imperative so that the agent can participate fully as an advocate when the patient is no longer able to communicate.
- Writing a formal **health care directive** – a written document in which a patient's wishes regarding the type or extent of medical treatment to be administered or withheld are described. A DNR form is not a sufficient health care directive. A health care directive goes into effect only when the patient becomes unable to communicate his/her preferences.

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There are programs designed to support and spread the use of advanced care planning (*Schwartz, 2002 [High Quality Evidence]*). See the [Implementation Tools and Resources Table](#) for more information.

The POLST (Physician/Provider Order for Life-Sustaining Treatment) is designed as a communication tool to translate the patient's advance care plan into clinician orders that clinicians (including EMTs, ER staff and hospitalists) can follow in emergencies and review with patients and families at transitions of care. It is becoming more widespread in its acceptance in many parts of the country and has been translated into several languages. POLST was developed as an advance care planning document to be completed by health care clinicians together with a patient or surrogate decision-maker. The actual form should consist of these sections:

- Resuscitation decision
- Medical intervention decisions
- Antibiotics
- Medically administered nutrition
- Signatures from the clinician and if possible, the patient/surrogate

(*Dunn, 2007 [Guideline]*)

The major advantages of the POLST form over standard advance directives is that, when adopted as the community standard, the information is clear, unambiguous, flexible, portable, available across all sites of care, and more likely to be honored by all clinicians when needed (<http://www.polst.org>). The Minnesota Medical Association has adopted a version of POLST for statewide use (<http://www.mnmed.org/portals/mma/pdfs/polstform.pdf>).

Barriers to completing advance directives:

- Many clinicians believe it is not appropriate to begin advance care directive planning on an outpatient basis. In reality, multiple studies have shown that **patients want their clinicians to discuss advance care planning** with them **before** they become ill. Many others have shown a positive response from patients when advance directive discussions are held during outpatient visits.

Overcoming this barrier: When beginning a discussion of advance care planning, simply ask, "Do you know what an advance directive is? Do you have one?" If you are afraid the patient may respond negatively, perhaps saying to you, "Is there something wrong with me? Am I sicker than you are letting on?" respond by saying, "I ask all of my patients this question, sick or well." The Patient Self-Determination Act of 1991 mandates that every person be asked about advance directives when first seen (inpatient and outpatient).

- Many people believe that if a loved one has financial power of attorney, he/she doesn't need a separate medical power of attorney. This is not true. **Most often these are separate legal roles.**

Overcoming this barrier: When discussing power-of-attorney with your patient, assess his/her understanding. Have literature in your office to clear up discrepancies.

- Many clinicians and patients feel that having an advance directive means "Don't treat." Unfortunately, advance directives can be a trigger for disengagement by the clinicians.

Overcoming this barrier: Make sure your patient and staff understand that advance directives don't mean "Don't treat me" but **instead "Treat me the way I want to be treated."**

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Algorithm Annotations

- Patients often fear that once a person names a proxy in an advance directive, he/she loses control of his/her own care.

Overcoming this barrier: When explaining advance directives to your patients, make sure he/she understand that as long as he/she retains decision-making capacity, he/she retains control of his/her medical destiny. Advance directives become active only when a person cannot speak for himself or herself.

- Many people believe that only elderly people need advance directives.

Overcoming this barrier: The stakes may actually be higher for younger people if tragedy strikes. Use the example of the Terry Schiavo case (a young person who had a tragic accident and left in a vegetative state with no directives) as a trigger to enlighten the discussion. Ask, "What would you want if you were in a similar situation?"

(Warm, 2005 [Guideline])

Eliciting values

Because of the diversity of backgrounds – cultural, educational, other differences – that patients represent, clinicians cannot assume that a patient shares their values.

If an individual has not discussed and documented goals and preferences before the person has become incapacitated, he/she forfeits autonomy, and articulating these devolves to the surrogate. The surrogate then must make a decision that is authentic to the person's values (*Scheunemann, 2012 [Low Quality Evidence]*). Even a thoughtfully crafted health care directive or POLST may be difficult to interpret in a clinical setting, and a surrogate can help clinicians apply a patient's values to the decisions at hand.

Scheunemann, et al. have proposed a framework for eliciting a patient's values from surrogates:

Facilitated values history

- Attend to surrogates' emotions
 - Respect the time surrogates need to process their emotions. The authors cite the NURSE acronym (Name emotion, Understand the emotion, Respect the family, Support the family, Explore the emotion)
- Help surrogates understand their contribution to decision-making
 - Difference between substituted judgment and best interests
- Understand the patient as a person
- Explore specific values and value conflicts
 - Help surrogates prioritize conflicting values
- Summarize the patient's values relevant to the discussion
- Bridge from the patient's values to specific treatment pathways
- Give permission to follow the patient's wishes

Such an approach may assist in resolving misunderstandings and conflicts surrounding difficult decision making, or applying existing health care directives in complex clinical circumstances.

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Non-Beneficial/Low-Yield Therapy (formerly named Medical Futility)

The term "medical futility" has previously been used by clinicians to discuss the appropriateness of a medical treatment option. The public, policy-makers, ethicists and the medical profession have been unable to agree on a clear, concise definition of futility that can be applied to all medical situations. One commonly used definition is that a futile intervention is one that a) is unlikely to be of any benefit to a particular patient in a particular medical situation, and b) will not achieve the patient's intended goals. The sticking point in all futility definitions is the concept of **benefit**, as the perception of benefit is highly subjective. Clinicians, patients and families often have very different views on what is potentially beneficial. Medical futility can be easily misunderstood as health care rationing. While economic issues may impact shared decision-making, the ultimate question is not "How much does this therapy cost?" but rather "Do the advantages of this therapy outweigh the disadvantages in a given patient?"

Clinicians are not legally, professionally or ethically required to offer medically futile treatments, **as defined by the standard of care of the medical community**. Ethics committees, hospitals and local/state medical organizations can provide resources to understand non-beneficial/low-yield therapy and professional responsibilities in one's practice area. For critically ill patients who ultimately died during hospitalization, Schneiderman has shown lower utilization of ICU resources in patients when ethics consultation occurred (*Schneiderman, 2003 [High Quality Evidence]*).

Most literature on futility is based on the perspective of clinicians. Patients and families may have different perspectives that must be recognized and acknowledged. A multicenter qualitative study, based on semi-structured interviews with surrogate decision-makers for critically ill patients, found that 64% of the surrogates did not fully accept the clinicians' determinations of physiologic futility. They were equally divided between those with religious objections and those who either doubted the ability of clinicians to make these predictions or who needed more information from other sources (*Zier, 2009 [Low Quality Evidence]*).

Reframing the discussion from "futility" or non-beneficial/low-yield therapy to a clarification of goals of care allows the clinician to identify potential disagreement and customize discussions to address these areas.

Suggestions

- Check with your health care institution about the presence of an existing futility policy.
- Avoid using the term "futility" in discussion with patients/families; rather, speak in terms of benefits/burdens of treatment and patient- or family-specific goals of care.
- Involve a palliative care and/or ethics consultant in any situation where "futility" will be invoked as a process step in formulating decisions.

(*Cuezzie, 2006 [Guideline]*)

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10. Develop or Revise Palliative Care Plan and Establish Goals of Care Through the Process of Shared Decision-Making

(See [Appendix B](#) for the ICSI Shared Decision-Making Model.)

Recommendations:

- Clinicians should engage in shared decision-making with the patient and/or their families when establishing or revising goals of care (*Low Quality Evidence, Strong Recommendation*).

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Algorithm Annotations

When shared decision-making and collaborative conversations are used with patients and their families, the following will occur:

- Prognosis, goals of plan of care, and advanced care planning are discussed.
- Patient/family knows the plan of care.
- Patient is provided optimal medical management.
- Care plan has prepared for changes.
- Patient/family knows point person(s).
- Patient/family discusses options.
- Patient is prepared for final days.
- Hospice, other options are discussed.

Use "shared decision-making" when developing or revising the plan of care. Shared decision-making promotes collaboration between the clinician and patient in making treatment decisions, where the clinician shares information and knowledge about the treatment options and the patient uses his/her values to weigh the risks and benefits of the different care options. Note that this does not preclude the clinician making a strong treatment recommendation based on clinical knowledge and experience. However, level of interest in medical information tends to be stronger with younger age and increased educational attainment; older patients may prefer less information and want to rely more on the clinician's expertise alone. More acutely ill patients may have limited ability to successfully weigh risks and benefits of the different options and thus may rely more on family members or on the clinician's recommendation. This underscores the need to individualize care option discussions to patient preferences and illness status. Discussions on treatment preferences should be periodically revisited to account for changes in patient preferences and course of illness, especially given that treatment strategies at one stage of the illness may be inappropriate for another stage. Also see [Annotation #3, "Assess Patient's Palliative Care Needs Based on the Following Domains of Palliative Care."](#)

Although patients and family members should have a say in treatment options, the clinician should make a clear recommendation based on his/her expertise and experience. It is important that the patient does not feel rushed into deciding between treatment options, as he/she may need to digest the initial bad news first (*Back, 2005 [Low Quality Evidence]*).

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11. Does Patient Meet Hospice Criteria?

Hospice care, now available in most communities in the United States, offers palliative medical care from a multidisciplinary team and serves patients and families as a unit with emotional, social and spiritual support.

Medicare patients certified by their clinician as terminally ill with a life expectancy of six months or less may elect to receive hospice care. Most private insurances now have hospice benefits, although coverage may vary.

Discharge from hospice occurs if prognosis improves or if the patient wishes to seek curative treatment.

A patient may be readmitted at any time, as long as the criteria for hospice are met.

See [Appendix D, "Medicare Hospice Benefit: Eligibility and Treatment Plan."](#)

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13. Hospice Care Team Coordinates Palliative Care Plan with Primary Clinician

Although the palliative care model encompasses hospice care (see the diagram in the Introduction in the guideline), it is beyond the scope of this guideline to include all aspects of care once the patient is admitted to hospice. See [Appendix D, "Medicare Hospice Benefit: Eligibility and Treatment Plan."](#)

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17. Remission or Resolution of Disease?

While palliative care is delivered across care settings and throughout the full course of illness, a patient may no longer require focused palliative care when:

- there is a remission of symptoms and the illness is no longer progressing, or
- the disease process is resolved (cured).

If symptoms recur or the patient's condition deteriorates, a new evaluation of the patient's palliative care needs should be done.

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19. Patient Is Actively Dying

Recommendations:

- Clinicians should discuss the likelihood of disease progression to death with patients and/or their families (*Low Quality Evidence, Strong Recommendation*) (*Lamont, 2001; Brody, 1997; SUPPORT, 1995*).
- Clinicians should engage in ongoing communication with the patient and/or family regarding the dying process and the treatment plan (*Low Quality Evidence, Strong Recommendation*).

This portion of the guideline is meant to aid clinicians in identifying those patients actively dying.

Diagnosing dying is complex and at times, uncertain. Agreement between care team members that the patient is dying, and communicating this to the patient and family fosters trust and improves satisfaction.

Care of the actively dying patient requires an intensive plan of care. Essential to this plan is recognition of the dying patient. The plan must be medically sound and concordant with the patient's wishes and values. Despite barriers, it is important to have this plan available at the point of care, regardless of the site of care (inpatient, long-term care, home care, assisted living, ED, etc.) (*Solloway, 2005 [Low Quality Evidence]*).

Attention to adequate symptom management allays fears and allows comfort during the dying process. There are several example order sets and nursing care plans on the Center to Advance Palliative Care (CAPC) Web site:

<http://www.capc.org/tools-for-palliative-care-programs/clinical-tools/>

Also see [Annotation #4, "Physical Aspects of Care."](#)

Patient and family wishes regarding the site of death should be discussed. Studies show that from 70% to 90% of people indicate that they prefer to die at home; despite this, about 75% of all deaths in the United States occur in hospitals or nursing homes. Referral to a hospice program may be appropriate. (See [Annotation #11, "Does Patient Meet Hospice Criteria?"](#))

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Algorithm Annotations

The plan of care should include education for the patient and family. This education should include the signs and symptoms of imminent death. Attention to developmental, cultural and religious needs is critical. Ongoing communication remains key.

The following signs and symptoms may indicate that death is approaching. Not all individuals will show all of these signs; however, these are signs that death is likely to occur in hours to days.

- Delirium, often manifested by increased restlessness, confusion, agitation, inability to stay content in one position and insisting on changing positions frequently.
- Withdrawal from active participation in social activities.
- Increased periods of sleep, lethargy.
- Decreased intake of food and liquids.
- Periods of pausing in breathing (apnea) whether awake or sleeping. Very rapid breathing or cyclic changes in the patterns of breathing (Cheyne-Stokes respirations). Other abnormal breathing patterns.
- Patient reports seeing persons who have already died.
- Patient states that he or she is dying.
- Patient requests family visit to settle unfinished business and tie up loose ends.
- Inability to heal or recover from wounds or infections.
- Increased swelling (edema) of either the extremities or the entire body.
- Inability to arouse patient at all (coma) or ability to arouse patient only with great effort, but patient quickly returns to severely unresponsive state (semicoma).
- Severe agitation in patient, hallucinations, acting "crazy" and not in patient's normal manner or personality.
- Increased respiratory congestion or fluid buildup in the lungs. Shortness of breath.
- Inability to swallow any fluids at all. Not taking food by mouth. Vomiting.
- Patient breathing through wide-open mouth continuously and no longer can speak even if awake.
- Urinary or bowel incontinence in a patient who was not incontinent before.
- Marked decrease in urinary output and darkening color of urine or very abnormal color of urine, such as red or brown.
- Blood pressure dropping dramatically from patient's normal blood pressure range (more than a 20-30 point drop).
- Systolic blood pressure below 70. Diastolic blood pressure below 50.
- Patient's extremities feel very cold to the touch.
- Fever.
- Patient complains that his or her legs/feet are numb or cannot be felt at all.
- Cyanosis, or a blue or purple coloring to the patient's arms and legs, especially the hands and feet (mottling).
- Patient's body is held in a rigid, unchanging position.

20. Death and Bereavement

Grief is the normal, expected emotional suffering caused by a significant loss, such as the death of a loved one, that includes both physiologic and psychological reactions (*McQuay, 1995 [Low Quality Evidence]*). Grief can be anticipatory, such as that experienced by the patient or a loved one prior to the expected death of the patient (*Hallenbeck, 2005 [Guideline]*). Grief can also be complicated, leading to maladaptive behaviors associated with a distorted or prolonged grief period (*Ellifrit, 2003 [Low Quality Evidence]*). Grief following a death is called bereavement. However, bereavement interventions can begin prior to and in anticipation of the actual loss (*Chochinov, 1989 [Low Quality Evidence]*).

Clinicians play an important role in facilitating healthy grief and bereavement processes. Honesty at the end of life is essential. By avoiding mixed messages, patients may review their lives and assist loved ones in future plans. At this time it may be possible to identify bereavement needs of patients and their loved ones. By assessing the grief response prior to death, it is possible to identify risk of complicated grieving and to provide early intervention (*Ellifritt, 2003 [Low Quality Evidence]*).

Following the death of the patient, it is essential to allow the patient's loved ones to perform customs or rituals that are important to them, within the policy guidelines of the facility. Failure to do so may lead to complicated grieving (*Lebrocq, 2003 [Low Quality Evidence]*). Clinicians should be available to answer questions and offer support. This may be done informally or through a formal debriefing.

Contact by clinicians after the death of a patient can be comforting for the patient's loved ones (*Griffin, 2007 [Low Quality Evidence]*). Clinicians may wish to offer emotional support by sending a card expressing their condolences. Clinicians should also offer practical support by completing death certificates in a timely manner, filling out necessary forms or writing letters for the family as needed.

Several models defining grief are available, yet it is important to note that progress through grief is not predictable. Movement through grief varies from person to person, and the bereaved may vacillate between stages, or elements of stages may appear concurrently. **Grief is not on a linear continuum and does not follow a specific time frame.** In complicated grieving, the person may fail to progress through grief or may be "stuck" in one stage of the grief process.

Several factors may predispose an individual to complicated grief. These include:

- Dependent or ambivalent relationship
- Multiple previous bereavements
- Previous psychiatric history, especially depression
- Sudden and unexpected death
- Death of a young person
- Stigmatized deaths such as suicide or AIDS
- Culpable deaths
- Inability to carry out valued religious rituals
- Lack of social support
- Survivor under age 45 whose partner died suddenly, or over 65 whose partner had illness of five years or more
- Multiple life crises
- Gender of bereaved person – e.g., elderly male widower

(*Sheldon, 1998 [Low Quality Evidence]*; *Chochinov, 1989 [Low Quality Evidence]*)

Algorithm Annotations

Others who are vulnerable to complicated grief include children, confused elders and those with learning disabilities. Many resources are available for children, including storybooks, workbooks and a regional camp for grieving children. For confused elders or survivors with learning disabilities, repeated explanations and participation in important events, such as the funeral, may decrease the repetitious questions about the deceased (*Sheldon, 1998 [Low Quality Evidence]*).

In order to provide support through the first anniversary of the death, it is suggested that the length of follow-up with the bereaved is a minimum of 13 months (*Nesbit, 1997 [Low Quality Evidence]*; *Buchanan, 1996 [Low Quality Evidence]*; *Moseley, 1989 [Low Quality Evidence]*). Although it is not realistic for clinicians to personally provide bereavement services for the grieving loved ones of a patient, it is imperative that each clinician be aware of the needs of the bereaved, potential risk factors for complicated grieving and the services available within their area so that appropriate referrals can be made to promote healthy grieving. Possible community services include pastoral care, support groups, counseling services, grief groups, bereavement follow-up programs and communities of faith. A referral to social services or contacting a local hospice program may be appropriate for assistance in bereavement interventions.

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The Aims and Measures section is intended to provide protocol users with a menu of measures for multiple purposes that may include the following:

- population health improvement measures,
- quality improvement measures for delivery systems,
- measures from regulatory organizations such as Joint Commission,
- measures that are currently required for public reporting,
- measures that are part of Center for Medicare Services Physician Quality Reporting initiative, and
- other measures from local and national organizations aimed at measuring population health and improvement of care delivery.

This section provides resources, strategies and measurement for use in closing the gap between current clinical practice and the recommendations set forth in the guideline.

The subdivisions of this section are:

- Aims and Measures
- Implementation Recommendations
- Implementation Tools and Resources
- Implementation Tools and Resources Table

Aims and Measures

1. Increase the identification of patients who are in the early stages of a serious illness who would benefit from palliative care. (*Annotations #1, 2*)

Measure for accomplishing this aim:

- a. Percentage of adult patients with a serious illness who have been screened for palliative care.

2. Improve the effectiveness and comfort level of the primary care clinician in communicating the necessity and benefits of palliative care with those patients with a serious illness. (*Annotation #2*)

Measures for accomplishing this aim:

- a. Percentage of clinicians who have education and training regarding palliative care concepts.
- b. Percentage of clinicians who have training in the use of scripting for palliative care discussions.

3. Improve the assessment of the identified patient's palliative care needs utilizing the domains of palliative care. (*Annotations #3, 4-9*)

Measures for accomplishing this aim:

- a. Percentage of adult patients with a serious illness who have been assessed for the domains of palliative care.
- b. Percentage of adult patients with a serious illness who have a symptom assessment documented in the medical record.

4. Increase the percentage of patients in the early stages of a serious illness who have a care plan identified and documented. (*Annotations #3, 10*)

Measure for accomplishing this aim:

- a. Percentage of patients in the early stages of a serious illness who have the following identified/ documented:
 - A discussion of treatment options with risk and benefits to each option discussed.
 - Patient goals such as needs, preferences, values, concerns and fears.
 - Plan of care follows the patient across the care continuum (inpatient, outpatient, home care/ public health nursing, etc.).

5. Improve the ongoing reassessment and adjustment of the patient's plan of care as the condition warrants, utilizing the domains of care. (*Annotations #3, 4-9*)

Measures for accomplishing this aim:

- a. Percentage of adult patients with a serious illness who have a revised, documented care plan that addresses the domains of care.
- b. Percentage of adult patients with a serious illness who have a revised symptom assessment in the medical record.

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Aims and Measures

6. Increase the completion, documentation and ongoing utilization of advance directives for patients with a serious illness. (*Annotations #3, 9*)

Measures for accomplishing this aim:

- a. Percentage of adult patients with a serious illness who have documentation in the medical record of a completed advance directive.
- b. Percentage of adult patients who have a completed POLST form documented in the medical record.

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Measurement Specifications

Measurement #1a

Percentage of adult patients with a serious illness who have been screened for palliative care.

Population Definition

Patients ages 18 years and older with a diagnosis of a serious illness.

Data of Interest

$$\frac{\text{\# of patients who have been screened for palliative care}}{\text{\# of patients with a diagnosis of a serious illness}}$$

Numerator and Denominator Definitions

Numerator: Number of patients who have been screened for palliative care.

Denominator: Number of patients with a diagnosis of a serious illness that includes but is not limited to:

- Pulmonary disease
- Cancer/neoplasm
- Liver disease
- Renal disease
- Neurological disorders:
 - Stroke
 - Parkinson's
 - Amyotrophic lateral sclerosis
 - Multiple sclerosis

Method/Source of Data Collection

Identify from EMR patients in the clinic population age 18 years and older with a serious illness. Determine the number of patients who have been screened for palliative care.

Time Frame Pertaining to Data Collection

Monthly.

Notes

This is a process measure, and improvement is noted as an increase in the rate.

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Aims and Measures

Measurement #2a

Percentage of clinicians who have education and training regarding palliative care concepts.

Population Definition

Clinicians in the clinic who work with patients age 18 years and older who have a diagnosis of a serious illness.

Data of Interest

$$\frac{\# \text{ of clinicians with education and training regarding palliative care concepts}}{\# \text{ of clinicians working with patients with a diagnosis of a serious illness}}$$

Numerator and Denominator Definitions

Numerator: Number of clinicians with education and training regarding palliative care concepts.

Denominator: Number of clinicians who work with patients with a diagnosis of a serious illness that includes but is not limited to:

- Pulmonary disease
- Cancer/neoplasm
- Liver disease
- Renal disease
- Neurological disorders:
 - Stroke
 - Parkinson's
 - Amyotrophic lateral sclerosis
 - Multiple sclerosis

Method/Source of Data Collection

Identify a subset of clinicians through a survey in the clinic who work with patient population age 18 years and older with a serious illness. Determine the number of clinicians who have had education and training regarding palliative care concepts.

Time Frame Pertaining to Data Collection

Monthly.

Notes

This is a process measure, and improvement is noted as an increase in the rate.

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Aims and Measures

Measurement #2b

Percentage of clinicians who have training in the use of scripting for palliative care discussions.

Population Definition

Clinicians in the clinic who work with patients age 18 years and older who have a diagnosis of a serious illness.

Data of Interest

$$\frac{\text{\# of clinicians with training in the use of scripting for palliative care discussions}}{\text{\# of clinicians working with patients with a diagnosis of a serious illness}}$$

Numerator and Denominator Definitions

Numerator: Number of clinicians with training in the use of scripting for palliative care discussions.

Denominator: Number of clinicians who work with patients with a diagnosis of a serious illness that includes but is not limited to:

- Pulmonary disease
- Cancer/neoplasm
- Liver disease
- Renal disease
- Neurological disorders:
 - Stroke
 - Parkinson's
 - Amyotrophic lateral sclerosis
 - Multiple sclerosis

Method/Source of Data Collection

Identify a subset of clinicians through a survey in the clinic who work with patient population age 18 years and older with a serious illness. Determine the number of clinicians who have had training in the use of scripting for palliative care discussions.

Time Frame Pertaining to Data Collection

Monthly.

Notes

This is a process measure, and improvement is noted as an increase in the rate.

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Aims and Measures

Measurement #3a

Percentage of adult patients with a serious illness who have been assessed for the domains of palliative care.

Population Definition

Patients age 18 years and older with a diagnosis of a serious illness.

Data of Interest

$$\frac{\# \text{ of patients who have been assessed for palliative care domains}}{\# \text{ of patients with a diagnosis of a serious illness}}$$

Numerator and Denominator Definitions

Numerator: Number of patients who have been assessed for palliative care domains.

Denominator: Number of patients with a diagnosis of a serious illness that includes but is not limited to:

- Pulmonary disease
- Cancer/neoplasm
- Liver disease
- Renal disease
- Neurological disorders:
 - Stroke
 - Parkinson's
 - Amyotrophic lateral sclerosis
 - Multiple sclerosis

Method/Source of Data Collection

Identify patients from EMR in the clinic population age 18 years and older with a serious illness. Determine the number of patients who have been assessed for palliative care domains.

Time Frame Pertaining to Data Collection

Monthly.

Notes

This is a process measure, and improvement is noted as an increase in the rate.

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Aims and Measures

Measurement #3b

Percentage of adult patients with a serious illness who have a symptom assessment documented in the medical record.

Population Definition

Patients age 18 years and older with a diagnosis of a serious illness.

Data of Interest

of patients who have a symptom assessment documented

of patients with a diagnosis of a serious illness

Numerator and Denominator Definitions

Numerator: Number of patients who have symptoms assessment documented in the medical record.

Denominator: Number of patients with a diagnosis of a serious illness that includes but is not limited to:

- Pulmonary disease
- Cancer/neoplasm
- Liver disease
- Renal disease
- Neurological disorders:
 - Stroke
 - Parkinson's
 - Amyotrophic lateral sclerosis
 - Multiple sclerosis

Method/Source of Data Collection

Identify patients from EMR in the clinic population age 18 years and older with a serious illness. Determine the number of patients who have a symptom assessment documented in the medical record.

Time Frame Pertaining to Data Collection

Monthly.

Notes

This is a process measure, and improvement is noted as an increase in the rate.

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Aims and Measures

Measurement #4a

Percentage of patients in the early stages of a serious illness who have the following identified/documentated:

- A discussion of treatment options with risk and benefits to each option discussed.
- Patient goals such as needs, preferences, values, concerns and fears.
- Plan of care that follows the patient across the care continuum (inpatient, outpatient, home care/ public health nursing, etc.)

Population Definition

Patients age 18 years and older with a diagnosis of a serious illness.

Data of Interest

of patients who have treatment options, patient goals and a plan of care across care continuum documented

of patients with a diagnosis of a serious illness

Numerator and Denominator Definitions

Numerator: Number of patients who have the following identified/documentated:

- A discussion of treatment options with risk and benefits to each option discussed.
- Patient goals such as needs, preferences, values, concerns and fears.
- Plan of care follows the patient across the care continuum (inpatient, outpatient, home care/public health nursing, etc.)

Denominator: Number of patients with a diagnosis of a serious illness that includes but is not limited to:

- Pulmonary disease
- Cancer/neoplasm
- Liver disease
- Renal disease
- Neurological disorders:
 - Stroke
 - Parkinson's
 - Amyotrophic lateral sclerosis
 - Multiple sclerosis

Method/Source of Data Collection

Identify patients from EMR in the clinic population age 18 years and older with a serious illness. Determine the number of patients who have following identified/documentated:

- A discussion of treatment options with risk and benefits to each option discussed.
- Patient goals such as needs, preferences, values, concerns and fears.
- Plan of care that follows the patient across the care continuum (inpatient, outpatient, home care/ public health nursing, etc.)

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Aims and Measures

Time Frame Pertaining to Data Collection

Monthly.

Notes

This is a process measure, and improvement is noted as an increase in the rate.

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Aims and Measures

Measurement #5a

Percentage of adult patients with a serious illness who have a revised, documented care plan that addresses the domains of palliative care.

Population Definition

Patients age 18 years and older with a diagnosis of a serious illness.

Data of Interest

$$\frac{\# \text{ of patients who have a revised, documented plan of care addressing the domains of palliative care}}{\# \text{ of patients with a diagnosis of a serious illness}}$$

Numerator and Denominator Definitions

Numerator: Number of patients who have a revised, documented care plan that addresses the domains of palliative care.

Denominator: Number of patients with a diagnosis of a serious illness that includes but is not limited to:

- Pulmonary disease
- Cancer/neoplasm
- Liver disease
- Renal disease
- Neurological disorders:
 - Stroke
 - Parkinson's
 - Amyotrophic lateral sclerosis
 - Multiple sclerosis

Method/Source of Data Collection

Identify patients from EMR in the clinic population age 18 years and older with a serious illness. Determine the number of patients who have a revised, documented care plan that addresses the domains of palliative care.

Time Frame Pertaining to Data Collection

Monthly.

Notes

This is a process measure, and improvement is noted as an increase in the rate.

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Aims and Measures

Measurement #5b

Percentage of adult patients with a serious illness who have a revised symptom assessment in the medical record.

Population Definition

Patients age 18 years and older with a diagnosis of a serious illness.

Data of Interest

$$\frac{\text{\# of patients who have a revised symptom assessment in the medical record}}{\text{\# of patients with a diagnosis of a serious illness}}$$

Numerator and Denominator Definitions

Numerator: Number of patients who have a revised symptom assessment in the medical record.

Denominator: Number of patients with a diagnosis of a serious illness that includes but is not limited to:

- Pulmonary disease
- Cancer/neoplasm
- Liver disease
- Renal disease
- Neurological disorders:
 - Stroke
 - Parkinson's
 - Amyotrophic lateral sclerosis
 - Multiple sclerosis

Method/Source of Data Collection

Identify patients from EMR in the clinic population age 18 years and older with a serious illness. Determine the number of patients who have a revised symptom assessment in the medical record.

Time Frame Pertaining to Data Collection

Monthly.

Notes

This is a process measure, and improvement is noted as an increase in the rate.

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Aims and Measures

Measurement #6a

Percentage of adult patients with a serious illness who have documentation in the medical record of a completed advance directive.

Population Definition

Patients age 18 years and older with a diagnosis of a serious illness.

Data of Interest

$$\frac{\text{\# of patients who have a completed advance directive}}{\text{\# of patients with a diagnosis of a serious illness}}$$

Numerator and Denominator Definitions

Numerator: Number of patients who have documentation in the medical record of a completed advance directive.

Denominator: Number of patients with a diagnosis of a serious illness that includes but is not limited to:

- Pulmonary disease
- Cancer/neoplasm
- Liver disease
- Renal disease
- Neurological disorders:
 - Stroke
 - Parkinson's
 - Amyotrophic lateral sclerosis
 - Multiple sclerosis

Method/Source of Data Collection

Identify patients from EMR in the clinic population age 18 years and older with a serious illness. Determine the number of patients who have documentation in the medical record of a completed advance directive.

Time Frame Pertaining to Data Collection

Monthly.

Notes

This is a process measure, and improvement is noted as an increase in the rate.

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Aims and Measures

Measurement #6b

Percentage of adult patients with a serious illness who have a completed POLST form documented in the medical record.

Population Definition

Patients age 18 years and older with a diagnosis of a serious illness.

Data of Interest

$$\frac{\text{\# of patients who have a completed POLST}}{\text{\# of patients with a diagnosis of a serious illness}}$$

Numerator and Denominator Definitions

Numerator: Number of patients who have a completed POLST form documented in the medical record.

Denominator: Number of patients with a diagnosis of a serious illness that includes but is not limited to:

- Pulmonary disease
- Cancer/neoplasm
- Liver disease
- Renal disease
- Neurological disorders:
 - Stroke
 - Parkinson's
 - Amyotrophic lateral sclerosis
 - Multiple sclerosis

Method/Source of Data Collection

Identify patients from EMR in the clinic population age 18 years and older with a serious illness. Determine the number of patients who have a completed POLST form documented in the medical record.

Time Frame Pertaining to Data Collection

Monthly.

Notes

This is a process measure, and improvement is noted as an increase in the rate.

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Implementation Recommendations

Prior to implementation, it is important to consider current organizational infrastructure that address the following:

- System and process design
- Training and education
- Culture and the need to shift values, beliefs and behaviors of the organization.

The following system changes were identified by the guideline work group as key strategies for health care systems to incorporate in support of the implementation of this guideline:

- Develop a process to provide education to clinicians, patients and families regarding the elements and appropriateness of palliative care. It is important to address the difference between palliative care and hospice.
- Develop a process that will allow clinicians to identify and assess patients who would benefit from palliative care services. This process should include the use of a screening tool that utilizes the domains of palliative care.
- Develop scripts for clinicians that will assist them in initiating and discussing palliative care services.
- Develop a process for timely referral to palliative care consultation for patients with a serious illness.

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Implementation Tools and Resources

Criteria for Selecting Resources

The following tools and resources specific to the topic of the guideline were selected by the work group. Each item was reviewed thoroughly by at least one work group member. It is expected that users of these tools will establish the proper copyright prior to their use. The types of criteria the work group used are:

- The content supports the clinical and the implementation recommendations.
- Where possible, the content is supported by evidence-based research.
- The author, source and revision dates for the content are included where possible.
- The content is clear about potential biases and when appropriate conflicts of interests and/or disclaimers are noted where appropriate.

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Implementation Tools and Resources Table

Author/Organization	Title/Description	Audience	Web Sites/Order Information
Aging with Dignity	"5 Wishes" and "My Wishes." The documents address medical, personal, emotional, and spiritual needs that should be addressed when an adult or child is seriously ill and unable to speak for themselves.	Patients and Families	http://www.agingwithdignity.org
American Academy of Hospice and Palliative Medicine	A professional organization specializing in hospice and palliative care medicine.	Health Care Providers	http://www.aahpm.org
American Academy of Hospice and Palliative Medicine	An excellent resource for clinicians to share with patients and families. It has been developed by the American Academy of Hospice and Palliative Medicine.	Health Care Providers	http://www.palliativedoctors.org
American Board of Hospice and Palliative Medicine (ABHPM)	ABHPM promotes excellence in the care of all patients with advanced, progressive illness through the development of standards for training and practice in palliative medicine. The board is an independent, non-profit organization whose certificate is recognized as signifying a high level of clinician competence in the discipline of palliative medicine.	Health Care Providers	http://www.aahpm.org/certification/default/index.html
Caring Connections	Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer and community engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation.	Patients and Families	http://www.caringinfo.org
Center to Advance Palliative Care (CAPC) CAPC provides health care professionals with the tools and training necessary to start and sustain successful palliative care programs.	Tools for Palliative Care Programs. A collection of tools assembled by CAPC to assist in designing, strengthening, maintaining and defending Palliative Care programs.	Health Care Provider	http://www.capc.org/tools-for-palliative-care-programs/clinical-tools/
Center to Advance Palliative Care (CAPC)	CAPCconnect Forum: A free resource for health care professionals who want to share information, exchange ideas, and get advice from their colleagues on operational issues affecting their palliative care programs.	Health Care Provider	http://www.capc.org/forums/

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Implementation Tools and Resources Table

Author/Organization	Title/Description	Audience	Web Sites/Order Information
GetPalliativeCare.org The site is provided by the Center to Advance Palliative Care (CAPC)	The Web site provides clear, comprehensive palliative care information for people coping with serious, complex illness. Information includes description of what palliative care is, how it is different from hospice care, and information on advanced directives.	Patients and Families	http://www.getpalliativecare.org
Hank Dunn Hard Choices	Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care, and the Patient with a Life-Threatening Illness, Fourth Edition. Book: (ISBN 1-928560-30-2)	Patients and Families	To order: http://www.hardchoices.com To download or read online: http://hardchoices.com/about_hc.html
EPERC End of Life/Palliative Education Resource Center and the Medical College of Wisconsin	This Web site contains educational resource material for health care educators and providers. Materials include Fast Facts.	Health Care Provider	http://www.eperc.mcw.edu
Honoring Choices Minnesota	A large-scale, community-based initiative that introduces advance care planning conversations to all individuals over 18 years of age.	Health Care Providers; Patients, Families and Caregivers	http://www.honoringchoices.org
Hospice Patients Alliance	Signs & Symptoms of Approaching Death The article describes the signs and symptoms of approaching death.	Health Care Professionals; Patients and Families	http://www.hospicepatients.org/hospic60.html
Information Links for Brain Tumor	Preparing for Approaching Death The article discusses the dying process.	Patients and Families	http://www.virtualtrials.com/btlinks/death.cfm
Barbara Karnes	Gone from My Sight; The Dying Experience	Patients and Families	Bookstores
National Consensus Project	Clinical Practice Guidelines for Quality Palliative Care This is a revision of the original 2004 Clinical Guidelines with input from four major palliative care organizations: the American Hospice and Palliative Care Organization, Hospice and Palliative Nurses Association, National Hospice and Palliative Care Organization, and the Center to Advance Palliative Care. It includes updated references for each of the eight domains, exemplars illustrating implementation of the guidelines, and the relationship of the guideline domains with the National Quality Forum's Preferred Practices.	Health Care Provider	http://www.nationalconsensusproject.org

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Implementation Tools and Resources Table

Author/Organization	Title/Description	Audience	Web Sites/Order Information
National Hospice and Palliative Care Organization	NHPCO is the largest non-profit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people in America and their loved ones. This Web site provides information about end-of-life care, with resources, facts and figures, news briefs, patient advocacy, conferences and education.	Health Care Provider; Patients and Families	http://www.nhpco.org
Palliative.org (Regional Palliative Care Program in Edmonton, Alberta)	The Web site provides clinical information to health care professionals regarding palliative care. The assessment tools include including various tools such as the Edmonton Symptom Assessment System (ESAS). The site also includes a link to the American Academy of Hospice and Palliative Medicine Fast Facts.	Health Care Provider	http://www.palliative.org/newPC/professionals/tools/tools.html
POLST.org is sponsored by the Center for Ethics in Health Care and Oregon Health & Science University	POLST (Physician Orders for Life-Sustaining Treatment) is designed to help health care professionals honor the end-of-life treatment desires of their patients. The form includes clinician orders that follow patient wishes and treatment intentions, and enhances the appropriateness and quality of patient care.	Health Care Providers; Patients and Families	http://www.ohsu.edu/polst/
Put It In Writing, American Hospital Association	The Web site provides information about advanced directives, as well as educational resources to raise awareness regarding this issue. Resources include Put It In Writing brochure, wallet ID, advertisements and links.	Patients and Families; Health Care Providers	http://www.putitinwriting.org

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The subdivisions of this section are:

- References
- Appendices

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Links are provided for those new references added to this edition (author name is highlighted in blue).

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Appendix A – **Choosing Wisely[®]** Recommendations Regarding Palliative Care

For references, please click on the links below each society's name. Where applicable, links for patient materials are also included.

From the American Academy of Hospice and Palliative Medicine:

<http://www.choosingwisely.org/doctor-patient-lists/american-academy-of-hospice-palliative-medicine/>

1. **Don't recommend percutaneous feeding tubes in patients with advanced dementia; instead, offer oral assisted feeding.** In advanced dementia, studies have found feeding tubes do not result in improved survival, prevention of aspiration pneumonia, or improved healing of pressure ulcers. Feeding tube use in such patients has actually been associated with pressure ulcer development, use of physical and pharmacological restraints, and patient distress about the tube itself. Assistance with oral feeding is an evidence-based approach to provide nutrition for patients with advanced dementia and feeding problems; in the final phase of this disease, assisted feeding may focus on comfort and human interaction more than nutritional goals.

For patient-friendly materials regarding this recommendation:

<http://consumerhealthchoices.org/wp-content/uploads/2013/05/ChoosingWiselyFeedingTubeAGS-ER.pdf>

2. **Don't delay palliative care for a patient with serious illness who has physical, psychological, social or spiritual distress because they are pursuing disease-directed treatment.** Numerous studies – including randomized trials – provide evidence that palliative care improves pain and symptom control, improves family satisfaction with care and reduces costs. Palliative care does not accelerate death, and may prolong life in selected populations.
3. **Don't leave an implantable cardioverter-defibrillator (ICD) activated when it is inconsistent with the patient/family goals of care.** In about a quarter of patients with ICDs, the defibrillator fires within weeks preceding death. For patients with advanced irreversible diseases, defibrillator shocks rarely prevent death, may be painful to patients and are distressing to caregivers/family members. Currently there are no formal practice protocols to address deactivation; fewer than 10% of hospices have official policies. Advance care planning discussions should include the option of deactivating the ICD when it no longer supports the patient's goals.
4. **Don't recommend more than a single fraction of palliative radiation for an uncomplicated painful bone metastasis.** As stated in the American Society for Radiation Oncology (ASTRO) 2011 guideline, single-fraction radiation to a previously un-irradiated peripheral bone or vertebral metastasis provides comparable pain relief and morbidity compared to multiple-fraction regimens while optimizing patient and caregiver convenience. Although it results in a higher incidence of later need for retreatment (20% vs. 8% for multi-fraction regimens), the decreased patient burden usually outweighs any considerations of long-term effectiveness for those with a limited life expectancy.
5. **Don't use topical lorazepam (Ativan), diphenhydramine (Benadryl), haloperidol (Haldol) ("ABH") gel for nausea.** Topical drugs can be safe and effective, such as topical non-steroidal anti-inflammatory drugs for local arthritis symptoms. However, while topical gels are commonly prescribed in hospice practice, anti-nausea gels have not been proven effective in any large, well-designed or placebo-controlled trials. The active ingredients in ABH are not absorbed to systemic levels that could be effective. Only diphenhydramine (Benadryl) is absorbed via the skin, and then only after several hours and erratically at subtherapeutic levels. It is therefore not appropriate for "as needed" use. The use of agents given via inappropriate routes may delay or prevent the use of more effective interventions.

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www.icsi.org

From the American Geriatrics Society

<http://www.choosingwisely.org/doctor-patient-lists/american-geriatrics-society/>

Don't recommend percutaneous feeding tubes in patients with advanced dementia; instead offer oral assisted feeding. Careful hand feeding for patients with severe dementia is at least as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status and patient comfort. Food is the preferred nutrient. Tube feeding is associated with agitation, increased use of physical and chemical restraints, and worsening pressure ulcers.

From the American Society of Clinical Oncology

<http://www.choosingwisely.org/doctor-patient-lists/american-society-of-clinical-oncology/>

Don't use cancer-directed therapy for solid tumor patients with the following characteristics: low performance status (3 or 4), no benefit from prior evidence-based interventions, not eligible for a clinical trial, and no strong evidence supporting the clinical value of further anti-cancer treatment. Studies show that cancer-directed treatments are likely to be ineffective for solid tumor patients who meet the above stated criteria. Exceptions include patients with functional limitations due to other conditions, resulting in a low performance status or those with disease characteristics (e.g., mutations) that suggest a high likelihood of response to therapy. Implementation of this approach should be accompanied with appropriate palliative and supportive care.

For patient-friendly materials regarding this recommendation:

<http://consumerhealthchoices.org/wp-content/uploads/2013/02/Choosing-WiselyCancerTreatmentsASCO-ER.pdf> and

<http://consumerhealthchoices.org/wp-content/uploads/2012/10/ChoosingWiselyCancerASCO.pdf>

From the American Society of Nephrology

<http://www.choosingwisely.org/doctor-patient-lists/american-society-of-nephrology/>

- 1. Don't perform routine cancer screening for dialysis patients with limited life expectancies without signs or symptoms.** Due to high mortality among end-stage renal disease (ESRD) patients, routine cancer screening – including mammography, colonoscopy, prostate-specific antigen (PSA) and Pap smears – in dialysis patients with limited life expectancy, such as those who are not transplant candidates, is not cost effective and does not improve survival. False-positive tests can cause harm: unnecessary procedures, overtreatment, misdiagnosis and increased stress. An individualized approach to cancer screening incorporating patients' cancer risk factors, expected survival and transplant status is required.
- 2. Don't initiate chronic dialysis without ensuring a shared decision-making process between patients, their families, and their physicians.** The decision to initiate chronic dialysis should be part of an individualized, shared decision-making process between patients, their families, and their physicians. This process includes eliciting individual patient goals and preferences and providing information on prognosis and expected benefits and harms of dialysis within the context of these goals and preferences. Limited observational data suggest that survival may not differ substantially for older adults with a high burden of comorbidity who initiate chronic dialysis versus those managed conservatively.

For patient-friendly materials regarding these recommendations:

<http://consumerhealthchoices.org/wp-content/uploads/2012/10/ChoosingWiselyKidneyDiseaseASN.pdf>

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From the Society of Hospital Medicine

<http://www.choosingwisely.org/doctor-patient-lists/society-of-hospital-medicine-adult-hospital-medicine/>

Don't place, or leave in place, urinary catheters for incontinence or convenience or monitoring of output for non-critically ill patients (acceptable indications: critical illness, obstruction, hospice, perioperatively for < 2 days for urologic procedures; use weights instead to monitor diuresis). Catheter Associated Urinary Tract Infections (CAUTIs) are the most frequently occurring health care-acquired infection (HAI). Use of urinary catheters for incontinence or convenience without proper indication or specified optimal duration of use increases the likelihood of infection and is commonly associated with greater morbidity, mortality and health care costs. Published guidelines suggest that hospitals and long-term care facilities should develop, maintain and promulgate policies and procedures for recommended catheter insertion indications, insertion and maintenance techniques, discontinuation strategies and replacement indications.

From the AMDA – Dedicated to Long-Term Care Medicine (Formerly the American Medical Directors Association)

<http://www.choosingwisely.org/doctor-patient-lists/amda-dedicated-to-long-term-care-medicine/>

Don't insert percutaneous feeding tubes in individuals with advanced dementia. Instead, offer oral assisted feedings. Strong evidence exists that artificial nutrition does not prolong life or improve quality of life in patients with advanced dementia. Substantial functional decline and recurrent or progressive medical illnesses may indicate that a patient who is not eating is unlikely to obtain any significant or long-term benefit from artificial nutrition. Feeding tubes are often placed after hospitalization, frequently with concerns for aspirations, and for those who are not eating. Contrary to what many people think, tube feeding does not ensure the patient's comfort or reduce suffering; it may cause fluid overload, diarrhea, abdominal pain, local complications, less human interaction and may increase the risk of aspiration. Assistance with oral feeding is an evidence-based approach to provide nutrition for patients with advanced dementia and feeding problems.

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Appendix B – ICSI Shared Decision-Making Model

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The technical aspects of Shared Decision-Making are widely discussed and understood.

- **Decisional conflict** occurs when a patient is presented with options where no single option satisfies all the patient's objectives, where there is an inherent difficulty in making a decision, or where external influencers act to make the choice more difficult.
- **Decision support** clarifies the decision that needs to be made, clarifies the patient's values and preferences, provides facts and probabilities, guides the deliberation and communication and monitors the progress.
- **Decision aids** are evidence-based tools that outline the benefits, harms, probabilities and scientific uncertainties of specific health care options available to the patient.

However, before decision support and decision aids can be most advantageously utilized, a Collaborative Conversation™ should be undertaken between the provider and the patient to provide a supportive framework for Shared Decision-Making.

Collaborative Conversation™

A collaborative approach toward decision-making is a fundamental tenet of Shared Decision-Making (SDM). The Collaborative Conversation™ is an inter-professional approach that nurtures relationships, enhances patients' knowledge, skills and confidence as vital participants in their health, and encourages them to manage their health care.

Within a Collaborative Conversation™, the perspective is that both the patient and the provider play key roles in the decision-making process. The patient knows which course of action is most consistent with his/her values and preferences, and the provider contributes knowledge of medical evidence and best practices. Use of Collaborative Conversation™ elements and tools is even more necessary to support patient, care provider and team relationships when patients and families are dealing with high stakes or highly charged issues, such as diagnosis of a life-limiting illness.

The overall framework for the Collaborative Conversation™ approach is to create an environment in which the patient, family and care team work collaboratively to reach and carry out a decision that is consistent with the patient's values and preferences. A rote script or a completed form or checklist does not constitute this approach. Rather it is a set of skills employed appropriately for the specific situation. These skills need to be used artfully to address all aspects involved in making a decision: cognitive, affective, social and spiritual.

Key communication skills help build the Collaborative Conversation™ approach. These skills include many elements, but in this appendix only the questioning skills will be described. (For complete instruction, see O'Connor, Jacobsen "Decisional Conflict: Supporting People Experiencing Uncertainty about Options Affecting Their Health" [2007], and Bunn H, O'Connor AM, Jacobsen MJ "Analyzing decision support and related communication" [1998, 2003].)

1. Listening skills:

Encourage patient to talk by providing prompts to continue such as "go on, and then?, uh huh," or by repeating the last thing a person said, "It's confusing."

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Paraphrase content of messages shared by patient to promote exploration, clarify content and to communicate that the person’s unique perspective has been heard. The provider should use his/her own words rather than just parroting what he/she heard.

Reflection of feelings usually can be done effectively once trust has been established. Until the provider feels that trust has been established, short reflections at the same level of intensity expressed by the patient without omitting any of the message’s meaning are appropriate. Reflection in this manner communicates that the provider understands the patient’s feelings and may work as a catalyst for further problem solving. For example, the provider identifies what the person is feeling and responds back in his/her own words like this: *“So, you’re unsure which choice is the best for you.”*

Summarize the person’s key comments and reflect them back to the patient. The provider should condense several key comments made by the patient and provide a summary of the situation. This assists the patient in gaining a broader understanding of the situations rather than getting mired down in the details. The most effective times to do this are midway through and at the end of the conversation. An example of this is, *“You and your family have read the information together, discussed the pros and cons, but are having a hard time making a decision because of the risks.”*

Perception checks ensure that the provider accurately understands a patient or family member, and may be used as a summary or reflection. They are used to verify that the provider is interpreting the message correctly. The provider can say *“So you are saying that you’re not ready to make a decision at this time. Am I understanding you correctly?”*

2. Questioning Skills

Open and closed questions are both used, with the emphasis on open questions. Open questions ask for clarification or elaboration and cannot have a yes or no answer. An example would be *“What else would influence you to choose this?”* Closed questions are appropriate if specific information is required such as *“Does your daughter support your decision?”*

Other skills such as summarizing, paraphrasing and reflection of feeling can be used in the questioning process so that the patient doesn’t feel pressured by questions.

Verbal tracking, referring back to a topic the patient mentioned earlier, is an important foundational skill (Ivey & Bradford-Ivey). An example of this is the provider saying, *“You mentioned earlier...”*

3. Information-Giving Skills

Providing information and **providing feedback** are two methods of information giving. The distinction between providing information and giving advice is important. Information giving allows a provider to supplement the patient’s knowledge and helps to keep the conversation patient centered. Giving advice, on the other hand, takes the attention away from the patient’s unique goals and values, and places it on those of the provider.

Providing information can be sharing facts or responding to questions. An example is *“If we look at the evidence, the risk is...”* Providing feedback gives the patient the provider’s view of the patient’s reaction. For instance, the provider can say, *“You seem to understand the facts and value your daughter’s advice.”*

Additional Communication Components

Other elements that can impact the effectiveness of a Collaborative Conversation™ include:

- Eye contact
- Body language consistent with message
- Respect

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Appendix B – ICSI Shared Decision-Making Model

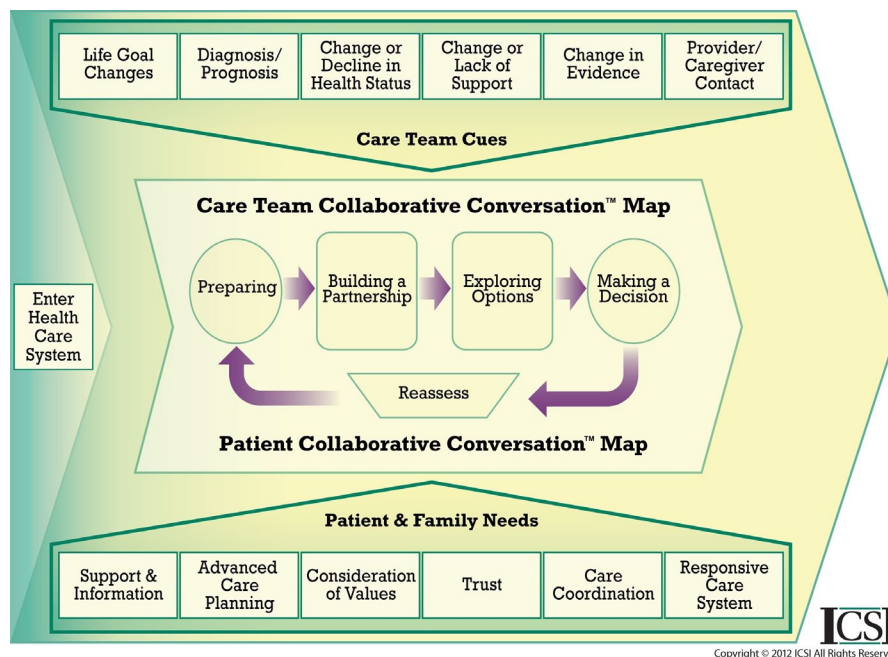
- Empathy
- Partnerships

Self-examination by the provider involved in the Collaborative Conversation™ can be instructive. Some questions to ask oneself include:

- Do I have a clear understanding of the likely outcomes?
- Do I fully understand the patient’s values?
- Have I framed the options in comprehensible ways?
- Have I helped the decision-makers recognize that preferences may change over time?
- Am I willing and able to assist the patient in reaching a decision based on his/her values, even when his/her values and ultimate decision may differ from my values and decisions in similar circumstances?

When to Initiate a Collaborative Conversation™

A Collaborative Conversation™ can support decisions that vary widely in complexity. It can range from a straightforward discussion concerning routine immunizations to the morass of navigating care for a life-limiting illness. Table 1 represents one health care event. This event can be simple like a 12 year-old coming to the clinic for routine immunizations, or something much more complex like an individual receiving a diagnosis of congestive heart failure. In either case, the event is the catalyst that starts the process represented in this table. There are cues for providers and patient needs that exert influence on this process. They are described below. The heart of the process is the Collaborative Conversation™. The time the patient spends within this health care event will vary according to the decision complexity and the patient’s readiness to make a decision.



Regardless of the decision complexity there are cues applicable to all situations that indicate an opportune time for a Collaborative Conversation™. These cues can occur singularly or in conjunction with other cues.

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Cues for the Care Team to Initiate a Collaborative Conversation™

- **Life goal changes:** Patient’s priorities change related to things the patient values such as activities, relationships, possessions, goals and hopes, or things that contribute to the patient’s emotional and spiritual well-being.
- **Diagnosis/prognosis changes:** Additional diagnoses, improved or worsening prognosis.
- **Change or decline in health status:** Improving or worsening symptoms, change in performance status or psychological distress.
- **Change or lack of support:** Increase or decrease in caregiver support, change in caregiver, or caregiver status, change in financial standing, difference between patient and family wishes.
- **Change in medical evidence or interpretation of medical evidence:** Providers can clarify the change and help the patient understand its impact.
- **Provider/caregiver contact:** Each contact between the provider/caregiver and the patient presents an opportunity to reaffirm with the patient that his/her care plan and the care the patient is receiving are consistent with his/her values.

Patients and families have a role to play as decision-making partners, as well. The needs and influencers brought to the process by patients and families impact the decision-making process. These are described below.

Patient and Family Needs within a Collaborative Conversation™

- **Request for support and information:** Decisional conflict is indicated by, among other things, the patient verbalizing uncertainty or concern about undesired outcomes, expressing concern about choice consistency with personal values and/or exhibiting behavior such as wavering, delay, preoccupation, distress or tension. Generational and cultural influencers may act to inhibit the patient from actively participating in care discussions, often patients need to be given “permission” to participate as partners in making decisions about his/her care.

Support resources may include health care professionals, family, friends, support groups, clergy and social workers. When the patient expresses a need for information regarding options and his/her potential outcomes, the patient should understand the key facts about options, risks and benefits, and have realistic expectations. The method and pace with which this information is provided to the patient should be appropriate for the patient’s capacity at that moment.

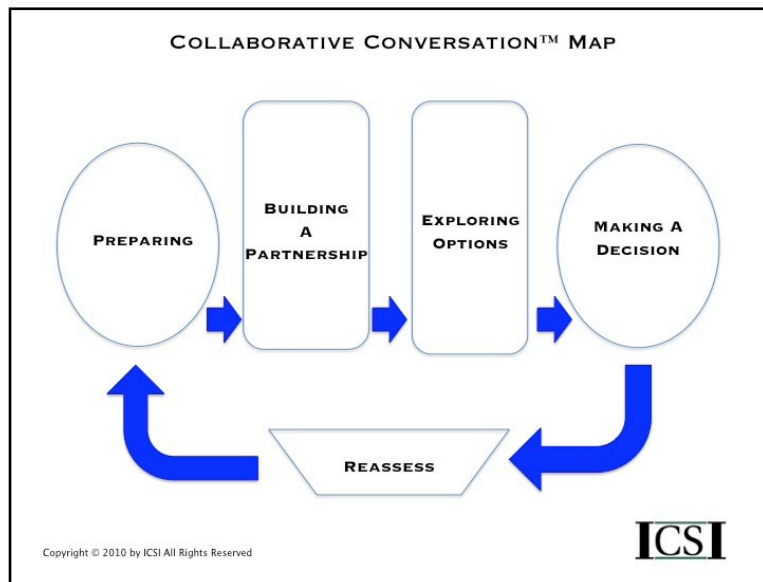
- **Advance Care Planning:** With the diagnosis of a life-limiting illness, conversations around advance care planning open up. This is an opportune time to expand the scope of the conversation to other types of decisions that will need to be made as a consequence of the diagnosis.
- **Consideration of Values:** The personal importance a patient assigns potential outcomes must be respected. If the patient is unclear how to prioritize the preferences, value clarification can be achieved through a Collaborative Conversation™ and by the use of decision aids that detail the benefits and harms of potential outcomes in terms the patient can understand.
- **Trust:** The patient must feel confident that his/her preferences will be communicated and respected by all caregivers.
- **Care Coordination:** Should the patient require care coordination, this is an opportune time to discuss the other types of care-related decisions that need to be made. These decisions will most likely need to be revisited often. Furthermore, the care delivery system must be able to provide coordinated care throughout the continuum of care.

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- **Responsive Care System:** The care system needs to support the components of patient- and family-centered care so the patient’s values and preferences are incorporated into the care he/she receives throughout the care continuum.

The Collaborative Conversation™ Map is the heart of this process. The Collaborative Conversation™ Map can be used as a stand-alone tool that is equally applicable to providers and patients as shown in Table 2. Providers use the map as a clinical workflow. It helps get the Shared Decision-Making process initiated and provides navigation for the process. Care teams can use the Collaborative Conversation™ to document team best practices and to formalize a common lexicon. Organizations can build fields from the Collaborative Conversation™ Map in electronic medical records to encourage process normalization. Patients use the map to prepare for decision-making, to help guide them through the process and to share critical information with their loved ones.



Evaluating the Decision Quality

Adapted from O’Connor, Jacobsen “Decisional Conflict: Supporting People Experiencing Uncertainty about Options Affecting Their Health” [2007].

When the patient and family understand the key facts about the condition and his/her options, a good decision can be made. Additionally, the patient should have realistic expectations about the probable benefits and harms. A good indicator of the decision quality is whether or not the patient follows through with his/her chosen option. There may be implications of the decision on patient’s emotional state such as regret or blame, and there may be utilization consequences.

Decision quality can be determined by the extent to which the patient’s chosen option best matches his/her values and preferences as revealed through the Collaborative Conversation™ process.

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Appendix C – Pediatrics

Special Considerations for Pediatric Patients

- Children with a serious illness and their families benefit from pediatric-specific palliative care services.
- It is important to manage developmental level concerns, as well as symptoms needing to be addressed.
- There are specific ethical and legal concerns related to the pediatric population.

Great strides are being made to improve care for adults with serious, advancing illness. Unfortunately, there is growing evidence that health care has failed to meet the specialized needs of children with life-limiting and life-threatening conditions. Advances in pediatric programs, clinical education, and research have occurred in response to the Institute of Medicine's Report, "When Children Die: Improving Palliative Care for Children and their Families (2003)." The continuum of pediatric palliative care extends across settings, including perinatal and neonatal palliative care, as well as for children who are not expected to live to adulthood. Pediatric palliative care programs and organizations are available to provide additional resources. (See [Implementation Tools and Resources Table](#).)

Children and families are a special population that may also be confronted by a life-threatening illness. Many children undergo painful procedures and suffer from the symptoms of advancing disease without sufficient management of symptoms, despite the fact that modern medicine has the means to relieve their pain and discomfort, as well as improve most symptoms. Families may feel abandoned and overwhelmed, often suffering emotional as well as financial loss for years. Social supports to children and families before and after death are often inadequate, and health care professionals themselves are often left without emotional support for the difficult work they do. Many clinicians and nurses have received virtually no training to practice the skills necessary for communicating effectively with dying children and their families. Practicing health care professionals often lack assistance on how to manage the goals and values that can be conflicting, as well as the broad cultural and religious diversity represented in the U.S.

The Children's Institute for Palliative Care (CIPPC) provides training, continuing education, resources, consultation and technical assistance to health care clinicians who are interested in developing more opportunities for pediatric palliative care in their communities. The institute also develops and supports a network of clinicians in the Midwest region to ensure access to quality palliative care. The End of Life Nursing Education Consortium – Pediatric Palliative Care (ELNEC-PPC), a curriculum developed for pediatric nurses and other clinicians, includes 10 modules on pediatric palliative care. In addition, two pediatric Palliative Care Leadership Centers offer operational training on pediatric palliative care (<http://www.capc.org/pclc>).

The Initiative for Pediatric Palliative Care (IPPC) provides both an education and a quality improvement effort aimed at enhancing family-centered care for children living with life-threatening conditions. IPPC's comprehensive, interdisciplinary curriculum addresses knowledge, attitudes and skills that health care professionals need in order to better serve children and families. These include:

- **Engaging with children and families** – enhancing the ability of health care professionals to understand, support and engage effectively with children with life-threatening conditions, their parents and loved ones, reflecting on core principles in pediatric palliative care and discovering what matters most to families, by incorporating the perspectives of children and families in treatment.
- **Relieving pain and other symptoms** – by learning competent assessment, documentation, reassessment and the continuously monitoring of a pediatric patient's pain and other symptoms using developmentally appropriate pain assessment tools and strategies.

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Appendix C – Pediatrics

- **Analyzing ethical challenges in pediatric end-of-life decision-making** – learning methods to support families as they confront an array of difficult choices often encountered when a child is gravely ill and unlikely to recover. This includes ethical recommendations for guiding decisions regarding withholding or withdrawing of life support to allow natural death, and strategies for handling circumstances in which parents and clinicians may disagree about goals of care. It includes the degree of benefit and burden associated with different treatment (and not treating) options, the importance of honoring parental discretion in decision-making, especially when there are uncertain benefits associated with the continuation of life-prolonging treatments, the legitimacy of quality-of-life considerations in goal setting, how to handle conflicts, and the extent to which mature minors should be able to guide their own decisions. Other topics include the use or foregoing of artificial nutrition and hydration, as well as ethical issues relevant to the treatment of pain and suffering, such as those related to palliative sedation.
- **Responding to suffering and bereavement** – enhances the ability of health care professionals to recognize, validate and respond to suffering in children, parents and family members by developing a perspective from which to understand and respond to the suffering and bereavement experience of children and families and how this interconnects with their own experience as professional caregivers. The potential contribution of palliative care to provide critical support to the dying child and grieving family members cannot be overstated.
- **Improving communication and strengthening relationships** – enhances health care professionals' communication and relational skills, specifically pertaining to what is known about working with children and families, including a cross-cultural undertaking in which the challenge is to understand and respond to the practices of the family.

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Appendix D – Medicare Hospice Benefit: Eligibility and Treatment Plan

In the United States, the Medicare Hospice Benefit (MHB) pays for the vast majority of all hospice care. Established in 1983, the MHB pays for medical, nursing, counseling and bereavement services for terminally ill patients and their families. The original goal of the MHB was to support families caring for their dying relative at home. Hospice services are not site specific; they can be provided in an acute care hospital, at home or in a long-term care facility. Referral for hospice care is appropriate when the overall plan of care is directed toward comfort rather than reversing the underlying disease process.

- Hospice services include medical equipment and supplies, medication for pain and symptom control, chemotherapy and radiation (if for palliation), grief counseling and bereavement support.
- Hospice benefits cover hospital services for short-term symptom control and temporary respite care to relieve family caregivers. They do not cover curative treatments or extensive evaluations inconsistent with the hospice approach.
- Patients, initially certified for two 90-day periods, may be recertified for an unlimited number of 60-day periods if the condition is still terminal with a life expectancy of less than six months if the disease runs its expected course.
- If a patient qualifies for MHB, Medicare and hospice benefits can be coordinated to cover the appropriate aspects of care.
- Under Medicare, DNR status cannot be used as a requirement for admission.

Plan of Care (POC)

The hospice team and the patient's clinician work together with the patient and family to maximize quality of life by jointly developing the Plan of Care. The POC is based on the patient's diagnosis, symptoms and goals of care. The hospice program and the patient's clinician must together approve any proposed tests, treatments and services. In general, only those treatments that are necessary for palliation and/or management of the terminal illness will be approved.

Clinician Role

At the time of enrollment, the patient indicates the primary clinician who will direct care; the patient may select a hospice clinician for this role or may select his/her usual primary doctor. The primary clinician is responsible for working with the hospice team to determine appropriate care.

Places of Care

Home. The majority (95%) of hospice care takes place in the home. Hospice team members visit the patient and family on an intermittent basis, determined by the Plan of Care. Medicare rules do not require a primary caregiver in the home, but as death nears, it becomes increasingly difficult to provide care for a patient who does not have someone (family, friends, hired caregivers) who can be present 24 hours a day in the home.

Long-term care facility. Twenty-five percent of patients in the U.S. die in nursing homes. Medicare recognizes that this can be the resident's home and that the patient's family frequently includes the nursing home staff. Hospice care under the MHB can be provided to residents in addition to usual care provided by the facility. Individual hospice programs must establish a contract with the facility to provide hospice care. The MHB does not pay for nursing home room and board charges.

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Hospice inpatient unit. Dedicated units, either freestanding or within other facilities, such as nursing homes or hospitals, are available in some areas. Permitted length of stay varies with the facility and its specific admission policies.

General inpatient facility. When pain or other symptoms related to the terminal illness cannot be managed at home, the patient may be admitted to a hospital or inpatient facility for more intensive management, still under the MHB. The inpatient facility must have a contract with the hospice program for acute care.

Emergency Department/Urgent Care

Patients may seek medical care at EDs or urgent care centers when unable to manage their care independently at home. It is essential that any testing or treatment be coordinated with the hospice team.

(Turner, 2006)

For specific Medicare Hospice Benefit information, see <http://www.cms.hhs.gov/center/hospice.asp>.

Hospice Care Team Coordinates Palliative Care Plan with Primary Clinician

At the time of enrollment, the patient indicates the primary clinician who will direct care. The patient usually selects the primary specialty care clinician who is currently directing his/her care but may elect to have the hospice medical director as the primary clinician in certain cases. The hospice team works with the primary clinician and patient and family to determine appropriate care. (See [Annotation #11, "Does Patient Meet Hospice Criteria?"](#))

Discharge from hospice may occur for several reasons. These may include:

- an improved prognosis,
- the patient wishes to seek curative treatment, or
- an unrelated problem forces the patient to disenroll in hospice.

Patient may be readmitted to hospice at any time, as long as the criteria for admission are still met. (See [Annotation #11, "Does Patient Meet Hospice Criteria?"](#))

To determine whether a Medicare-approved hospice program is available in your area, contact the nearest Social Security Administration office, your state or local health department, or your state hospice organization (in Minnesota, Hospice Minnesota 800-214-9597), or call the National Hospice Organization Hospice Help Line (800) 658-8898.

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ICSI has long had a policy of transparency in declaring potential conflicting and competing interests of all individuals who participate in the development, revision and approval of ICSI guidelines and protocols.

In 2010, the ICSI Conflict of Interest Review Committee was established by the Board of Directors to review all disclosures and make recommendations to the board when steps should be taken to mitigate potential conflicts of interest, including recommendations regarding removal of work group members. This committee has adopted the Institute of Medicine Conflict of Interest standards as outlined in the report, *Clinical Practice Guidelines We Can Trust* (2011).

Where there are work group members with identified potential conflicts, these are disclosed and discussed at the initial work group meeting. These members are expected to recuse themselves from related discussions or authorship of related recommendations, as directed by the Conflict of Interest committee or requested by the work group.

The complete ICSI policy regarding Conflicts of Interest is available at <http://bit.ly/ICSICOI>.

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Online at <http://www.ICSI.org>

Document History

The original guideline document was drafted in 2006 by a work group of 14 clinicians. It was approved for release early in 2007. In that year a subgroup of the work group was commissioned to develop an order set for symptom management for patients with a life-limiting, progressive illness. This order set was approved and released in December 2007. It contained numerous symptoms – both physical and psychological. Many options for treatment were described incorporating pharmacological, non-pharmacological and complementary/supportive therapies.

Controlling physical and psychological symptoms for patients with a serious illness is core to palliative care. Therapy should be individualized for each patient's unique circumstances. In 2011 the work group made the decision to discontinue revision of the order set. It recognizes that there is not a single order set that covers all symptoms and possible therapies. The guideline contains some resources that are available to assist the clinician in symptom management.

In 2009, ICSI formed a strategic initiative to integrate palliative care into routine care delivery, recognizing that a palliative care specialty may not be available in all health care settings. This initiative was designed to create a more efficient model for the delivery of pain and symptom management, care coordination and shared decision-making from the moment the patient was diagnosed with a serious illness.

A palliative care model and a communication plan were developed for introducing elements of palliative care at the time a patient was identified with a life-limiting illness. Goals included identifying metrics to evaluate the model and creating a plan to ensure the model's financial sustainability. The design team identified what palliative care might look like in primary care, long-term care, home care and specialty care settings by applying the agreed-upon elements of palliative care. In 2011 the specific work on the initiative was halted. Instead, the elements plus other principles learned through the effort were incorporated into other health care redesign efforts, such as Health Care Home, Reducing Avoidable Readmissions to Hospitals, and Shared Decision-Making.

The GRADE system as a method of assessing evidence and writing recommendations was implemented in 2011.

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ICSI Document Development and Revision Process

Overview

Since 1993, the Institute for Clinical Systems Improvement (ICSI) has developed more than 60 evidence-based health care documents that support best practices for the prevention, diagnosis, treatment or management of a given symptom, disease or condition for patients.

Audience and Intended Use

The information contained in this ICSI Health Care Guideline is intended primarily for health professionals and other expert audiences.

This ICSI Health Care Guideline should not be construed as medical advice or medical opinion related to any specific facts or circumstances. Patients and families are urged to consult a health care professional regarding their own situation and any specific medical questions they may have. In addition, they should seek assistance from a health care professional in interpreting this ICSI Health Care Guideline and applying it in their individual case.

This ICSI Health Care Guideline is designed to assist clinicians by providing an analytical framework for the evaluation and treatment of patients, and is not intended either to replace a clinician's judgment or to establish a protocol for all patients with a particular condition.

Document Development and Revision Process

The development process is based on a number of long-proven approaches and is continually being revised based on changing community standards. The ICSI staff, in consultation with the work group and a medical librarian, conduct a literature search to identify systematic reviews, randomized clinical trials, meta-analysis, other guidelines, regulatory statements and other pertinent literature. This literature is evaluated based on the GRADE methodology by work group members. When needed, an outside methodologist is consulted.

The work group uses this information to develop or revise clinical flows and algorithms, write recommendations, and identify gaps in the literature. The work group gives consideration to the importance of many issues as they develop the guideline. These considerations include the systems of care in our community and how resources vary, the balance between benefits and harms of interventions, patient and community values, the autonomy of clinicians and patients and more. All decisions made by the work group are done using a consensus process.

ICSI's medical group members and sponsors review each guideline as part of the revision process. They provide comment on the scientific content, recommendations, implementation strategies and barriers to implementation. This feedback is used by and responded to by the work group as part of their revision work. Final review and approval of the guideline is done by ICSI's Committee on Evidence-Based Practice. This committee is made up of practicing clinicians and nurses, drawn from ICSI member medical groups.

Implementation Recommendations and Measures

These are provided to assist medical groups and others to implement the recommendations in the guidelines. Where possible, implementation strategies are included that have been formally evaluated and tested. Measures are included that may be used for quality improvement as well as for outcome reporting. When available, regulatory or publicly reported measures are included.

Document Revision Cycle

Scientific documents are revised every 12-24 months as indicated by changes in clinical practice and literature. ICSI staff monitors major peer-reviewed journals every month for the guidelines for which they are responsible. Work group members are also asked to provide any pertinent literature through check-ins with the work group midcycle and annually to determine if there have been changes in the evidence significant enough to warrant document revision earlier than scheduled. This process complements the exhaustive literature search that is done on the subject prior to development of the first version of a guideline.

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Full Guidance for Using Gold Standards Framework

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V25



Full Guidance on Using QOF to Improve Palliative / End of Life Care in Primary Care

**Guidelines for practices on the revised Quality Outcome Framework (QOF)
points for Palliative Care and the
Gold Standard Framework (GSF)**

**This Guidance may be of particular use to practice managers, enabling
their practices to institute changes to claim QOF points in the GMS
contract for April 06.**

***Drs Amanda Free, Keri Thomas, Wendy-Jane Walton and Teresa Griffin of
The Gold Standards Framework National Central Team***



NHS

**End of Life Care
Programme**

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"The college is pleased to support the Gold Standards Framework, which is having a huge impact on the quality of care at the end of patients' lives. The values expressed in this framework are central to the College ethos of Knowledge with Compassion."
Dr Graham Archard
Vice Chairman Royal College of General Practitioners, March '05

1 Introduction - Why bother?

The challenge:-

Each GP will have about 20 patient deaths/year. About 1% of the population will die each year - e.g. with a list size of 10,000 patients, an average practice will have about 100 patient deaths/ year

Most of our patients now die from

- cancer (about a quarter)
- organ failure - heart failure, COPD etc (about a third)
- or frailty/dementia/multiple co-morbidities (about a third)

With the predicted demographic changes over the coming years, more people are living longer with serious illness, and more will die from non cancer illnesses, often related to their long term conditions.

How can we predict which will be the patients in the last year of life?

How can we ensure that these patients are given the best care in this their final stage of life? - in particular the final year of life?

Improving care for patients nearing the end of their lives is one of the most important and highly valued aspects of our work in general practice. Yet until now, we have often failed to target care towards this group of patients, mainly because of difficulty in identifying them and responding to their needs. Using the Gold Standards Framework in Community Palliative Care, already used by about a third of the practices in England, Scotland and Northern Ireland, many have found that they can provide better quality and more focused care for these patients. They also feel that the service provided feels better organised and managed. The result is a greater consistency in the standard of care, with fewer patients 'slipping through the net' and more reliable community care provided by the Primary Health Care Team.

As from April 06, there are now some QOF points specifically targeted for palliative care patients - 3 points for having a register for all patients predicted to be in the last 6- 12 months of life with any diagnosis, and 3 points for holding a multidisciplinary meeting at least 3 monthly (plus other general points included in end of life care - see later e.g. dementia).

For GSF Practices For those already using the GSF in their practice, this is an opportunity to be rewarded for some of the work you are already doing. But as the register is for ALL patients in the last 6-12 months of life, it is an opportunity to maybe extend your registers to move beyond cancer patients to include more non cancer patients also. We know that far fewer non-cancer patients are currently receiving supportive care than may be eligible to do so, (just compare the lung cancer patient with the COPD patient with the same prognosis) - some guidance for this is given in the following pages and in the separate prognostic indicators paper.

For those practices that are not using GSF currently, this may be an opportunity to focus on this important group of patients, to identify and collate their information using a register and to discuss their management plans as a team. This is the first step in improving palliative care organisation within your practice team. You might like then to develop this care further with the suggestions made in other key task areas of GSF. Although you may well be doing much of it in an ad hoc way already, by pulling it together into a practice framework or protocol, with an agreed plan of care for people in the last year of life, you are likely to find, as others have, that care can in fact become easier, more fulfilling and lead to more people dying a good death, in the place and in the manner of their choosing. So by undertaking and claiming these QOF points, this may be the first step to focusing more on your patients nearing the end of life.

Fig 1: The three main illness trajectories and deaths / GP / year and end stage illness
 (Assuming GP list size of 2000 patients)
 After Lynn et al in WHO Guidance Palliative Care The Solid Facts Ed Higginson

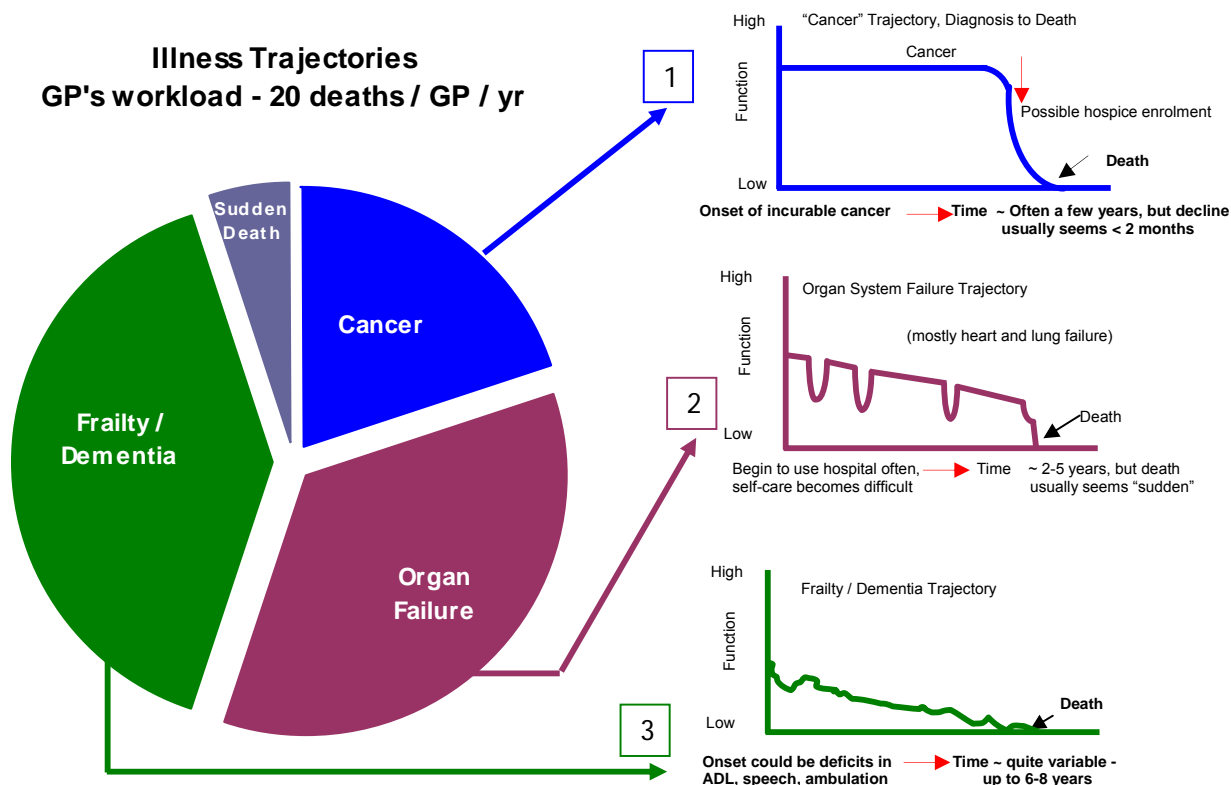


Fig 1 The three main illness trajectories and deaths/GP/year and three trajectories of end stage illness

Every GP will average about 20 deaths/ 2000 patients/ year. These will be from broadly three groups of patients (See Fig 1).

Rapid Decline

- 1) **Cancer patients** - about 5 deaths/GP/year, with a roughly predictable disease trajectory of slow decline, varying in timescale with each cancer group, then steady deterioration. This picture epitomizes the standard patient in need of palliative care, and the predicted hospice/ specialist palliative care input at certain stages - most palliative care services are currently directed mainly to cancer patients with this trajectory of illness.

- 2) **The Organ Failure patients** - about 6 patient deaths/GP/Year. This represents an increasing number of patients dying not of cancer but of predominantly single organ failure, such as heart, lung, nerve, kidney, liver or other organ failure. Their picture is much more of steady decline over years with intermittent exacerbations, often requiring hospitalisation, with often an unclear terminal phase leading to death. There is difficulty predicting which exacerbation will be their last, so in the end, death may come as a shock, with little preparation beforehand by the patient, family and staff. These patients often miss out on the benefits given to many cancer patients. However, by estimating which patients fall into this rough category of being in the final year of life using the predictive indicators suggested, and by raising awareness of their needs, more can be done to enable good palliative symptom control, service provision, carer support and respite and life closure discussions for these patients. Also some hospital admissions might be averted, especially in the terminal stages, and more patients would be enabled to live out the end of their lives where they would choose to. As their picture is that of a slower decline, supportive care for example using GSF at an early stage is important to enable them to live well until they die.

Gradual Decline

- 3) **Frailty / dementia patients** - with multiple co-morbidities and organ failures. About 7-8 patient deaths/GP/Year. This group of patients consists mainly of elderly patients with multiple organ failures, with cumulative co-morbidities and frailty. With increasing age also, the prevalence of dementia increases, and this contributes to or can dominate their overall condition. This number is increasing and is likely to be the predominant group over the next few years. Their needs are different from those of the traditional cancer patient, with more long term community support needed, better support for carers; and more are within institutionalised care. However, their end of life stories may be equally needy though less well voiced, and greater support is needed. As many frail elderly live in care homes, where one in five deaths occur, and there are particular issues sometimes with primary palliative care provision in care homes, particular attention is required for those living in care homes (see GSF in care homes programme on GSF website).

2 Getting going - New recommendations for palliative care in QOF

In summary in the new GP contract's Quality and Outcome Framework (QOF) from April 06:-

New points specifically now available relating to palliative care for all patients

3 points for assembling a palliative/supportive care register for all patients estimated to be in the last 6-12 months of life, with cancer and non- cancer illnesses.

3 points for holding regular (at least 3 monthly) multi-disciplinary case review meetings where all patients on the palliative care register are discussed. The aim of these meetings is to

- ensure that each patient has a management plan as defined by the practice team and are acted upon by the most appropriate member of the team.
- Ensure that the management plan includes preferences for place of care.
- Ensure that the support needs of carers are discussed and addressed wherever reasonably possible.

Total 6 points

Current and related points available for cancer and other long term conditions relevant to palliative care

5 points for producing a register of all cancer patients excluding non-melanotic skin cancers.

6 points for recording a cancer care review within 6 months of diagnosis on patients diagnosed with cancer within the last 18 months.

5 points for producing a register of patients with dementia.

15 points for reviewing the care of patients diagnosed with dementia in the previous 15 months.

6 points for undertaking a minimum of 3 significant event reviews in the past year.

4 points for having undertaken a minimum of 12 significant event reviews in the last 3 years which include (amongst other things) new cancer diagnoses and deaths where terminal care has taken place at home.

2 points for having a system to alert the out of hours service to patients dying at home.

3 points for having a protocol for the identification of carers and a mechanism for the referral of carers for a social services assessment.

Total 52 points Total number of points in the QOF 2 available for those using GSF in their practice

Further information and guidance on QOF is available at www.nhsemployers.org

Palliative care Points

a) Setting up the Palliative/ Supportive care register

b) Holding the MDT meetings

level 1/C1 of GSF

- a) **A total of three points will be awarded for setting up and maintaining a palliative care register.**
All patients in the last 6-12 months of life should be included on this register.

For those already using GSF this register is already in place in the form of the supportive care register (SCR), but to claim the points the patients must be entered on the computer with one of the recommended Read codes.

As the points awarded are not many it is important to maximise the prevalence figures to maximise income generated. It is intended that the palliative care register, in order to provide equity for all our patients, should include all patients with palliative care needs, not just our cancer patients.

If we look at an average GP list of 2000 patients, there will be an average of 20 deaths per year. Between one and three of these will be sudden deaths. It can therefore be argued that it should have been possible to identify the other 17 to 19 patients as having end stage illness, and therefore they should all have been on the palliative care register. Within the new guide and in the non cancer section of the GSF website, there are papers on the prognostic indicators and ideas on how to identify these patients, but it has to be accepted that this can never be entirely accurate

In summary, to identify these patients we can use any of the following methods:

1. **The surprise question, "Would you be surprised if this patient were to die in the next 6-12 months".**
2. **The patient prefers comfort care only rather than increasingly misnamed 'curative' treatment.**
3. **Clinical indicators (see Prognostic Indicators in Guide and on website)**

We are hoping to develop further this guidance, which includes clinical indicators, validated and agreed by some of the UK specialist bodies, to make it easier for PHCT's to identify those patients in the last 6-12 months of life. Currently though we are using indicators validated by some UK Specialist bodies with some other guidance taken from the USA.

- b) **Three points will be awarded for discussing those patients on the register at three monthly (at least) MDT meetings.**

As before, GSF practices will already be doing this, and will probably be meeting monthly.

Practices not using GSF will first need to identify those it would be useful to meet with - a core group would be GP's, District nurse, Community specialist palliative care nurse, Practice nurses and administrative staff in many teams, Social services

It is then useful to appoint a coordinator to organise the meetings and keep the project "on track", and a lead GP.

At the meeting the Register's first summary sheet, SCR1 (see templates on website) acts as a good template upon which to base discussion about the patients, ensuring for example that their wishes re place of care have been shared, management plans have been agreed, and that someone in the team has sent information to the out of hours service. It also provides a written summary for audit and a written record that the meetings have taken place.

Once the non-cancer patients are included on the register the number of different professionals involved will increase. For example, the respiratory nurse and the heart failure nurse should now be consulted and included in the meetings.

This will become logistically more complicated and teams will have to find local solutions dependant upon such things as list size and geography. We envisage that some teams will choose to split the register into cancer and non-cancer and could, for example, discuss the non-cancer patients 3 monthly and the cancer patients at the meetings on the other 2 months. This may make better use of the specialist teams' time.

Examples of ways of holding MDT meetings are in the Guide below.

3 Further steps

3.1 GSF 7 C's and levels of adoption

Once teams have the register and meetings in place we hope that they will want to take it further, to further improve the care that they offer to their dying patients.

In the Gold Standards Framework programme there are seven key tasks, also known as the Seven C's.

C1 - Communication

- set up the register and meet regularly as a team.
- ensure that the patients have the information they need e.g. in home packs
- ensure that the patient's wishes are taken into account e.g. re place of care

C2 - Co-ordination

- appoint a co-ordinator and a lead GP and DN.

C3 - Control of symptoms

- pool knowledge and expertise to address physical, psychological, social and spiritual needs
- use symptom assessment tools

C4 - Continuity of care

- inform the out of hours service about the patients
- work together with the secondary care teams

C5 - Continued learning

- use audit (e.g. place of death) and significant event or after death analysis
- identify and address knowledge gaps
- develop practice protocols

C6 - Carer support

- identify and address their emotional, practical and financial needs
- extend care into the bereavement phase

C7 - Care in the dying phase

- use a protocol for the last 48hrs of life such as the Liverpool Care Pathway, for more information www.endoflifecare.nhs.uk
- ensure that drugs are prescribed in anticipation of need

After completing C1 (register and meetings) teams will find that it is very easy and very natural to progress through the other C's, but it can be done at their own pace. For help and advice, e.g. on After Death Analysis, teams should register with the central GSF team and contact their local facilitator (details from SHA End of Life Care lead). Other information is available on the GSF web site.

In order to track progress locally and nationally we have divided the Framework into 4 levels, roughly equating to the 7 C's, so that we can measure not only how many teams have adopted GSF, but how deeply it is being adopted and used, in order to improve the care that we deliver to our patients in their last year of life. See appendix 5 for more details.

3.2 Read Codes

In order to qualify for the QOF points it is important to use the qualifying diagnostic codes for Palliative Care:

ZV57C	(V)Palliative care
8H7g.	Referral to Palliative care service
8BAP.	Specialist palliative care
8BAT.	Specialist palliative care treatment - outpatient
8H6A.	Refer to terminal care consult
8CM1.	On gold standards palliative care framework
8HH7.	Referred to community specialist palliative care team
8BJ1.	Palliative treatment
8BA2.	Terminal care
8H7L.	Refer for terminal care
8BAS.	Specialist palliative care treatment - daycare
9EB5.	DS1500 Disability living allowance completed
1Z01.	Terminal illness - late stage

Other useful Read codes for palliative care are in appendix 4, including for example Read codes for preferences on place of death.

3.3 Out of hours palliative care and handover forms

Few GP's now work weekends or nights, so it is important that we work together with the out of hours service to provide as much continuity of care for our patients as possible. All the good work done in hours can rapidly be undone out of hours if for example the patient is advised inappropriately to call an ambulance, resulting in a distressing A&E attendance and wait.

We must inform the out of hours service of our patients condition, preferences and plans. Most out of hours services have developed their own forms to be faxed over to them, ensuring that these patients are treated as a priority and that their wishes are taken into account, and the PHCT needs to develop a system to ensure that these forms are used. Alternatively the SCR2, or Supportive Care Register Front Sheet can be used, see appendix 2.

We must also ensure that drugs are left in the home in anticipation of need. This is particularly important for those patients choosing to die at home as they enter the terminal phase of their illness. A supply of diamorphine, glycopyrronium, midazolam and cyclizine, for example, may well save the carer driving miles to get the drugs, and again may save inappropriate hospital admissions, as well as meaning that symptoms can be treated promptly.

3.4 Assessment tools

Better symptom control for patients must be one of our most important goals. We must address their physical, psychological, social and spiritual symptoms. But there is some evidence, for example, that doctors are only aware of a proportion of patients' symptoms, and symptom assessment tools may help us with this. There are many choices of these tools, and their use should be agreed as a team. Some examples are included on the website. Tools can also help with audit, enabling us to build a case for improved local resourcing. But it is important that we remain patient focussed, addressing our patients' priorities rather than simply pen-pushing.

Appendix 1: Prognostic Indicators for patients who are “sick enough to die” and who are reasonably likely to be “in the last 6-12 months of life

Although inherently a difficult area to predict we know that currently we are not recognising the actual likely prognostic trajectory for many patients, especially for non-cancer patients with advanced disease, and therefore we are under-estimating the number of people in need of palliative/ supportive care. These clinical prognostic indicators are an attempt to estimate when patients are in the last year or so of life. They have been drawn and referenced from a number of sources including from specialist centres in this country and abroad- they will be updated as more information is obtained. Although these are intrinsically only a very approximate guide to prognosis, these clinical indicators can therefore act as a rough guide to indicate to those in specialist secondary services and primary care that patients may be in need of palliative / supportive care and could be included on the register.

In summary, to identify these patients we can use any of the following methods:

1. The surprise question, “Would you be surprised if this patient were to die in the next 6-12 months”.
2. The patient prefers comfort care only, not increasing misnamed ‘curative’ treatment.
3. Clinical indicators - general or disease specific (see Prognostic Indicators below)

Prognostic Indicator Guidance

Revised Vs 5. Sept 08

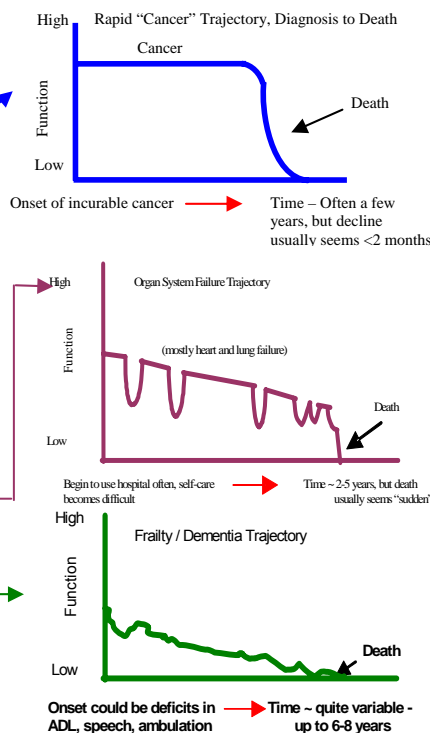
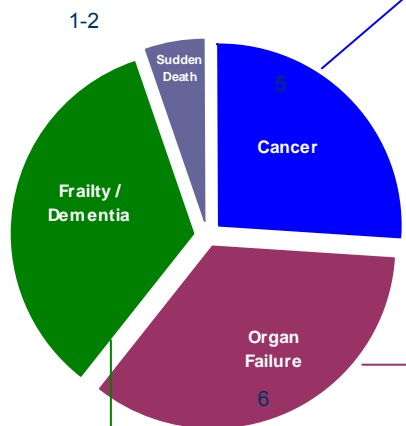
“Earlier recognition of people nearing the end of their life leads to earlier planning and better care”
Guidance to enable better identification of patients who may need supportive/palliative care

About 1% of the population die each year, yet it is intrinsically difficult to predict or identify which patients may be in their last year of life. If predicted earlier, some supportive care measures could be introduced that would enable earlier discussion of their wishes, improve care aligned to their preferences and fewer crises. In short, if we could better identify these patients, we might be more able to provide better care for them as they approach the end of their lives. This guidance paper suggests which adult patients with any condition predicted to be in the final 6-12 months of life might be in need of supportive/palliative care. It was developed originally to support primary care teams using the Gold Standards Framework (GSF) and Quality Outcome Framework (QOF) to include more appropriate patients on their Palliative/Supportive Care Registers, and thereby to encourage better prediction of possible need and provision of care. The focus is more on improving prediction of need for support, rather than pure prognostication of time remaining. Though all prognostication is inherently inexact, and as people live longer with more co-morbid conditions, there can be disparity between levels of care provided to patients with different diagnoses. This guidance aims to help clinicians to support more patients nearing the end of life, whatever their underlying illness. It contributes to the development of accepted indicators for patients in the last months/year of life, which will aid identification of such patients and promote excellence in end of life care.

Three triggers for Supportive/ Palliative Care are suggested - to identify these patients we can use any combination of the following methods:

- 1. The surprise question** ‘Would you be surprised if this patient were to die in the next 6-12months’ - an intuitive question integrating co-morbidity, social and other factors. If you would not be surprised, then what measures might be taken to improve their quality of life now and in preparation for the dying stage. The surprise question can be applied to years/months/weeks/days and trigger the appropriate actions at each stage ie “the right think to happen at the right time”
- 2. Choice/ Need** - The patient with advanced disease makes a **choice** for comfort care only, not ‘curative’ treatment, or is in special **need** of supportive / palliative care eg refusing renal transplant
- 3. Clinical indicators** - Specific indicators of advanced disease for each of the three main end of life patient groups - cancer, organ failure, elderly frail/ dementia (see over)

GP's workload - Average 20 deaths/GP/yr (approximate proportions)



Typical Case Histories



1) Mrs A - A 54 year old woman with cancer of colon with liver secondaries and requiring a stent for jaundice who is feeling increasingly weak and tired. Likely rapid decline



2) Mr B - A 76 year old man with heart failure with increasing breathlessness on walking who finds it difficult to leave his home has had 2 hospital admissions in the last year and is worried about the prospect of any more emergencies and coping in the future



3) Mrs C - An 81 year old lady with COPD, heart failure, osteoarthritis and increasing forgetfulness, who lives alone. She fractured her hip after a fall, eats a poor diet and finds mobility difficult. She wishes to stay at home but is increasingly unable to cope alone and appears to be 'skating on thin ice'. Likely slow decline, difficult to predict dying phase. Common picture in care homes

The Department of Health's new End of Life Care Strategy July 08 suggests development of a care pathway begins with the "identification of people approaching the end of life and initiating discussions about preferences for end of life care" (Exec.Summary 9 p.11). It also suggests use of this guidance to support such early identification "For many people suffering from a chronic illness a point is reached where it is clear that the person will die from their condition. Despite this, for many conditions it may be difficult, if not impossible and potentially unhelpful, to estimate prognosis accurately. The Prognostic Indicator Guidance developed as part of the Gold Standards Framework (GSF) provides useful prompts or triggers to a healthcare professional that discussions about the end of life should be initiated, if this has not already happened". (3.22)

Trigger 3 – Specific clinical indicators of advanced disease

These clinical prognostic indicators are an attempt to estimate when patients have advanced disease or are in the last year or so of life. These are only indicators and must be interpreted with clinical judgement for each individual patient, but they can help to alert clinicians to the need for extra supportive care. They have been drawn from a number of expert sources from the UK and abroad, and are updated regularly. Some use such indicators routinely, to assess patients' need for palliative/supportive/hospice care. Although these are intrinsically only a very approximate guide to prognosis, these clinical indicators can therefore act as a rough guide to indicate to those in primary care and in secondary services that patients may be in need of palliative / supportive care. Primary care teams may include these patients on their Supportive/palliative care registers and hospital staff may suggest to GPs in discharge letters that such patients are included on the registers, if helpful.

Co-morbidities or other General Predictors of End Stage illness^{1/2}

Co-morbidity is increasingly the biggest predictive indicator of mortality and morbidity. Also-

- Weight loss - Greater than 10% weight loss over 6 months
- General physical decline
- Serum Albumin < 25 g/l
- Reducing performance status / ECOG/Karnofsky score (KPS) < 50%. Dependence in most activities of daily living(ADLs)

1. Cancer Patients

Cancer³

Any patient whose cancer is metastatic or not amenable to treatment, with some exceptions – this may include some cancer patients from diagnosis e.g. lung cancer. 'The single most important predictive factor in cancer is performance status and functional ability' – if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less. More exact predictors for cancer patients are available elsewhere on the GSF website.

2. Organ Failure Patients

2.1 Heart Disease - CHF⁴

At least two of the indicators below :-

- CHF NYHA stage III or IV – shortness of breath at rest or minimal exertion
- Patient thought to be in the last year of life by the care team - the 'surprise' question
- Repeated hospital admissions with symptoms of heart failure
- Difficult physical or psychological symptoms despite optimal tolerated therapy

2.2 Chronic Obstructive Pulmonary Disease – COPD⁵

- Disease assessed to be severe e.g. (FEV1 <30%predicted – with caveats about quality of testing)
- Recurrent hospital admission (>3 admissions in 12 months for COPD exacerbations)
- Fulfils Long Term Oxygen Therapy Criteria
- MRC grade 4/5 – shortness of breath after 100 meters on the level or confined to house through breathlessness
- Signs and symptoms of right heart failure
- Combination of other factors e.g. anorexia, previous ITU/NIV/resistant organism, depression
- >6 weeks of systemic steroids for COPD in the preceding 12 months

2.3 Renal Disease⁶

- Patients with stage 5 kidney disease who are not seeking or are discontinuing renal replacement therapy. This may be from choice or because they are too frail or have too many co-morbid conditions.
 - Patients with stage 5 chronic kidney disease whose condition is deteriorating and for whom the one year 'surprise question' is applicable ie overall you would not be surprised if they were to die in the next year?
 - Clinical indicators:
 - CKD stage 5 (eGFR <15 ml/min)
 - Symptomatic renal failure -Nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload)
 - Increasingly severe symptoms from comorbid conditions requiring more complex management or difficult to treat
- NB. many people with Stage 5 CKD have stable impaired renal function and do not progress or need RRT.

2.4 Neurological Disease - a) Motor Neurone Disease⁷

MND patients should be included from diagnosis, as it is a rapidly progressing condition

Indicators of rapid deterioration include:

- Evidence of disturbed sleep related to respiratory muscle weakness in addition to signs of dyspnoea at rest
- Barely intelligible speech
- Difficulty swallowing
- Poor nutritional status
- Needing assistance with ADL's
- Medical complications eg pneumonia, sepsis
- A short interval between onset of symptoms and diagnosis
- A low vital capacity (below 70% of predicted using standard spirometry)

b) Parkinson's Disease⁸

The presence of 2 or more of the criteria in Parkinson disease should trigger inclusion on the Register

- Drug treatment is no longer as effective / an increasingly complex regime of drug treatments
- Reduced independence, need for help with daily living
- Recognition that the condition has become less controlled and less predictable with "off" periods
- Dyskinesias, mobility problems and falls
- Swallowing problems
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)

c) Multiple Sclerosis⁹

Indications of deterioration and inclusion on register are:-

- Significant complex symptoms and medical complications
- Dysphagia (swallowing difficulties) is a key symptom, leading to recurrent aspiration pneumonias and recurrent admissions with sepsis and poor nutritional status
- Communication difficulties e.g. Dysarthria ± fatigue
- Cognitive impairment notably the onset of dementia
- Breathlessness may be in the terminal phase

3. Patients with Frailty and Dementia

Frailty¹⁰

- Multiple comorbidities with signs of impairments in day to day functioning
- Deteriorating functional score eg EPOC/ Karnofsky
- Combination of at least 3 symptoms of: weakness, slow walking speed, low physical activity, weight loss, reduced weight loss, self reported exhaustion

Dementia¹¹

- Unable to walk without assistance, and
- Urinary and fecal incontinence, and
- No consistently meaningful verbal communication, and
- Unable to dress without assistance
- Barthel score < 3
- Reduced ability to perform activities of daily living

Plus any one of the following:

10% weight loss in previous six months without other causes, Pyelonephritis or UTI, Serum albumin 25 g/l, Severe pressure scores eg stage III / IV, Recurrent fevers, Reduced oral intake / weight loss, Aspiration pneumonia

Stroke¹²

- Persistent vegetative or minimal conscious state / dense paralysis / incontinence
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / Post-stroke dementia

Functional scores- 1) Karnofsky Performance Status Score

The Karnofsky score, measures patient performance of activities of daily living. Score Function

100	Normal, no evidence of disease	50	Requires considerable assistance
90	Able to perform normal activity with only minor symptoms	40	Disabled, requires special assistance
80	Normal activity with effort, some symptoms	30	Severely disabled
70	Able to care for self but unable to do normal activities	20	Very sick, requires active supportive treatment
60	Requires occasional assistance, cares for most needs	10	Moribund

2) WHO/ ECOG Performance Status¹

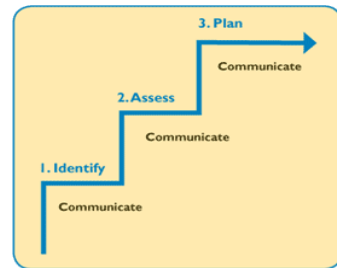
- 0 Fully active, able to carry on all pre-disease performance without restriction
- 1 Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. light housework, office work
- 2 Ambulatory and capable of self care but unable to carry out work activities: upright more than 50% of waking hours
- 3 Capable of only limited self care, confined to bed or chair more than 50% of waking hours
- 4 Completely disabled, cannot carry on any self care, totally confined to bed or chair
- 5 Dead

Prognostication or Prediction of need. Prognostication is inherently difficult and inaccurate, even when informed by objective clinical indicators, and the trend is usually to over-estimate prognosis and to under-estimate planning for possible need, especially for those with non-cancer illnesses. The aim of this paper is to enable better identification of patients who may need supportive/ palliative care. It focuses more on pragmatically and instinctively improving prediction of decline, leading to better anticipation of need for support, and less on pure prognostication of time remaining, for which there is much more accurate guidance available (see GSF website). In anticipating this possible deterioration, earlier discussions about preferences and needs can be initiated; some practical measures could be introduced leading to prevention of crises and referral sought for extra help or advice. The aim of such Advance Care Planning discussions, is to seek out their particular unmet needs and preferences, sometimes previously unvoiced, enabling more people to live out the final stage of life as they wish. We suggest a change towards instinctive, anticipatory and 'insurance-type' thinking, rather than pure prediction of likely timescale, so that appropriate support and care can be mobilised. We know that some attempt to improve this prediction, however inaccurate, is key to beginning the process that leads to better end of life care for all.

How to use this Guidance

This Guidance document aims to clarify triggers for consideration of patients in need of supportive/palliative care. This is not attempting to answer the question 'how long have I got?' but more in answer to the question 'what can we do?', and is in response to the common way of thinking 'Hope for the best but prepare for the worst'.

The main processes used in GSF are to **identify**, **assess**, **plan**, and at all times **communicate** about patient care and preferences. Use of this guidance might enable better **identification** of patients nearing the end of their lives i.e. in the last 6-12 months of life, to trigger better **assessment** and **pre-planning** e.g. holistic needs assessment, Advance Care Plans, and the appropriate management care plan and provision of **supportive care** related to their **needs**.



For primary care teams, this is the first step towards developing a Supportive/ Palliative Care Register, now part of QOF palliative care points in the GMS contract. For more details of suggestions for claiming the QOF points, templates etc see the www.goldstandardsframework.nhs.uk/gp_contract.php. For those using the Gold Standards Framework (GSF), this might trigger inclusion of more non-cancer patients in the current Supportive Care Register. Of course, not all of these tests are performed in primary care, but GPs/DNs collate information from hospitals and, together with their own holistic assessment, form an overall view of a patient's likely prognosis. N.B: It can be much harder to predict whether patients in the third category of frail elderly patients are nearing end of their lives, as they are intrinsically more complex and vulnerable, with a more chronic variable illness trajectory. We do not suggest necessarily that all patients in this third category are included on the GSF Supportive Care Register, unless they fulfil the other criteria of co-morbidity, need or predicted decline, but we are suggesting that more non-cancer organ failure patients be included i.e. with Heart Failure and COPD, to the expected prevalence or to represent at least half the patients in the Supportive Care registers

For hospital teams, in addition to accessing supportive/palliative care services and consideration of supportive measures, it would also be helpful to notify the GP/Primary care team that this patient has advanced disease and could be included on their Supportive/Palliative Care Register.

For specialist palliative care/ hospice teams - Although traditionally focussed mainly on cancer patients, specialist palliative care now extends to patients with non-cancer illnesses. There is greater collaboration with other teams e.g. heart failure nurses, to provide best patient care, and these indicators may help clarify referrals.

For PCTs /Commissioners/managers etc - This could be used as part of an End of Life care strategic plan for the area, with improved provision of services for all patients nearing the end of life. **NB Long Term Conditions**. There is a strong overlap with care for patients with Long Term Conditions and prediction of unplanned admissions to hospital and that of patients with advanced disease in the last year of life. This is especially true for patients with heart failure or COPD. Close collaboration with Case Managers to support good end of life care is very important.

For Care Homes - Use of some broad prognostic indicators has been found to help identify patients most in need in some care homes, and help focus care and trigger key actions (see below and GSF Care Homes on website)

Examples of prognostic indicators used as part of patient needs assessment

Patients have differing requirements at varying stages of their illness. Some GPs categorise their patients on the Supportive Care Register according to estimated prognosis and need, and colour code them accordingly. Care Homes using the GSF for Care Homes Programmes have also found the intuitive grouping of their residents to be very helpful. Although only a rough guide, this helps teams 'awareness of patients' varying needs, focuses care to ensure that the right care is directed at the right time, ensures regular review, and triggers key actions at each stage. A needs/support plan is therefore developed. Suggested prognostic coding could be:

A - 'All' Stable Years + prognosis	B - 'Benefits' eg DS1500 Unstable / frequent exacerbations Months prognosis	C - 'Continuing Care' Deteriorating Weeks prognosis	D - 'Days' Dying / terminal phase Days prognosis
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The use of means of estimating approximate prognosis and need i.e. the intuitive 'surprise' question, needs/choice based care, and these clinical indicators, may help to ensure that patients with advanced illness receive higher quality proactive care and support as they near the end of their lives.

Development of this guidance paper. This paper was developed and later fully revised following wide consultation with a large number of specialist clinical bodies, special interest groups, national disease associations, Royal College of General Practitioners and major palliative care texts. We were helped also by considering prognostic indicators from other countries eg USA, used to trigger referral of non-cancer patients to hospice/palliative care. Since its first development in June 06, this 'PIG' paper has been widely used by clinicians nationally and internationally, by GPs in the UK (90% of whom now have supportive/palliative care registers), by care homes' staff, researchers and many others. We undertake regular reviews and would be pleased to receive any comments or ideas for improvements or example of usage. The accompanying Needs Support Matrixes are also in development for most conditions.

**Further information and other prognostic guidance is available from www.goldstandardsframework.nhs.uk
Prof Keri Thomas, Dr Amanda Free and members of the National GSF Centre info@goldstandardsframework.nhs.uk**

References

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Appendix 2 - SCR1, SCR2, MDT

C SCR1

Summary of Palliative Care Patients														
Name of patient Name of Carer	Diagnosis(+code)	G P	D N	Problems/ Concerns	Anticipated needs	Information given/ Carer issues	DS 1500 date	Mac-millan Nurse/ CNS	Hospice/ SPC	OOH Hand-over Form Date sent	Preferred place of Care stated + date	Actual place death + date	Bereavement Care	Crisis Events/ Notes

SCR1 Summary sheet - Gold Standards Framework © Keri Thomas and Department of Health England 2005

B SCR2 Supportive Care Register Front sheet

<u>Name</u> Comp No DOB Hosp No	<u>Diagnosis</u> <u>Secondaries</u> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%;">Date of diagnosis</td> <td style="width: 50%;">DS 1500 date/Ca registered.....</td> </tr> </table>	Date of diagnosis	DS 1500 date/Ca registered.....							
Date of diagnosis	DS 1500 date/Ca registered.....									
<u>Address</u> Tel No	<u>Family/carer contacts</u> 									
<u>Personnel involved</u> Oncologist Other specialists Macmillan/Nurse/SPC <input type="checkbox"/> Hospice <input type="checkbox"/> Others eg SS.....	<table style="width: 100%;"> <tr> <td style="width: 50%;"><u>Key GP</u></td> <td style="width: 50%;"><u>Key DN</u></td> </tr> <tr> <td>.....</td> <td>.....</td> </tr> <tr> <td>.....</td> <td>.....</td> </tr> <tr> <td>.....</td> <td>.....</td> </tr> </table> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="padding: 5px;">Other conditions</td> </tr> </table>	<u>Key GP</u>	<u>Key DN</u>	Other conditions
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Current Medication										
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Preferred place of care:										
Date:										
Comments:										

C Example of holding a Meeting for palliative care using GSF

- Combine with your usual MDT meeting
 - Meet with GPs, District Nurses, admin staff eg practice manager
 - Invite specialist palliative care nurses / Macmillan / hospice nurses
 - Sometimes representatives from other groups eg practice nurses, receptionists, social services etc
 - Preferably monthly meetings or more regular - minimum 3 monthly
 - Suggested plan of meeting
1. **Discuss new patients** for inclusion on the register according to your inclusion criteria eg cancer patients, those eligible for DS1500, those suspected to be in last year of life with the surprise question etc
 2. **Discuss existing patients** on register- use the SCR1 and 2 to act as checklist and reminders- keep in mind current plans, patient preferences, communication with others, anticipating future needs and proactive planning.
 3. **Review patient deaths** - use Significant Event Analysis, After Death Analysis etc Staff support and debriefing. Bereavement follow up for family and carers.
 4. **Action points** - learning needs, commissioning issues, practice protocols/ procedures, audit etc AOB
Next meeting date.

SIGNIFICANT EVENT ANALYSIS

SCR 6

WHAT WENT WELL?

WHAT DIDN'T GO SO WELL?

WHAT COULD HAVE BEEN DONE BETTER?

Traffic lights SEA -© Gold Standards Framework 2005

Appendix 4 - Palliative Care Read Codes - GSF Template

Supportive Care Register		
8CM1	On Gold Standards Palliative Care Framework	QOF Points
9EB5	DS1500 issued to patient	QOF Points
8H7g	Palliative Care Referral	QOF Points
Preferred Place of Care		
8CN1	Preferred Place of care /death (Chosen / Discussed) - PPD	Suggested as useful
94Z1	PPD - home	Suggested as useful
94Z2	PPD - Hospice	Suggested as useful
94Z3	PPD - Community hospital	Suggested as useful
94Z4	PPD - hospital	Suggested as useful
94Z5	PPD - nursing home	Suggested as useful
Advance Care Planning		
1R1	Not for resuscitation	Suggested as useful
13VH	Living Will	Suggested as useful
9X0	Advance directive discussed with patient	Suggested as useful
9X1	Advance directive discussed with relative	Suggested as useful
9X2	Advance directive signed	Suggested as useful
9X20	Advance directive signed, copy in notes	Suggested as useful
Treatment plan / care plan		
8BC1	Treatment plan given	Suggested as useful
8BAD	Pain and symptom management	Suggested as useful
8BC4	On a syringe driver	Suggested as useful
Out of Hours		
9e0	GP OOH service notified	Suggested as useful
Specialist Palliative Care		
8HH7	Referred to Community Specialist Palliative Care Team	QOF Points
8HY	Referral to hospice	Suggested as useful
8BAR	Referral to Specialist Palliative Care In-patient	Suggested as useful
8BAS	Referral to Specialist Palliative Care Day-care	QOF Points
8BAT	Referral to Specialist Palliative Care Out-patient	QOF Points
8BAP	Specialist Palliative Care	QOF Points
8H6A	Refer to terminal care consult	QOF Points
8H7L	Refer for terminal care	QOF Points
8BJ1	Palliative treatment	QOF Points
Care of the Dying		
8BA2	Terminal care	QOF Points
8BAQ	End of Life pathway	Suggested as useful
Read Codes for Carers		
918F	Has a carer	Suggested as useful
971E	Discussed with carer	Suggested as useful
13Hc	Bereavement	Suggested as useful
8081	Bereavement support	Suggested as useful
Read Codes following death		
949	Patient died to record Place of death	Suggested as useful
9491	Died at home	Suggested as useful
9493	Died in nursing home	Suggested as useful
9495	Died in hospital	Suggested as useful
949A	Died in hospice	Suggested as useful
949B	Died in community hospital	Suggested as useful
949C	Died in surgery	Suggested as useful
94B	Cause of death	Suggested as useful

Appendix 5 - Levels of Adoption of GSF

Level 1 - C 1, 2

First Gear

Set up SC Register, Primary Care Team Meeting and Coordinator

Level 2 - C 3, 4, 5

Second Gear

Assessment Tools, Out of Hours Handover, Education Audit and Reflective Practice

Level 3 - C 6, 7

Third Gear

Carer/family support, bereavement plan and care in the final days

Level 4 - Sustain embed extend

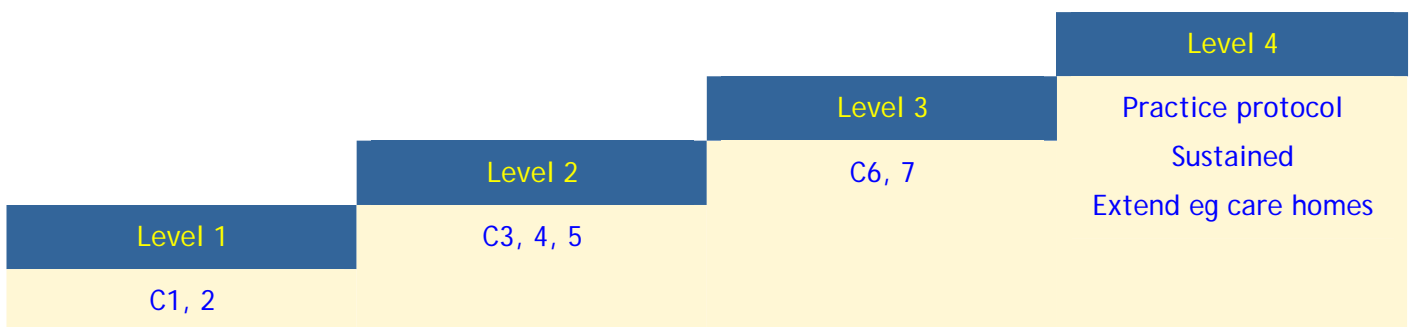
Fourth Gear

Sustain and build on all developments as standard practice

Embed - develop a practice protocol, PCT LES etc

Extend to other settings e.g. care homes, non cancer, Advance Care Planning, pathway for the last days (LCP) and other areas

Then cruise on in fifth gear!



Appendix 6 – Suggested QOF Assessment for Palliative Care Points

		Y	N
1	Palliative/Supportive Care Register in place for patients in last year of life	<input type="checkbox"/>	<input type="checkbox"/>
2	Evidence of inclusion of non-cancer patients	<input type="checkbox"/>	<input type="checkbox"/>
3	Dates of multidisciplinary team meetings _____ _____ _____ _____ _____ _____ _____ _____		
		Y	N
4	Meetings are multidisciplinary case review meetings to discuss those patients on the register	<input type="checkbox"/>	<input type="checkbox"/>
5	Evidence that a management plan/advance care plan, which includes preference for place of care, is used	<input type="checkbox"/>	<input type="checkbox"/>
6	Evidence that carers' needs are addressed	<input type="checkbox"/>	<input type="checkbox"/>

Further related areas to look at see page 6, please note that 52 points can be covered using GSF

Glossary to terms in PIG

ADL: Activities of daily living

Barthel's index: Assessment of ability to perform activities of daily living, using 10 different areas of activity and a score of 0-20. A higher score denotes greater functional independence.

CHF: Congestive heart failure. A condition where the heart is unable to meet the body's needs. This results in a build up of fluid, or congestion, in the tissues.

CKD: Chronic kidney disease, measured in stages 1 to 5, with stage 5 being established renal failure.

COPD: Chronic obstructive pulmonary disease. A chronic, progressive disorder characterised by airways obstruction and little or no reversibility.

DS1500: form that should be completed in order to claim the Disability Living Allowance. All patients in the last 6 months of life are entitled to this.

eGFR: Estimated glomerular filtration rate. A formula-based estimation of glomerular filtration rate, calculated and reported automatically by clinical biochemistry laboratories using serum creatinine, age, sex and ethnicity.

GFR>60: stages 1+2 CKD

GFR 30-59: stage 3 CKD

GFR<30: stages 4+5 CKD

FEV1: Forced expiratory volume in 1 second, is the volume of air expelled in the first second of a forced expiration using spirometry, measured in litres.

Forced Vital Capacity (FVC): The volume expired during a full forced expiration into a spirometer. The FEV1/FVC ratio gives an estimate of severity of airflow obstruction.

ITU: Intensive therapy unit, formerly known as Intensive care unit.

Karnofsky Performance Status (KPS): A scoring system to assess the well-being of palliative care patients and their ability to perform ordinary tasks, from 0% (dead) to 100% (fully active) and used in prognostication. Further details are in the Prognostic Indicators Guidance paper.

MDT: Multi-disciplinary team; involving nurses, doctors, social worker, occupational therapist, etc. as appropriate, working together.

MRC grade: The Medical Research Council dyspnoea scale for grading the degree of a patient's breathlessness.

1. Not troubled by breathlessness except on strenuous exercise.
2. Short of breath when hurrying or walking up a slight hill.
3. Walks slower than contemporaries on the level because of breathlessness, or has to stop for breath when walking at own pace.
4. Stops for breath after about 100m or after a few minutes on the level.
5. Too breathless to leave the house, or breathless when dressing or undressing.

NIV: Non-invasive ventilation, as opposed to ventilation via tracheostomy or intubation; often known as NIPPV or non-invasive positive pressure ventilation. Ventilatory assistance to aid respiration at night time, and as disease progresses it can also be used during the day.

NYHA class: The New York Heart Association classification of functional severity in heart failure.

Class I: heart disease present but no undue dyspnoea.

Class II: comfortable at rest; dyspnoea on ordinary activities.

Class III: less than ordinary activity causes dyspnoea, which is limiting.

Class IV: dyspnoea present at rest; all activity causes discomfort.

OOH form: form to be faxed to the Out of Hours service informing them of the patient's needs and preferences.

Pressure Sore grades: Classification of pressure sores improves patient assessment and subsequent intervention.

Grade I: The precursor phase. Redness which blanches with light pressure.

Grade II: Redness which remains when light pressure applied.

Grade III: Full thickness loss of skin not including the subcutaneous tissue.

Grade IV: The sore extends into subcutaneous tissue and deep fascia.

PHCT: Primary health care team, a community based, multidisciplinary team, working from or with the GP practice.

Read codes: A standard set of clinical terms produced and maintained by the NHS Information Authority, used for inputting data into clinical IT systems.

SCR: Supportive care register. A register of all patients with supportive or palliative care needs.

QOF: Quality and outcomes framework of the new GMS contract for GPs. The framework, by awarding points for achievement of certain targets, is an attempt to reward GPs for good practice.

General References

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End Stage Disease Indicators, Community Hospices Leaders in End of Life Care Since 1888, Maryland, Northern Virginia and Washington DC

Gold Standards Framework

Update #1

Improving Early Identification

[Click Here to return to the Table of Contents](#)

[Click Here for algorithm](#)

1. Evidence that use of GSF improves early identification of patients in different settings.

Thomas K, Armstrong Wilson J A., Tanner T, National GSF Centre. Sept 2016

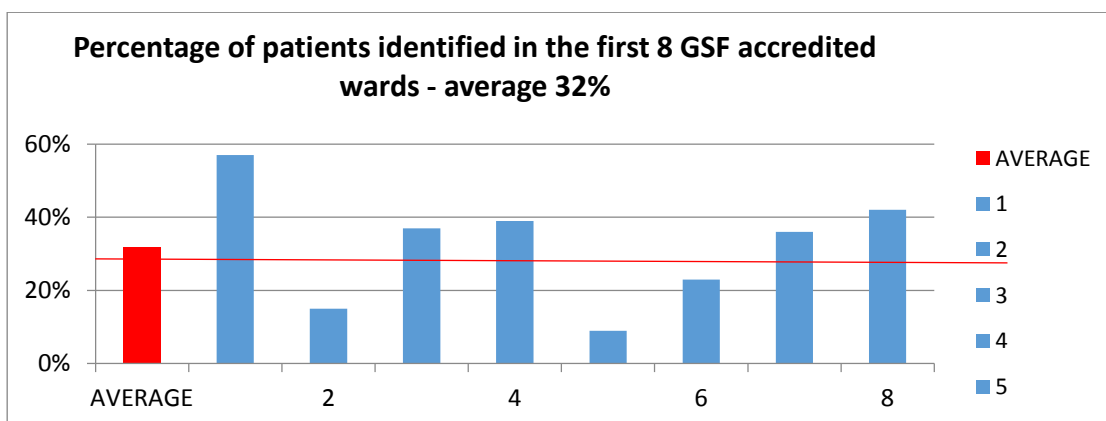
There is good evidence that use of the GSF Prognostic Indicator Guidance improves early recognition or identification of patients considered to be in their last year of life. However, this is only the first key step in the full GSF Quality Improvement Programme used in different settings (primary care, care homes, hospitals, domiciliary care, prisons hospices etc). Intrinsic comparative evaluations of teams progressing with the GSF programme demonstrates significant change towards current population-based estimates (eg 1%,30%,80%), and that high levels of early identification in line with can be achieved. The further steps of GSF, including use of Needs-based Coding, MDT discussions ,assessment and planning, all then work together to ensure more proactive care for patients in line with preferences.

1. Evidence from Intrinsic GSF Evaluation Audit

Early identification is GSF’s first key step. The GSF training and coaching enables staff to increase their identification rate over time, supported by use of the GSF Prognostic Indicator Guidance and abbreviated forms of it (eg Mini-PIG, PIGLET) through teaching, , coaching , use of run-charts, workshop feedback ,peer-support etc. Over the course of the full GSF Programme (6-24 months), teams demonstrate increased identification rates for all patients, assessed regularly in a variety of ways. Before and after evaluations are assessed, plus Accreditation portfolio submissions includes clarification of consistency and sustainability, examined further at the Visit.

a) **Acute Hospital wards** -Cumulated data from 8 GSF Accredited Hospital wards in different hospitals ie wards that have undertaken GSF training and were successfully accredited.

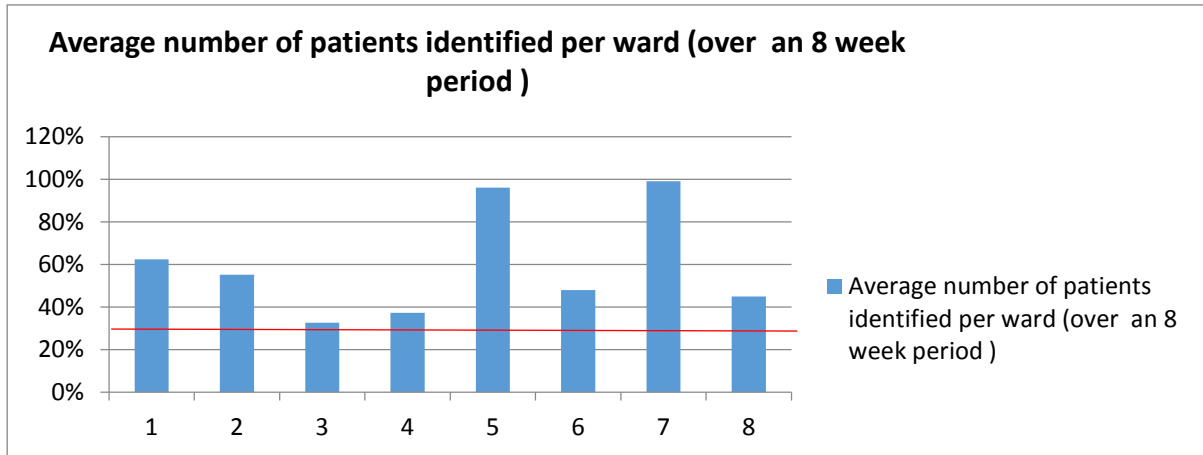
Conclusion for these GSF wards – an average identification rate 32% of all patients (in line with Clarke study) – snapshot survey at one specific time cumulated



The above graph demonstrates what is achievable on an acute hospital ward. The wards identified covered a range of specialities including oncology, haematology, stroke rehabilitation, renal unit, general medicine, orthopaedic and elderly care. The range of identification rates was between 9% and 57%, the average was **32%**.

b) Community Hospital wards

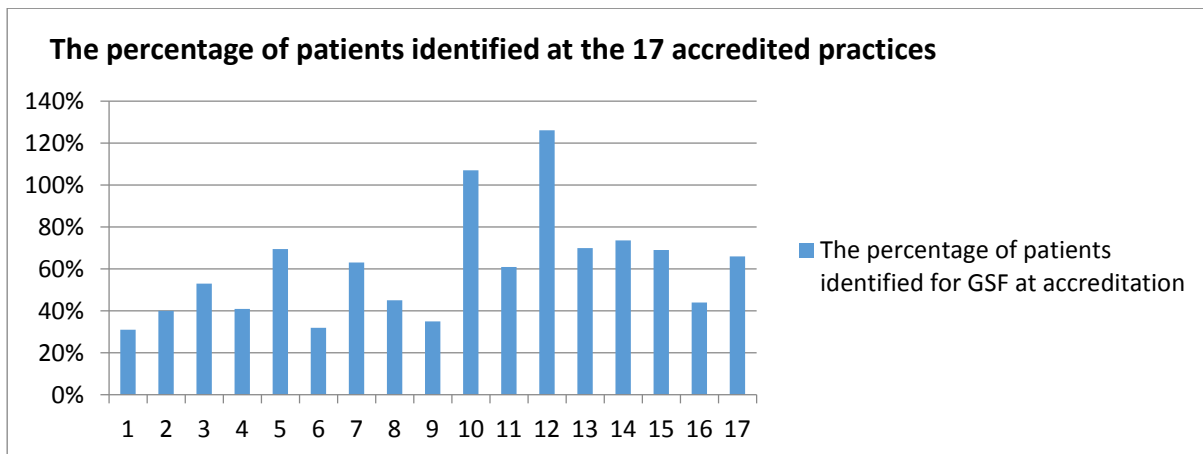
Findings from the last 8 accredited community hospital wards 2015-16 (numbered 1-8), taking an average over 8 week period of their identification rates. This demonstrates an average identification rate for all 8 hospitals of **59% (range 31-100%)** and confirms that all Accredited wards identify over 30% of their patients, in line with evidence from the Clarke paper (though this refers to Acute hospitals).



c) Primary care

Cumulated data from 17 GSF Accredited GP Practices (more details available).

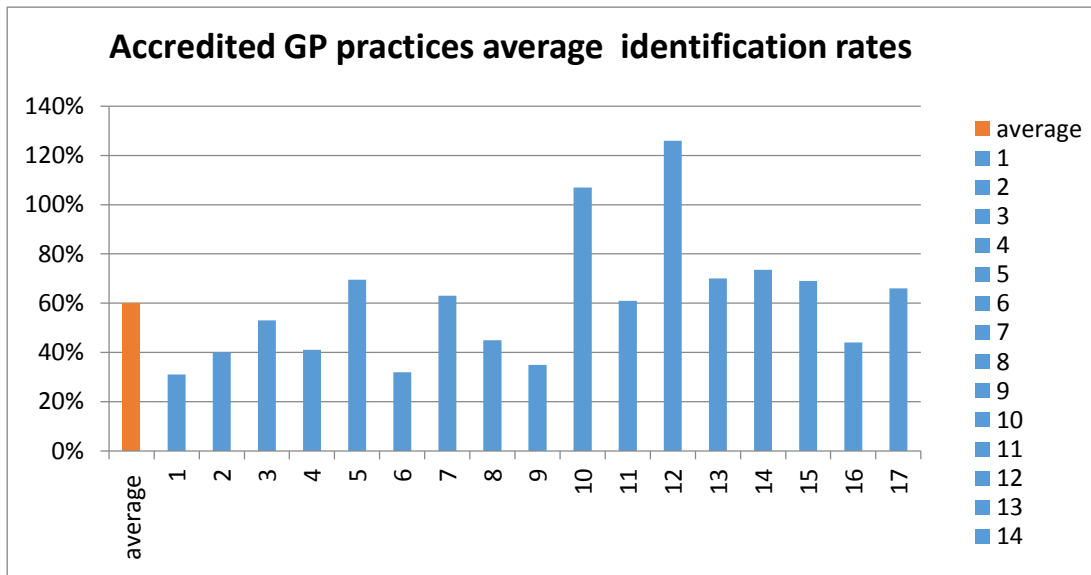
Conclusion for these GSF GP Practices – an average identification rate of 60% of all patients that died were identified for their practices register (in line with population figures of estimate 1% population dying/ year).



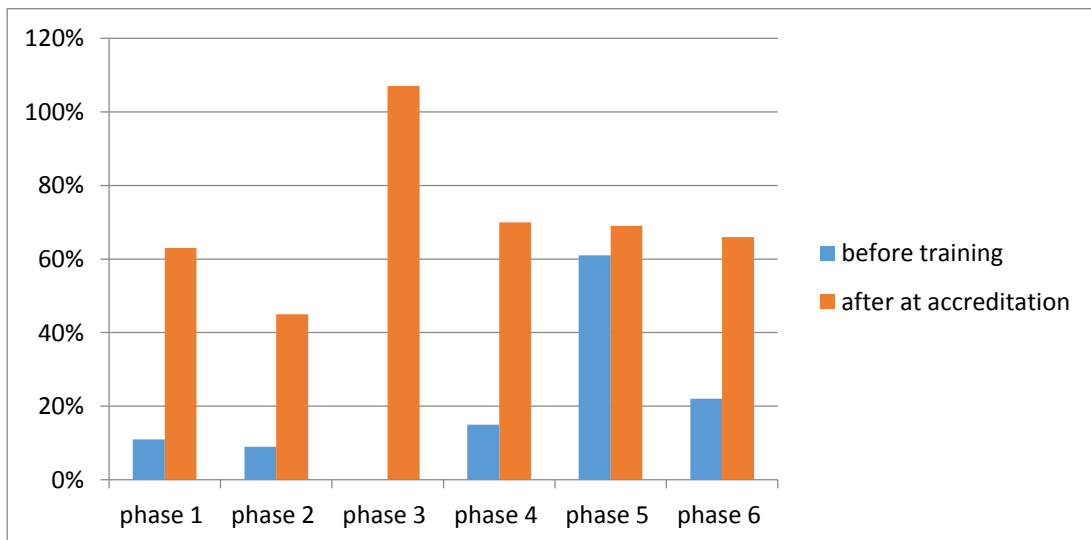
The graph above demonstrates that some GP practices, following GSF Going for Gold training and Accreditation, are attaining high rates of identification of patients for their GSF/Palliative Care Register, **averaging 60%**. This demonstrates what is possible to achieve by a few and could be an encouragement for others.

Attainment of GSF Accredited practices- achieving identification of an average of 60% of all patients that died. Identification rates increase in these practices following GSF Going for Gold training, from about 20% to an average of **60% of all patients that died identified** for the palliative care register.

This includes data from the last 17 practices to be accredited. Further work has been done to demonstrate sustained improvements in following years (more data available).

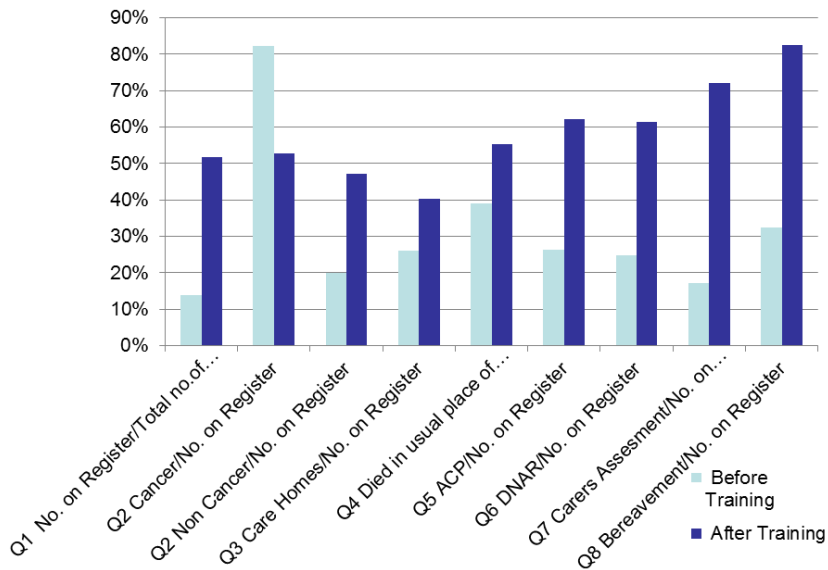


Increase in identification rates following GSF training. The graph below demonstrates that GP practices (in a sample of one practice per phase) show a significant increase in identification rates following the GSF training and in preparation for Accreditation, showing what can be achieved.



Early identification leads to more proactive planning and improved outcomes for all patients.

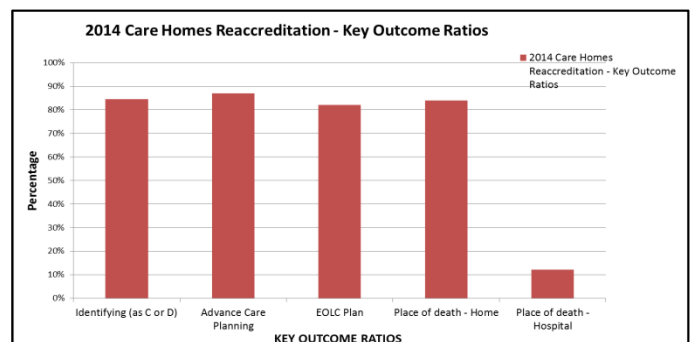
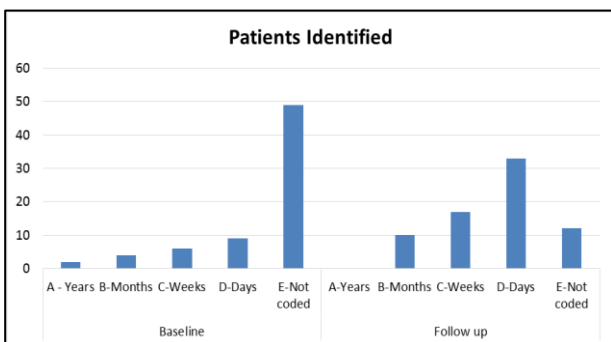
Sample of measurements cumulated from the GSF Key Outcomes Ratios for the first 7 accredited practices 2014, demonstrating improvements in outcomes in many areas.



Care Homes

For Care Homes, consideration of early identification is different: all residents are considered to be approaching the end of their life and coded appropriately, with many considered to have years to live (blue code) and about 80% considered to be in their last year of life. The Needs Based Coding relates to the predicted stage of decline. An assessment at accreditation is made of the allocated coding for people when they die (red/amber) through the After Death Analysis and most care homes are found to estimate decline appropriately. See Summary of Evidence Care Homes for more details.

Patients identified to be in the final days and weeks of life when they died in GSF accredited care homes 2014.



2. Evidence from the literature that use of the GSF and GSF Prognostic Indicator Guidance supports earlier identification of patients considered to be in their last year of life.

Date	Location	Study group	Finding / Conclusion/ Message	Reference
2015	Hospital Australia	Geelong Australia - study in a general hospital admissions	The use of an objective clinical tool identifies a high prevalence of patients with palliative care needs in the acute tertiary Australian hospital setting, with a high 1 year mortality and poor return to independence in this population. The low rate of documentation of discussions about treatment limitations in this population suggests palliative care needs are not recognised and discussed in the majority of patients.	Sharyn Milnes et al A prospective observational study of prevalence and outcomes of patients with Gold Standard Framework criteria in a tertiary regional Australian Hospital BMJ Supportive & Palliative Care 2015;0:1–8. doi:10.1136/bmjspcare-2015-000864 doi:10.1136/bmjspcare-2015-
2012	Hosp. - UK	Hospital	A modified GSF PIG identified most patients in last year of life	Mason C, Shah S, Palliative Medicine, June 2012, vol./is.26/4(469-470), 0269-2163
2012	Hospital UK	Acute Coronary Syndrome	<i>This study has highlighted a potentially large number of ACS patients eligible for EoL care. GSF or GRACE could be used in the hospital setting to help identify these patients. GSF identifies ACS patients with more comorbidity and at increased risk of hospital readmission</i> GSF PIG effective in identifying pts with ACS EOL	Penning s Woolcock R , Haga K , Iqbal J , Fox KA , Murray SA , Denvir MA Identifying acute coronary syndrome patients approaching end-of-life. PLoS One . 2012;7(4):e35536. doi: 10.1371/journal.pone.0035536. Epub 2012 Apr 18.
2012	H UK	Emergency admissions	Qualitative study to explore the perspectives of patients palliative care needs were received while in hospital.	Richards N., Gardiner C., Ingleton C., Gott M. Palliative Medicine, June 2012, vol./is.26/4(537-538),0269-2163
2013	Hosp UK	Hospitals-high symptom burden	The paper highlights elevated levels of burden experienced by patients with palliative care requirements. Moreover, the paper also indicates that a large proportion of such patients are not in receipt of palliative approaches to their care. le GSF PIG helps identify patients with a high symptom burden in hospital	Ryan T et al Symptom burden, palliative care need and predictors of physical and psychological discomfort in two UK hospitals. BMC Palliat Care . 2013 Feb 26;12:11. doi: 10.1186/1472-684X-12-11.
2013	New Zealand	Acute hospital	<i>One fifth of hospital inpatients met criteria for palliative care need, the majority of whom were aged >70 years.</i>	Gott M et al BMC Palliat Care . 2013 Mar 28;12:15. doi: 10.1186/1472-684X-12-15.Palliative care need and management in the acute hospital setting: a census of one New Zealand Hospital.
2013	Hosp. UK	Acute	GSF helps identify a third of all patients (NB Pre	Gardiner C et al Extent of palliative care need

		Hospital	Clarke- paper) <i>The results reveal that according to the GSF prognostic guide, over a third of hospital in-patients meet the criteria for palliative care need.</i>	in the acute hospital setting: a survey of two acute hospitals in the UK. Palliat Med. 2013 Jan;27(1):76-83. doi: 10.1177/0269216312447592. Epub 2012 May 22.
2014	New Zealand	Acute Hospital	<i>The sensitivity, specificity and predictive values of the Gold Standards Framework Prognostic Indicator Guidance in this study are comparable to, or better than, results of studies identifying patients with a limited life expectancy in particular disease states (e.g. heart failure and renal failure). Screening utilising the Gold Standards Framework Prognostic Indicator Guidance in the acute setting could be the first step towards implementing a more systematic way of addressing patient need - both current unrecognised and future anticipated - thereby improving outcomes for this population</i>	O'Callaghan A et al Palliat Med. 2014 May 22. pii: 0269216314536089. Can we predict which hospitalised patients are in their last year of life? A prospective cross-sectional study of the Gold Standards Framework Prognostic Indicator Guidance as a screening tool in the acute hospital setting.
2015		ACS	A study to find the most accurate method of identifying the last year of life in patients presenting with acute coronary syndrome: A multi-centre prospective study.	Moretti C et al, Eurointervention , May 2015(no pagination), 1774-024X
2014	Hospital UK	COPD	This study showed wide variation in survival in a patient population on LTOT. The ADO score could be used as an early trigger for referral to palliative services, thus enhancing end-of-life care, which improves quality of life in COPD. A prospective study of this application would be required to prove this hypothesis le GSF PIG and other tools helps predict COPD patients in the last year of life	Law S¹ , Boyd S , Macdonald J , Raeside D , Anderson D Predictors of survival in patients with chronic obstructive pulmonary disease receiving long-term oxygen therapy. BMJ Support Palliat Care. 2014 Mar 25. doi: 10.1136/bmjspcare-2012-000432.
2014	H- New Zealand	General admissions	Can we predict which hospital patients are in their last year of life? A prospective cross-sectional study of the Gold Standards Framework Prognostic Indicator Guidance as a screening tool in the acute hospital setting	O Callahan A, Palliative Medicine , September 2014, vol./is.28/8(1046-1052),0269-2163;1477-030X
2015	H-UK	Liver Disease	Screening for poor prognosis can improve end of life care for patients with chronic liver disease.	Hudson B.E., Ameneshoa K., Collinbs P., Portal A.J., Gordon F.H., Verne J., McCune A. Hepatology , October 2015, vol./is62/(490A)
2016	H-Italy	(STORM) Acute Coronary Syndrome patients	A study into risk assessment in acute coronary syndrome in patients towards the end of life.	Moretti C et al, Emergency medicine journal : EMJ, Jan 2016, vol33, no.1, p. 10-16, 1472-2013

Note- The key paper by David Clark in 2014 confirms that 29% of all hospital patients are in their last year of life, and this provides us with the evidence on which to base our aspirations for early identification rates in all our GSF Hospital programmes. Ref Clark et al **Imminence of death among hospital inpatients: Prevalent cohort study.** [Palliat Med.](#) 2014 Mar 17;28(6):474-479

3. Evidence for conference abstracts, grey literature and qualitative research

Accredited GSF Hospitals

Earlier identification of patients considered to be in the last year of life is a recognised pre-cursor to improved end of life care. 22 Acute and Community Hospital wards that were GSF Accredited and received the GSF Quality Hallmark Award supported by the British Geriatric Society and Community Hospitals association in 2014-5 demonstrated high levels of early identification of patients (average over 30% patients acute hospitals and 45% community), and high levels of patients offered advance care planning discussions to each identified patient (75%-100%), leading to an improved systematic approach to care for patients in the last year of life with any diagnosis.

Source: Ref Thomas Armstrong Wilson National GSF Centre in End of life care GSF Accreditation flyers EAPC May 2015 Accepted Abstract <http://tinyurl.com/hz7qeob>

HW Wright Palliative Care Team Leader Barking Havering and Redbridge Hospitals- said following GSF accreditation of their first ward: *“We believe that the GSF has developed within the hospital a greater awareness for the need to have conversations about death and dying in order to plan end of life care. By raising awareness this has enabled clinicians to gain confidence in identifying patients earlier in their disease trajectory and helped to prompt effective end of life communication where needed.”*

LB Practice Nurse at Grosvenor Medical Centre

“When the practice started GSF there were only 13 patients on the register. There are now 51 and the proportion of non-cancer patients has risen from 25% to 53%. The biggest benefit of doing GSF has been the continuity of care. Whereas in the past we would tend to hand over responsibility to the district nursing team, now a named GP and the nursing team at the practice is involved throughout and the patients feel much better cared for. Now the DNs enter our team not the other way round.”

HMP Norwich

Lead Nurse SR, said: *“GSF has helped us do everything that little bit better. We are certainly better at identifying people approaching the end of life because we now look more closely and have a mental checklist. It’s also helped us to be better planned and more organised – things really flow now. It’s really helped the team feel justifiably confident in the care they are providing. Having their work acknowledged means they can boast about it.”*

Airedale General Hospital

GSF helped increase identification of patients in last year of life to 30%. Dr RM, Consultant Geriatrician at Airedale, said: *“The GSF and Gold Line provides me with the added reassurance that my patients and their family have a plan, and the added resources in place as they move from secondary care to the community.”*

Saltaire Medical Practice.

Increased number of patients on the register from six to 84. Dr IL, said: *“We only have one chance to get it right. With an ageing population, this is becoming an increasingly important part of our work as GPs and so we have to ensure consistency and equality*

Ilkley Moor Medical Practice

Prior to doing the GSF Going for Gold programme, we had 27 patients on the GSF register, almost all of whom were cancer patients. Now we have 236 on the register, 70% of whom are non-cancer.

Gold Standards Framework

Update #2

Improving Advance Care Planning Discussions

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2. Evidence that use of GSF helps improve Advance Care Planning Discussions in different settings

Thomas K, Armstrong Wilson J A. Foulger, Tom Tanner National GSF Centre. Sept 2016

GSF encourages increased advance care planning discussions. A core part of all the GSF programmes in primary care, care homes, hospitals and other settings is the second key step of GSF – assessing their personal and clinical needs and those of carers. Therefore offering all people identified to be in or approaching the last year or so of life the chance to have an open, person-centred advance care planning discussion is intrinsic within GSF programmes, evaluations and accreditation. These discussions, parts of which are communicated to others such as out of hour’s providers, enable more people to stay in their preferred place of care and help reduce inappropriate hospital admissions and deaths.

The GSF statement on Advance Care Planning is that:-

“Every appropriate person should be offered the chance to have Advance Care Planning (ACP) discussions, mainly ‘Advance Statements’ of preferences, by their usual healthcare provider,

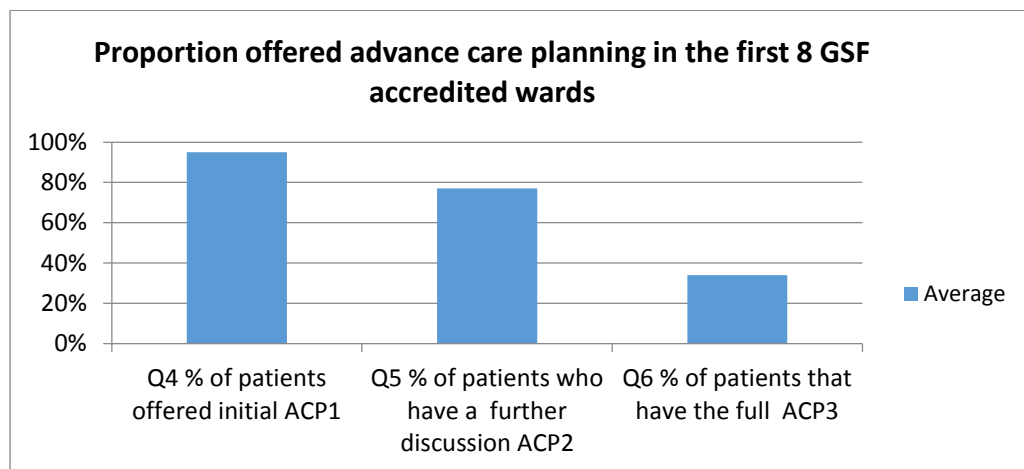
which then becomes an action plan against which quality of care is assessed.

In hospitals three levels of ACP discussions are encouraged, and all are recommended to attain Levels 1 and 2, but not all patients receive Level 3, the full documented ACP discussion, though continue discussion with their GP and communication of progress of this discussion is recommended.

There is therefore extensive evidence within all GSF Evaluations and for accredited teams that high numbers of patients are offered ACP discussions, leading to more voicing their preferences, enabling more to live and die where they choose.

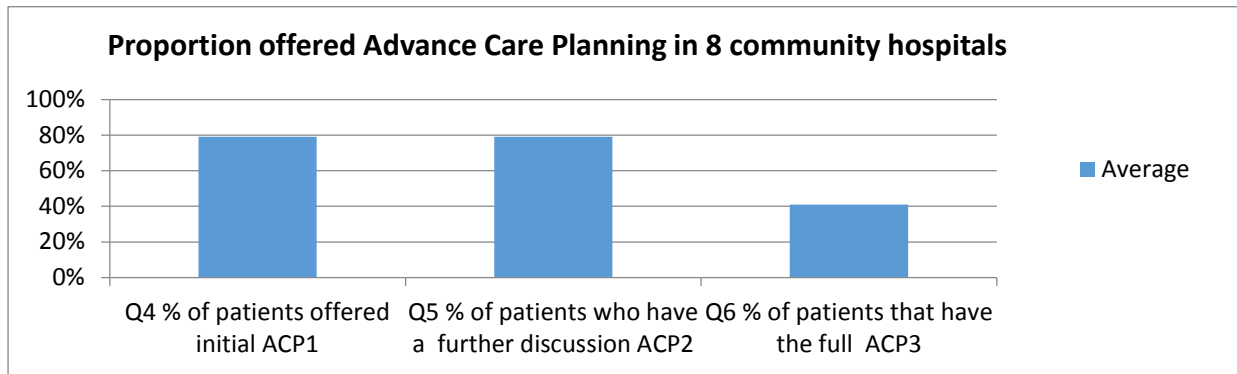
1. Evidence from Intrinsic GSF Evaluation Audit

Acute hospital wards - average 95% offered Levels 1, 75% both Levels 1 and 2 ACP discussions



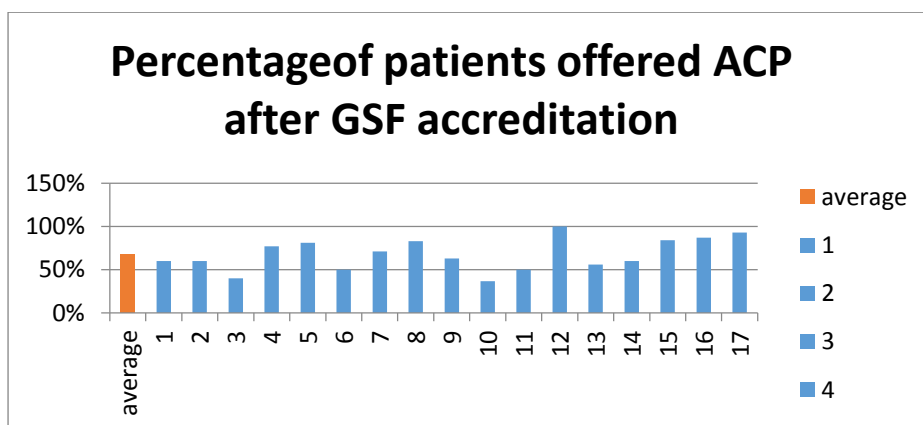
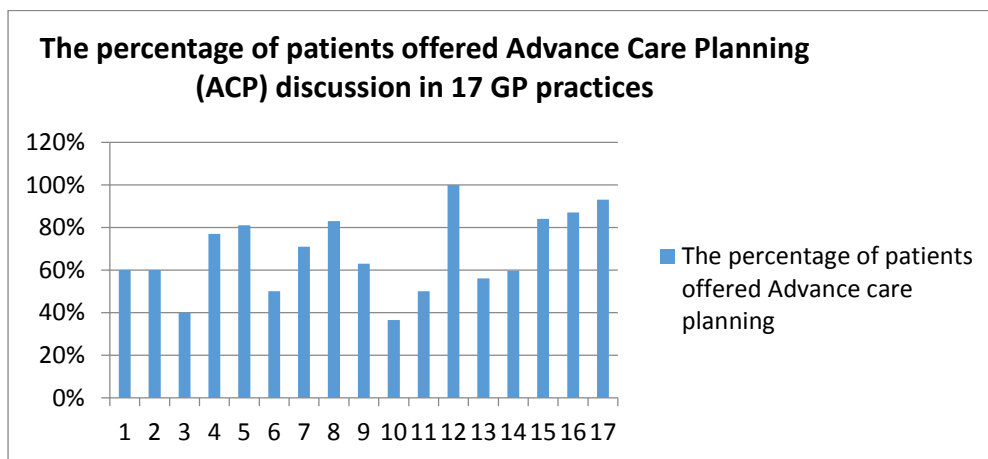
The graph above demonstrates what is achievable on an acute hospital ward- 95% offered an ACP discussion the range was between 62% - 100%.

Community Hospitals – average 79% offered ACP discussions (range 38% - 100%).



The graph above demonstrates that community hospitals are achieving high rates of offering ACP discussions to all identified patients (79% of all identified patients offered an ACP discussion)

Primary care – 68% identified patients offered ACP discussions (range 37%-100%).



The graph above demonstrates what is achievable in primary care in 17 different practices. The average would be 68% the range (37%-100%)

Primary Care- increased uptake of ACP discussions following GSF Going for Gold programme.

In practices progressing through the GSF Going for Gold Programme and accreditation, the level of ACP is measured before and after, as in the example below, demonstrating that increased ACP rates were attained by GSF Accredited practices, (selecting one practice per phase).

Care Homes

GSF accreditation for care homes include offering ACP discussions to every resident as one of the key standards to be attained, as demonstrated by evaluations, portfolio and on the assessment visit. Therefore offering a ACP discussion is mainstreamed to every resident of a GSF Accredited home- See Care Homes Summary of Evidence. .

Attainment of GSF Accredited teams in different settings

	1. Identify	2. Assess	3. Plan Living well	4. Plan Dying well
Aims of GSF accredited organisations	Early recognition of patients- aim 1% primary care 30% hospital 80% care homes	Advance Care Planning discussion offered to every person	Decreased hospitalisation + improved carers support	Dying where they choose using personalised care plan in final days
GP practices (Rounds 1-6, 17 practices)	60% average patients identified (range 31-126%)	68% average offered ACP discussion (range 37-100%)	Halving hospital deaths, <small>not sure how you have captured this as there is no date to back it up</small> 71% carers offered support (15-100% -15 practices)	65% die where they choose (16 practices) 64% using 5P plan final days (7 practices)
Acute Hospitals (Round 1-3, 8 wards)	32% average identified early (range 9-58%)	95% average offered ACP discussion (range 62-100%)	Length of stay reduced Carers support improved	More discharged home, 80% 5Ps care final days plan (2 wards)
Community Hospitals (Round 3-5, 8 wards)	59% average identified (range 31-100%)	79% average offered ACP (range 38%-100%)	Carers support improved	More discharged home 100% 5Ps care final days plan (7 wards)
Care Homes accredited	100% identified, 81% identified in dying stages	100% offered 95% uptake	Halving hospital deaths+ admissions 97% carer support	84% dying where choose, 90% using 5Ps care plan

2. Evidence that use of the GSF increases ACP discussions and enables more to stay in their preferred place of care

Primary care. End of Life care for GSF Accredited GP practices the first ten practices that undertook GSF Going for Gold training in primary care and progressed to GSF RCGP Accreditation showed significant improvement in key processes in End of Life Care as recognised by NICE Guidance and best practice. This trend has been continued three years on following annual appraisal. Evaluations demonstrate

- Earlier identification rates of patients in the last year of life, (average 0.54%) (with a range of 30-60%) ie half of all those who died included on the register, which is well above the national average of a quarter of all patients identified
- increased non-cancer patients on their register (18%-47%), increased numbers of care homes residents (22%- 40%)
- efforts to increase the numbers offering and recording advance care planning discussions showed significant increases with an average of 46% (range 26%- 62%) ie about half of all patients on the register offered ACP discussions
- greatly improved systematic carer support offered (17%- 72%)

- more dying in their preferred place of care(44%- 59%), with some halving hospital deaths

Source: <http://www.goldstandardsframework.org.uk/accredited-gp-practicesspecific>

<http://tinyurl.com/zcnac55> <http://www.goldstandardsframework.org.uk/evidence>

Hospitals- Increasing home deaths, reducing hospital deaths and improving advance care planning

- Reductions in hospital deaths and emergency admissions enabling people to live and die in their care home are sustained long term following use of the GSF Care Homes Training program. 75% of first time GSF accredited homes achieved over 80% home death rate. This level is sustained over time with care homes who have undergone a third round of GSF Accreditation demonstrating continued improvements in home death rate, with 89.63% of residents remaining in their care home until the end of their life, and 100% of residents in these care homes being offered ACP discussion. On the third round GSF accreditation 64.28% (n=14) of these care homes achieved between 90 and 100% home death rate and 21% of those had a 100% home death rate. (Data from Round 15 GSF accreditation & reaccreditation report August 2015).
- Crisis admissions and length of stay in hospital Crisis admissions in the last six months of life in 45 care homes were evaluated prior to and following participation in the Gold Standards Framework Care Home Programme. Outcome measurement showed a significant reduction from 44.4% of care home resident admissions to hospital in the last six months of life to 12% admissions. Hospital bed days fell from 87 to 36 (58%).
- Advance Care Planning Following GSF Accreditation, homes reported offering 100% of residents an advance care plan discussion GSF data shows that 96% (n=441) of those residents who died, had an Advance Care Plan in place (Barking the Havering & Redbridge project, Phase 10 data from 45 care homes. 2014/15). 2014).

Source: Ref <http://www.goldstandardsframework.org.uk/accredited-care-homes>

EAPC May 2015 Conference Copenhagen Reaccredited Care Homes Accepted Abstract – Thomas K Stobbart-Rowlands M et al. <http://tinyurl.com/jlqsa3a>

Care Homes GSF training programme improves staff confidence to manage the challenges in end of life care including symptom management, discussions around death and dying and working collaboratively with other multi-professional teams. GSF Care home programmes measure confidence across ten areas pre and post participation in the GSF programme. The largest increases in confidence were evident in the areas of planning cross boundary care, having and recording ACP discussions with residents and assessing their clinical needs although increases in confidence were seen across all ten areas measured. Overall confidence levels increased by 24% - 28% across three cohorts. In addition qualitative feedback was sought and staff reported being more confident in their role and that the GSF tools enable them to make the most of what they do (BHR GSF Data 2014-2015 across 45 care homes. Source:

<http://tinyurl.com/j9acdpt> <http://www.goldstandardsframework.org.uk/evidence>

2. Grey literature/ qualitative feedback

Dr HR GP from GSF Accredited practice said: In terms of quantitative results, we've increased the number of patients on the register almost sixfold and upped the non-cancer patients from 10% to 70%. And of those on the register, we've had advance care planning discussions with over two thirds. This has played a big part in reducing the hospital admissions (a major priority for the CCG) and enabled us to support more than 50% of patients to die in their preferred place – their home. So we're providing better quality cost-effective care.

Gold Standards Framework

Update #3

Reduction in Hospitalization

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3. Evidence that GSF helps reduce hospitalisation in all settings (admissions, hospital deaths, hospital bed days, rapid discharges home, re-admissions etc).

Thomas K, Armstrong Wilson J A. Foulger, Tom Tanner National GSF Centre. Sept 2016

GSF helps reduce hospitalisation, enabling more to live and die in their preferred place of care. By taking a more proactive approach, with earlier identification and assessment of needs, teams undertaking GSF find that hospitals admissions, deaths and lengths of stay are significantly reduced. This has been a consistent finding in all GSF Evaluations in all settings, particularly in care homes and primary care, where some homes and practice show a halving of hospital deaths and crisis admissions.

Reducing hospitalisation however is a very complex area and requires consistent change across a wide range of areas: including for example in a care home it requires effective training and communication to all staff including bank and night staff, effective documentation of ACP discussions an preferred place of care for all residents, development of care homes policies, implementation of preventative measures, communication with GPs and out of hours providers and regular reflection and audit to review progress. In hospitals reduced hospitalisation is incorporated into means of reducing length of stay, rapid discharge and transition home and reducing read-missions, many of which require complex interventions, improved communication and good community support.

1. Evidence from Intrinsic GSF Evaluation Audit

Acute hospital data

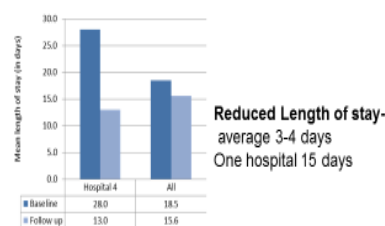
There is strong evidence of reduced length of stay across all early phases of the GSF Acute Hospital Programme. Data is taken from the GHK independent Evaluation using Before and After GSF After Death Analysis for 15 deaths and 15 discharges (ref see GHK phase 3 and phase 4 report on GSF evidence section website).

<http://www.goldstandardsframework.org.uk/evidence>.

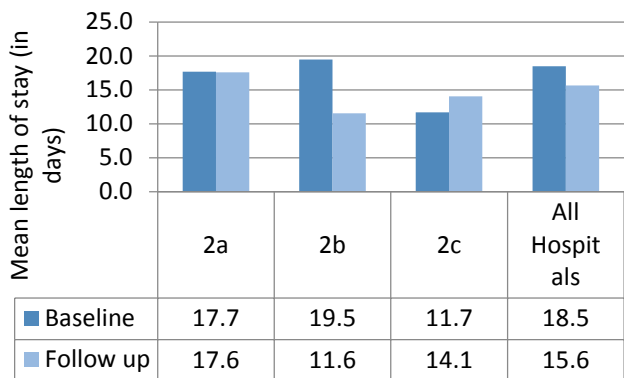
There is also anecdotal evidence from some hospitals of reduced readmissions- pending further data. On completion of the Phase 3 AH training programme – Average Length of Stay (LOS) for all the hospitals was reduced by 3 days (from 18 to 15 days).

Plan Living Well and Dying Well

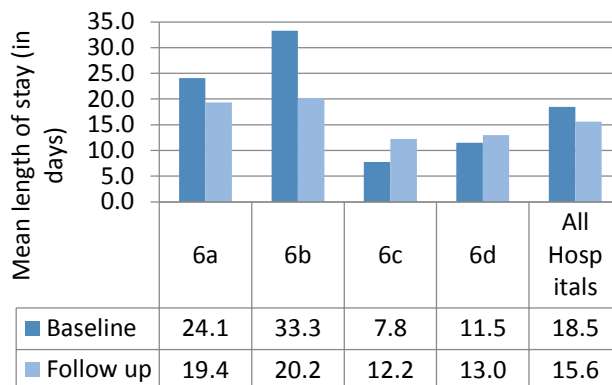
- Living well
- Enabling more to live well at home +reducing hospitalisation
- Dying Well
- More dying at home or where they choose



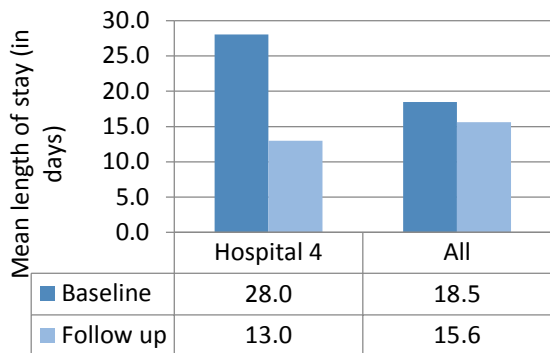
Phase 3 Data - LOS on 2b ward was reduced by 8 days



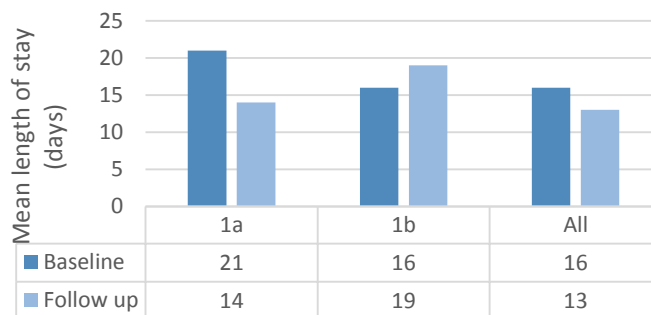
Phase 3 LOS on 6a, 6b was reduced by 4.5 and 13 days



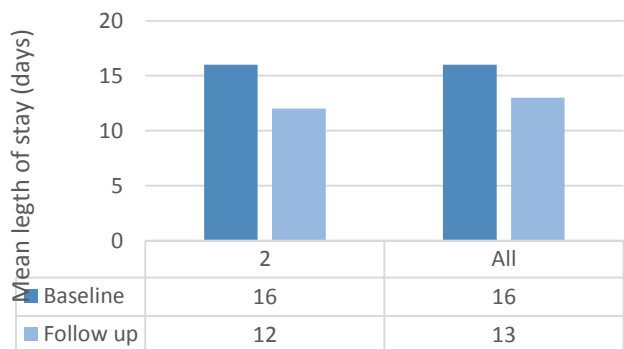
Phase 3 LOS on ward 4 was reduced by 15 days



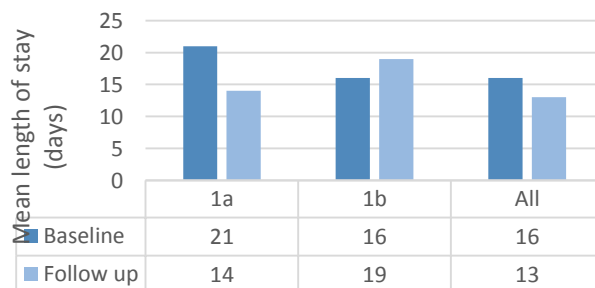
Phase 4 LOS on ward 1a was reduced by 7 days



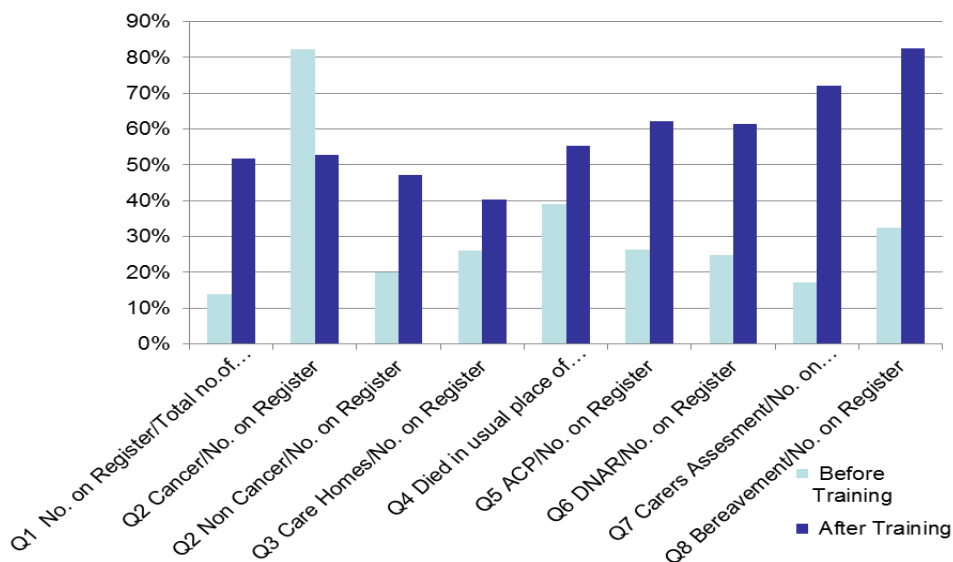
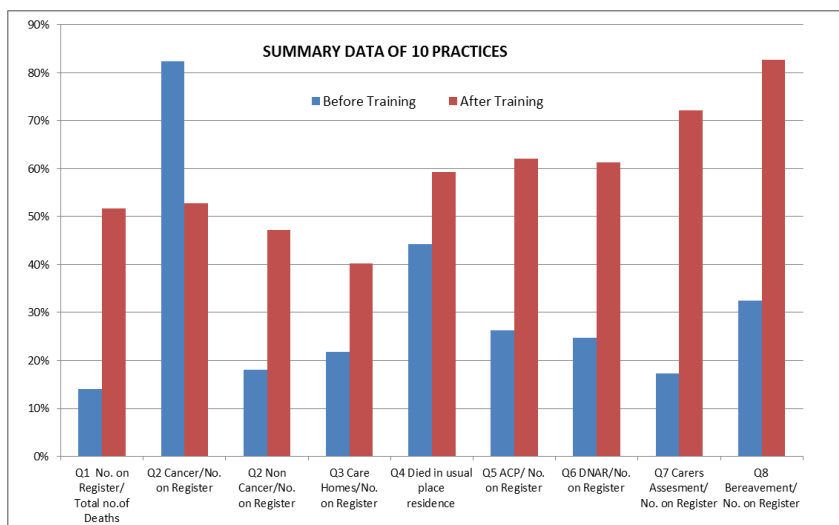
Phase 4 LOS for ward 2 was reduced by 4 days



Phase 4 LOS on ward 1a was reduced by 7 days

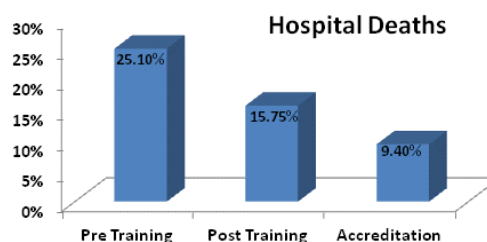
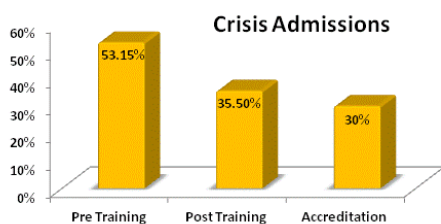


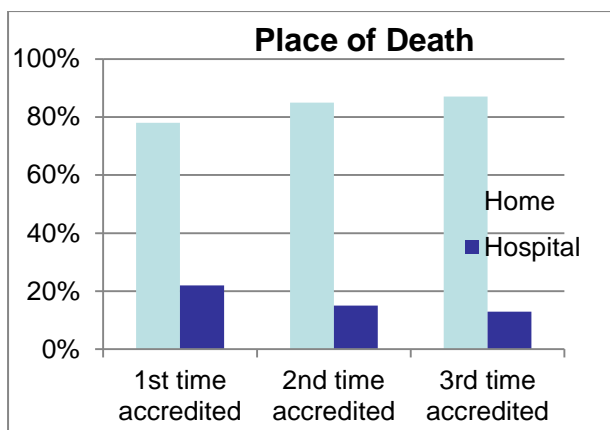
Primary care Data – Summary from the first 10 GSF Accredited practices 2015



Care Homes

Following GSF care Homes training and accreditation, cumulative before and after ADA analysis for care homes shows reduction on hospital deaths and admissions- see Summary of Evidence and project based audits for further details. Cumulated Care Homes results Phases 7-12.





Cumulative GSF Care Homes ADA results for first time, second time and third time accredited care homes 2015

Attainment of GSF Accredited teams in different settings

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Increasing home deaths, reducing hospital deaths and improving advance care planning in GSF care homes.

a) Reductions in hospital deaths and emergency admissions enabling people to live and die in their care home are sustained long term following use of the GSF Care Homes Training program. 75% of first time GSF accredited homes achieved over 80% home death rate. This level is sustained over time with care homes who have undergone a third round of GSF Accreditation demonstrating continued improvements in home death rate, with 89.63% of residents remaining in their care home until the end of their life, and 100% of residents in these care homes being offered ACP discussion. On the third round GSF accreditation 64.28% (n=14) of these care homes achieved between 90 and 100% home death rate and 21% of those had a 100% home death rate. (Data from Round 15 GSF accreditation & reaccreditation report August 2015).

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Source: Ref <http://www.goldstandardsframework.org.uk/accredited-care-homes> EAPC May 2015 Conference Copenhagen Reaccredited Care Homes Accepted Abstract – Thomas K Stobart-Rowlands M et al. <http://tinyurl.com/jlqsa3a>

Positive Response from Care Home Staff undertaking GSF Care Home programme

Qualitative interviews with Nurses, health care assistants and managers regarded the training and support afforded by the GSFCH programme to inform EoLC for older residents positively. The framework has the potential to promote a coordinated approach to EoLC for older people. In the post accreditation period, there is a need for ongoing support and development to help embed the key tenets of the GSFCH in the culture of caring.

Three core themes were identified: (i) a positive regard for the GSF for care homes (GSFCH); (ii) challenges around end of life care for older people; and (iii) difficulties in using the GSFCH.

Int J Palliat Nurs. 2015 Jan;21(1):35-41. doi: 10.12968/ijpn.2015.21.1.35. Views and experiences of nurses and health-care assistants in nursing care homes about the Gold Standards Framework. Nash A¹, Fitzpatrick JM. <http://www.ncbi.nlm.nih.gov/pubmed/25615833>

3. Other Published literature/ qualitative feedback

See extensive published literature on use of GSF in care Homes and Summary of Evaluations

See <http://www.goldstandardsframework.org.uk/evidence>.

Gold Standards Framework

Update #4

Improving Coordination, Communication, and Care

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4. Evidence that use of GSF Improves coordination, continuity of care and better communication in different settings.

Thomas K, Armstrong Wilson J A. Foulger, Tom Tanner National GSF Centre. Sept 2016

GSF helps improve coordination, communication and cross boundary care. There is growing evidence that by taking a systematic proactive approach as introduced with the GSF Quality Improvement Programmes, with earlier identification and assessment of needs and preferences, better planning and delivery of coordinated care can ensue for GSF trained and accredited teams in primary care, care homes and hospitals.

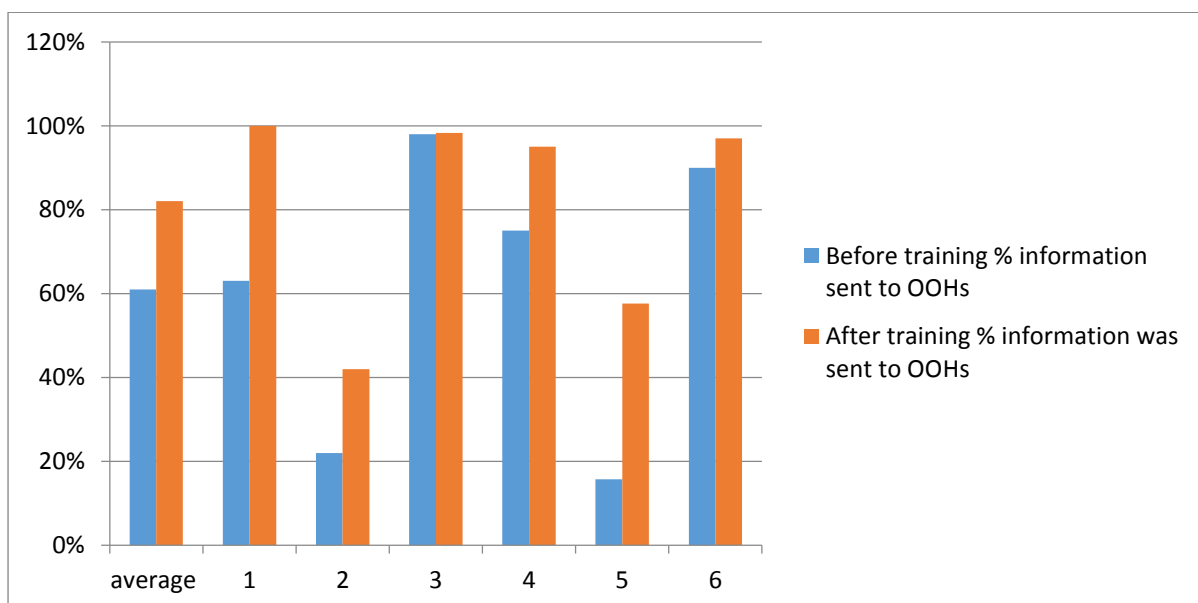
GSF introduced to specific settings can have a beneficial effect and impact in care for people in these settings. But further work is underway in examining the progress and impact on integrated cross boundary care across a whole area such as a CCG, Local Authority or STP footprint, with the work in our 8 GSF Cross Boundary care Sites and development of pilot EOLC metrics, in line with national guidance and policy. Further work is currently ongoing.

Contact GSF team or see <http://www.goldstandardsframework.org.uk/evidence>

1. Evidence from Intrinsic GSF Evaluation Audit

Primary Care

The graph below demonstrates that GSF has improved communication to OOHs on average by 21% (6 practices from phase 4 & 5)



Acute Hospitals Phase 3 ADA report by GHK demonstrates improved communication, referral for DS1500, rapid discharge home and therefore more enabled to die where they choose (home) .

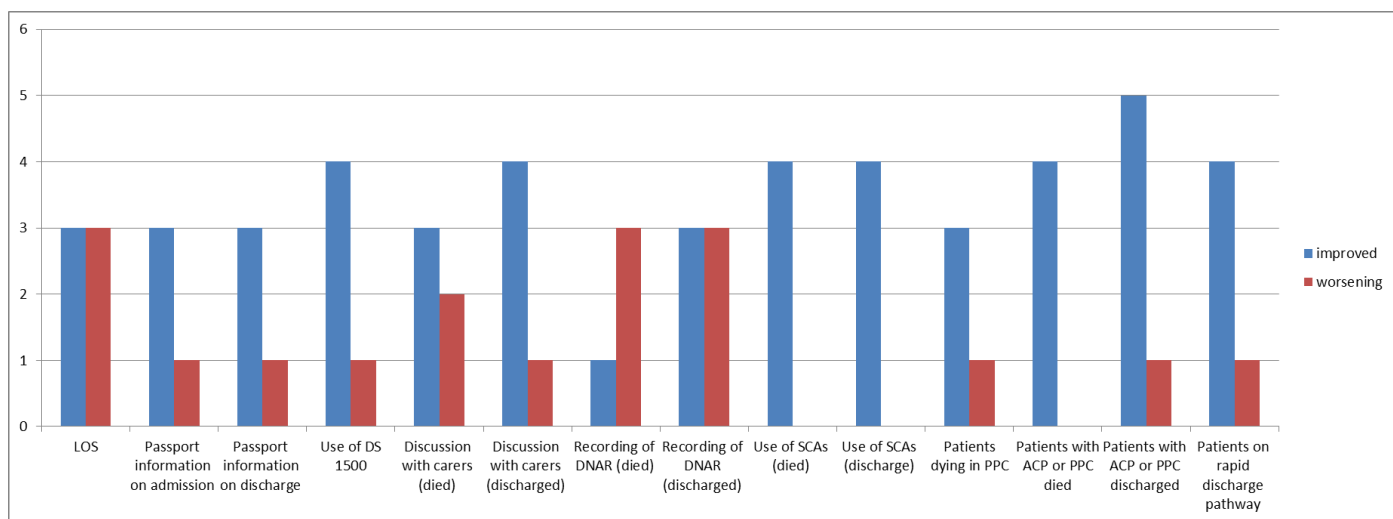


Table 6.1 Summary results of ADA by hospital- green improving, grey no change, red worsening , white no data

	Hospital 2	Hospital 4	Hospital 5	Hospital 6	Hospital 8	Hospital 9	All
Length of stay	Green	Green	Red	Green	Red	Red	Green
Passport info - admission	Grey	Green	Red	Green	Grey	Green	Green
Passport info – discharge	Grey	Green	Red	Green	Grey	Green	Green
Use of DS1500	Green	Red	Grey	Green	Green	Green	Green
Discussion with carers	Died	Green	White	Red	Green	Red	Green
	Discharge	Green	Grey	Green	Green	Red	Green
Recording of DNAR/NCR/ AND	Died	Green	White	Red	Red	Grey	Green
	Discharge	Green	Green	Red	Red	Green	Green
Use of SCAs	Died	Green	White	Grey	Green	Green	Green
	Discharge	Green	Green	Grey	Green	Grey	Green
Patients dying in PPC	Green	White	Grey	Green	Red	Green	Green
Patients with ACP or PPC	Died	Green	White	Grey	Green	Green	Green
	Discharge	Green	Green	Red	Green	Green	Green
Patients on RDP	Green	Red	Grey	Green	Green	Green	Green
Patients on LCP/ other ICP	Grey	White	Red	Green	Red	Red	Red

Care Homes

One of the essential ‘must do’ standards to be attained by GSF Accredited care homes is improved communication and coordination with GPs and with Out of Hours providers. Care Homes must demonstrate significant improvement in this area both quantitatively, in the portfolio and at the GSF assessment visit. There are many examples of good practice demonstrating improved and effective communication and coordination – (more details in Summary of Evidence and available directly)

2. Additional published/ Grey literature/ independent qualitative feedback

CH Accredited GP practice Before they started the training there were 41 patients on the register, now there more than three times that – 125. And the vast majority of those (110) have had advance care planning discussions, five out of six have a care plan in place and 118 have had their clinical symptoms assessed. More than two thirds of the patients on the list die in their preferred place now and that figure rises to 88% for those that have expressed a preference, compared with just over half (56%) prior to the training.

Dr LP, GP Partner at Cape Hill: *“A lot of EoLC is about wanting to do it well. What GSF has helped us do is actually deliver better more coordinated care, not just well intentioned care. We’re more skilled at symptom management and while delivering better end of life care can take more time, the rewards are great.”*

Dr HR GSF accredited practice Yorkshire *“In terms of quantitative results, we’ve increased the number of patients on the register almost sixfold and upped the non-cancer patients from 10% to 70%. And of those on the register, we’ve had advance care planning discussions with over two thirds. This has played a big part in reducing the hospital admissions (a major priority for the CCG) and enabled us to support more than 50% of patients to die in their preferred place – their home. So we’re providing better quality cost-effective care.*

But for me, the greatest results have been qualitative. We’ve seen a significant culture change in the practice. The administrative staff have gained the confidence to identify patients they think are approaching the end of life – they can be better placed to do this than the doctors most of the time as they often see subtle changes in patients sooner than the GP team do!

“We have reduced by 50% hospital admissions for this patient group, and with the help of GSF are providing better, cheaper care for our patients and their carers. As a family doctor whose job it is to see people through to the end it is much more satisfying to care for your patients in a calm, planned way.”

GSF accreted practice Derbyshire Macklin Street Surgery

Following our most recent audit of palliative care patients who have subsequently died between 2014-15. 95% of our palliative patients had their PPOC documented.

95% of our palliative patients had a documented resuscitation discussion

96.4% of our palliative patients had their ACP communicated to the OOH service

The above Advanced Planning led to **62.5% of our patients achieving a comfortable death at home.**

We were unable to complete the above discussion with all of our patients [2-3 patients missing] due to circumstances beyond our control, excluding these patients would give figures of towards 100%.

Dr SG, GP said: *"I've been here for 15 years, and seen a number of my patients through to the end of their life. It is a humbling and incredibly rewarding experience and is also one of the most important aspects of care that we provide as GPs. We are passionate about providing the best care we can for our patients, particularly in the final months of their life. Ensuring our patients have a 'good' death is really important to their families."*

LB Practice Nurse at Grosvenor Medical Centre

"The biggest benefit of doing GSF has been the continuity of care. Whereas in the past we would tend to hand over responsibility to the district nursing team, now a named GP and the nursing team at the practice is involved throughout and the patients feel much better cared for. Now the DNs enter our team not the other way round."

When the practice started GSF there were only 13 patients on the register. There are now 51 and the proportion of non-cancer patients has risen from 25% to 53%.

Care Homes- Belong Group

JB Practice Development Facilitator (PDF) at the Wigan site says: *"GSF has undoubtedly helped us reduce the amount of hospital admissions and more people are dying in their preferred place – here,"* says Julie. *"And because we are better at planning and are more proactive, their needs are better catered for and the care and support is quicker and more effective."*

Improving confidence in planning cross boundary care in care homes using GSF

GSF training programme improves staff confidence to manage the challenges in end of life care including symptom management, discussions around death and dying and working collaboratively with other multi-professional teams. GSF Care home programmes measure confidence across ten areas pre and post participation in the GSF programme. The largest increases in confidence were evident in the areas of planning cross boundary care, having and recording ACP discussions with residents and assessing their clinical needs although increases in confidence were seen across all ten areas measured. Overall confidence levels increased by 24% - 28% across three cohorts. In addition qualitative feedback was sought and staff reported being more confident in their role and that the GSF tools enable them to make the most of what they do (BHR GSF Data 2014-2015 across 45 care homes)

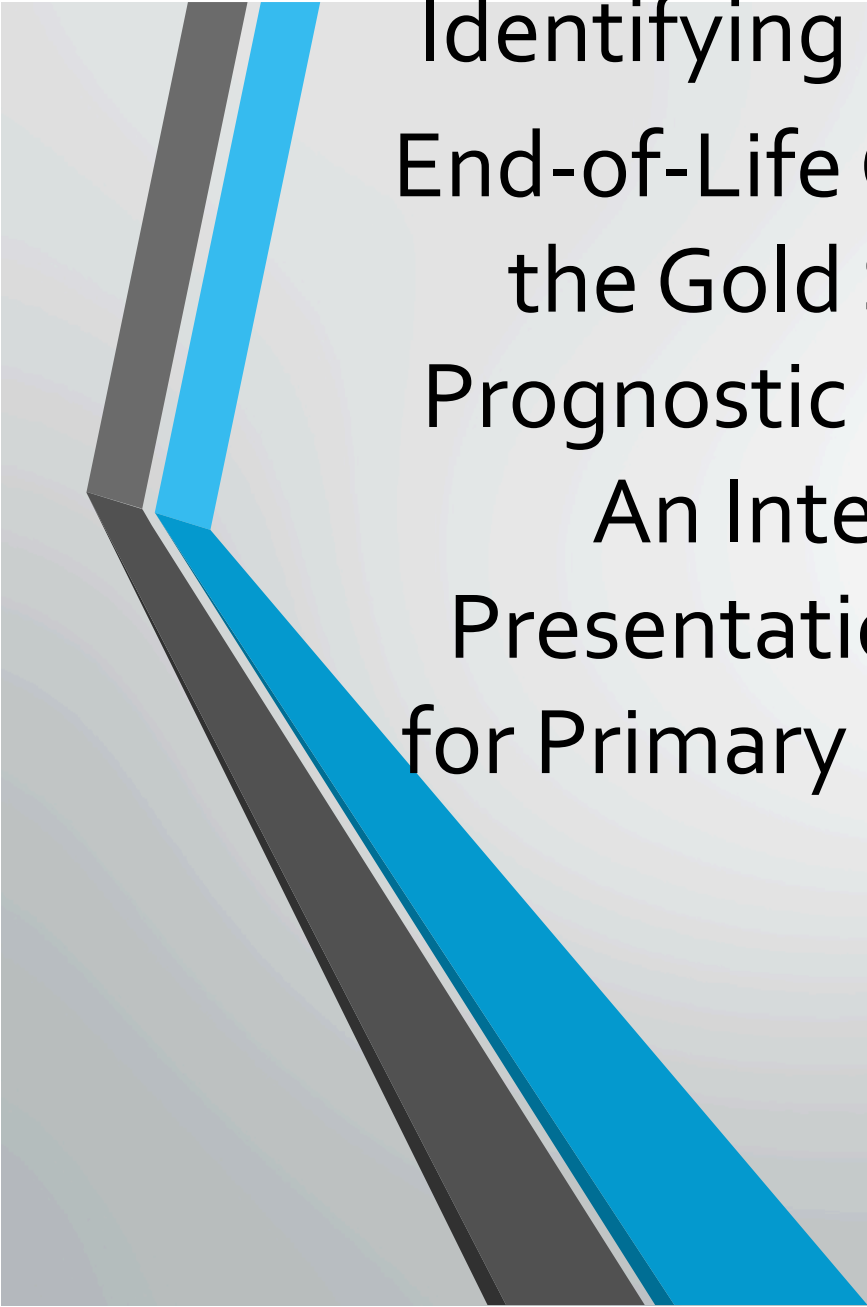
.Source: <http://tinyurl.com/j9acdpt>

Hospital

University Hospitals of Morecambe Bay NHS Foundation Trust GSF Accredited ward

Stroke Consultant Dr PK says overcoming these challenges was hugely rewarding. *"I think the biggest change has been the culture change. It's about getting patients and their families to take ownership of their care. GSF is the framework that allows us to make that happen. The best bit is making sure that patients receive the care they want, where they want it, when and how they want it and the satisfaction they and we get from that."*

Appendix C
PowerPoint Presentation



Identifying Patients Appropriate for
End-of-Life Care Interventions Using
the Gold Standards Framework
Prognostic Indicator Guidance Tool:
An Integrative Review with
Presentation and Resource Packet
for Primary Care Providers and Staff.

Melissa Ellis, DNPc, BSN

University of Massachusetts – Amherst

College of Nursing

Overview

- DNP Project
- Objectives
- Introduction/Background
- Statistics
- Integrative Review Findings
- Evidence-Based Guideline at a Glance
- End-of-Life Screening Resource Packet
- Conclusion
- Questions?

DNP Project

- Culmination of doctoral education focused on application of nursing knowledge to improve practice, effect patient outcomes and policy, and drive advancement of the profession.
- Focus on Integrative Review and Presentation including Resource Packet guiding early screening for end-of-life care interventions.
- Presentation provides opportunity to explore evidence based practice and disseminate information with intent to effect practice change and improve patient care outcomes.
- Packet increases exposure to resources and tolls to assist providers in primary care settings to screen and identify end-of-life care needs for patient early.

Objectives

- Improve knowledge regarding importance and benefits of early identification of patients that could benefit from palliative care interventions.
- Increase exposure to Gold Standards Framework Prognostic Indicator Guidance Tool—Surprise Question and MOST; provide adapted tools for future implementation.
- Share other resource packet inclusions and explore *best practice* use opportunities.

Introduction and Background

- Primary care providers are the ideal people to implement end-of-life care discussions.
- The answers to when and why a person dies cannot always be manipulated, but we can plan for how and where a person dies.
- Initiating advance care planning discussions to benefit the patient and their family, and to assist the provider to facilitate end of life wishes should be standard practice.
- **The key to improving this process is to make it easier to identify timing of interventions and available resources.**

Statistics

- About 1% of the population dies each year and many of those are seen by a primary care provider in their last year of life.
- In 2013, there were 1.3 million hospice patients in the U.S.
- In 2012, the national and Texas state average use of hospice care was 28 patients per 1,000 persons aged 65 and older.
- In 2013, there were 4,000 hospice agencies in Texas.

Statistics

- In 2009, Medicare alone spent \$12.1 billion on hospice care.
- If palliative care was fully integrated, the nation could save \$6 billion/year.

Statistics

- The top 12 non-cancer diagnosis for 1998-2009 Hospice patients were:
 - Parkinson's Disease
 - Alzheimer's Disease
 - Non-Alzheimer's Dementia
 - Non-infectious respiratory disease
 - Heart disease
 - Congestive Heart Failure
 - Failure to Thrive
 - Debility
 - Pneumonias
 - Cerebral Vascular Accident/Stroke
 - Chronic liver disease
 - Chronic kidney disease.
- There are approximately 90 million Americans living with serious illness.
- Approximately 6 million of those people could benefit from palliative care.

Integrative Review Findings

- The integrative review revealed exceptionally positive results from the use of the Gold Standards Framework (GSF) and the Prognostic Indicator Guidance (PIG) tool in the United Kingdom and several other countries with socialized healthcare systems.
- The United States does not have a healthcare system that would support the design of the GSF.
- An efficient screening tool for all patients with chronic illness or multiple comorbidities can be effectively used in primary care.
- Screening early and often for end-of-life care intervention appropriateness improves patient care and quality of life for patients.

Integrative Review Findings

- Use of the Prognostic Indicator Guidance (PIG) tool continually increased the number of patients identified as being in the last year of life.
- Early interventions implemented as a result of the screening led to improved quality of end-of-life care for their patients.
- Providers and staff who routinely use the PIG:
 - Provide better continuum of care for their patients
 - Engage more in patient care
 - Improved patient quality survey outcomes
 - Improved end-of-life care experiences reported by patients/families.

Integrative Review Findings

- Providers and staff were found to be uncomfortable initiating end-of-life care conversations:
 - Fear of taking away the patient's hope for a good outcome
 - Unsure of where/how to start the conversation
 - Not enough time to start or complete the conversation
- Providers have the opportunity to not say "you are dying in so many days/months" but to say, **"here is the trajectory of your illness and the anticipated effects, let's talk about how you want to handle this process, what your wishes are when things become advanced, and here is some very helpful information"**.

Evidence-Based Practice Guidelines at-a-

Palliative care for adults. Glance

Major recommendations:

- Educate providers on philosophy and structure of palliative care
- *Increase identification of patients in the early stages of serious illness who would benefit from palliative care*
- Improve effectiveness and comfort level of primary care providers in communicating necessity and benefits of palliative care with patients who have a serious illness
- *Improve percentage of patients identified in early stages of serious illness who have a care plan identified and/or documented*
- *Improve ongoing reassessment and adjustment of patient's care plan as condition warrants*
- Increase completion of documentation and ongoing utilization of advance directives for patients with serious illness

- Care of dying adults in the last days of life.

End-of-Life Screening Resource Packet

IDENTIFYING PATIENTS AT THE END OF LIFE

Resource Packet

Designed and shared to distribute information and resources to effectively and efficiently screen patients for end of life care interventions by primary care providers and staff.

For Primary Care Providers and Staff

Primary care involves patients from conception to death.

**Embrace it,
Plan for it.**

Life and death are but phases of the same things. ...

Death is as necessary for Man's growth as life itself.

-Mahatma Gandhi

Early end of life conversations and advance care planning are necessary for all patients.



Conclusion



- Primary care providers need to facilitate end-of-life discussion with all patients.
- The resource packet will aid to facilitate easier identification of patients in need of intervention and provide resources.
- The resource packet is available to you for use and reference.
- Thank you for your valuable time. I look forward to working with you all in the future and appreciate your future efforts to improve end of life screening.

Questions?



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Appendix D
Pre-Presentation Survey

1. Have you ever heard of:
 - a. Gold Standards Framework _____
 - b. Prognostic Indicator Guidance tool _____
 - c. Surprise Question _____

2. Do you routinely screen for end-of-life/palliative care interventions? Why or why not?

3. Are you interested in learning more about end-of-life screening?

4. Are you aware of or currently use any one place as a source of information and resources regarding end-of-life/palliative care? If so, where?

5. Are you confident identifying and referring patients for end-of-life care interventions?

Appendix E
Post-Presentation Survey

1. Did you find this presentation informative? _____

2. Did you learn anything new (that you didn't know before)? What was it?

3. Do you think this resource packet would be beneficial to you in practice?

4. Would you consider using the resource packet or implementing the screening tool with appropriate patients? Do you think the resource packet is usable?

5. What are your thoughts and perceptions on this presentation and resource packet?

6. Do you have any suggestions?

Appendix F IRB Approval Letter



University of Massachusetts Amherst

108 Research Administration Building
70 Butterfield Terrace
Amherst, MA 01003-9242

Telephone: 545-3428 FAX: 577-1728

FAX: 577-1728

Human Research Protection Office
Research Affairs

MEMORANDUM

To: Melissa Ellis, Nursing
From: Human Research Protection Office
Date: November 21, 2016

Project Title: **Identifying Patients Appropriate for End of Life Care Interventions Using the Gold Standards Framework Prognostic Indicator Guidance Tool: An Integrative Review with Presentation and Resource Packet for Primary Care Providers and Staff**

IRB Number: 16-141

The Human Research Protection Office (HRPO) has evaluated the above named project and has made the following determination:

- The activity does not involve research that obtains information about living individuals and therefore does NOT require IRB review and approval.
- The activity does not involve intervention or interaction with individuals OR does not use identifiable private information and therefore does NOT require IRB review and approval.
- The activity is not considered research under the human subject regulations (Research is defined as "a systematic investigation designed to develop or contribute to generalizable knowledge.") and therefore does NOT require IRB review and approval.
- The activity is determined to meet the definition of human subject research under federal regulations and therefore DOES require submission of applicable materials for IRB review.

For activities requiring review, please see our web pages for more on [types of review](#) or [submitting a new protocol](#). For assistance do not hesitate to contact the Human Research Protection Office at 545-3428 for assistance.

Appendix G
Provider Handout

IDENTIFYING PATIENTS AT THE END OF LIFE

For Primary Care Providers and Staff

Provider Handout

Early end of life conversations and advance care planning are necessary for all patients.



Introduction

[Click Here to return to the Table of Contents.](#)

Advanced Care Planning

Advanced care planning should include discussing a patient's code status (would they want to be resuscitated in the event that their heart stops, would they want to be intubated in the event they become unable to breath on their own, would they want to be given nutrition artificially in the event they became unable to eat or drink, as well as the necessity for Advanced Directives, Living Wills, Medical Power of Attorney, and documentation of those wishes with their primary care provider, family, and if necessary, an attorney. The state of Texas accomplishes a large portion of this planning via a Medical Order for Scope of Treatment (MOST).

Guidance

This resource packet will provide easy access to tools and resources for provider and staff. While it cannot be all encompassing to meet every provider's needs, it has information and resources to various places in which further information and guidance can be obtained. Please see the reference list for all resources used in the creation of this resource packet. Additionally, there are hyperlinks used throughout the resource packet to make it easier to use and navigate.

Development and Purpose

This resource packet was created as a Doctorate of Nursing Practice Family Nurse Practitioner Capstone project with the intent to take evidenced based practice information and resources for implementation into practice for the purpose of improving patient care and filling an identified gap. Routine screening of patients for end of life care interventions is not routinely done in primary care settings. The culmination of an integrative review on the Gold Standards Framework and associated Prognostic Indicator Guidance tool led to the adaptation and development of this resource packet.

Special Thanks and Consideration

My sincerest gratitude to my husband and three children, who tirelessly survived on take-out food, a messy house, and limited quality time so that I could truly dedicate myself to this project. A special thanks to my husband for my being my rock and support, thank you for never giving up on me (and for picking up the slack while I finished school). A heartfelt thank you to the rest of my family and friends who understood that I while I focused on school they remained loved and important.

My gratitude and immeasurable thanks to my advisor, chair, mentor, and cheerleader Dr. Jean DeMartinis for never giving up on me, for truly teaching me to *trust the process*. Thank you to Dr. Terri Black for your input, ideas, patience, and efforts to make this project successful. And a great big thank you to Dr. Pamela Aselton for always having my back and for your endless efforts with Dr. D ensuring we could all contribute to our profession, hold our heads high, and graduate, I have faith we will all make you proud.

-Melissa A. Ellis, DNPc, BSN



Evidence Based Guidelines at a Glance

[Click Here to return to the Table of Contents.](#)

Evidence Based Guideline at a Glance

Guideline summary: Palliative care for adults.

In: National Guideline Clearinghouse (NGC) [Web site]. Rockville (MD): Agency for Healthcare Research and Quality (AHRQ); 2013 Nov 01. [cited 2017 Feb 15]. Available: <https://www.guideline.gov>

Major recommendations:

- Educate providers on philosophy and structure of palliative care
- Increase identification of patients in the early stages of serious illness who would benefit from palliative care
- Improve effectiveness and comfort level of primary care providers in communicating necessity and benefits of palliative care with patients who have a serious illness
- Improve percentage of patients identified in early stages of serious illness who have a care plan identified and/or documented
- Improve ongoing reassessment and adjustment of patient's care plan as condition warrants
- Increase completion of documentation and ongoing utilization of advance directives for patients with serious illness

National Guideline Clearinghouse (NGC) Guideline: Caring for dying adults in the last days of life.

****this guideline is not addressed in this integrative review and only referenced in the resource packet as the goal is to intervene appropriately before this late in the life continuum**.**

Online Resources

[Click Here to return to the Table of Contents.](#)

Resources

- Gold Standards Framework Centre.....www.goldstandardsframework.org.uk
- Center to Advance Palliative Care.....www.capc.org
- Agency for Healthcare Research and Quality.....www.ahrq.gov
- American Academy of Hospice and Palliative Medicine.....www.aahpm.org
- American Hospital Association.....www.aha.org
- Compassion and Support.....www.compassionandsupport.org
- Education on Palliative and End of Life Care.....www.epec.net
- National Consensus Project for Quality Palliative Care.....
.....www.nationalconsensusproject.org
- The Joint Commission.....www.jointcomission.org
- Vitaltalk.....www.vitaltalk.org
- National Hospice and Palliative Care Organization.....www.nhpco.org
- Get Palliative Care.....www.getpalliativecare.org
- Hospice Action Network.....www.hospiceactionnetwork.org
- Centers for Medicare and Medicaid.....www.cms.gov
- Texas and New Mexico Hospice Organizations.....www.txnmhospice.org
- North Texas Respecting Choices.....www.northtexasrespectingchoices.com
- Texas Academy of Palliative Medicine.....www.tapm.org
- Care Planning Council of Texas.....www.caretexas.net
- North Texas Veterans Administration.....www.northtexas.va.gov/services/hospice.asp
- Dallas Area Chapter of Hospice and Palliative Care Nurses Association.....
.....<https://hpnadallas.nursingnetwork.com/>
- Palliative Care for Adults Guideline Resources.....
.....<https://www.guideline.gov/summaries/summary/47629/palliative-care-for-adults?q=palliative+care+for+adults>
- Baylor Scott & White Palliative Care.....
.....<http://www.baylorhealth.com/SPECIALTIESSERVICES/PALLIATIVECARE/Pages/Default.aspx>
- Methodist Health System Palliative Care.....
.....<http://www.methodisthealthsystem.org/palliativecare>

UT Southwestern Medical Center Palliative Care.....
.....<http://www.utsouthwestern.edu/education/medical-school/departments/internal-medicine/divisions/general-internal-medicine/palliative/>
Texas Health Presbyterian Palliative and Hospice Services.....
.....<https://www.texashealth.org/dallas/Pages/Services/Hospice-Care.aspx>
Care of Dying Adults in the Last Days Guideline.....
.....<https://www.guideline.gov/summaries/summary/49956/care-of-dying-adults-in-the-last-days-of-life?q=end+of+life+care>

Advance Care Planning – Selected Resources for the Public

The following resources represent a broad array of materials to assist the public in better understanding advance care planning and related topics such as hospice and palliative care, caregiving, cognitive impairment, and legal issues. While extensive, this list is by no means exhaustive and other quality resources are also available.

Guidance on Completing an Advance Directive

Caring Conversations Workbook

Published by the Center for Practical Bioethics, guide helps individuals and their families share meaningful conversations regarding end-of-life decisions
<http://www.practicalbioethics.org/documents/caring-conversations/Caring-Conversations.pdf>

Five Wishes

Guide on advance care planning available in 26 languages
<http://www.agingwithdignity.org/five-wishes.php>

Consumer's Tool Kit for Health Care Advance Planning

Developed by the American Bar Association Commission on Law and Aging
http://apps.americanbar.org/aging/publications/docs/consumer_tool_kit_bk.pdf

The African American Spiritual and Ethical Guide to End of Life Care - What Y'all Gon' Do With Me?

Guide prepared by Heart Tones addressing historical, cultural and spiritual factors that influence African-Americans' decisions about end-of-life care and planning
<http://www.hearttones.com/resources.php>

CRITICAL ConditionsSM

A community education program helping people understand the importance of planning for their end-of-life medical care, this comprehensive advanced care planning program developed by Georgia Health Decisions includes the *CRITICAL ConditionsSM Planning Guide*

<http://georgiahealthdecisions.org>

Thinking Ahead: My Way, My Choice, My Life at the End

Workbook and video created by California advocates with developmental disabilities
<http://www.dds.ca.gov/ConsumerCorner/ThinkingAhead.cfm>

Loving Conversations

Produced by American Health Lawyer Association, follows fictional family through difficult process of making decisions for loved one who did not have advance directive
<http://www.healthlawyers.org/hlresources/PI/InfoSeries/Pages/LovingConversations.aspx>

Respecting Choices

Internationally-recognized, evidence-based program established in 2000 addressing process of advance care planning

<http://respectingchoices.org/>

Advanced Care Planning: Resources for Caretakers and Health Care Professionals Providing Aging Counseling

Online course developed by Carolina Geriatric Education Center that provides evidence-based and culturally-competent geriatrics education and training

<http://clipper.med.unc.edu/acp/>

For Health Care Proxies/Agents: Making Decisions for Someone Else: A How To Guide

Guide published by American Bar Association Commission on Law and Aging

http://www.americanbar.org/groups/law_aging.html

“Good to Go” Toolkit and Resource Guide

Guide published by Compassion and Choices

<http://community.compassionandchoices.org/document.doc?id=425>

Growth House, Inc.

Offers free access to over 4,000 pages of educational materials about end-of-life care, palliative medicine, and hospice

http://www.growthhouse.org/radio_channel_education.html

National Healthcare Decisions Day – April 16

Initiative encouraging individuals to express their wishes regarding health care; provides variety of resources, including materials for public, media kits, and suggested activities

<http://www.nhdd.org/>

Senior Connection

Offers several videos on death and dying that provide information to help seniors and their caregivers help themselves.

<http://www.seniorconnection.org/video.htm>

More on Advance Directives

“Speak Up” Video

Highlights the value of advance care planning and provides helpful information on Health Care Decisions Day on April 16

<http://www.youtube.com/watch?v=Bar0qZTUGdw>

U.S. Living Will Registry

Electronically stores advance directives and makes available to health care providers 24 hours a day via secure Internet or telephone-facsimile; also stores organ donation

<http://www.uslivingwillregistry.com/>

State Specific Advance Directive Form

Free downloadable advance directive forms and information from state bar associations and other reputable state groups.

<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>

Medline Plus

Website of the National Library of Medicine (a part of the National Institutes of Health) offers easy-to-understand information on advance directives

<http://www.nlm.nih.gov/medlineplus/ency/patientinstructions/000472.htm>

Advance Directives and Cancer

Fact sheet providing cancer patients and their families with outline for thinking about end-of-life care issues and guidelines for discussion with doctors, family members, and loved ones

<http://www.cancer.gov/cancertopics/factsheet/support/advance-directives>

Hospice and Palliative Care:**National Association of Home Care and Hospice (NAHCH)**

Nation's largest trade association representing the interests and concerns of home care agencies, hospices, and home care aid organizations.

<http://www.nahc.org/>

National Hospice and Palliative Care Organization (NHPCO)

Represents hospice and palliative care programs and professionals in the United States and works to expand access to hospice care and improve end-of-life

<http://www.nhpc.org/templates/1/homepage.cfm>

Caregivers and Health Care Surrogates:**Family Caregiver Alliance (FCA)**

Addresses needs of family members and others providing long-term care at home; offers programs at the national, state and local levels to support and sustain caregivers

<http://www.caregiver.org/caregiver/>

National Family Caregivers Association (NFCA)

Educates and supports more than 65 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age <http://www.thefamilycaregiver.org/> and

<http://www.familycaregiving101.org/>

AARP Caregiving Resource Center

Caregiving Resource Center offers helpful tools, work sheets and tips on how to plan, prepare and succeed as a caregiver

<http://www.aarp.org/content/aarp/en/home/relationships/caregiving.html>

Administration on Aging's National Family Caregiver Support Program

Provides grants to states and territories to fund range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible

http://www.aoa.gov/aoaroot/aoa_programs/hcltc/caregiver/index.aspx

Cognitive Impairment:

End-of-life Decisions: Honoring the Wishes of the Person with Alzheimer's Disease

Brochure from the Alzheimer's Association addresses issues a family may face when the person with dementia nears the end of life

http://www.alz.org/national/documents/brochure_endoflifedecisions.pdf

Facts and Figures

Annual report of Alzheimer's Association detailing burden of Alzheimer's disease and dementia on individuals, families, state and local governments, and the health care system

http://www.alz.org/alzheimers_disease_facts_figures.asp?type=homepage

Legal Issues:

The National Legal Resource Center

Collaborative effort of the Administration on Aging that provides legal support to aging advocacy network and highlights resources on medical decision making

<http://www.nlrc.aoa.gov/>

Patient Self Determination Act (PL 101-508)

Requires hospitals, nursing homes, home health agencies, hospice providers, and other institutions to inform patients of their rights on decisions about their medical care

<http://www.gpo.gov/fdsys/pkg/GAOREPORTS-HEHS-95-135/pdf/GAOREPORTS-HEHS-95-135.pdf>

Legal Guide for the Seriously Ill: Seven Key Steps to Get Your Affairs in Order (2009)

Prepared by the American Bar Association Commission on Law and Aging for the National Hospice and Palliative Care Organization

http://www.healthcarechaplancy.org/userimages/Legal_Guide_for_the_Terminally_Ill.pdf

Making Medical Decisions for Someone Else: A Florida Handbook

Based on a handbook created in 2006 by the American Bar Association's Commission on Law and Aging, this booklet helps one adult make health care choices for another

<http://med.fsu.edu/index.cfm?page=innovativecollaboration.publicationspresentations>

Five Big Myths of Advance Care Planning and How to Stay Anchored in Reality

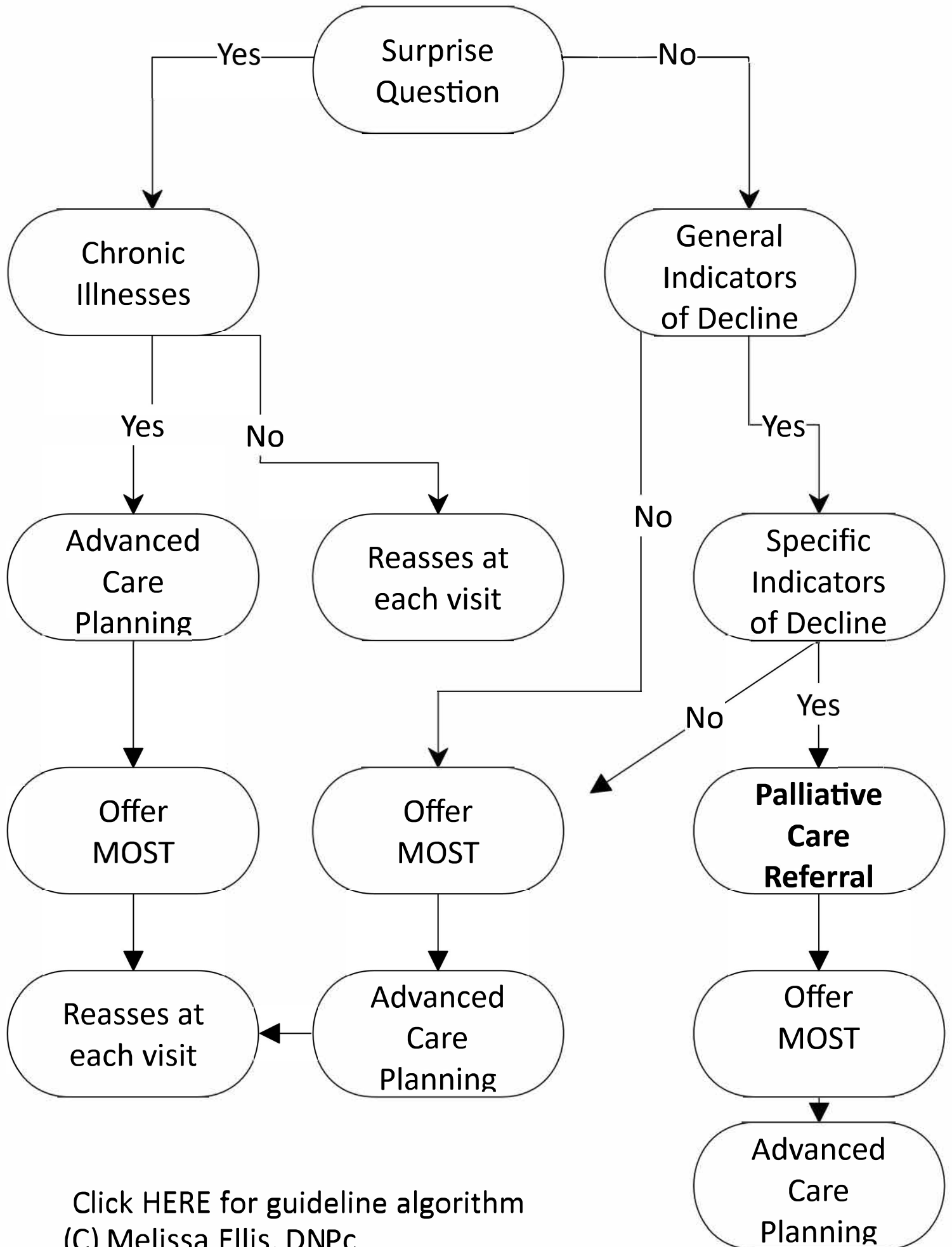
Podcast slides address five biggest myths regarding advance care planning and how to make advance care planning more effective

http://www.americanbar.org/groups/health_law/resources/podcast0410_advance_dir.html

Algorithm for Early Screening

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End of Life Care Screening Algorithm



Click [HERE](#) for guideline algorithm
(C) Melissa Ellis, DNPc

Screening Tool

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Adopted from Gold Standards Framework Prognostic Indicator Guidance Tool.

Screening Tool

Guidance for providers and staff to facilitate earlier identification of patients nearing the end of life who could benefit from a hospice palliative care approach

Why is it important to identify people nearing the end of life?

About 1% of the population dies each year. Although some deaths are unexpected, many more in fact can be predicted. This is inherently difficult, but if we were better able to predict people in the final year of life, whatever their diagnosis, there is good evidence that they are more likely to receive well-coordinated, high quality care.

This Screening Tool aims to help primary care providers and staff in earlier identification of those patients nearing the end of life who could benefit from a hospice palliative care approach to care.

The tool has been adapted from the Gold Standards Framework (GSF) Prognostic Indicator Guidance¹ tool developed by the GSF Centre in the UK. The UK has been using the tool along with a comprehensive education program to support providers and staff in various setting in identifying patients and placing them on a register to help trigger specific support.

Three steps that indicate patients could benefit from a hospice palliative care approach

1. **The Surprise Question: 'Would you be surprised if the patient were to die in the next year?'**
 - ****this is often the most important indicator! Trust your instinct. ****
2. **General indicators of decline: deterioration, advanced disease, decreased response to treatment, choice for no further disease modifying treatment.**
3. **Specific clinical indicators related to certain conditions.**

Definition of Hospice Palliative Care³

Hospice palliative care is a philosophy of care that aims to relieve suffering and improve the quality of living and dying. It strives to help individuals and families to:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears;
- prepare for and manage self-determined life closure and the dying process;
- cope with loss and grief during the illness and bereavement;
- treat all active issues;
- prevent new issues from occurring;
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

1. Thomas.K et al. *Prognostic Indicator Guidance, 4th Edition*. The Gold Standards Framework Centre In End of Life Care CIC, 2011.

Screening Tool

Guidance for providers and staff to facilitate earlier identification of patients nearing the end of life who could benefit from a hospice palliative care approach

More details of indicators – the intuitive surprise question, general decline and specific clinical

The Surprise Question

For patients with progressive life-limiting illness – Would you be surprised if the patient were to die in the next year?

The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

General Indicators of Decline

Are there general indicators of decline and increasing needs?

- Advancing disease – unstable, deteriorating complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Choice of no further disease modifying treatment
- General physical decline
- Declining functional performance status (e.g. Palliative Performance Scale⁴(PPS) ≤ 60 , reduced ambulation, increasing dependence in most activities of daily living)
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- Weight loss - >10% in past six months
- Repeated unplanned/crisis hospital admissions
- Sentinel event, e.g. serious fall, bereavement, retirement on medical grounds
- Serum albumin <25g/l

Specific Clinical Indicators

Flexible criteria with some overlaps, especially with those with frailty or other co-morbidities

a. Cancer - rapid or predictable decline

- Metastatic cancer
- More exact predictors for cancer patients are available e.g. PPS, ECOG
- The single most important predictive factor in cancer is performance status and functional ability - if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less

b. Organ failure - erratic decline

- | | |
|---|---|
| Lung Disease (COPD) (at least 2) | <ul style="list-style-type: none">• Disease assessed to be very severe (e.g. FEV1 <30% predicted⁵)• Recurrent hospital admissions (≥ 3 in last 12 months due to COPD)• Fulfills long term oxygen therapy criteria• MRC grade 4 to 5 – dyspnea after 100m on the level or confined to house• Signs and symptoms of right heart failure• More than 6 weeks of systemic steroids for COPD in preceding 6 months |
| Heart Disease (CHF) (at least 2) | <ul style="list-style-type: none">• CHF NYHA Stage 3 or 4 - shortness of breath at rest on minimal exertion• Repeated hospital admissions with heart failure symptoms• Difficult physical or psychological symptoms despite optimal tolerated therapy |

1. Thomas.K et al. *Prognostic Indicator Guidance, 4th Edition*. The Gold Standards Framework Centre In End of Life Care CIC, 2011.

Screening Tool

Guidance for providers and staff to facilitate earlier identification of patients nearing the end of life who could benefit from a hospice palliative care approach

Renal Disease (CKD)	Stage 4/5 Chronic Kidney Disease (CKD) with deterioration plus 2 of these: <ul style="list-style-type: none">• Patients choosing the 'no dialysis' option or discontinuing dialysis (by choice or due to increasing frailty, co-morbidities)• Patients with difficult physical/psychological symptoms despite optimal tolerated renal replacement therapy• Symptomatic Renal Failure – nausea/vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload
Liver Disease	<ul style="list-style-type: none">• Advanced cirrhosis with one or more complications in past year:<ul style="list-style-type: none">• diuretic resistant ascites, hepatic encephalopathy, hepatorenal syndrome, recurrent variceal bleeds⁶• Liver transplant contraindicated⁶• Child-Pugh Class C
Neurological Diseases	<p>General</p> <ul style="list-style-type: none">• Progressive deterioration in physical/cognitive function despite therapy• Symptoms which are complex and too difficult to control• Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure• Speech problems: increasing difficulty in communications and progressive dysphasia <p>Motor Neuron</p> <ul style="list-style-type: none">• Marked rapid decline in physical status• First episode of aspirational pneumonia• Increased cognitive difficulties• Weight Loss• Significant complex symptoms and medical complications• Low vital capacity (below 70% of predicted using standard spirometry)• Dyskinesia, mobility problems and falls• Communication difficulties <p>Parkinson's</p> <ul style="list-style-type: none">• Drug treatment less effective or increasingly complex regime of drug treatments• Reduced independence, needs ADL help• The condition is less well controlled with increasing "off" periods• Dyskinesias, mobility problems and falls• Psychiatric signs (depression, anxiety, hallucinations, psychosis)• Similar pattern to frailty- see below <p>Multiple Sclerosis</p> <ul style="list-style-type: none">• Significant complex symptoms and medical complications• Dysphagia + poor nutritional status• Communication difficulties e.g. Dysarthria + fatigue• Cognitive impairment notably the onset of dementia

1. Thomas.K et al. *Prognostic Indicator Guidance, 4th Edition*. The Gold Standards Framework Centre In End of Life Care CIC, 2011.

Screening Tool

Guidance for providers and staff to facilitate earlier identification of patients nearing the end of life who could benefit from a hospice palliative care approach

c. Frailty/Dementia - gradual decline

Frailty

- Multiple co-morbidities with significant impairment in day to day living and:
- Deteriorating functional performance status
- Combination of at least three of the following symptoms: weakness, slow walking speed, significant weight loss, exhaustion, low physical activity, depression

Dementia

- Unable to walk without assistance and
- Urinary and fecal incontinence, and
- No consistently meaningful verbal communication and
- Unable to do self-care without assistance
- Reduced ability to perform activities of daily living

Plus any of the following:

- Weight loss, urinary tract infection, severe pressure sores (stage 3 or 4), recurrent fever, reduced oral intake, aspiration pneumonia

Stroke

- Persistent vegetative or minimal conscious state or dense paralysis
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / post-stroke dementia

References:

1. Thomas.K et al. *Prognostic Indicator Guidance, 4th Edition*. The Gold Standards Framework Centre in End of Life Care CIC, 2011.
2. Lunney JR, Lynn J, Foley DS, Lipson S, Guralnik JM. *Patterns of functional decline at the end of life*. JAMA 2003; 289:2387-92.
3. Ferris, F. et al. *Model to Guide Hospice Palliative Care*. Canadian Hospice Palliative Care Association, 2002.
4. *Palliative Performance Scale (PPSv2) version 2*. Medical Care of the Dying, 4th ed.; p. 121. ©Victoria Hospice Society, 2006.
5. O'Donnell DE et al. *Canadian Thoracic Society recommendations for the management of chronic obstructive pulmonary disease – 2007 update*. Canadian Respiratory Journal, 2007;14 (Suppl B).
6. *Supportive and Palliative Care Indicators tool (SPICT)*. NHS Lothian and The University of Edinburgh Primary Palliative Care Research Group, 2013.

1. Thomas.K et al. *Prognostic Indicator Guidance, 4th Edition*. The Gold Standards Framework Centre In End of Life Care CIC, 2011.

Medical Orders for Scope of Treatment

The First Step in Advanced Care Planning

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TEXAS MEDICAL ORDERS FOR SCOPE OF TREATMENT (MOST) [TXMOSTCoalition2-26-16]

First Name:	Last Name:	Follow this MOST and patient preferences first, then contact a physician. Any section not completed implies full treatment for that section and does not invalidate the form. Send this MOST with the patient for all transfers between treatment sites. Comfort care and dignity will be provided to all patients.
Date of Birth:	Date Form Prepared:	

A	Check ONLY one	PHYSICIAN RESUSCITATION ORDER: If patient does not have a pulse and is not breathing: <input type="checkbox"/> Attempt Resuscitation (CPR) Place tube in the windpipe, electrical shocks to the chest, chest compression, and IV tubes for fluids/medications. <input type="checkbox"/> Do Not Attempt Resuscitation/Allow Natural death (DNAR/AND) Provide physical comfort, emotional, and respectful spiritual support to patient and family. <input type="checkbox"/> Out-Of-Hospital-Do-Not-Resuscitate Form completed If patient is not in cardiopulmonary arrest, follow orders found in Sections B and C
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B	Check ONLY one	MEDICAL INTERVENTION SCOPE: If patient is unstable, has pulse and is breathing: <input type="checkbox"/> FULL INTERVENTIONS: <u>Transfer to a hospital, and if necessary to ICU.</u> Use comfort and selective measures, and may add medically appropriate ICU interventions like, but not limited to, intubation/ventilator support, ICU-only medications, and dialysis. <input type="checkbox"/> SELECTIVE INTERVENTIONS: <u>If necessary, transfer to a hospital.</u> In addition to comfort measures, may add interventions like intravenous antibiotics, non-invasive breathing support (BiPAP/CPAP), and fluid resuscitation. <input type="checkbox"/> COMFORT INTERVENTIONS ONLY: <u>Avoid hospitalization unless needed to provide comfort care.</u> Focus on symptom control, dignity, and allowing gentle, natural death should it occur. Use comfort interventions like oral, subcutaneous, or intravenous medications (e.g., opioids), comfort foods/liquids, oxygen, and emotional/spiritual support. ADDITIONAL ORDERS: _____
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C	Check ONLY one	MEDICALLY ASSISTED NUTRITION/HYDRATION Offer nutrition and hydration by mouth at all intervention levels if feasible. <input type="checkbox"/> No medically assisted nutrition. <input type="checkbox"/> Unless medically contra-indicated*, defined trial of medically assisted nutrition. Length of trial _____ Goal _____ <input type="checkbox"/> Long-term medically assisted nutrition. <small>*In some circumstances including, but not limited to, heart, lung, liver or kidney failure, assisted nutrition or hydration may increase suffering or hasten death, and is therefore medically contraindicated.</small>
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DOCUMENTATION OF DISCUSSION AND SIGNATURES:				
Discussed with:	<input type="checkbox"/> Patient (Patient has capacity) <input type="checkbox"/> Health Care Agent or Decision Maker: _____ <input type="checkbox"/> Court Appointed Guardian _____ <input type="checkbox"/> Others in Attendance: _____	Rationale for these orders:	(Choose all that apply) <input type="checkbox"/> Living Will (Directive to Physicians and Family or Surrogates) <input type="checkbox"/> Medical Power of Attorney <input type="checkbox"/> Other: _____	
D	Physician Signature: My signature certifies both the order and preferences above and the basis for them.			
X	Physician Signature:	Print Physician Name:	Date:	Phone Number:
Patient or Patient's Surrogate Signature:				
X	Patient or Surrogate Signature:	Print Patient or Surrogate's Name, if signing:	Date:	Phone Number:

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED	
Organization or Facility Identifier:	

Patient Last Name:		First Name:		DOB:	
Facilitator Information: If someone other than patient's physician is facilitating this conversation:					
Facilitator Last Name:		Facilitator First Name:		Credentials:	Phone Number:

Instructions for MOST Form

What is MOST?

MOST stands for Medical Orders for Scope of Treatment. It is a physician order set and care planning tool based upon patient treatment preferences that travels with the patient from one site of treatment to another.

Intent or Purpose of MOST: The MOST form is intended to promote patient centered health care and improve communication about that health care between hospitals, nursing facilities and other sites of care. The order and treatment preferences should be based upon:

- The patient's medical condition as determined by a physician; and
- The patient's preferences as directly expressed by the patient, the Living Will, or by the patient's surrogate (patient representative) if the patient can't communicate and lacks a Living Will.

Section A: Translates patient preferences regarding resuscitation into a physician order. It applies when a patient does not have a pulse and is not breathing. If a patient is not in cardiopulmonary arrest, then go to Sections B, C, D. At all times, health care professionals should remember that a DNAR/AND order does not mean that other health problems should go untreated.

Information Regarding Cardio-Pulmonary Resuscitation (CPR): CPR is sometimes helpful but other times can be harmful. It is most effective when a patient dies unexpectedly. CPR is rarely effective in advanced cancer, organ failure, other advanced illness, or advanced age when death would not be a surprise. CPR started in the nursing home almost never leads to survival. If CPR is initially successful in resuscitating a patient, the patient will be on a breathing machine in the ICU. Patients should discuss with their physician the potential to benefit from CPR based on their medical condition.

Section B and C: Provide guidance for more specific orders which a treating physician may issue according to the patient's medical condition, medical appropriateness, and local medical and nursing facility policy. These sections apply when a patient has a pulse and is breathing.

Is MOST a Valid Physician Order for Non-EMS Personnel? Yes. MOST is a valid order for health care personnel in an out of hospital setting other than Emergency Medical Services professionals, as stated in Section 166.102 of the Texas Health and Safety Code: PHYSICIAN'S DNR ORDER MAY BE HONORED BY HEALTH CARE PERSONNEL OTHER THAN EMERGENCY MEDICAL SERVICES PERSONNEL. (a) ...a licensed nurse or person providing health care services in an out-of-hospital setting may honor a physician's do-not-resuscitate order.

Is MOST a Valid Physician Order for EMS Personnel? NO. If EMS comes to a patient in arrest, they will attempt CPR unless a completed (8 signatures) Texas-Out-of-Hospital DNR is present.

What Should Health Care Professionals (Other than EMS) Do With This Form? Make the form a part of the patient's medical record in your facility. Honor the order to attempt or not attempt CPR and patient treatment preferences in accordance with the standard of care in your community. If patient is transferred to any other medical facility, send the form with the patient.

Living Will, MPOA, and OOH-DNR Order: MOST is vital but does not replace these documents. EMS should honor and execute an OOH-DNR order or device [Tex. H&S Code, 166.102(b)] Although this MOST conveys important information about a patient's treatment preferences, it does not replace a Living Will, MPOA, or OOH-DNR Order. A patient's Living Will, MPOA, or OOH-DNR Order controls over this MOST. Health care professionals should be aware that when responding to a call for assistance, EMS personnel shall honor only a properly executed or issued OOH-DNR Order or identification device. [Tex. H&S Code, §166.102(b)].

Copy of MOST and HIPAA: A copy of a completed MOST is as valid as the original, and HIPAA permits disclosure of a completed MOST to other health care providers as necessary for treatment purposes. The complete MOST and associated documents will also be available to your treating physicians electronically via a secure local health information exchange.

Review: Physicians and patient/surrogate should review this form yearly or upon change in care setting, medical condition, or patient treatment preferences. If no changes, physician may simply initial the date of review in the boxes above. If changes are desired by the patient or surrogate, create a new form!

Date of Review								
Physician Initials								

SEND the MOST FORM ON ALL TRANSFERS BETWEEN HEALTHCARE SITES

Supportive Tools for Special Populations

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Eastern Cooperative Oncology Group (ECOG)

Developed by the Eastern Cooperative Oncology Group, Robert L. Comis, MD, Group Chair.*

GRADE	ECOG PERFORMANCE STATUS
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours
3	Capable of only limited self-care; confined to bed or chair more than 50% of waking hours
4	Completely disabled; cannot carry on any self-care; totally confined to bed or chair
5	Dead

*Oken M, Creech R, Tormey D, et al. Toxicity and response criteria of the Eastern Cooperative Oncology Group. *Am J Clin Oncol.* 1982;5:649-655.

Karnofsky Performance Scale

The Karnofsky Performance Scale Index allows patients to be classified as to their functional impairment. This can be used to compare effectiveness of different therapies and to assess the prognosis in individual patients. The lower the Karnofsky score, the worse the survival for most serious illnesses.

Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead

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FAST FACTS AND CONCEPTS #125
THE PALLIATIVE PERFORMANCE SCALE (PPS)
L. Scott Wilner, MD and Robert Arnold, MD

The **Palliative Performance Scale (PPS)** uses five observer-rated domains correlated to the Karnofsky Performance Scale (100-0). The PPS is a reliable and valid tool and correlates well with actual survival and median survival time for cancer patients. It has been found useful for purposes of identifying and tracking potential care needs of palliative care patients, particularly as these needs change with disease progression. Large validation studies are still needed, as is analysis of how the PPS does, or does not, correlate with other available prognostic tools and commonly used symptom scales.

PALLIATIVE PERFORMANCE SCALE (PPS)

% Ambulation	Activity Level Evidence of Disease	Self-Care	Intake	Level of Consciousness	Estimated Median Survival in Days			
					(a)	(b)	(c)	
100	Full	Normal <i>No Disease</i>	Full	Normal	Full	N/A	N/A	108
90	Full	Normal <i>Some Disease</i>	Full	Normal	Full			
80	Full	Normal with Effort <i>Some Disease</i>	Full	Normal or Reduced	Full			
70	Reduced	Can't do normal job or work <i>Some Disease</i>	Full	as above	Full	145		
60	Reduced	Can't do hobbies or housework <i>Significant Disease</i>	Occasional Assistance Needed	as above	Full or Confusion	29	4	
50	Mainly sit/lie	Can't do any work <i>Extensive Disease</i>	Considerable Assistance Needed	as above	Full or Confusion	30	11	41
40	Mainly in Bed	as above	Mainly Assistance	as above	Full or Drowsy or Confusion	18	8	
30	Bed Bound	as above	Total Care	Reduced	as above	8	5	
20	Bed Bound	as above	as above	Minimal	as above	4	2	6
10	Bed Bound	as above	as above	Mouth Care Only	Drowsy or coma	1	1	
0	Death	-	-	-	--			

(a) See Virik and Glare, reference below. Survival post admission to inpatient palliative unit.

(b) See Anderson, reference below. Days until inpatient death following admission to an acute hospice unit, diagnoses not specified.

(c) See Morita, reference below. Survival post admission to inpatient palliative unit, cancer patients only.

REFERENCES:

Anderson F, Downing GM, Hill J. Palliative Performance Scale (PPS): A New Tool. *Journal of Palliative Care*. 1996; 12(1); 5-11.

Adelaide Activities Profile

N	Question			
1	How often have you prepared a main meal?			
	Never	Less than once a week	1-2 times a week	Most days
2	How often have you washed the dishes?			
	Less than once a week	1-2 days a week	Most days	Every day
3	How often have you washed the clothes?			
	Never	About once a month	About once a fortnight	Once a week or more
4	How often have you done light housework?			
	Never	Once a fortnight or less	About once a week	Several days a week
5	How often have you done heavy housework?			
	Never	About once a month	About once a fortnight	Once a week or more
6	How many hours of voluntary or paid employment have you done?			
	None	Up to 10 hours/week	10-30 hours/week	More than 30 hrs/week
7	How often have you cared for other family members?			
	Never	About once a month	About once a fortnight	Once a week or more
8	How often have you done household shopping?			
	Never	About once a month	About once a fortnight	Once a week or more
9	How often have you done personal shopping?			
	Never	Once in three months	About once a month	Once a fortnight or more
10	How often have you done light gardening?			
	Never	About once a month	About once a fortnight	Once a week or more
11	How often have you done heavy gardening?			
	Never	About once a month	About once a fortnight	Once a week or more
12	How often have you done household and/or car maintenance?			
	Never	Once in three months	About once a month	Once a fortnight or more
13	How often have you needed to drive a car or organise your own transport?			
	Never	Up to once a month	Up to once a fortnight	Once a week or more
14	How often have you spent some time on a hobby?			
	Never	About once a month	About once a fortnight	More than once a week
15	How many telephone calls have you made to friends or family?			
	None	Up to three calls/week	4-10 calls/week	Over 10 calls/week
16	How often have you invited people to your home?			
	Less than once/fortnight	About once a fortnight	About once a week	More than once a week
17	How often have you participated in social activities at a centre such as a club, a church or a community centre?			
	Less than once/month	About once a month	About once a fortnight	More than once a week
18	How often have you attended religious services or meetings?			
	Never	About once a month	About once a fortnight	Once a week or more
19	How often have you participated in an outdoor social activity?			
	Never	About once a month	About once a fortnight	Once a week or more
20	How often have you spent some time outdoor participating in a recreational or sporting activity?			
	Never	About once a month	About once a week	More than once a week
21	How often have you walked outdoors for 15 minutes or more?			
	Once/month or less	About once a fortnight	About once a week	Most days

Reference:
Clark & Bond, 1985