NURSING HOME PALLIATIVE CARE TOOLKIT

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We welcome the opportunity to respond to your questions as they relate to this Toolkit and the Nursing Home Palliative Care Collaborative. If you would like further information, please contact Healthcentric Advisors at 401-528-3200.

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1 INTRODUCTION



Background

Launched in August 2013, the Nursing Home Palliative Care Collaborative of Rhode Island was a partnership between Healthcentric Advisors, the Quality Improvement Organization for Rhode Island, and long term care facilities and stakeholders in Rhode Island. The aims of this twelve month collaborative were to improve access to and quality of palliative care services in nursing homes in Rhode Island. This was a learning collaborative focused on providing nursing homes with the tools needed to develop and/or improve their palliative care infrastructure.

The collaborative focused on education, best practice sharing, and inter-facility discussion. It used the Holistic Approach to Transformational Change (HATCh[™]) model for systems change and a rapid cycle quality improvement approach. The HATCh[™] model for systems change supports a facility in the change process of moving from an institutional model of care to a model of individualized care. The HATCh[™] model keeps the consumer at the center of all change efforts so that the consumer's quality of life becomes the focus.

The Nursing Home Palliative Care Collaborative of Rhode Island included the following components:

- One webinar
- Two in-person learning sessions
- Six conference calls
- Outcomes Congress at the completion of one year of the collaborative

Rhode Island nursing homes participating in this collaborative focused on the following hallmarks of palliative care:

- Identifying proxy decision-makers
- Advanced care planning
- Pain assessment
- Discussion of resident prognosis
- Discussion of resident goals
- Assessment and access to spiritual care

Healthcentric Advisors designed this Toolkit to provide educational support and intervention ideas to participants within the learning collaborative. Healthcentric Advisors has since adapted the Toolkit and developed this edition for use outside of the Nursing Home Palliative Care Collaborative of Rhode Island.

Over the course of the collaborative, participating facilities measured their completion rates for the seven process measures outlined in this Toolkit. All seven process measures showed improvement over the baseline data measurement at the completion of one year. Further evidence of success of this collaborative included personal testimony from participants and state-wide reductions in readmissions for Medicare beneficiaries discharged to skilled nursing facilities. In hopes of sustaining and also spreading the success of these achievements, Healthcentric Advisors will continue to provide access to this Toolkit on its website.

Toolkit Link on Healthcentric Advisors' Website

Overview: Palliative Care in Nursing Homes

According to the National Consensus Project for Quality Palliative Care, the goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies ⁽¹⁾. The population of persons over the age of 65 is growing and will continue to grow over the next few decades as baby boomers age. In addition, technological advances and improvements in medicine and health have increased our life expectancy. These factors lead to an increasing number of individuals living with chronic or serious illnesses later in life. Over three million people in the United States will be living in nursing homes by the year 2030⁽²⁾. Whether a nursing home represents a short term stay or is the long term residence for an individual, it becomes their locus for care and support.

The improvement of palliative care across all settings has been identified as a national priority by the National Priority Partnership ⁽³⁾. Research has shown that many nursing homes do not have a current framework for providing palliative care. In addition, many residents who have complex or serious illness are subject to frequent transitions between the hospital and nursing home. These transitions lead to concerns around communication between providers regarding care plans, potential medication errors and increased discomfort for the resident⁽⁴⁾.

Within the nursing home setting, residents are now staying longer and the number of people in the United States dying in nursing homes is increasing. Projections show that the number of people in the United States who will die in a nursing home is expected to increase from the current figure of 22% to 50% by the year 2020⁽⁵⁾. These trends highlight the importance of having an established infrastructure and protocol for palliative care in the nursing home setting. In a review of Medicare patients who died in one of four settings (hospital, home care, hospice, or nursing home) the nursing home setting ranked very low and at times the lowest in rates of satisfaction with pain management, emotional support and doctor-patient-family communication ⁽⁶⁾.

The very reason that residents are admitted to long term care and rehabilitation facilities, the loss of function and/or increased care needs for an illness or injury, make it likely that the individual will be experiencing pain, discomfort, emotional distress, spiritual disharmony, and other issues affecting their quality of life⁽⁷⁾.

These are the concerns that palliative care practices address and therefore, the long term care setting becomes a critical venue in which to introduce palliative care. Currently in the United States, research shows that few nursing homes have formal palliative care programs although care practices include elements of palliative care ⁽⁸⁾. The Center to Advance Palliative Care's review of research shows that most nursing homes need to improve in the area of advance care planning, having discussions around goals of care and in the area of pain and symptom management. A comprehensive and systematic delivery of palliative care services would address these areas of concern.

Barriers to providing palliative care in nursing homes include poor transitions between care settings, understaffing at the majority of US nursing homes, and the training and educational needs of staff ⁽⁹⁾. The current payment structure for nursing homes emphasizes reimbursement for residents to return to higher functioning status or to be transferred from the facility for acute care, rather than symptom relief. This can also be a barrier to

providing palliative care⁽¹⁰⁾. In addition, cultural differences in accessing the healthcare system, as well as how aging, death and dying is viewed among different cultures for both residents and staff, influence the provision of palliative care services⁽¹¹⁾.

In essence, the residents of nursing homes want to have a fulfilled life according to their definition of such a life. Researcher Joanne Lynn noted that there are seven promises that patients and families want from their health care providers:

- · Medical treatment that is appropriate and evidence based
- No overwhelming symptoms
- Continuity of comprehensive care
- Planning ahead for complications and death
- · Care customized to their preferences
- Care adapted to serve the patient's family
- Help to live as fully as possible ⁽¹²⁾

A comprehensive palliative care program within the nursing home setting would allow clinicians to fulfill these promises to their residents and families, thus improving the satisfaction for the resident and care provider.

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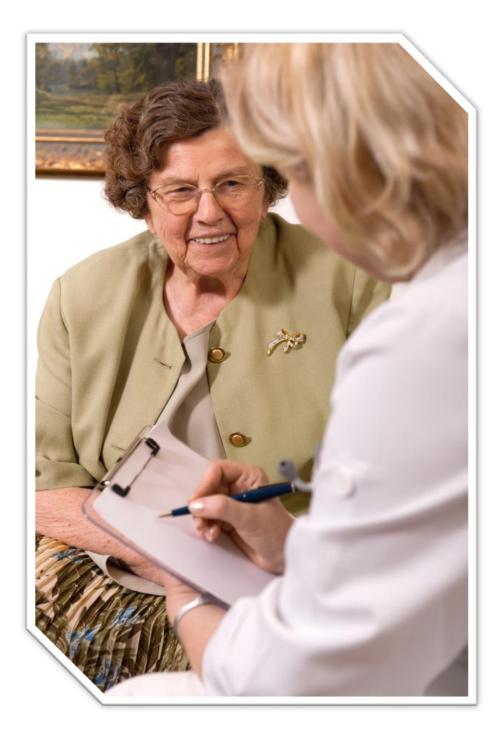
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2 GENERAL PALLIATIVE CARE RESOURCES



Palliative Care Preferred Practices

The following Preferred Practices are excerpted from the document "A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A National Quality Forum (NQF) Consensus Report". To access the full NQF Consensus Report, go to:

NQF Consensus Report: A National Framework and Preferred Practices for Palliative and Hospice Care Quality.

Provide palliative and hospice care by an interdisciplinary team of skilled palliative care professionals, including, for example, physicians, nurses, social workers, pharmacists, spiritual care counselors, and others who collaborate with primary healthcare professional(s).

- 1. Provide access to palliative and hospice care that is responsive to the patient and family 24 hours a day, 7 days a week.
- 2. Provide continuing education to all healthcare professionals on the domains of palliative care and hospice care.
- 3. Provide adequate training and clinical support to assure that professional staff is confident in their ability to provide palliative care for patients.
- 4. Hospice care and specialized palliative care professionals should be appropriately trained, credentialed, and/or certified in their area of expertise.
- 5. Formulate, utilize, and regularly review a timely care plan based on a comprehensive interdisciplinary assessment of the values, preferences, goals, and needs of the patient and family and, to the extent that existing privacy laws permit, ensure that the plan is broadly disseminated, both internally and externally, to all professionals involved in the patient's care.
- 6. Ensure that upon transfer between healthcare settings, there is timely and thorough communication of the patient's goals, preferences, values, and clinical information so that continuity of care and seamless follow-up are assured.
- 7. Healthcare professionals should present hospice as an option to all patients and families when death within a year would not be surprising and should reintroduce the hospice option as the patient declines.
- 8. Patients and caregivers should be asked by palliative and hospice care programs to assess physicians'/healthcare professionals' ability to discuss hospice as an option.
- 9. Enable patients to make informed decisions about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.
- 10. Provide education and support to families and unlicensed caregivers based on the patient's individualized care plan to assure safe and appropriate care for the patient.
- 11. Measure and document pain, dyspnea, constipation, and other symptoms using available standardized scales.
- 12. Assess and manage symptoms and side effects in a timely, safe, and effective manner to a level that is acceptable to the patient and family.
- 13. Measure and document anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms using available standardized scales.

- 14. Manage anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms in a timely, safe, and effective manner to a level that is acceptable to the patient and family.
- 15. Assess and manage the psychological reactions of patients and families (including stress, anticipatory grief, and coping) in a regular, ongoing fashion in order to address emotional and functional impairment and loss.
- 16. Develop and offer a grief and bereavement care plan to provide services to patients and families prior to and for at least 13 months after the death of the patient.
- 17. Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, to discuss goals of care, disease prognosis, and advance care planning, and to offer support.
- 18. Develop and implement a comprehensive social care plan that addresses the social, practical, and legal needs of the patient and caregivers, including but not limited to relationships, communication, existing social and cultural networks, decision making, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment.
- 19. Develop and document a plan based on an assessment of religious, spiritual, and existential concerns using a structured instrument, and integrate the information obtained from the assessment into the palliative care plan.
- 20. Provide information about the availability of spiritual care services, and make spiritual care available either through organizational spiritual care counseling or through the patient's own clergy relationships.
- 21. Specialized palliative and hospice care teams should include spiritual care professionals appropriately trained and certified in palliative care.
- 22. Specialized palliative and hospice spiritual care professionals should build partnerships with community clergy and provide education and counseling related to end-of-life care.
- 23. Incorporate cultural assessment as a component of comprehensive palliative and hospice care assessment, including but not limited to locus of decision making, preferences regarding disclosure of information, truth telling and decision making, dietary preferences, language, family communication, desire for support measures such as palliative therapies and complementary and alternative medicine, perspectives on death, suffering, and grieving, and funeral/burial rituals.
- 24. Provide professional interpreter services and culturally sensitive materials in the patient's and family's preferred language.
- 25. Recognize and document the transition to the active dying phase, and communicate to the patient, family, and staff the expectation of imminent death.
- 26. Educate the family on a timely basis regarding the signs and symptoms of imminent death in an age-appropriate, developmentally appropriate, and culturally appropriate manner.
- 27. As part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for the site of death, and fulfill patient and family preferences when possible.
- 28. Provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase, and address concerns and fears about using narcotics and of analgesics hastening death.

- 29. Treat the body after death with respect according to the cultural and religious practices of the family and in accordance with local law.
- 30. Facilitate effective grieving by implementing in a timely manner a bereavement care plan after the patient's death, when the family remains the focus of care.
- 31. Document the designated surrogate/decision maker in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.
- 32. Document the patient/surrogate preferences for goals of care, treatment options, and setting of care at first assessment and at frequent intervals as conditions change.
- 33. Convert the patient treatment goals into medical orders, and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospital care, through a program such as the Physician Orders for Life-Sustaining Treatment (POLST) program.
- 34. Make advance directives and surrogacy designations available across care settings, while protecting patient privacy and adherence to HIPAA regulations, for example, by using Internet-based registries or electronic personal health records.
- 35. Develop healthcare and community collaborations to promote advance care planning and the completion of advance directives for all individuals, for example, the Respecting Choices and Community Conversations on Compassionate Care programs.
- 36. Establish or have access to ethics committees or ethics consultation across care settings to address ethical conflicts at the end of life.
- 37. For minors with decision making capacity, document the child's views and preferences for medical care, including assent for treatment, and give them appropriate weight in decision making. Make appropriate professional staff members available to both the child and the adult decision maker for consultation and intervention when the child's wishes differ from those of the adult decision maker.

On-Line Resource Links

(Updated 06/2014)

American Academy of Hospice and Palliative Care Medicine

This organization is dedicated to expanding patient and family access to high-quality palliative care, and advancing the discipline of Hospice and Palliative Medicine, through professional education and training, development of a specialist workforce, support for clinical practice standards, research and public policy.

Center to Advance Palliative Care (CAPC)

CAPC is a national program that provides health care professionals with the tools, training, and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings. As a leading resource in program development, CAPC offers comprehensive training for palliative care programs at every stage – from strategic planning and funding to operations and sustainability.

CAPC Consumer Page: Get Palliative Care

The site is provided by the CAPC with a direct focus on educating people with serious, complex illnesses on how and where to access palliative care. Key components of the site include a <u>Palliative Care Provider Directory of Hospitals</u>, a definition of palliative care and detailed descriptions of what palliative care does and how to get it. It also provides an interactive questionnaire to assist the consumer in determining whether palliative care might be appropriate for him/her or a loved one. There is also a "For Clinicians" section outlining when your patient may be appropriate for palliative care.

CAPC Resources Page

A CAPC page that summarizes resources for palliative care, services in nursing homes and to identify successful models of palliative care service delivery in these settings.

CAPC Leadership Centers

Palliative Care Leadership Centers[™] (PCLC) provide intensive, operational training and year-long mentoring for palliative care programs at every stage of development and growth. Established by the Center to Advance Palliative Care and the Robert Wood Johnson Foundation in 2004, PCLC has trained almost half of the nation's hospital palliative care programs.

Center to Improve Value in Health Care (CIVHC)

CIVHC supports achieving the health care Triple Aim for Colorado: Better Health, Better Care, and Lower Costs and has a focus area in palliative care. They developed the "Best

Practices for Palliative Care: A Guide for Long Term Care and Hospice" for Colorado area long term care facilities which can be downloaded in a PDF format from their website.

EndLink: Resource for End of Life Care Education

This is an internet based end-of-life care education program. There are 16 modules including Goals of Care, Advance Care Planning, and Communicating Bad News. Funded through a research grant by the National Cancer Institute.

Five Wishes

Five Wishes helps bridge the medical and the legal worlds of advance care planning in a document that is easy for most people to use and understand. *Five Wishes* is used in all 50 states and in countries around the world. It meets the legal requirements for an advance directive in 42 states.

Hospice and Palliative Nurses Association

Established in 1986, the Hospice and Palliative Nurses Association is the nation's largest and oldest professional nursing organization dedicated to promoting excellence in hospice and palliative nursing care.

End of Life Palliative Care Education Resource Center (EPERC)

A project based at Northwestern University's Feinberg School of Medicine that educates health care professionals on the essential clinical competencies in palliative care, including FAST FACTS FOR CLINICIANS

National Consensus Project for Quality Palliative Care

The NCP represents a coalition of leading palliative care organizations working to heighten awareness of palliative care as an option in treating those with a life-limiting or chronic debilitating illness, condition or injury, and to raise public understanding of the growing need for such care. The NCP developed Clinical Practice Guidelines for Quality Palliative Care as a national consensus of what the standard of good palliative care should be.

National Hospice and Palliative Care Organization

NHPCO is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the US. 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 dying in America and their loved ones.

Physician Orders for Life-Sustaining Treatment (POLST)

The POLST Paradigm program is designed to improve the quality of care people receive at the end of life. It is based on effective communication of patient wishes, documentation of medical orders on a brightly colored form, and a promise by health care professionals to honor these wishes. In many states, this may also be called MOLST (Medical Orders for Life-Sustaining Treatment).

Spiritual Care Curriculum

Hillel Bodek, MSW, LCSW-R, BCD, Chairperson of the Committee on Palliative and Endof-Life Care of the New York State Society for Clinical Social Work, has created a curriculum on spiritual care which can be self-guided or used to teach others. The training modules and tools can be downloaded for free from the Growthhouse website.

Stanford End of Life Care Curriculum

With support from the Robert Wood Johnson Foundation, The <u>Stanford Faculty</u> <u>Development Center</u> (SFDC) developed a 16-hour faculty development course incorporating basic material designed to be used by physicians in any area of expertise. The web-based curriculum includes a Teacher's Handbook and eight modules. Each module is implemented as a PowerPoint slide presentation, with slides and teachers' notes on both the content and teaching process available for free viewing or downloading.

The Institute for Patient and Family Centered Care

The Institute for Patient- and Family-Centered Care provides leadership to advance the understanding and practice of patient- and family-centered care in hospitals and other health care settings.

The End-of-Life Research Program

The End-of-Life Care Research Program is composed of clinical and health services investigators and staff focused on specific projects that have as their overall goal the improvement of end-of-life care. In addition to providing the core support for these specific projects, the program serves as a resource to other investigators conducting related research.

The Gold Standards Framework (GSF)

GSF is a systematic evidence-based approach to optimize care for patients nearing the end of life that is delivered by generalist providers. It is concerned with helping people live well until the end of life and includes care in the final years of life for people with any end stage illness in any setting. GSF is extensively used in the UK and increasingly in other countries. It is regarded by many as "the bedrock of generalist palliative care."

Publications List for Further Research

(Updated 06/2014)

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3 GENERAL TEAM RESOURCES



Nursing Home Palliative Care Team Contact List

PC Role	Name	Title	Email	Phone
PC Team Co- Leaders:				
1.				
2.				
Administrative Champion:				
Med. Director / Physicians:				
Pharmacy:				
Social Worker:				
Palliative Care Consultants:				
Other:				
Clergy:				
Additional Team Members:				
Other:				
Other:				
Other:				

Nursing Home Palliative Care One Year Work Plan

Activity	References and Resources	Expected Completion
Seek palliative care team members and gain their commitment to champion palliative care	Lynn, J, et al. <i>The common Sense Guide to Improving</i> <i>Palliative Care.</i> New York; Oxford University Press; 2007 (Chapter 2, Basics of Quality Improvement: Establishing a Good Team)	Week 1
Gather research and information regarding the need for palliative care improvement in your facility	Nursing Home Palliative Care Toolkit, Sections 1 and 2	Week 2
Seek leadership approval to focus on palliative care improvement, identify co- leaders for the team	Lynn, J, et al. <i>The common Sense Guide to Improving</i> <i>Palliative Care.</i> New York; Oxford University Press; 2007 (Chapter 2, Basics of Quality Improvement: Establishing a Good Team)	Week 3
Establish infrastructure for regular palliative care team meetings at your facility	Suggest that these occur bi-weekly for the first 2-3 months and then a minimum of monthly, at regular intervals, i.e. second Tuesday of each month at 2 p.m.	Week 4
If no external providers are on your team, reach out to these partners to inform them of your plan and invite their assistance/input	Seek list of licensed providers through your state Department of Public Health, visit the <u>Center to Advance Palliative Care</u> or <u>National Hospice and Palliative Care Organization</u> websites to search list of providers in your area	Week 4
Have first interdisciplinary palliative care team meeting and establish mission, vision and participation agreement	Nursing Home Palliative Care Toolkit, Section 3, PC Team Meeting Agenda Template	Month 2
Determine how the team plans to measure success. Review possible process measures and outcome measures.	Nursing Home Palliative Care Toolkit, Section 4, Data Collection and Measurement	Month 2
Determine how this initiative aligns with other initiatives under QAPI, QIO efforts or other learning collaboratives. Ensure that staff resources are well utilized and efforts are synergistic, not duplicative.	Review with QAPI team and QIO contacts	Month 2

Activity	References and Resources	Expected Completion
Review principles of HATCh™ as a team	Nursing Home Palliative Care Toolkit, Section 5, HATCh™ Model to Support Transformational Change	Month 2
Review Model for Improvement as a team	Nursing Home Palliative Care Toolkit, Section 5, Introduction to Quality Improvement	Month 2
Complete an interdisciplinary palliative care in-service for staff using local palliative care providers	Seek external partners with palliative care expertise to provide curriculum, review Nursing Home Palliative Care Toolkit, Section 2, On-Line Resource Links for programs with established curricula such as EndLink and Stanford Faculty Development Center as needed	Month 2
Determine areas of need for change in your facility through review of staff education needs assessment and interdisciplinary team discussion	Nursing Home Palliative Care Toolkit, Section 5, Change Idea Sheets, Section 6, The Educational Needs Assessment Tool	Month 3
At a team meeting, develop an aim statement and establish a PDSA cycle to implement a change process	Nursing Home Palliative Care Toolkit, Section 5, Introduction to Quality Improvement	Month 3
Implement the first PDSA cycle	Nursing Home Palliative Care Toolkit, Section 5, Introduction to Quality Improvement	Month 3
At team meeting, review results of first PDSA cycle and determine whether to adopt the change, adapt the change or abort the change	Nursing Home Palliative Care Toolkit, Section 5, Introduction to Quality Improvement	Month 4
Use first PDSA results and initial needs assessment to determine next PDSA cycle	Nursing Home Palliative Care Toolkit, Section 5, Introduction to Quality Improvement	Month 5
At team meeting, develop a second aim statement and implement second PDSA cycle	Nursing Home Palliative Care Toolkit, Section 5, Introduction to Quality Improvement	Month 5
At team meeting, review results of second PDSA cycle and determine whether to adopt the change, adapt the	Nursing Home Palliative Care Toolkit, Section 5, Introduction to Quality Improvement	Month 6

Activity	References and Resources	Expected Completion
change or abort the change Review palliative care team infrastructure, vision and mission to ensure your team meetings and PDSA cycles are supporting the original intent of the team.		Month 6
Complete a six month review of efforts and put together a storyboard to share results with staff, facility visitors and/or leadership. Be sure to evaluate your facility performance using the original determinants of success outlined during month 2 of the work plan.	Nursing Home Palliative Care Toolkit, Section 5, Sharing Results, Section 4 Data Collection and Measurement	Month 6
Review first two PDSA cycle results and initial needs assessment. Complete a second needs assessment if necessary to develop next palliative care aim statement.	Nursing Home Palliative Care Toolkit, Section 5, Model for Improvement, Section 6, The Educational Needs Assessment	Month 6
Develop third aim statement and implement third PDSA cycle based on ongoing assessment of needs	Nursing Home Palliative Care Toolkit, Section 5, Introduction to Quality Improvement	Month 7
At team meeting, review results of third PDSA cycle and determine whether to adopt the change, adapt the change, or abort the change	Nursing Home Palliative Care Toolkit, Section 5, Introduction to Quality Improvement	Month 8
At team meeting, review the ongoing effectiveness of the changes implemented during the first three PDSA cycles. If the facility has not sustained the improvements, complete a root cause analysis.	Nursing Home Palliative Care Toolkit, Section 5, Introduction to Quality Improvement	Month 8
Use outcome of root cause analysis to	Lynn, J, et al. The common Sense Guide to Improving	Month 9

Activity	References and Resources	Expected Completion
support the facility in sustaining the positive changes made through first three PDSA cycles.	Palliative Care. New York; Oxford University Press; 2007 (Chapter 2, Basics of Quality Improvement: Making the changes stick)	
Reviewing all completed needs assessment and team discussion, determine next palliative care aim statement.	Nursing Home Palliative Care Toolkit, Section 5, Introduction to Quality Improvement	Month 10
Implement fourth PDSA cycle	Nursing Home Palliative Care Toolkit, Section 5, Introduction to Quality Improvement	Month 10
At team meeting, review results of fourth PDSA cycle and determine whether to adopt the change, adapt the change or abort the change	Nursing Home Palliative Care Toolkit, Section 5, Introduction to Quality Improvement	Month 11
Determine your facility's plan to sustain all positive changes resulting from your four PDSA cycles	Lynn, J, et al. <i>The common Sense Guide to Improving</i> <i>Palliative Care.</i> New York; Oxford University Press; 2007 (Chapter 2, Basics of Quality Improvement: Making the changes stick)	Month 11
Update your story board to include the successes of months six through twelve. Share results with staff, facility visitors, external partners.	Nursing Home Palliative Care Toolkit, Section 5, Sharing Results	Month 12
Establish your facility's performance according to your original measures of success. Report your results to leadership, industry partners and collaborators.	Nursing Home Palliative Care Toolkit, Section 5, Sharing Results	Month 12

Palliative Care Team Meeting Agenda Template

Agenda Item	Facilitator	Time Allocation
1. Action items from previous meetings		
2. Engagement Activity (Updates on team composition, multi- disciplinary champions and additional outreach efforts)		
3. Education Activity (Review the KSA grids; change idea sheets; root cause analysis results, needs assessment results to determine area of needed improvement, discuss plan and progress for each item)		
4. Execution Work (Discuss efforts to implement practice changes, conduct root cause analysis, PDSA cycles and improvement work)		
5. Evaluation (Results from PDSA cycles and data outcomes)		

4 DATA COLLECTION AND MANAGEMENT



Palliative Care Practices: Measurement Guidelines and Tools

Collecting data is a cornerstone of any quality improvement project. This section of the Toolkit is designed to provide information on how data can be used to drive improvement efforts and prove the benefits of change. In Section 3 of this Toolkit, the Work Plan outlines how to implement a year-long change improvement project; this Section provides guidance on measurement opportunities that may help guide your improvement project.

The following seven care practices are potential process measures for tracking palliative care improvement. Facility care teams can determine their current completion rates for these practices by randomly selecting a portion of their residents and through a record review or chart audit, determine completion of the measures as documented at time of admission or most recent change in diagnosis/prognosis. This will provide a baseline measurement that will help facilities determine their focus area for a PDSA cycle (see Section 5 of the Toolkit). The baseline data analysis will allow facility care teams to properly develop an aim statement with reasonable goals. A 100% completion rate for all of the care practices is the overall goal; however, facilities may need to work incrementally towards that goal.

1. Identify a proxy decision-maker and document in the medical record within 14 days of admission, within 14 days of change of diagnosis/prognosis indicating a significant decline in overall health.

This measure requires the following within 14 days:

- Proxy decision-maker is identified by the resident
- Contact information for decision maker is gathered
- Information as to whether this decision-maker has been legally designated or is the resident's choice without legal documentation in place.
- This information is documented in both the electronic and hard copy chart in a readily available location and in an easily identifiable way.
- Documentation of this information is recorded by a MD, NP, PA, RN, LPN or SW.

Rationale: National Framework and Preferred Practices for Palliative and Hospice Care Quality*

Preferred Practice #32: Document the designated surrogate/decision maker in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.

Tools: Refer to toolkit Section 6 Intervention Tools: Advance Care Planning Tools and Resident-Family Communication Tools

2. Pain assessment must be completed and documented within 24 hours of admission, within 24 hours of change of diagnosis/prognosis indicating a significant decline in overall health.

This measure requires the following within 24 hours:

- Pain assessment and documentation reflects the policy that each nursing home has established regarding initial assessment and reassessment.
- Methods of assessment include but not limited to: patient self-report, physical examination, observation of patient, behavior, family member's report and physiological cues.
- Pain assessment may include: location, intensity, quality, onset, and duration, acute vs. chronic, and relieving and aggravating factors. Effects of pain on sleep, mobility, appetite, mood, etc., past experiences with pain, methods used to alleviate pain, specific medication, reactions/allergies are important components.
- Measure of pain intensity tool that is utilized must be consistent and validated, such as:
 - o 0-10 scale for cognitively intact patients
 - The Wong-Baker FACES Pain Rating Scale for cognitively intact, nonverbal or non-English speaking patients
 - FLACC behavioral scale for cognitively impaired or patients unable to communicate
- Documentation is recorded by MD, NP, PA, RN or LPN.

Rationale: National Framework and Preferred Practices for Palliative and Hospice Care Quality

Preferred Practice #12: Measure and document pain, dyspnea, constipation and other symptoms using available standardized scales.

Preferred Practice #13: Assess and manage symptoms and side effects in a timely, safe, and effective manner to a level that is acceptable to the patient and family.

Tools: Refer to toolkit Section 6: Intervention Tools: Pain Assessment Tools and Section 8: Rhode Island Specific Resources: Pain Management Regulations in RI

3. Have an Advanced Care Planning discussion with the resident (and family per resident choice) and document this meeting within 14 Days of admission, within 14 Days of change of diagnosis/prognosis indicating a significant decline in overall health.

The measure requires the following within 14 days:

- Discussion with resident (and family per resident choice) occurs
- Assessment completed of whether resident already has an advance directive document
- Assessment completed of whether resident would like to create such a document, relay specific wishes, or edit an existing document
- Documentation is recorded in the medical record by the MD, NP, PA, RN, LPN or SW

Rationale: National Framework and Preferred Practices for Palliative and Hospice Care Quality

Preferred Practice #10: Enable patients to make informed decisions about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.

Preferred Practice #18: Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, to discuss goals of care, disease prognosis, and advance care planning, and to offer support.

Preferred Practice #35: Make advance directives and surrogacy designations available across care settings, while protecting patient privacy and adherence to HIPAA regulations, for example, by using Internet-based registries or electronic personal health records.

Tools: Refer to toolkit page Section 6: Intervention Tools: Advance Care Planning Tools and Section 8: Rhode Island Specific Resources: Rhode Island Laws and Regulations Pertaining to Palliative Care

4. Discussion of resident prognosis must occur with resident (and family per resident choice) and be documented in the medical record within 14 days of admission, within 14 days of change of diagnosis/prognosis indicating a significant decline in overall health.

The measurement requires the following within 14 days:

- Discussion that includes clear information about the resident's prognosis occurs with the resident (and family per resident choice)
- Information must be presented in a way that resident and/or family understand and with an opportunity for questions
- At least two members of the care team are present at the meeting
- Documentation includes who was present and prognosis discussed and is recorded by MD, NP, PA, RN, LPN or SW

Rationale: National Framework and Preferred Practices for Palliative and Hospice Care Quality

Preferred Practice #10: Enable patients to make informed decisions about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.

Preferred Practice #18: Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, to discuss goals of care, disease prognosis, and advance care planning, and to offer support.

Tools: Refer to toolkit page Section 6: Intervention Tools: Resident-Family Communication Tools and Section 8: Rhode Island Specific Resources: Rights of Nursing Home Patients

5. Discussion of resident goals around care and treatment occurs and is documented within 14 days of admission, within 14 days of change of diagnosis/prognosis indicating a significant decline in overall health.

The measurement requires the following within 14 days

- Discussion with resident (and family per resident choice) outlining the resident's goals for care, treatment, and quality of life issues occurs
- At least two members of the care team are present at the meeting
- Documentation includes who was present, outline of goals relayed by resident/family, and is recorded by MD, NP, PA, RN or SW

Rationale: National Framework and Preferred Practices for Palliative and Hospice Care Quality

Preferred Practice # 6: Formulate, utilize, and regularly review a timely care plan based on a comprehensive interdisciplinary assessment of the values, preferences, goals and needs of the patient and family and, to the extent that existing privacy laws permit, ensure that the plan is broadly disseminated, both internally and externally, to all professionals involved in the patient's care.

Preferred Practice #18: Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, to discuss goals of care, disease prognosis, and advance care planning, and to offer support.

Preferred Practice #28: As part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for the site of death, and fulfill patient and family preferences when possible.

Preferred Practice #34: Covert the patient treatment goals into medical orders, and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospital care, through a program such as the Physician Orders for Life-Sustaining Treatment (POLST) program.

Tools: Refer to toolkit Section 6: Intervention Tools: Resident-Family Communication Tools and Advance Care Planning Tools and Section 8: Rhode Island Specific Resources: Rhode Island Laws and Regulations Pertaining to Palliative Care

6. Assessment for resident's need for spiritual care and support is completed 14 days of admission, within14 days of change of diagnosis/prognosis indicating a significant decline in overall health.

The measure requires the following within 14 days:

- Assessment occurs that identifies the resident's religious, spiritual and/or cultural preferences, assessment is documented in medical record
- Resident's preference regarding whether referral for further spiritual support is wanted or needed is identified and documented,
- Individual (resident, family, or staff) who will make referral for further spiritual support is identified and documented.
- Individual and/or religious entity to whom this referral will be made is identified and documented.

Rationale: National Framework and Preferred Practices for Palliative and Hospice Care Quality

Preferred Practice # 20: Develop and document a plan based on an assessment of religious, spiritual, and existential concerns using a structured instrument, and integrate the information obtained from the assessment into the palliative care plan.

Preferred Practice #21: Provide information about the availability of spiritual care services, and make spiritual care available either through organizational spiritual care counseling or though the patient's own clergy relationships.

Tools: Refer to toolkit Section 6: Intervention Tools: Spiritual Care Tools

7. For those residents who expressed a desire or need for spiritual care, that care is provided within 3 days of having identified this need.

The measure requires the following:

- Once a need/desire for spiritual care is identified either through assessment or resident/family request, the referral is made in a timely manner and with request that it be provided within 3 days.
- The requested spiritual care is then provided within 3 days
- Referral for spiritual care and confirmation that it was provided must be documented in the medical record by MD, NP, PA, RN, LPN or SW

Rationale: National Framework and Preferred Practices for Palliative and Hospice Care Quality

Preferred Practice # 20: Develop and document a plan based on an assessment of religious, spiritual, and existential concerns using a structured instrument, and integrate the information obtained from the assessment into the palliative care plan.

Preferred Practice #21: Provide information about the availability of spiritual care services, and make spiritual care available either through organizational spiritual care counseling or though the patient's own clergy relationships

*<u>A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A</u> <u>National Quality Forum Consensus Report</u>. December 2006

Palliative Care Measures Data Collection Tool

Resident Name:	Room #/Unit
DOB:	MR#:

□ Data collected for baseline purposes □ Data collected for new admission or change

Identification of Proxy Decision-Maker	Yes or No	
Discussion occurs where resident is requested to identify a proxy decision maker	□ YES	
Contact information for decision maker is gathered (N/A is appropriate if a resident refuses to identify a proxy decision maker after more than one attempt to discuss with resident)	□ YES □ N/A	□ NO
Information gathered as to whether decision maker is legally appointed or resident's choice without legal documentation (N/A is appropriate if a resident refuses to identify a proxy decision maker)	□ YES □ N/A	□ NO
All information documented (both presence or absence of proxy decision maker) in both electronic and hard copy chart in a readily identifiable location	□ YES	□ NO
Identified and documented within 14 days of admission or assessed change in diagnosis/prognosis indicating a significant decline in health	□ YES	□ NO
Data Entry for this measure should be: ☐ YES (all aspects of measure met with a YES or N/A response) ☐ NO (one or more aspects of measure unmet)		

Pain Assessment Completed	Yes or No	
Pain assessment completed and documented using standardized tool that is 1) consistently used according to nursing home policy and 2) a validated tool such as the 0-10 scale, Wong-Baker FACES Pain Rating Scale, FLACC behavioral scale	□ YES	□ NO
Documentation is recorded by MD, NP, PA, RN, or LPN	□ YES	
Completed and documented within 24 hours of admission or assessed change in diagnosis/prognosis indicating a significant decline in health	□ YES	□ NO
Data Entry for this measure should be:		

Advance Care Planning Discussion with Resident Completed	Yes or No	
Discussion occurred with resident and any family per resident choice	□ YES	□ NO
Discussion occurred within 14 days of admission or assessed change indicating a significant decline in health	□ YES	□ NO
Assessment completed of whether resident already has an advance directive document	□ YES	□ NO
Assessment completed of whether resident would like to create such a document or edit an existing document	□ YES	□ NO
Documentation of discussion is recorded by MD, NP, PA, RN, LPN or SW	□ YES	□ NO
Data Entry for this measure should be:		
□ YES (measure can be met even if consumer does not have and does not want to complete an advance directive document)		
□ NO (one or more aspects of measure unmet)		

Prognosis Discussion with Resident Completed	Yes or No	
Discussion occurred with resident and family per resident choice and includes clear information on resident's prognosis	□ YES	□ NO
Information presented to resident/family with opportunity to ask questions and seek clarification	□ YES	□ NO
Discussion occurred within 14 days of admission or assessed change indicating a significant decline in health		□ NO
At least two members of the care team were present at the discussion	□ YES	
Documentation of discussion includes who was present, prognosis discussed and is recorded by MD, NP, PA, RN, LPN or SW		□ NO
Data Entry for this measure should be:		
\Box YES (all aspects of measure met with a YES response)		
□ NO (one or more aspects of measure unmet)		

Discussion of Resident Goals for Care	Yes or No	
Discussion occurred with resident and family per resident choice where resident is allowed to outline goals for care, treatment, and quality of life issues	□ YES	□ NO
At least two members of the care team were present for the discussion	□ YES	
Documentation includes who was present, outline of goals relayed by resident/family/ and is recorded by MD, NP, PA, RN, LPN or SW	□ YES	□ NO
Discussion occurred within 14 days of admission or assessed change in prognosis/diagnosis indicating a significant decline in health		□ NO
Data Entry for this measure should be:		
\Box YES (all aspects of measure met with a YES response)		
□ NO (one or more aspects of measure unmet)		

Assessment of Resident's Need for Spiritual Care	Yes or No	
Assessment occurs that identifies the resident's religious, spiritual and/or cultural preferences	□ YES	□ NO
Assessment occurs that identifies whether further spiritual support is wanted or needed	□ YES	□ NO
Assessment is completed within 14 days of admission or assessed change in prognosis/diagnosis indicating a significant decline in health	□ YES	□ NO
Individual responsible to make further referral for support is identified (if spiritual care is not requested, N/A is the appropriate response)	□ YES □ N/A	□ NO
Individual/entity to whom referral will be made is identified (if spiritual care is not requested, N/A is the appropriate response)	□ YES □ N/A	□ NO
 Data Entry for this measure should be: □ YES (all aspects of measure met with YES or N/A Response) □ NO (one or more aspects of measure unmet) 		
Spiritual Care Provided When Requested/Needed	Yes or No	
Once identified as need through assessment or request, referral is made in a timely manner with request that spiritual care support is provided to resident within 3 days of referral (<i>N/A is the appropriate response if</i> <i>spiritual care was not requested or identified as a need during the</i> <i>assessment</i>)	□ YES □ N/A	□ NO
Spiritual care is provided within 3 days of referral (N/A is the appropriate response if spiritual care was not requested or identified as a need during the assessment)	□ YES □ N/A	□ NO
Referral for care documented and confirmation that it was provided documented in medical record by MD, NP, PA, RN, LPN or SW. (N/A is the appropriate response if spiritual care was not requested or identified as a need during the assessment)	□ YES □ N/A	□ NO
Data Entry for this measure should be:		
□ YES (all aspects of measure met with YES Response)		
□ NO (one or more aspects of measure unmet)		
□ N/A (measure unnecessary as spiritual care was not requested or identified as a need during the assessment)		

Palliative Care Measurement Calculations

1) Proxy decision-maker identified Calculation:

Number of residents with healthcare decision-maker documented according to guidelines

Number of eligible residents

2) Pain assessment Calculation:

Number of residents with pain assessments according to guidelines

Number of eligible residents

3) Advance Care Planning Calculation:

Number of residents with Advance Care Planning discussion according to guidelines

Number of eligible residents

4) Resident prognosis discussion Calculation:

Number of residents with prognosis discussions completed according to guidelines

Number of eligible residents

5) Resident goals discussed at the care plan/family meeting Calculation: Number of residents with goals for care conversations completed according to guidelines

Number of eligible residents

6) Need for spiritual care assessed Calculation:

Number of residents with spiritual care assessed according to guidelines

Number of eligible residents

7) Spiritual care provided within 3 days when assessed as a need Calculation:

Number of residents with spiritual care provided according to guidelines

Number of residents with spiritual care assessed as a need

Palliative Care Data Entry

Because no current standardized system collects data directly related to palliative care or the process measures outlined in this Toolkit, data entry must be completed through a separate system. Facility care teams are encouraged to develop a method that will allow for easy tracking and development of reports. For the Nursing Home Palliative Care Collaborative of Rhode Island, Healthcentric Advisors developed a data collection system using Survey Monkey that allowed facilities to capture data on a monthly basis without providing any personal health information. A screenshot of the data entry screens are shown here. This tool is not available for public use but is easily replicable.

The data entry tool is composed of three screens, the initial screen asks if the data is being collected for baseline and whether or not the resident meets exclusionary criteria. The second screen will be either the Exclusion Criteria or the Palliative Care Measures, dependent on the box clicked on the initial screen. The third screen is a Record Complete screen.

Data Entry Start:

Palliative Care Data Collection
*1. Select Data Category:
 Data collected on this resident for baseline information
New admission or current resident with change in prognosis/diagnosis
Residents must meet one of the following criteria to be excluded:
-Resident not diagnosed with a serious or chronic medical condition
 Resident is not a fee for service Medicare beneficiary (regardless of payor source for facility) Resident declines all palliative support
-Resident is currently receiving hospice services through the Medicare Hospice Benefit
* 2. Exclusion Criteria?
○ Yes
O No

Topic 1 "Select Data Category"

Topic 2 "Exclusion Criteria"

If the record meets one of the four exclusionary criteria then select "*Yes*", otherwise choose "*No*" to move on to the Palliative Care Measures screen.

If "Yes" for exclusionary criteria, the second screen will ask for the exclusionary details.

Exclusion Criteria Screen:

Palliative Care Data Collection		
Exclusion Criteria		
*1. Please check all that apply to the exclusion criteria:		
Resident not diagnosed with a serious or chronic medical condition		
Resident is not a fee for service Medicare beneficiary (regardless of payor source for facility)		
Resident declines all palliative support		
Resident is currently receiving hospice services through the Medicare Hospice Benefit		
	Prev	Next

When finished selecting the exclusion criteria, click on "*Next*". This will direct users to the "Record Complete" screen.

Please note, the exclusion criteria screen only appears when you select "Yes" to exclusion criteria on the first screen. If the resident did not meet Exclusion Criteria and the user clicked "*No*" on the first screen, the user will be advanced to the screen allowing entry of the Palliative Care Measures.

For the Nursing Home Palliative Care Collaborative of Rhode Island, the exclusions were necessary for data comparison reasons and to support resident choice. Each care team can determine if there is any subset of individuals for whom the team will not collect data.

Palliative Care Measures Screen:

F	alliative Care Data Collection					
P	Palliative Care Measures					
	* 1. Palliative Care Measures					
		Yes	No			
	1.a.) Proxy decision-maker identified AND documented in medical record?	\bigcirc	\bigcirc			
	1.b.) Pain assessment completed AND documented in medical record?	\bigcirc	\bigcirc			
	1.c.) Presence or absence of advance directive identified AND documented in medical record?	\bigcirc	\bigcirc			
	1.d.) Discussion of resident prognosis occurred with resident or family member AND documented in medical record?	\bigcirc	\bigcirc			
	1.e.) Discussion of resident goals occurred at family or care plan meeting AND documented in medical record?	\bigcirc	\bigcirc			
	1. f.) Discussion with resident of desire/need for spiritual care occurred AND documented in medical record?	\bigcirc	\bigcirc			
	★ 2. Palliative Care Measure: Spiritual Care					
		Yes	No	N/A		
	2.a.) For those requesting spiritual care, this care was provided within 3 days of resident request AND documented in medical record?	\bigcirc	\bigcirc	\bigcirc		
	Prev	Next				

Topic 1: Palliative Care Measures

Use the Palliative Care Measures Data Collection Tool to understand how a "Yes" or "No" answer correlates to the resident's records.

Topic 2: Palliative Care Measure Spiritual Care

This question contains an additional answer choice of "N/A" to indicate "not applicable". Use "N/A" only when the resident has requested <u>not</u> to pursue spiritual care.

All questions must be answered. When finished click "Next".

Record Complete Screen:

Palliative Care Data Collection					
Record Complete!					
This record is complete and has been saved. You can click on New Record to start entering a new record or, if you are finished entering records, you can close your browser.					
Prev New Record					

When the user reaches the "Record Complete" screen, the record has been saved.

5 QUALITY IMPROVEMENT & CULTURE CHANGE



Overview of Change Methods

When implementing a change process, there are several models of change and learning from which to choose. Each of these approaches has a unique methodology with different intents whether it is to educate direct care staff or to incorporate a system-wide culture change. Some of these models of change are explained in this section.

The **HATCh[™] Model** (Holistic Approach to Transformation Change) is the systems change model that can serve as the backdrop for all change processes in a nursing facility. More detailed information about this approach is reviewed in this section of the Toolkit. This model empowers facility staff to maintain their focus on their resident while implementing improvement projects within the domains of care.

Learning the cause of a problem or situation from a systems perspective can be a critical step when determining what changes a facility team should implement. Completing a **Root Cause Analysis** allows facility teams to focus on the changes they need to make. The commonly accepted method to implement a change process is to complete a rapid cycle improvement project. This **Model for Improvement: Plan, Do, Study, Act (PDSA)** methodology allows facilities to implement small changes, evaluate the results quickly, and either readjust and test again or spread those changes system wide. More information about this improvement method and sample PDSA worksheets are included in this section.

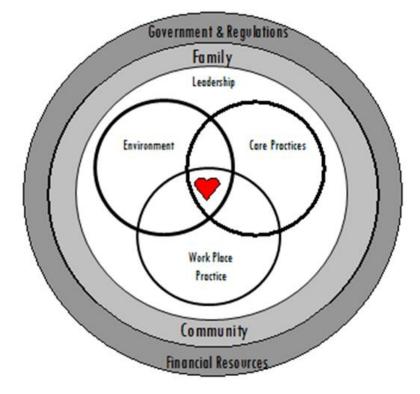
The **Knowledge**, **Skills**, **and Attitude** (KSA) approach is used for new learning or to reinforce current knowledge. This is a competency based model that operationalizes learning by dividing each necessary step to building competency into the following categories:

- Knowledge: Cognitive abilities, remembering, relating ideas, judging an idea
- Skills: The understanding that allows us to execute tasks, the "doing"
- Attitudes: The state of mind, feelings or beliefs

In this Toolkit, certain palliative care quality measures are defined within a competency grid. Facility teams can then review what is needed to have proficiency in these domains of palliative care. With this information, facilities can determine their area of needed improvement and use this information to drive their PDSA cycles.

The **change idea sheets** incorporated into this Toolkit are designed to give each facility more background and possible change ideas specific to selected domains of palliative care. The change ideas explored under each domain can be developed into a facility's AIM statements and drive the PDSA cycles. These change idea sheets encourage providers to keep the resident at the center of any improvement process.

HATCh[™] Model to Support Transformational Change The Holistic Approach to Transformational Change HATCh[™]



The HATCh[™] model visually depicts the 6 important domains that are the key to the transformational change from institutional care to individualized care in nursing homes. The heart in the center depicts the resident. The interrelated domains of environment, care practices, and work-place practice are most closely linked to the resident. These three domains sit in the midst of the leadership domain. The domain of family and community encircles these domains, showing their important role in all aspects of the nursing home. The outer ring of Government & Regulations/Financial Resources represents that those with power and influence outside of the nursing home should be brought into the transformation process.

The possibility for change occurs within each domain. The result is the opportunity for each individual to retain a quality of life while living in the facility that they define as positive with aspects that are important to him or her. The care becomes individualized, moving away from the institutional model of care.

Examples include:

Domain 1: Workplace Practice

• Establish relationships as the number one organizational priority

- Support necessary changes and adjustments that will allow relationships to flourish personally, organizationally, and environmentally
- Include elders, caregivers, and families in developing avenues for relationship building, feedback and inclusion in community
- Consistent assignment
- Document proxy decision maker information in each medical chart
- Peer mentoring
- Learning circles
- Vibrant, nurturing orientation programs that imbue a sense of community
- Communities / neighborhoods
- Social support for staff's needs
- Ways of welcoming new families, staff, and residents
- Community mourning
- Self-managed work teams
- Opportunities for leadership development among front-line staff
- On-going & Consistent recognition
- Sense of mission shared by all staff
- A philosophy of being a learning organization by sharing the wealth and value of education by sending staff to conferences, workshops
- Self-governed work teams
- Cross training
- Identify quality of life educational opportunities such as pain management and palliative care
- Elimination of unjustifiable work, care processes, and mandates
- Adopting an attitude of openness within the organization for the personal needs, personal accomplishments, personal tragedies of all
- Assure the accessibility and provision of all necessary equipment
- Adopt scheduling that reflects resident and staff needs
- Redesign space and schedule
- In-service training that responds to the interests and needs of caregivers

Domain 2: Environment

- The creation of sanctuary, shelter and peace that provides a sense of community, safety and free of unwanted intrusions
- The creation of beauty and comfort
- Have rooms available for family meetings that are comfortable and provide space to accommodate the resident, family members and an interdisciplinary team
- De-institutionalize the common rooms (bathrooms, living areas)
- Design for accessibility
- Diminish barriers
- Attention to adequate lighting
- Provide for nature
- Opportunities to contribute, participate and immerse oneself in rituals & celebrations
- Demonstrate affection, validation and support

- Encourage personal items that reflect individuality-Refrigerators, calendars, pictures, comforters, personal space, shrines
- Shift towards neighborhoods, communities

Domain 3: Care Practices

- Opportunities to maintain life-long daily routine
- Clinical practices that consider health promotion along with risk prevention
- Assess residents for palliative care needs on a regular basis i.e. care plan meetings
- The choice of when to awaken and go to sleep
- The opportunity to sleep without interruption
- Choice with regard to food (meals, service, delivery, variety, ethnicity, diet)
- Choice related to bathing and other ADLs-frequency, time, method
- Activities that reflect the individual interests of each person
- Ensure staff are aware and understand a resident's advance directives
- Include pastoral care wishes in care plans
- High quality clinical care with resident, family, staff input
- The elimination of iatrogenic helplessness
- Freedom from restraints, pressure ulcers, depression, incontinence, & pain
- Innovative, creative care solutions
- "I" format care plans to include goals for care
- Care plans that support a resident's goals of care
- Community mourning
- The implementation of the Model for Improvement to support change with hallmarks of:
 - o Evidence-based practice using measurement strategies
 - PDSA cycles
 - Root cause analysis

Domain 4: Leadership Practice

- High quality leadership at all levels of the organization
- Leadership practices that: model the way, inspires a shared vision, challenges the process, enables others to act, encourages the heart (based on the work of Kouzes and Posner)
- Manage by walking around
- Offer and receive regular positive and constructive feedback
- Support for interdisciplinary care teams
- Inclusive, non-hierarch decision making
- Allows the truth to be heard
- Imbue an attitude that places elders and caregivers at the heart of all decisions and at the heart of the home
- Values staff day-to-day in policy and practice, word and deed
- Provide consistent recognition
- Support the full empowerment of workers allowing them to grow, direct, and affect the care of elders
- High performance, high commitment HR policies

- Work systems aligned with and serving organizational goals
- Sufficiency of staff and resources to care humanely

Domain 5: Family/Community Inclusion

- Accommodate and commit to inclusion of families in all aspects of nursing home community life
- Care conference
 - Committee
 - \circ Councils
 - o Volunteers
- Incorporate resident prognosis and goals of care discussions into regularly held family meetings such as care plan meetings
- Porous nursing homes that become hubs in which community activity is welcome and encouraged
- Create a service organization by partnering with the community to offer services, events, space and resources
- Encourage staff to share their talents, expertise and skill to the community, hospitals, and health care organizations
- Become mentors, speakers and leaders on elder health care issues
- Provide guidance to educational programs that train healthcare professionals

Domain 6: Regulatory/Government

- Bring regulators into your culture change story
- Develop collaborative approaches that create synergies between SSA, Ombudsman, Trade, families, other key state groups into the culture change process.
- The creation of action plans that cross organizations
- Develop an approach that supports the interpretive guidelines for Resident Rights, Quality of Life and Quality of Care regulatory groups

The HATCh[™] model was developed by Healthcentric Advisors under contract with The Center for Medicare and Medicaid Services (CMS) to create and pilot test a model and a methodology for achieving transformational change. This model is the lens through which facility teams can approach palliative care changes. For more information on applying the HATCh[™] model to your facility, contact Healthcentric Advisors.

Root Cause Analysis

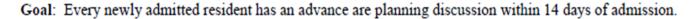
Conducting a root cause analysis allows facility teams to complete an in-depth breakdown of a problem. Generally, it is used to determine how and why something happened or to identify actions that can be changed to improve a process or eliminate a problem. It is important that a root cause analysis have a systems focus rather than individual blame. There are several methods to use when completing a root cause analysis.

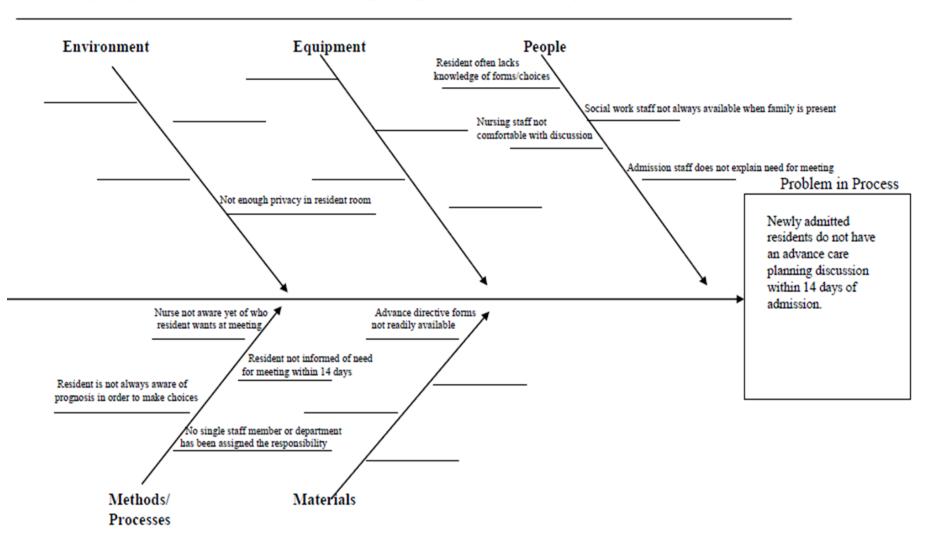
An effective method is called the: "**Five Whys**". State the problem, ask "why", answer and then ask "why" again. An example of this method may look like:

- 1. Data shows that newly admitted residents do not have an advance care planning discussion within 14 days of admission. **Why**?
- 2. The admission process covers basic paperwork needed to be in compliance with determining code status but does not include further discussion. **Why**?
- 3. Staff may not know the resident's comfort level with these discussions or who they want to have with them at an advance care planning meeting. **Why**?
- 4. Admissions staff has not discussed the team's goal to have an advance care planning meeting with the resident prior within 14 days. **Why**?
- 5. Admissions staff was not included in the discussions on why advance care planning discussions with residents are so important and how this new initiative will be rolled out.

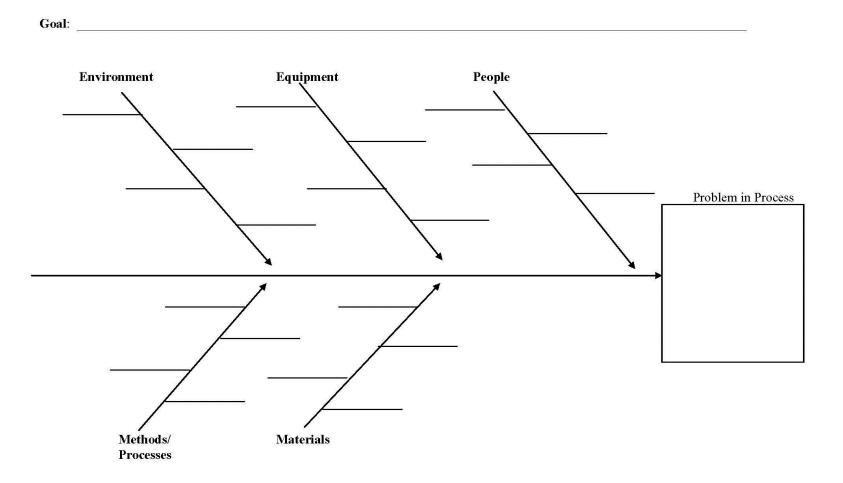
Another way of conducting a root cause analysis is to complete a fishbone style causeeffect diagram. Developing this type of diagram allows team members to consider multiple factors that may lead to certain outcomes. Use of these diagrams also facilitates communication between team members and fosters teamwork in developing a solution focus. An example of a completed fishbone diagram and a template for facility teams to use and replicate are in this section. Facility teams can use the information gathered during a root cause analysis to drive their PDSA cycles, explained later in this section.

Sample Fishbone Diagram



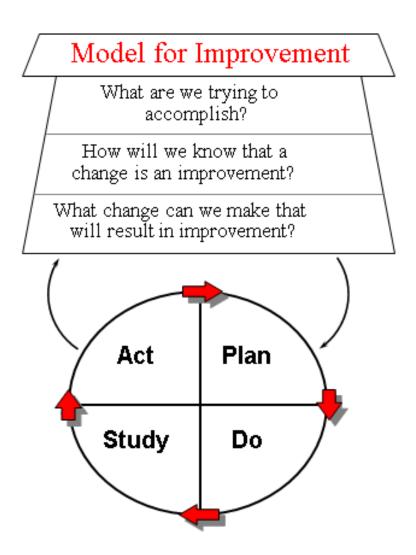


Fishbone Diagram Template



Model for Improvement

The Model for Improvement is an improvement process that relies on current knowledge and shortens the discovery process for improvement. It makes use of a rapid trial and learning method and relies heavily on taking action. This diagram demonstrates this method.



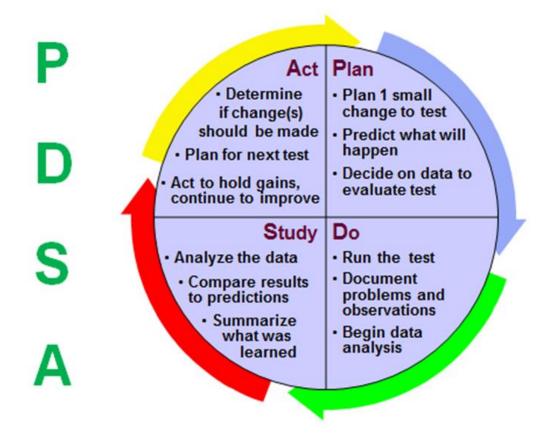
The Model for Improvement starts with developing an aim statement. This asks and answers the first question: "What are we trying to accomplish?"

Developing Your Aim:

The aim should be stated clearly and include numerical goals that require the current system to change. Agreement by the team and facility leadership on the aim statement is critical to achieve success. This section of the Toolkit contains a template for an aim Worksheet as well as a sample related to palliative care.

Making the Change:

Once you have developed your Aim statement, it is time to take action and decide what change needs to happen and what measures will clarify your aim. The next step is to implement a Plan, Do, Study, Act (PDSA) cycle. The diagram below exemplifies this process. A template of a PDSA worksheet and a sample related the palliative care is included in this section of the Toolkit.



Palliative Care Best Practice AIM Worksheet (Template)

Nursing Home: _____

What are we trying to accomplish?

This is a general overarching statement describing what you intend to accomplish during the time you work on this process. It answers the first question of the Model for Improvement. The process is identified in the statement, any specific or segmented area is mentioned and words like improve, reduce, and increase are often utilized

By when?

Time frame, i.e., date, month, year in which you intend to accomplish improvement

By how much?

This is the target performance measurement that the team has identified

Complete AIM Statement:

Palliative Care Best Practice AIM Worksheet (Sample)

Nursing Home Team: Quality Nursing & Rehab Center

What are we trying to accomplish?

This is a general overarching statement describing what your team intends to accomplish during the time you work on this process. It answers the first question of the Model for Improvement. The process is identified in the statement, any specific or segmented area is mentioned and words like improve, reduce, and increase are often utilized

Improve compliance with identification and documentation of proxy decision maker within 14 days of admission to the nursing home.

By when? Time frame, i.e., date, month, year in which you intend to accomplish improvement November 15, 2013______

By how much?

This is the target performance measurement that the team has identified

50% (from 50% to 75% compliance)_____

Complete AIM Statement:

Identification and documentation of proxy decision maker within 14 days of admission to the nursing home improves from 50% to 75% by November 15, 2013.

PSDA Worksheet (Template)

Palliative Care	Team Name:			
PDSA Worksheet (Template)	Cycle start date:	Cycle end date:		
PLAN: Area to work on:				
Describe the change you are testing and state the q	uestion you want this test to a	inswer (If I do x will y happen?)		
What do you predict the result will be?				
What measure will you use to learn if this test is suc	cessful or has promise?			
Plan for change or test: who, what, when, where				
Data collection plan: who, what, when, where				
DO: Report what happened when you carried out the test. Describe observations, findings, problems encountered, special circumstances.				
STUDY: Compare your results to your prediction	ns. What did you learn? Any s	surprises?		
ACT: Modifications or refinements for the next cy	cle; what will you do next?			

PDSA Worksheet (Sample)

Proxy Decision Maker PDSA Worksheet	5.1.1.1.1.1.1 Team Name: Quality Nursing & Rehab Center
(sample)	Cycle start date: <u>Sept 15</u> Cycle end date: <u>Sept 23</u>

PLAN: Area to work on

Describe the change you are testing and state the question you want this test to answer

(If I do x will y happen?)

We want to improve use of the Proxy Decision-Maker field in the electronic medical record.

Test: Provide a one-hour mandatory in-service training to all admissions staff that includes a review of the Proxy Decision-Maker section in the EMR and review of the policy and procedure that outlines the expectation that this field is utilized for all residents.

What do you predict the result will be?

Predict that identification and documentation of proxy decision-maker improves by at least 25% at time of admission.

What measure will you use to learn if this test is successful or has promise?

measure = <u># of Residents whose EMR field is completed within 14 days of admission</u>

All residents Admitted to Rehab Unit during the Sept 15-23 timeframe

Plan for change or test: who, what, when, where

Who: DON will provide training on Policy and Procedure, MDS Coordinator will review the correct EMR field during the training, QA coordinator will collect the data.

What: EMR field is already incorporated into the current system. Training will be provided to Admissions RN and Unit Managers regarding the use of the field and Policy and Procedure.

When: September 15-Sept 23

Where: Rehabilitation Unit

Data collection plan: who, what, when, where

Who: Jane Doe, QA coordinator

What: Review the utilization of the EMR field "Proxy Decision-Maker" on admitted residents from September 15- September 23 and collect data:

When: September 23-October 7 (allowing for the 14 day window)

Where: Electronic Medical Record

DO: Report what happened when you carried out the test. Describe observations, findings, problems encountered, and special circumstances.

Use of the Proxy Decision-Maker field improved by 75%. The only barrier encountered was when a resident did not have a proxy decision-maker at time of admission and the admission staff needed to "hand over" the responsibility of discussion and documentation over to the social work department.

This sometimes caused a lapse of longer than 14 days. Because this was the rehab unit, some residents were discharged prior to having that discussion with staff.

STUDY: Compare your results to your predictions. What did you learn? Any surprises?

Results were better than predicted. We learned that the EMR field was easy to use and provided the information needed in a readily accessible way. We were surprised that our own information transfer between departments was not clearly defined and caused delays.

ACT: Modifications or refinements for the next cycle; what will you do next?

We will implement this for new admissions to all units and then for all long term care residents. We plan to address the communications between departments in the next cycle.

Knowledge, Skills and Attitude (KSA)

The Knowledge, Skills and Attitude (KSA) approach to learning breaks down learning into the steps needed to gain full competency in a defined area. In this section of the Toolkit, specific domains of palliative care have been modeled into competency grids using the KSA approach. Each facility team can use these grids to determine where improvement is needed and to drive their PDSA cycles.

The competencies in each grid are for the general knowledge, skills and attitude required for each task. Depending on the discipline of the person completing the task, there may be additional clinical knowledge or skills required. Facility teams are encouraged to develop competency grids for discipline specific clinical tasks in order to evaluate their own processes, determine best practices and drive the improvement cycle.

The K-S-A Competency Model for Learning

Knowledge: Cognitive abilities, remembering, relating ideas, judging an idea

Skills: The understanding that allows us to execute tasks, the "doing"

Attitude: The state of mind, feelings or beliefs that influence learning

Competency Grids

Competency: Identifying a Proxy Decision-Maker	K	S	Α
1. Understand the importance for each resident to have an identified proxy decision-maker	Х		
2. Believe that having a proxy decision-maker identified is beneficial to the resident			Х
3. Develop a tool for recording this information in the record both on paper and electronically		Х	
4. Feel comfortable and confident in posing questions to residents about care scenarios that may involve a proxy-decision maker			Х
5. Assess each resident individually on the best method to obtain proxy decision-maker information (i.e. family meeting, individual meeting, which care team member)		x	
6. Have presence of self and understand if one's own bias is interfering in the process of obtaining proxy decision-maker	Х		
7. Recognize cultural issues and how this may intersect with identifying proxy decision-makers	Х		
8. Have a pre-defined script for discussing proxy-decision makers with residents.	Х		
9. Be able to adapt the script in the moment to given situations and conversations as they arise		Х	
10. Document the identified proxy-decision maker		Х	
11. Assess whether further follow up will be required (i.e. legal documents, referrals) and act on that assessment		Х	

Сс	ompetency: Advance Care Planning Discussion with Residents	K	S	Α
1.	Recognize the value of having discussions around choices in care prior to needing that care			х
2.	Understand the scope and content of an Advance Care Planning discussion	Х		
3.	Have thorough knowledge of the state's legally accepted documents and how to obtain/complete them	Х		
4.	Have thorough knowledge of how Advance Care Planning can be completed without identified legal documents if resident does not wish to create documents	x		
5.	Develop a tool for recording the discussion, resident choices, and legal documentation both on paper and electronically		Х	
6.	Feel comfortable and confident in posing questions to residents about care scenarios that may involve changes in their current care plan and around issues of life limiting illness			х
7.	Recognize cultural issues and how this may intersect with an Advance Care Planning discussion	х		
8.	Assess each resident individually for the best approach to advance care planning (i.e. during a care plan meeting, with family present/not present)		Х	
9.	Have presence of self and understand if one's own bias is interfering with the discussion	Х		
10	Assess whether further follow up will be required (i.e. legal documents, referrals) and act on that assessment		Х	
11	. Document the discussion and resulting care choices		Х	

Сс	ompetency: Have Discussion of Resident Prognosis with Resident/Family	к	S	Α
1.	Identify prognosis or change in prognosis	Х		
2.	Value the importance of a resident's or designated decision-maker's right to know the diagnosis and prognosis			Х
3.	Determine most appropriate team member to have discussion of prognosis with resident/family		Х	
4.	Assess for each resident individually the most appropriate manner in which to have a discussion of prognosis		Х	
5.	Develop a tool for documenting this discussion with resident/family both electronically and on paper		Х	
6.	Have an understanding of how certain phrases and terminology can help residents understand and accept their prognosis	х		
7.	Prepare for discussion by reviewing all test results, diagnostic indicators, physical and psychosocial history for the resident		Х	
8.	Have presence of self to determine if personal history or concerns may influence your participation in this discussion	Х		

Competency: Have Discussion of Resident Prognosis with Resident/Family	κ	S	A
 During discussion, assess resident/family's understanding of prognosis and alter course of conversation according to their health literacy and ability to process information 		x	
10. Assess need for follow up discussions in order to accurately relay all information the resident and family must have		Х	
11. Assess the need for further follow-up by other professionals (i.e. spiritual or mental health counseling) and act on that assessment		Х	
12. Document the discussion and any outcomes		Х	

Co Ca	mpetency: Have a Discussion with Resident/Family about Goals for re	κ	S	Α
1.	Recognize the importance of understanding a resident's goals for care			Х
2.	Understand the importance of the resident having a full understanding of his/her prognosis in order to formulate care goals based on appropriate information			x
	Develop a model for including the opportunity for residents to share their goals for care during all care discussions		Х	
4.	Develop a system for documenting a resident's care goals both in paper record and electronic record		х	
	Be comfortable and confident in posing care scenarios in order to elicit information about a resident's care goals, even those scenarios that may involve life limiting illness			x
6.	Understand how certain phrases and terminology will assist residents in understanding how to establish their care goals and how you can best elicit goals from the resident	х		
7.	Assess whether the resident or decision-maker understands the resident's prognosis prior to forming care goals		Х	
8.	Recognize how cultural factors may influence a resident's care goals	Х		
9.	Be able to process a resident's care goals without judgment based on personal beliefs		Х	
10	Have presence of self to understand if personal beliefs interfere with acceptance and execution of resident's care goals	х		
11	Recognize when a resident's stated care goals differ from their actions and demands and be able to address those differences during discussion in order to clarify goals		х	
12	Assess whether resident's stated care goals require a change in the current plan of care, necessitating further team action		Х	
13	Document discussion and resident goals for care		Х	

	mpetency: Assessing Need for Spiritual Care & Providing Access to iritual Care	K	S	А
1.	Understand the positive impact that spiritual care may have on a resident			Х
2.	Understand different spiritual beliefs and how this may impact resident life	Х		
3.	Recognize that having an identified religion is different than completing a spiritual needs assessment	Х		
4.	Do not assume that a resident's beliefs and religious practices will always follow the commonly accepted methods for his/her identified religion			Х
5.	Develop an appropriate tool to assess a resident's need for spiritual care		Х	
6.	Assess each resident individually for the most appropriate manner and method to administer the assessment tool		Х	
7.	Develop a method to document a resident's spiritual care needs assessment and resulting identified needs		Х	
8.	Judge how to respond to a resident's spiritual needs once identified	Х		
9.	Make appropriate referrals to spiritual providers as requested/needed by residents		Х	
10.	Have presence of self and understand if personal beliefs are influencing your ability to assess and follow up on a resident's spiritual care needs	х		
11.	Recognize the fluidity and changeable nature of spiritual needs	Х		
12. Determine when re-assessment, re-referral is needed			Х	

Сс	mpetency: Completing a Pain Assessment	K	S	А
1.	Recognize the need for pain assessments on an ongoing basis	Х		
2.	Understand the link between pain and quality of life	Х		
3.	Value how the pain assessment will provide staff with an opportunity to improve quality of life			Х
4.	Understand the fluctuating nature of pain and the need to identify type, locale, and severity.	Х		
5.	Have thorough understanding of current best practices for evidence based pain assessments	Х		
6.	Understand the standardized schedule of when pain assessments must be completed	Х		
7.	Recognize when the pain assessment must be completed outside of/in addition to the standardized schedule (i.e., change in resident complaints, change in behavior)		х	
8.	Be able to administer the appropriate pain assessment at the appropriate time (i.e., using a verbal scale or behavioral observational scale)		Х	
9.	Recognize when staff assumptions regarding pain may interfere with the ability to complete pain assessment or interpret results	Х		
10	Understand how to respond to results of pain assessment (i.e., consultation with doctor for changes in orders, accessing additional therapies)	Х		

Competency: Completing a Pain Assessment	K	S	А
11. Develop a system to document the pain assessment and resulting change/recommendations		Х	
12. Document the pain assessment and resulting change/recommendation or resulting actions		Х	
13. Act on changes in orders to treat pain		Х	
14. Ensure that all staff have information needed to act on changes in orders		Х	
15. Determine the protocol for reassessing pain after implementing the pain management regimen		Х	
16. Upon reassessment, act on information obtained to determine best course of action for the resident (i.e., continuing with current orders, requesting change in orders or seeking outside consultation)		x	
17. Continue to document all pain assessments and resulting changes/recommendations or actions taken		х	

Change Idea Sheets

Change Idea Sheet: Proxy Decision-Makers and Advance Care Planning

Definition: Identifying a proxy decision-maker is the process whereby a resident determines who would make their care decisions in the event he or she is unable. Preferably, this identification is made per a written legal document acceptable in the state of residence. An advance care planning discussion involves more detail than simply identifying the decision maker. This discussion involves determining a resident's wishes around potential or possible care needs in the future. The advance care planning discussion may present hypothetical care situations to a resident and request detailed information for the preferred treatment or non-treatment in these circumstances. As with the identification of a proxy decision maker, it is preferable to use currently accepted legal documents in order to formally establish care wishes.

A few strong arguments for having these discussions with residents and families include:

- Providing residents with the opportunity to determine who would make their health care decisions is empowering.
- Residents have more control over their future when given the opportunity to outline their care wishes.
- Nursing home staff feel more comfortable and confident providing care or in the decision not to provide certain treatments when assured that it is in accordance with the resident's documented wishes.
- Proxy decision makers experience less guilt and anxiety when care wishes of loved ones are clearly outlined.
- Advance care planning discussions are opportunities for staff, residents and family members to build trust, confidence in each other and develop a mutual respect for each other. Trusting relationships are the cornerstone of culture change.
- Advance care planning discussions have been shown to improve patient and family satisfaction with health care.

Typical Issues: Often times, identifying proxy decision makers and advance directives are approached at the time of admission to the nursing home. Staff has not had the opportunity to build rapport with the resident and the resident is often anxious, tired and sometimes confused at this transition time. Staff has to balance their need for certain information with the residents' ability to provide that information at this specific time. Setting aside time for the detailed discussion and organizing the multi- disciplinary team and appropriate family members in order to have a comprehensive advance care planning discussion is labor intensive and presents coordination difficulties.

Barriers: The nursing facility has to gather information immediately upon admission to be sure that current care needs are understood by staff and that should an emergency arise, a plan is in place. However, a resident's situation may change frequently over the course of their time in the facility and this may impact their care choices. A resident's family structure may also change thus necessitating the need to address the choice of proxy decision maker. Staff can also find it very difficult to address the difficult care questions, the so called "what if" scenarios, with residents, particularly if they have not had time to build rapport and learn more about the resident's values and beliefs. If a resident with a

known cognitive deficit is admitted to the facility, his or her proxy decision maker may not be readily available to have a discussion for advance care planning.

Regulatory Support: There is much regulatory support around the need to assist residents in the creation of advance directives. Under **F155 Resident Rights** the regulation states "the resident has the right to refuse treatment, to refuse to participate in experimental research, and to formulate an advance directive..." In addition, the **F156 Resident Rights** interpretive guidelines state that the facility must "provide written information concerning his/her rights under State law to make decisions concerning medical care, including the right to accept or refuse medical or surgical treatment, and the right to formulate advance directives". The interpretive guidelines further indicate that those advance directives must be documented, cannot be a cause for discrimination against an individual, and that the facility must also provide education for staff regarding the facility's procedures and policies on advance directives.

In addition, **F242 Self-Determination and Participation** states "The resident has the right to-- (1) Choose activities, schedules, and health care consistent with his or her interests, assessments, and plans of care; (2) Interact with members of the community both inside and outside the facility; and (3) Make choices about aspects of his or her life in the facility that are significant to the resident." The explanation of the intent and Interpretive Guidelines for **F242 Self-Determination and Participation** charges the nursing homes with "actively seeking information" to understand a resident's preferences and choices for care. **F280 Comprehensive Plan of Care** also support a resident's right to be involved in the care planning process and make choices for care and treatment and to change those choices according to their wishes.

In 2012, interpretive guidelines for **F309 Quality of Care** were changed to incorporate the need for further support for residents during end of life situations. These changes resulted in the following interpretive guidelines "In order to promote the physical, mental, and psychosocial well-being of a resident who is approaching the end of life, the facility and the practitioner must: Identify the resident's prognosis with supporting documentation; and initiate discussions/considerations with the interdisciplinary team regarding advance care planning and resident choices to clarify resident goals and preferences regarding care as the resident is approaching the end of life." The same interpretive guidelines also state "A resident's goals and preferences for care, which should be identified upon admission and updated periodically, provide the basis for selecting and implementing care and services at the end of life."

Goals:

- To provide residents the opportunity to relay their care preferences and identify a proxy decision maker thus empowering residents, fostering their right to self-determination and improving quality of care.
- To enhance the relationship and communication between provider and residents/families through the thoughtful and mutually respectful discussion of values, beliefs and wishes for care.

Making the Change: Embarking on a change process requires planning and diligence. To change a facility's process around advance care planning discussions, start by putting together a team of individuals who will share in the commitment to change. This team can work together to develop shared goals and therefore a shared commitment to change. The Model for Improvement, using the PDSA Cycle (Plan-Do-Study-Act) will allow your team to approach the change process in a systematic way.

With your team, ask:

- 1. What are we trying to accomplish? (Example: a more effective system for identifying a resident's proxy decision maker; an advance care planning discussion with every resident at each quarterly reassessment?)
- 2. How will we know a change is an improvement? To answer this, your team needs to know how to measure your outcomes.
- 3. What changes can we make that will result in an improvement? Find others who have achieved your goal and learn from their methods, talk with experts.

Your team may decide there are several changes you are trying to accomplish and have many ideas on how to make an improvement. It is important not to try all of these ideas, despite how excited your team feels about making a positive impact. Instead, try one idea, using a small test or pilot program. Test it, measure it and if it is not working, adjust it. This is implementing the PDSA process.

Plan: Develop your aim and how you plan to measure it.

Do: Enact the plan and collect data using the method the team selected during the Plan phase. Do this on a small scale, do not try to implement the plan system-wide.

Study: Decide if your team is headed in the right direction. Review the data and the outcomes of your small pilot. Review the things that happened that you did not expect.

Act: By now, your team should understand the problem and understand the barriers and challenges to improvement. Using the information obtained, you have three options:

- Adapt the change
- Adopt the change
- Abort the change

When going through the improvement process, you can let your entire facility learn of its progress through a storyboard. Sharing and celebrating success helps spread the enthusiasm for and understanding of the change process.

Questions to Consider:

- How would having staff know a resident's preferences for care help a resident feel empowered?
- Would you want your wishes known to those providing care to you?
- When would you feel most comfortable having an important discussion about your care preferences?
- How does having mutual respect and rapport with a resident affect a resident and family member's ability to have discussions around preferences for care?
- How important is it to residents to have family members participate in advance care planning discussions?

Change Ideas:

- Consider getting what information is needed at the time of admission while opening the possibility for a more detailed discussion with the resident around care goals and preferences at a time when the resident, family and clinicians can fully participate.
- When a resident has created advance directives and or selected a proxy decision maker, consider the best way to document this. It is imperative that this information be readily available for care emergencies and at possible times of transition. This information needs to be available in both the hard copy chart and the resident's electronic file.
- Plan to revisit advance care planning at frequent intervals. A resident's care preferences and goals for care may change as his or her condition changes.
- Ideally, advance care planning is intertwined with a discussion of a resident's prognosis. Having this information will allow the resident to make fully informed choices.
- Advance care planning can start as a discussion that is goal-based rather than treatment-based. For example, knowing a resident's goal is to maximize comfort and live as pain-free as possible, the care professionals can define treatments and care choices and explain them in relation to supporting this goal. This allows residents an understanding of their choices in relation to their wishes.
- Consider incorporating advance care planning into each care plan meeting. This
 compels the residents to review their care goals routinely and at a time when
 multiple members of the care team can be involved in the discussion. When the
 designated proxy decision maker is present, he or she can also fully understand the
 care wishes being documented and ask questions if needed.
- Consider using the team approach for advance care planning discussions. Multiple disciplines can offer important information about prognosis, eliciting family support and also have different levels of rapport with residents. When determining the care team, consider members such as nursing assistants, activities staff or others with whom the resident has strong connections.
- When using a team approach, ensure that all team members have the most up to date information prior to meeting with the resident including the clinical recommendations and information about the resident's support system. A premeeting may be the best way to accomplish this.
- Be sure that materials given to residents and families are written to their level of understanding. Be sensitive to language issues and reading ability. Use different methods of communications: verbal, written, visual (videos, documents with pictures) throughout the course of the meeting and in preparation for the meeting.
- Have the legal forms accepted in your state ready for residents and families in order to legally document their advance care directives.
- Be sure that the words used accurately and clearly describe the situation and conditions at a level that all present will understand. For example, telling a resident he may experience a "cognitive deficit" may not adequately explain the level of confusion he could experience.

- Consider who on your staff may be a "champion" for advance care planning and can help train other staff and lead improvement efforts.
- If staff is comfortable having these conversations in their own families, they may feel more comfortable having them with residents. Consider using resources such as The Conversation Project or videos developed through Compassion and Support with staff and encourage them to start their advance care planning journey at home.
- Sensitivity to different cultures is important during advance care planning discussions. Make sure the team is aware of a resident's cultural background. Consider developing a resource library that may explain how different cultures and religions view old age, family relationships and death. Be sure that any family meetings provide a supportive environment for residents and families to explain their beliefs and values. Understand that while having general information about a culture or religion is important, it is more important not to make generalizations based on this information. Consider a staff educational training that explains the difference between using general information which is helpful and making generalizations which can be harmful.
- Recognize that a resident may want to speak to a spiritual advisor prior to or during an advance care planning discussion. Develop a routine to assess a resident's need for spiritual care as it relates to advance care planning prior to scheduling any meetings.

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- 7. Advance Care Planning: An Introduction for Public Health and Aging Services Professionals. An online course developed by the CDC, available at: www.cdc.gov/aging/advancecareplanning/care-planning-course.htm
- 8. The Conversation Project is designed for families to start their conversation around end of life care. They have an online and printable starter kit, available at <u>www.theconversationproject.org</u>.
- 9. Compassion and Support at the End of Life produces videos and booklets for consumer and professional education. They have a 15 minute video, 5 Easy Steps for Advance Care Planning available on their website, www.compassionandsupport.org or You Tube at http://www.youtube.com/watch?v=w95MzkQnp2g.

Change Idea Sheet: Completing a Pain Assessment in Nursing Homes

Definition: Completing a pain assessment is the first step in enacting a comprehensive pain care program for nursing home residents. The facility administration and direct care staff have an important role in developing and implementing the pain assessment component of any pain management regime. Assessing pain involves multiple factors that require staff to understand how pain is affecting their residents, how to ascertain the resident's level of pain and to then ensure this information is relayed to the appropriate personnel. In addition, this assessment process is ongoing without a clearly defined end point. Several factors regarding the pain assessment process are considered best practices either determined through research or are mandated through regulatory agencies.

- Pain assessments should include standardized tools that are evidence-based.
- Pain assessments should include more than one method of assessment, for example, observations of resident behavior in addition to a standardized algorithm or pain scale.
- Both aggravating and alleviating factors add further important information to the assessment. This may also involve information on the pain history.
- Reassessment is necessary on an ongoing basis to ascertain the effectiveness of the designated pain management program as well as assess for changes in the severity and nature of the resident's pain.
- Understanding how the resident perceives his or her pain is part of the pain assessment process. Staff must understand how a resident's beliefs around his or her pain and the relief options may greatly affect the pain that they report.

Typical Issues and Barriers: Nursing home staff risk becoming desensitized to pain and its impact due to the chronic nature of pain for many of the residents. This can also lead to a sense of staff powerlessness over pain. Many residents also present their own barriers to experiencing relief from pain. Research shows that residents may be hesitant to report their pain or request pain medication in order to avoid complaining or being viewed as a problematic resident. If a resident perceives the staff as busy, they are less likely to request pain relief. In addition, a resident's concern over the side effects of medications or lack of understanding around pain management can result in resistance to reporting their pain to staff. A resident's beliefs around pain are important. If a resident believes that he is supposed to experience pain due to age or disease, he will be less likely to request pain medication. Age, gender, ethnicity, and culture may affect a resident's beliefs around pain and pain relief.

Regulatory Support: There is extensive regulatory support around the issues of pain management for nursing home residents. It is clear that having comprehensive pain assessment standards is necessary not only to provide needed care and support to residents but also to be in compliance with regulations.

The interpretive guidelines for **F309 Quality of Care** has a strong focus on end of life care and managing resident's preferences for care, including controlling pain. These guidelines use the ABCDE mnemonic as an example of an approach to manage symptoms, including pain: "A: Ask the resident or his or her legal representative about (and screen for) pain and other symptoms related to the resident's end of life status on admission and periodically thereafter;

A: Assess regularly and systematically for symptoms (such as dyspnea, fatigue, declining function, anorexia/eating difficulties/weight loss, pain, loneliness, anxiety/apprehension, depression, constipation, and delirium) and their impact on the resident;

B: Believe the resident's report of pain and other symptoms, what precipitates it or makes it worse, and what relieves it;

C: Choose symptom control options that are appropriate for the resident;

D: Deliver interventions in a timely, logical, and coordinated manner;

E: Empower the resident to participate in defining the goals of treatment and planning the interventions to the extent possible; and

E: Evaluate the effectiveness of the chosen interventions."

In addition, **F246 Accommodation of Needs** encourages nursing homes to evaluate the physical environment to be sure that a resident's needs are being accommodated. For residents with chronic pain, a review of their room set-up and location is in order to assess if adaptations could assist with the pain management care plan.

F272 Comprehensive Assessments and F78 Accuracy of Assessment and F279 Comprehensive Care Plans all point to how facilities are using the Minimum Data Set (MDS) Resident Assessment Instrument (RAI) and linking information obtained to the resident's care plan. The interpretive guidelines state, "The requirements reflect the facility's responsibilities to provide necessary care and services to attain or maintain the highest practicable physical, mental and psychosocial well-being, in accordance with the comprehensive assessment and plan of care." The MDS RAI assesses resident's pain and may trigger a Care Area Assessment (CAA) that must be addressed in the care plan. The pain assessment protocol and follow up care plan must support the resident's highest level of functioning and care preferences.

Goals:

- To relieve each resident's pain using a comprehensive system of assessment and creation of an individualized pain management plan
- To improve the quality of life for residents by both understanding their level of pain and then responding to their pain

Making the Change: Embarking on a change process requires planning and diligence. To change a facility's process around pain assessment, start by putting together a team of individuals who will share in the commitment to change. This team can work together to develop shared goals and therefore a shared commitment to change. The Model for Improvement, using the PDSA Cycle (Plan-Do-Study-Act) will allow your team to approach the change process in a systematic way.

With your team, ask:

1. What are we trying to accomplish? (Example: a more effective system for identifying when a resident is in pain when they cannot or will not self-report their pain)

- 2. How will we know a change is an improvement? To answer this, your team needs to know how to measure your outcomes.
- 3. What changes can we make that will result in an improvement? Find others who have achieved your goal and learn from their methods, talk with experts.

Your team may decide there are several changes you are trying to accomplish and have many ideas on how to make an improvement. It is important not to try all of these ideas, despite how excited your team feels about making a positive impact. Instead, try one idea, using a small test or pilot program. Test it, measure it and if it is not working, adjust it. This is implementing the PDSA process.

Plan: Develop your aim and how you plan to measure it.

Do: Enact the plan and collect data using the method the team selected during the Plan phase. Do this on a small scale, do not try to implement the plan system-wide.

Study: Decide if your team is headed in the right direction. Review the data and the outcomes of your small pilot. Review the things that happened that you did not expect.

Act: By now, your team should understand the problem and understand the barriers and challenges to improvement. Using the information obtained, you have three options:

- Adapt the change
- Adopt the change
- Abort the change

When going through the improvement process, you can let your entire facility learn of its progress through a storyboard. Sharing and celebrating success helps spread the enthusiasm for and understanding of the change process.

Questions to Consider:

- Ask staff to think of themselves as a resident in pain. If everyone around them appears very busy, would they be inclined to ask for extra help?
- When a resident has frequent complaints of pain, how is the staff affected? Is staff frustrated with their inability to help? Does staff judge the resident, even without malice, as a difficult person?
- Do you expect pain to be a part of life or growing older?
- At what point does pain interfere with function and quality of life?
- Once you know a resident has pain, how do you document that and to whom do you report that information?
- Do residents make choices not to report pain because they do not fully understand pain management or fear side effects from medications?
- If a resident's pain was well managed, would other aspects of care improve for the resident?

Change Ideas:

• In order to help staff understand how pain may affect residents, ask them to recall a time when they experienced pain. Ask them to describe how it felt, how it may have interfered with their ability to work or complete tasks. Next brainstorm ideas on how it may be affecting residents beyond the physical discomfort.

- Identify a pain assessment champion on staff who will help train staff in implementing the pain assessment and build enthusiasm for improvement processes.
- Put together an improvement team that is multidisciplinary and includes the prescribers of medications and the pharmacists. As many pain interventions involve medications, prescribers and pharmacists must understand the efforts being made to accurately assess resident pain levels.
- Review your current pain assessment process and decide if the assessment tools currently used meet the following requirements:
 - ✓ Standardized across units and used consistently with residents
 - ✓ Identifies the intensity of the pain (e.g. numeric rating scale or visual scale)
 - Includes observational assessment such as behavioral indicators and staff/family observations, especially when a resident cannot verbalize their pain
 - Offers residents the opportunity to describe their pain and its impact (e.g. limiting my walking due to pain today)
 - Current aggravating and alleviating factors as well as what has successfully alleviated pain during past occurrences
 - ✓ History of pain, identifying if this a chronic or acute pain issue
- Review the ABCDE mnemonic listed in the F309 Quality of Care interpretive guideline. Decide which of these points needs improvement in your facility. Choose one to start and build a PDSA cycle on that one aspect of care.
- Consider ways to assess pain that may come from sources other than physical causes. Spiritual and psychosocial pain can cause discomfort to residents in addition to physical causes of pain. Non-pharmacological interventions may need to be considered, especially if no physical source for the resident's pain can be identified.
- Offer tools to residents to augment their ability to self-manage pain through techniques such as distraction, imagery, deep breathing, meditation, music, and use of heat or cold among other methods. Learn what strategies residents have successfully used in the past and provide the resources they need to implement them in the nursing home.
- Consider how the use of alternative or complementary therapies, such as massage or acupuncture, may offer residents options in their pain management care plan. Find a champion for alternative therapies who can work with both management and direct care staff to determine the best use of these therapies in your setting.
- Consider developing an individualized pain" toolkit" for residents who experience chronic pain. In their toolkit can be the tools, tips and ideas that have been successful in alleviating their pain.
- Review your process of assessing pain after the care intervention has been implemented. Is staff returning within 30 minutes to see if the medication has started to alleviate the issue? Does staff return to the resident after providing the ice pack to determine if the resident continues to feel discomfort? Monitor and record these activities for one week to determine if there is a need for improvement.
- Once a resident's pain is assessed, how does this information get relayed to the care team? What is the threshold for calling to request a change in the current

orders for pain relief? Does this process need to be further defined to prevent ineffective care plans from remaining in place?

• Look at the research as to why residents do not report their pain (e.g. stoicism, concerns about medications, feeling that staff are too busy). Think of your residents, could these reasons apply on your unit? Consider ways to empower residents to self-report pain and creating an environment that supports residents sharing this information. Staff can where buttons that say "Tell me if you are in pain" and can approach residents who seem reluctant to share. Displaying posters that let residents know that you want to treat their pain may also help.

Resources and References:

- Review different pain assessment scales. The Promoting Excellence in End-of-Life Care program that was funded through the Robert Wood Johnson Foundation has resources as well as the National Palliative Care Research Center. Available at <u>www.promotingexcellence.org</u> and <u>www.npcrc.org</u>. In addition, different states may have specific tools required or encouraged through regulations or guidelines. Check with your state's governing agencies.
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Change Idea Sheet: Having Discussions with Residents Regarding Prognosis and Goals of Care

Definition and Background: Discussions with nursing home residents regarding their prognosis and their goals of care would seem to be a necessary and integral part of providing care in a nursing home setting. However, research shows that these discussions are not occurring with regularity for some residents.

Discussions with residents and families regarding goals of care and prognosis should occur at regularly scheduled intervals and at times of change or decline in health. In addition, discussions with residents around prognosis and goals of care are best done with an interdisciplinary team format.

The discussion must first encompass what is happening clinically with the resident. In order to make informed choices around goals for care, the resident and family must understand the current disease process and trajectory. Ideally, the physician is providing this information. However, due to the challenges inherent in a nursing home setting, the physician or medical director may not be physically present for the team goals of care conference. In this circumstance, the nursing staff at the facility should be reiterating the prognosis information previously provided to the resident by the physician, and ensuring that the resident and family understand. At that point, the facility staff can move into goals of care discussions.

Nursing home residents and their families may have goals for care that are influenced by many aspects of their life. Research shows there are generally six types of goals:

- 1. Curative
- 2. Prolonging life
- 3. Improving or maintaining function and quality of life
- 4. To be free from pain and other uncomfortable symptoms
- 5. Achieving specific life goals
- 6. Providing support for other family members

Others may classify goals in terms of medical goals and then human or relationship goals. However the goals are classified, or in which categories they are couched, the goals represent the values of the resident and their families. For some residents, the expressed goals of care may reveal the very reason they want to live or die. For example, some residents may want to live for a specific family event and be willing to endure pain and discomfort to get to that point. Others may feel that enduring pain is necessary and will provide more reward in the afterlife. Through the goals of care discussion, the values and beliefs of the resident relevant to the individual get transformed into a plan for daily care that will support those goals.

Once goals of care are established, the facility staff may also be able to move the conversation towards forming advance directives that will support the identified goals. It is recommended that advance care planning discussions be initiated as goals of care discussions.

Typical Issues: Explaining a prognosis is typically the role of a physician. However, in the nursing home setting, medical directors and physicians are often not on site daily. This can cause difficulty in trying to organize an interdisciplinary approach to the discussion of

prognosis and goals of care. When the discussion is left to one staff member to pursue alone, it becomes fragmented. Information from the different disciplines is then not available to support that staff and resident in their understanding of the issues and the development of goals.

These discussions can also take a significant amount of time. Residents and families may only be able to process the information provided to them in small quantities. Thus, more than one meeting may be needed. In addition, many times, information is exchanged in less formal ways than an interdisciplinary conference. This is particularly evident when a goals of care discussion is occurring due to a change or decline in health. These are times when it may be difficult to schedule a room and plan in advance for a meeting. These meetings often happen at bedside or in private areas of the hallway. This setting may make it more difficult for residents and families to share information about their beliefs and values and understand the prognosis information being provided.

Barriers: Research shows that there are several reasons why clinicians do not have goals of care discussions with nursing home residents:

- 1. Concern for future legal action
- 2. Lack of education on how to have a goals of care discussion
- 3. Lack of family involvement with the resident
- 4. Not having enough time to devote to the discussion
- 5. Lack of an interdisciplinary team approach

Goals of care discussions can require more time from multiple team members. They also must be coordinated with the resident and family's schedule. Many in nursing homes cite that it is also unclear whose responsibility it is to initiate such a discussion.

Many facilities will have a discussion with residents regarding their goals upon admission. However, if no process exists for revisiting those goals of care at regular intervals, the facility may provide care a resident does not want when there is sudden change in condition. In addition, the information gathered at admission may answer questions as to direct care needed but may not offer the opportunity for residents to explain any specific life achievements or non-medical goals they want supported by the facility.

Regulatory Support: There is much regulatory support around the need to engage residents in discussions regarding prognosis and goals. Under **Resident Rights**, **F154** the regulation states "the resident has the right to be fully informed in language that he or she can understand of his or her total health status, including but not limited to, his or her medical conditions." In addition, **F155** states "the resident has the right to refuse treatment, to refuse to participate in experimental research, and to formulate an advance directive..." In addition, the **Resident Rights F156** interpretive guidelines state that the facility must "provide written information concerning his/her rights under State law to make decisions concerning medical care, including the right to accept or refuse medical or surgical treatment, and the right to formulate advance directives". The interpretive guidelines further indicate that those advance directives must be documented, cannot be a cause for discrimination against an individual, and that the facility must also provide education for staff regarding the facility's procedures and policies on advance directives.

Additional regulatory support for having discussions with residents regarding prognosis and goals of care is written into **Quality of Life F240**. The interpretive guidelines for this regulation add "The intention of the quality of life requirements is to specify the facility's responsibilities toward creating and sustaining an environment that humanizes and individualizes each resident." The goals of care discussions should be eliciting from the resident what is important to him or her to sustain or improve quality of life. **F242 Self-Determination and Participation** expounds the resident's right to "choose activities, schedules and health care consistent with his or her interests, assessments and plans of care".

The interpretive guidelines for **F309 Quality of Care** explain that nursing homes are expected to "identify the resident's prognosis with supporting documentation; and initiate discussions/considerations with the interdisciplinary team regarding advance care planning and resident choices to clarify resident goals and preferences regarding care as the resident is approaching end of life." In addition, these guidelines state that the facility must "provide and periodically review resident plan of care, addressing services, and support that accommodate and honor the resident's choices and rights, manage pain and other physical, mental and psychosocial symptoms and strive to meet the resident's physical, mental and psychosocial, and spiritual needs."

Goals:

- To ensure that all residents and appropriate family members understand their prognosis thus empowering them to be active participants in their health.
- To provide all residents and appropriate family members with the opportunity to develop their goals for care that will be supported and carried out by their care providers.

Making the Change: Embarking on a change process requires planning and diligence. To change a facility's process around discussions of prognosis and goals of care, start by putting together a team of individuals who will share in the commitment to change. This team can work together to develop shared goals and therefore a shared commitment to change. The Model for Improvement, using the PDSA Cycle (Plan-Do-Study-Act) will allow your team to approach the change process in a systematic way.

With your team, ask:

- 1. What are we trying to accomplish? (Example: a system of discussing prognosis and goals of care at each care plan meeting)
- 2. How will we know a change is an improvement? To answer this, your team needs to know how to measure your outcomes.
- 3. What changes can we make that will result in an improvement? Find others who have achieved your goal and learn from their methods, talk with experts.

Your team may decide there are several changes you are trying to accomplish and have many ideas on how to make an improvement. It is important not to try all of these ideas, despite how excited your team feels about making a positive impact. Instead, try one idea, using a small test or pilot program. Test it, measure it and if it is not working, adjust it. This is implementing the PDSA process.

Plan: Develop your aim and how you plan to measure it.

Do: Enact the plan and collect data using the method the team selected during the Plan phase. Do this on a small scale, do not try to implement the plan system-wide.

Study: Decide if your team is headed in the right direction. Review the data and the outcomes of your small pilot. Review the things that happened that you did not expect.

Act: By now, your team should understand the problem and understand the barriers and challenges to improvement. Using the information obtained, you have three options:

- Adapt the change
- Adopt the change
- Abort the change

When going through the improvement process, you can let your entire facility learn of its progress through a storyboard. Sharing and celebrating success helps spread the enthusiasm for and understanding of the change process.

Questions to Consider:

- How does knowing his or her prognosis help a resident make choices and care decisions?
- How does an interdisciplinary team help with these discussions with residents and family members?
- What may residents experience when they have not defined their goals for care?
- How does knowledge of a resident's prognosis and care goals improve the care staff provide?
- How will discussions of prognosis and care goals help individualize a resident's care?

Change Ideas:

- Identify a nurse champion and an administrative champion around having interdisciplinary discussions with residents regarding prognosis and goals of care. These champions can lead improvement efforts and build excitement for making positive changes.
- Have prognosis and goals of care discussions implemented at every care plan meeting with every resident.
- Implement a palliative care screening practice at each care plan meeting for each resident. This will allow staff to capture any declines in health and functioning over time that may warrant a change in prognosis or goals of care.
- Incorporate different modalities of learning into your prognosis and goals of care discussions. Prior to meetings and/or during meetings, provide written materials to residents and families. Review possible video options that you can have residents and families view that may aid their understanding of the prognosis or the need to develop goals of care.
- Review your facility's current policies on having discussions regarding prognosis and goals of care. Next, monitor if these policies are implemented and determine if improvement is needed. Choose one area, such as which disciplines should be present at the interdisciplinary care conference, and launch a P-D-S-A cycle in that area.

- Consider using a standardized protocol for discussing a difficult prognosis such as the six step protocol developed by Robert Buckman (review the resources section to access more information):
 - 1. Getting started (planning what to say, creating a conducive environment)
 - 2. Finding out what the resident knows
 - 3. Finding out how much the resident wants to know
 - 4. Share the information (sensitive but straightforward)
 - 5. Responding to feelings (listen, acknowledge emotions)
 - 6. Planning, follow up (establish a plan for next steps)
- Consider a very simple reminder posted where physician partners access records. The sign may say in large, bold font "Doctors: Did you discuss diagnosis and prognosis with resident and family and then document resident's diagnosis and prognosis on initial history and physical assessment?"
- Develop a tool for nurses to assess whether residents and family members understand the diagnosis and prognosis.
- Review the interpretive guidelines for **F309 Quality of Care** specifically delineating a facility's responsibility for end of life care. Is there a need for improvement in your facility? Launch a P-D-S-A cycle for the area that needs the most improvement.
- Work with the resident council to develop a format for a goals of care discussion that allows residents to feel comfortable sharing what is important to them.
- Be prepared to segue from a goals of care conversation to the formation of advance directives. Have the state designated legal documents available.
- Review literature around interdisciplinary team work. Does your facility maximize the use of different disciplines and respect how each discipline interacts with residents and adds value to a goals of care discussion?
- Ensure that all of your care plan and prognosis/goals of care discussions provide an opportunity for each resident and family member to share their belief and value system. Understand how this may impact both how they want information relayed, and how they want care to be implemented.
- Review the five barriers to having these discussions outlined in the **Barriers** section. Do any apply to you or your facility? Discuss these barriers with the interdisciplinary team at your facility. Can a change process help overcome one these barriers?
- Review the six over-arching types of goals in the **Definition** section. Is your facility prepared to assist residents with all of these types of goals? When a care goal does not center around physical care needs, such as the desire to make amends with an extended family member, does your facility support the resident with this goal? Are residents aware of your facility's willingness and ability to support all of their care goals?

Resources and References:

EndLink: An Internet-based End of Life Care Education Program
 <u>http://endlink.lurie.northwestern.edu</u> (an online learning program with 16 modules
 including Goals of Care, Advance Care Planning, and Communicating Bad News –
 the six step Buckman protocol. Funded through a research grant by the National
 Cancer Institute)

- 2. Pocket Guides for Clinicians: Developed by the Medical College of Wisconsin and made available through the Center to Advance Palliative Care, they assist clinicians with resident-family communication issues. Available at www.capc.org/tools-for-palliative-care-programs/clinical-tools/pocket-clinical-cards/
- 3. Fast Facts for Clinicians: One to two page briefs on various topics around end of life care and palliative care. Available at www.eperc.mcw.edu/EPERC/FastFactsIndex
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- 13. Strand, Jacob J., MD, Mihir M. Kamdar, MD, and Elise C. Carey, MD. "Top 10 Things Palliative Care Clinicians Wished Everyone Knew About Palliative Care." *Mayo Clinic Proceedings* August 2013.88(8): 859-65. Print.

Change Idea Sheet: Spiritual Care for Nursing Home Residents

Background: Incorporating spiritual care as a component of medical care dates back to the early years of organized medicine. The founder of modern day nursing, Florence Nightingale, believed nursing care to be holistic, bringing body, mind and spirit together for healing. Medical care became increasingly less holistic and secular into the 20th century when many started to view medical interventions as the singular cause of healing. In the 21st century, society has started to take a closer look at spiritual care as a viable intervention with healing results. A 2001 Joint Commission regulation has brought the need to perform a spiritual assessment back into focus for medical providers. However, many current care providers underwent formal education and training during a time when medical care lacked any focus on spiritual care.

Incorporating spirituality in healthcare requires providers to respect the inherent value and dignity of all persons regardless of health status. Spirituality should not be reduced to matters of an individual's affiliation with a specific religion. Faith and spirituality in many forms provide important coping resources for residents, especially in times of illness and stress. Staff needs to understand the impact of religious belief on both treatment decisions and compliance with medical recommendations. Research has shown that spiritual distress is associated with poorer health and quality of life outcomes (Puchalski, 2012).

Typical Issues and Barriers: There have been several studies that have indicated the majority of people receiving care in a health care facility would like their spiritual issues addressed, yet find that these needs are not regularly considered or assessed by healthcare personnel (Pulchaski, 2008). Barriers identified have included feeling that there is little time to provide spiritual care to patients (Cavendish, et al., 2003), and caregivers not feeling "qualified" to provide this care especially when the care provider and resident are of different faiths or have no specific faith base. Others consider spirituality a "private" matter and are unsure as to whether or not they should be engaging in such conversations with residents (Gallison et al., 2012). In addition, how spiritual care is defined or the lack of a definition can be a barrier for many providing care (Dossey, et al. 2005). The lack of support for spirituality in the workplace is yet another barrier. (Garcia-Zamor, 2003).

Regulatory Support: There is some regulatory support for the provision of spiritual care within nursing homes. **F248 Activities** indicates that an activity program must meet individual needs of residents. The guidelines explain that the activity assessment must gather information regarding a resident's spirituality. Activities planning must include connections to the community including places of worship; and, examples of one-to-one activities include "spiritual support, nurturing (e.g., daily devotion, Bible reading, or prayer with or for resident per religious requests/desires)". The guidelines state that activities professionals should offer spiritual support to residents in pain or who are terminally ill. In addition, the guidelines suggest visits from spiritual counselors or spiritual leaders for residents who prefer to remain in their rooms or for those residents with diverse ethnic backgrounds.

The interpretive guidelines for **F309 Quality of Care** include information regarding the assessment and management of care at end-of-life. These guidelines state that nursing homes must discuss with residents their preferences for care, which may include "controlling pain and other symptoms; maintaining mental, physical, spiritual, and psychosocial functions." In addition, the facility must "strive to meet the resident's physical, mental, psychosocial, and spiritual needs." While assessing a resident at end-of-life, the facility staff must assess for "spiritual issues that may affect the resident's physical and/or psychological comfort". In addition, the interpretive guidelines state that care planning for a resident at end-of-life must address spiritual care needs as part of a plan to enhance quality of care and life for the resident.

The interpretive guidelines for **F319 Mental/Psychosocial Treatment** also state that facility staff must consider "spiritual distress (disturbances in one's belief system)" as one of the possible manifestations of "mental and psychosocial adjustment difficulties".

Goals:

- To strengthen and honor caregiving relationships and provide opportunities for residents to express and experience their own spirituality and to reap the physical and emotional benefits of doing so.
- To create a work culture/environment that is respectful of both resident and staff spirituality.

Making the Change: Embarking on a change process requires planning and diligence. To change a facility's process around spiritual care, start by putting together a team of individuals who will share in the commitment to change. This team can work together to develop shared goals and, therefore, a shared commitment to change. The Quality Improvement Model for Improvement, using the PDSA Cycle (Plan-Do-Study-Act), will allow your team to approach the change process in a systematic way.

With your team, ask:

- 1. What are we trying to accomplish? (Example: implement a standardized assessment of our residents' spiritual care needs?)
- 2. How will we know a change is an improvement? To answer this, your team needs to know how to measure your outcomes.
- 3. What changes can we make that will result in an improvement? Find others who have achieved your goal and learn from their methods, talk with experts, and implement best practices.

Your team may decide there are several changes they are trying to accomplish and have many ideas on how to make an improvement. It is important not to try all of these ideas, despite how excited your team feels about making a positive impact. Instead, try one idea, using a small test or pilot program. Test it, measure it and if it is not working, adjust it. This is implementing the PDSA process. More specifically follow these steps:

Plan: Develop your aim and how you plan to measure it.

Do: Enact the plan and collect data using the method the team selected during the Plan phase. Do this on a small scale, do not try to implement the plan system-wide.

Study: Decide if your team is headed in the right direction. Review the data and the outcomes of your small pilot. Review the things that happened that you did not expect.

Act: By now, your team should understand the problem and understand the barriers and challenges to improvement. Using the information obtained, you have three options:

- Adapt the change
- Adopt the change
- Abort the change

When going through the improvement process, you can let your entire facility learn of its progress through a storyboard. Sharing and celebrating success also helps spread the enthusiasm for and understanding of the change process.

Questions to Consider:

- Mostly, staff are trained to respond to physical needs, but how does your facility train staff to respond to a resident's spiritual needs? Physical illness, and especially terminal illness often includes spiritual distress. A therapeutic environment that includes physical and spiritual domains of care is of great benefit to residents.
- How does the cultural work environment support the spiritual aspect of caregiving staff?
- What barriers, if any, have you experienced in trying to deliver spiritual care to residents?
- What strategies can leadership use to help the care team overcome barriers to spiritual care?

Change Ideas:

- As a care team, define and label what you consider spiritual care.
- Conduct spiritual assessments for all residents utilizing a standardized spiritual assessment tool (e.g., Spiritual Assessment Tool – FICA©).
- Spiritual assessment should include at a minimum:
 - Spiritual screening questions which will identify religious or spiritual/existential background, preferences, practices and rituals
 - Related beliefs such as belief in an after-life, and how spiritual/cultural beliefs affect understanding of illness, pain, guilt, and forgiveness
 - Questions related to prior history with symptoms of spiritual distress, pain, hopelessness, and coping skills
- Ask staff about their perspectives on providing spiritual care and if there are any perceived barriers to this provision of care.
- Provide spiritual care education for staff with a focus on "caring, healing and wholeness, rather than on disease, illness and pathology." (Watson, 2006a, ¶3) This can be accomplished by:
 - Measuring nursing competencies in spiritual care with a validated tool (e.g., Spirituality and Spiritual Care Rating Scale - SSCRS).
 - Providing information on skills needed to incorporate spiritual care in practice such as being non-judgmental and respectful of the resident's view of spirituality, being truly present, active listening, effective communication skills, being open to talking about spirituality, being aware of one's own

spirituality and being comfortable with ambiguity and mystery – you don't have to have all the answers!

- Ensuring that staff are aware and take ownership in the role of assessing and addressing spiritual, religious and existential dimensions of care.
- Documenting spiritual care needs, goals, concerns and interventions in the interdisciplinary care plan and in case of discharge, convey these needs to other providers during transitions of care and/or in discharge planning.
- Modeling of spiritual care behavior.
- Adopt a holistic model of care, such as HATCh[™] which encourages an individualized care environment (care practices, delivery systems, daily routine) that are focused on the needs, interests, lifestyles and preference choices of residents. Holistic care supports the physical, emotional, social and spiritual needs of residents.
- Review the physical environment within your facility to determine an appropriate space for residents to engage in spiritual and/or religious practice.
- Offer opportunities for residents to experience "quiet time" where they can pray, meditate, listen to uplifting music, or read desired materials.
- Support residents and families in their desire to display and use their own religious/spiritual and/or cultural symbols.
- Provide access for residents to clergy or other spiritual care professionals as desired by the resident and/or family.
- Review resources to determine if having a chaplain on-staff is attainable. Consider creative alternatives such as pooling resources with other providers or grant funding.

References and Resources:

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- Watson Caring Science Institute & International Caritas Consortium. *Caring Science* (*Definitions, Processes and Theory*). Available on the <u>Watson Caring Science</u> website.
- <u>The Association of Professional Chaplains</u> has educational resources as well as professional standards for long term care chaplains.

Sharing Results

When embarking on a change process, it is important to share results. Sharing results allows facility teams to spread the success of PDSA cycles and efforts at improvement. Benefits of sharing results:

- 1. Spark enthusiasm from all disciplines who hear or see the success story
- 2. Garner participation in spreading the improvement or change across systems and departments
- 3. Praise those who have completed the work
- 4. Ensuring that leadership remains informed about the positive changes
- 5. Informing outside partners and collaborators of your success

There are several ways to share results. One method is to put together a storyboard. This could be as simple as a tri-fold board displayed in a staff meeting room or the lobby area of the facility. A storyboard allows people to follow the improvement process using a visual format and provides an opportunity to display results creatively. This will fulfill all five of the benefits of sharing results listed above.

Putting together an effective storyboard is important and you may want to consider doing this at several benchmark periods throughout your improvement process. An effective storyboard will include the following details¹:

- 1. Description of the situation/problem
- 2. Articulation of the aim statement
- 3. Description of the proposed intervention or solution to address the situation/problem
- 4. Description of what was done to address the situation/problem
- 5. Description of the analysis/evaluation of the intervention/actions taken
- 6. Description of the subsequent action that took place to standardize the improvement
- 7. Overarching lessons learned

It may be helpful to use a storytelling tool that allows providers to collate the necessary information to present a story. On the following page is a list of questions that assist providers in organizing key points for a presentation on the project. Creating a document with these questions and answers allows providers to retain proof of your Quality Assurance Performance Improvement (QAPI) efforts. These efforts should also be shared with the local Quality Improvement Organization (QIO). The QIO teams support culture change and quality improvement in all settings and support peer to peer learning. The QIO team may provide a forum for sharing your successful strategies.

1 "Guidelines for the Development of Quality Improvement Storyboards" available at: http://nnphi.org/CMSuploads/Storyboard-Guidelines-FINAL-05868.pdf

Storytelling: Answer these questions to develop your facility's improvement story

- 1. What area for improvement did your team select to address?
- 2. Aim statement: what is your team trying to accomplish?
- 3. Who are the key players responsible for implementing changes?
- 4. How have you involved patients/residents or family members?
- 5. While implementing your quality improvement plan, what did your team find to be the most challenging?
- 6. How did your team overcome these challenges?
- 7. While implementing your quality improvement plan, what did your team find to be the most rewarding?
- 8. How effective have your efforts been?
- 9. How do you know how effective your efforts have been?
- 10. What improvements have been made (no matter how big or small)? If applicable include both numeric and anecdotal results. (Example: reduced costs, improved efficiency, increased satisfaction)
- 11. What proved to be the most valuable in achieving these improvements?
- 12. How did your team track the progress? Describe what record keeping/monitoring was done.
- 13. Provide an example of how the improvement(s) impacted a PATIENT or RESIDENT. Response can vary from an elaborate story to a simple quote.
- 14. Provide an example of how the improvement(s) impacted an EMPLOYEE. Response can vary from an elaborate story to a simple quote.
- 15. What does your team wish had been done differently? Example: a different plan or a different implementation of the same plan.

Patient/Resident Storytelling

Just as storytelling is an important tool for providers, it is also important for patients and residents. It can be empowering for a nursing home resident or their family members to speak of their healthcare journey. It is important for healthcare providers to use these stories to understand ways to improve and find opportunities to provide better care. Residents, families and caregivers can offer a unique perspective in helping to improve healthcare. It is incumbent on providers to use these insights to create positive change.

Healthcentric Advisors developed an online storytelling tool available for residents and family members<u>(Hear With Your Heart)</u>. "Hear With Your Heart" is designed to serve as a guide so that those stories may be told without judgment or blame. It is a place where individuals who have encountered the healthcare system can capture their story and offer feedback and edification to those who are working to improve healthcare. All providers across healthcare settings can encourage use of tools such as Hear With Your Heart to empower their consumers and support powerful learning.

6 INTERVENTION TOOLS



Staff Assessment Tools

Interdisciplinary Team Competency Grid

Assess whether your interdisciplinary team meets Novice, Proficient or Expert level in the areas of Team Function, Working with Patients and Families, Working with Team Members, Communication, Qualities of a High Functioning Team Member, Collaborative Problem Solving. This tool was developed by the <u>National Hospice and Palliative Care</u> <u>Organization</u> and is available on their website.



		ream competency on a	
COMPETENCY	NOVICE	PROFICIENT	EXPERT
	Defines the interdisciplinary team	 Collaborates with the interdisciplinary team to identify and meet patient/family identified needs 	 Models and teaches interdisciplinary team process and function to new team members
	 Explains the difference between the medical model and the hospice philosophy of care 	 Assesses patient/family needs using patient/family-centered, holistic approach 	 Advocates for reframing the focus of care cooperatively with medical model practitioners/organizations
	 Describes the purpose and value of the interdisciplinary team to hospice care 	 Articulates the purpose and value of the interdisciplinary team to patients and families, fellow team members and community 	 Serves as a role-model for interdisciplinary care, demonstrates expertise in utilizing the strengths of each discipline/perspective and recognizing their limitations
	 Describes the purpose and value of the interdisciplinary team meeting 	 Participates in the interdisciplinary team meeting and considers the perspectives of all disciplines in the care planning process 	 Facilitates in-depth exploration of patient/family needs and engages in care planning processes that include all disciplines and address all patient/family identified needs
TEAM FUNCTION	 Identifies interdisciplinary team related regulations and complies with them 	 Demonstrates compliance by putting regulations into context/practice 	 Keeps abreast of and educates colleagues about regulatory changes and assists in the development of organizational policy and process to ensure compliance
	 Describes ethical practice in end-of-life care 	 Participates in discussion of ethical issues and problem-solving 	 Models ethical practice, is skilled in leading discussions about ethical issues and leads the problem-solving and resolution process
	 Identifies the elements of team process/team development (using B. Tuckman's [1965] "forming, storming, norming, performing" or other model of group development) 	 Describes the relevance of and applies group process/development to his/her interdisciplinary team 	 Observes group process and the development of his/her interdisciplinary team and reflects observations back to the group in efforts to further its development
	 Describes team discussion, team meeting, collaborative practice, evaluation, support, memorial and team activities 	 Participates in team discussion, team meeting, collaborative practice, support, memorial and team activities 	 Observes team discussion, meetings, collaborative practice, support, memorial and team activities, reflects observations back to the group and facilitates full integration of all members of the team

Interdisciplinary Team Competency Grid

3/3/11 ©NHPCO, 2010

Physician's Brief

Healthcentric Advisors developed this form to facilitate nursing homes' ability to engage physician partners regarding participation in the Nursing Home Palliative Care Collaborative. It has been edited to be universal for any nursing home palliative care improvement project.

Nursing Home Palliative Care Physician Information

Overview: The nursing home you collaborate with is taking part in a wide-scale effort to improve access to palliative care in the nursing home. The nursing home aims to institute a system-wide culture change regardi palliative care. As with any nursing home culture change process, improving quality of life for residents remai the primary aim. This project plans to improve access to and quality of palliative care within the nursing home

In this project, the facility will review its processes around the following six domains of palliative care:

- Identifying a proxy decision maker
- Engaging residents and families in advance care-planning discussions
- Having discussions of prognosis with residents/family
- Having discussions regarding goals for care with residents/family
- Assessing need for spiritual care and providing access to spiritual care
- Completing pain assessments

What are the measures of success?

- Data will be collected monthly on the completion of care measures related to these domains of palliative care.
- The facility team will analyze nursing home satisfaction surveys to track improvements in resident-family-provider communication related to advance care-planning issues and understanding of the benefits of palliative care.
- The facility team will analyze hospital admissions and readmissions data.

What improvement tools are used?

- The facility is using a Nursing Home Palliative Care Toolkit complete with tools and information to support the change process (<u>http://www.healthcentricadvisors.org/nhpcc.html</u>). Healthcentric Advisors, the Quality Improvement Organization for Rhode Island, developed this Toolkit.
- The facility will complete rapid cycle improvement projects concerning the palliative care measures over the course of a year.

For more information, please contact:

What does this mean for you?

The facility staff may inquire about:

- Consults for palliative care
- Prognosis discussions with residents
- The MOLST/POLST form for residents
- Pain management strategies
- Your participation in learning events and team meetings
- Your input on improvement projects related to palliative care

The Educational Needs Assessment Tool

The Educational Needs Assessment tool can be used with physicians or nurses to gather information on their self-confidence and comfort with common palliative care clinical tasks. The tool is best administered preceding an educational intervention to guide curriculum planning. This tool is defined as a best practice by the <u>Center to Advance Palliative Care</u> and is available through this link.

Part I:

Please rank your degree of competence with the following patient/family interactions and patient management topics, using the following scale:

- 4 = Competent to perform independently
- 3 = Competent to perform with minimal supervision
- 2 = Competent to perform with close supervision/coaching
- 1 = Need further basic instruction
 - Conducting a family conference to discuss goal setting
 - Giving bad news to a patient or family member
 - Discussing DNR orders
 - Discussing home hospice referral
 - Discussing a shift in treatment approach from curative to comfort care
 - Discussing treatment withdrawal (e.g., antibiotics, hydration, ventilator)
 - Managing requests for futile treatments
 - Performing a basic pain assessment
 - Using oral opioid analgesics
 - Using parenteral opioid analgesics
 - Using adjuvant analgesics (e.g., tricyclics, steroids, anticonvulsants)
 - Converting from one opioid to another
 - Assessing and managing delirium
 - Assessing and managing dyspnea
 - Assessing and managing nausea/vomiting
 - Assessing and managing constipation
 - Assessing patient decision–making capacity
 - Discussing advance directives with patients
 - Managing common opioid side effects (sedation confusion, nausea, constipation)

Part II:

Clinicians often have concerns that certain medical decisions may either be contrary to accepted legal, ethical or professional standards or that they may be contrary to their own personal beliefs. For each of the situations listed below, please indicate the type and amount of concern you have, using the following scale:

- 4 = Very concerned
- 3 = Somewhat concerned
- 2 = Somewhat unconcerned
- 1 = Not concerned

A. Decision: Providing maximal pain relief throughout a cancer patient's illness, even before the terminal phase. Concerns:

- This violates state law.
- This violates medical practice standards and represents malpractice.
- This violates accepted ethical norms.
- This violates my personal religious or ethical beliefs.

B. Decision: Withdrawing non-oral feedings (G-tube or NG tube) from a decisional terminal cancer patient who asks for such feeding to be discontinued. Concerns:

- This violates state law.
- This violates medical practice standards and represents malpractice.
- This violates accepted ethical norms.
- This violates my personal religious or ethical beliefs.
- C. Decision: Withdrawing IV hydration from a terminal cancer patient who can no longer

take oral fluids and who is clearly dying. Concerns:

- This violates state law.
- This violates medical practice standards and represents malpractice.
- This violates accepted ethical norms.
- This violates my personal religious or ethical beliefs.

D. Decision: Withdrawing parenteral antibiotics from a non-decisional dementia patient with urosepsis, at the request of his/her power of attorney for health care or legal guardian.

Concerns:

This violates state law.

This violates medical practice standards and represents malpractice.

This violates accepted ethical norms.

This violates my personal religious or ethical beliefs.

E. Decision: Withdrawing ventilator support from a non-decisional dementia patient at

the request of his/her power of attorney for health care or legal guardian. Concerns:

This violates state law.

This violates medical practice standards and represents malpractice.

This violates accepted ethical norms.

This violates my personal religious or ethical beliefs.

Part III:

Please indicate which of the following topics you would like included in future educational programs, using the following codes:

1 = Yes 2 = No

Pain assessment and management

Assessment and management of nausea and vomiting

Assessment and management of delirium

Assessment and management of dyspnea

Assessment and management of constipation

Giving bad news

Running a family conference

Discussing prognosis

Managing requests for futile treatments

Hospice Care: the who, why, when & where

Ethics: DNR orders, advance directives, decision making capacity

Use of intravenous hydration and/of non-oral feedings in palliative care

Spirituality in palliative care – role of the physician

Palliative Care Screening Tools

Use of the MDS Section V: Care Assessment Summary

This section of the MDS displays triggered areas that require further review based on the assessment. These areas require further review, assessment and may need to be addressed in the Care Plan. Nursing homes may be able to use this section in determining if palliative care is appropriate for their resident. Please review the following excerpts from the CMS RAI Version 3.0 Manual that support usage of the CAA to assist in assessing residents for palliative care:

CMS'S RAI VERSION 3.0 MANUAL CH 4: CAA PROCESS AND CARE PLANNING MAY 2013 PAGE 4-2

The CAA process framework. The CAA process provides a framework for guiding the review of triggered areas, and clarification of a resident's functional status and related causes of impairments. It also provides a basis for additional assessment of potential issues, including related risk factors. The assessment of the causes and contributing factors gives the interdisciplinary team (IDT) additional information to help them develop a comprehensive plan of care.

When implemented properly, the CAA process should help staff:

- Consider each resident as a whole, with unique characteristics and strengths that affect his or her capacity to function;
- Identify areas of concern that may warrant interventions;
- Develop, to the extent possible, interventions to help improve, stabilize, or prevent decline in physical, functional, and psychosocial well-being, in the context of the resident's condition, choices, and preferences for interventions; and
- Address the need and desire for other important considerations, such as advanced care planning and palliative care; e.g., symptom relief and pain management.

Flacker Mortality Scale

This scale identifies residents who are at risk of dying within 1 year. It is used in conjunction with the Resident Assessment Instrument to identify these at risk residents. This tool can be used as a routine screening to assess for appropriateness of palliative care. It is available through the <u>University of Colorado Medical School</u> website.

Flacker Mortality Score

Using the Flacker Mortality Score* and the Resident Assessment Instrument to Identify Resident at High Risk for Dying Within One Year

Resident: _____ Date: _____

Resident Characteristic	Information Location	Scoring Chart	Score
Functional Ability	MDS Section G1.See	If Summary functional	
Score	Chart Below	ability score is greater	
		than 4, Score 2.50.	
Weight Loss	Weight sheet	If lost 5 or more	
		pounds in last 30 days	
		or 10 or more pounds	
		in last 180 days, score	
		2.26.	
Shortness of Breath	MDS Section J1	If has shortness of	
		breath, score 2.08.	
Swallowing Problems	MDS Section K1b,	If has swallowing	
	K5c, also see diet	problems, score 1.81.	
	order for special		
	texture		
Male Sex	MDS Section AA2	If Male, Score 1.76.	
Body Mass Index	MDS Section K2 – Use	If BMI is less than 22	
	BMI Chart	kg/m2, score 1.75.	
Congestive Heart	MDS Section 11f	If has CHF, score 1.57.	
Failure			
Age > 88 Years	DOB – MDS Section	If age greater than 88,	
	AA3 or face sheet	score 1.48.	

If Total Score Is	Probability of dying within 1 year is approximately:
0 - 2	7%
3 - 6	19%
7 - 10	50%
11 +	86%

Flacker Mortality Score

Functional Ability Score: To derive functional ability score, use MDS Section G1 data for the following 7 items: Each item is scored on a scale of 0 (no impairment) to 4 (high impairment), for a summary scale score ranging from 0-28.

- a) Bed Mobility _____
- b) Transferring _____
- c) Eating
- d) Toileting _____
- e) Hygiene
- f) Locomotion on unit _____
- g) Dressing
- h) Total

*Derived from: Flacker, J.M. & Kiely, D.K. (1998). A practical approach to identifying mortalityrelated factors in established long-term care residents. *Journal of the American Geriatrics Society*, 46, 1012-1015.

Karnofsky Performance Scale Index

The Karnofsky Performance Scale Index allows residents to be classified as to their functional impairment (functional status). This can be used to compare effectiveness of different therapies and to assess the prognosis of individual residents. This tool can be incorporated as a routine screening for palliative care. It is included as one of the Measurement and Evaluation Tools at the <u>National Palliative Care Research Center</u> and is available through this link.

KARNOFSKY PERFORMANCE STATUS SCALE DEFINITIONS RATING (%) CRITERIA

		Normal no complaints; no evidence of disease.
Able to carry on normal activity and to work; no special care needed.	90	Able to carry on normal activity; minor signs or symptoms of disease.
1	80	Normal activity with effort; some signs or symptoms of disease.
		Cares for self; unable to carry on normal activity or to do active work.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	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		Disabled; requires special care and assistance.
		Severely disabled; hospital admission is indicated although death not imminent.
institutional or hospital care; disease may be progressing rapidly.	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
		Dead

References:

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Oxford Textbook of Palliative Medicine, Oxford University Press. 1993;109.

Schag, CC, Heinrich RI, Ganz PA. Karnofsky performance status revisited: Reliability, validity, and guidelines. J Clin Oncology. 1984; 2:187-193.

Palliative Care Consult Services Screening Tool

This tool was developed by Home and Hospice Care of Rhode Island to determine appropriateness for a palliative care consult.

dical Rec	ord Number:		ONSULT SERVICES (Age: Reason for	PCCS) SCREENING		
Would y	ou be surprised if this pa	tiont were		Consuit.	50	CORE
would y	Yes – Score 3 points	uent were	alive in one year:			
	No – Score 0					
				TOTAL SECTION 1 (0 OR 3)	
Basic Dis	sease Process		Score 2 points ead			
а	Cancer (metastatic/rec	urrent)	······			
b	Advanced COPD (requires home oxygen)					
c	Neurological disease (d	ifficulty sw	allowing or incontinent)			
d	End stage renal disease	(consideri	ng stopping dialysis)			
	Advanced congestive h					
	+		ED visits for incurable disease in	past year		
	Not a candidate for cur					
h	Other terminal or incur	able diseas	e causing significant symptoms			
				TOTALSEC	TION 2	
Uncontro	ollable Symptoms or Clin					
	Score 2 points		Score 1 point each	Score 1 poir	nt each	
	Pain Dyspnea		Anxiety	i Prolonged vent support		
	Nausea		Depression Weight loss	J. Other		
	Bowel obstruction		Constipation			
				TOTAL SEC	TION 3	
Anticinat	ted Functional Status of	Patient at	Time of Discharge	TOTALOLO		
-			(Eastern Cooperative Oncology G	roun)		
	are asing coole remaining					
G			(Score	
G	rade Scale				Score	
	rade <u>Scale</u> Fully active, able	to carry or	n all pre-disease activities withou	t restriction or restricted in	Score 0	
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General Questionnaire

The Center to Advance Palliative Care hosts a site with a questionnaire for consumers to answer to determine if palliative care may be right for them. Consumers or their loved ones can click the "Is it Right for You" tab to pull up a 5 question survey that will return a response to seek a palliative care consult or further information about palliative care if the answer is "yes" on two or more questions. There is also a section for clinicians to review whether a referral to palliative care may be appropriate for their patients. Clinicians can click the "For Clinicians" tab to pull up a list of general reference criteria divided into four categories: Presence of a Serious Chronic Illness, Intensive Care Unit Criteria, Oncology Criteria, and Emergency Department Criteria. This tool is available at:

Available at the CAPC consumer-friendly website "Get Palliative Care"

The following is an excerpt from this page:

General Referral Criteria (one or more of the following):

Presence of a Serious, Chronic Illness

- Declining ability to complete activities of daily living
- Weight loss
- Multiple hospitalizations
- Difficult to control physical or emotional symptoms related to serious medical illness
- Patient, family or physician uncertainty regarding prognosis
- Patient, family or physician uncertainty regarding goals of care
- Patient or family requests for futile care
- DNR order conflicts
- Use of tube feeding or TPN in cognitively impaired or seriously ill patients
- Limited social support and a serious illness (e.g., homeless, chronic mental illness)
- Patient, family or physician request for information regarding hospice appropriateness
- Patient or family psychological or spiritual distress

General Palliative Care Education

The American Medical Director's Association has a training program available for purchase. Medical directors can utilize this program to lead an interdisciplinary staff training specific to palliative care in the long term care setting. This tool is available through the <u>AMDA</u> website.

An additional tool is a series of self-guided modules focusing on all different aspects of end-of-life care, including symptom management, advance care planning, communicating bad news and more. Healthcare professionals created EndLink: Resource for End of Life Care Education for those working with patients and families at end-of-life. This tool is available at the Endlink website at Northwestern University.

Resident-Family Communication Tools

Fast Facts for Clinicians

The End of Life/Palliative Education Resource Center (EPERC), through support from the Medical College of Wisconsin, offers "Fast Facts" for clinicians. These are one-two page briefs that focus on various topics around end of life and palliative care.

Available at the Medical College of Wisconsin's website.

042 Broaching the Topic of a Palliative Care Consultation with Patients and Families, 2nd edition

FAST FACT# 042

Author(s): Robert Arnold MD and David E Weissman MD

Introduction Palliative care consultative services are becoming commonplace in academic and community hospitals. Patients and families often, although not always, have negative perceptions of palliative care and hospice – viewing such a discussion as signaling that the physician is "giving up on the patient" and that the reality of impending death must be faced. For the attending physician, the decision to convey to a patient and family that a consultation is needed can provoke anxiety. Physicians may fear such a discussion will provoke anxiety, anger or a sense of hopelessness. This Fast Fact provides tips for beginning a discussion leading to a visit by a palliative care consultation team.

First, decide why you want assistance from the palliative care team. Typically, physicians seek assistance in four domains: 1) pain and non-pain symptom assessment and management; 2) assistance in making difficult decisions, usually about continued use or withdrawal of potentially life-prolonging treatments such as feeding tubes, antibiotics, dialysis, or ventilators; 3) assistance in planning for the most appropriate care setting to meet patient/family goals for end-of-life care; and 4) providing psychological support to patients, families and the health care team.

Second, contact the palliative care team. Discuss your reason(s) for consultation along with pertinent details of the patient's history and family support structure. Describe both what your goals are for the consultation, as well as what the family's/patient's goals may be. This is a good time to discuss any concerns you have about using the term *palliative care* with the patient or family.

Third, engage the patient/family in a discussion of the current medical condition and goals of care. Introduce the topic of a consultation by saying: *To best meet some of the goals we've been discussing* (fill in with the goals mentioned by the family/patient) *I'd like to have some consultants from the Palliative Care Team visit with you.* You can follow this by saying, *They are experts in treating the symptoms you are experiencing* (fill in symptom). *They are also good at helping your family deal with all the changes brought on by your illness; they can answer your questions about* (fill in previously discussed patient questions).

You should not say that the reason you are asking Palliative care to be involved is "that there is nothing more to do" or because "I have nothing more to offer." Talk about the positive goals Palliative Care can help you and the patient achieve.

Finally, emphasize your continued involvement: You and I will talk about the recommendations of the palliative care experts. I'll make sure all your questions are answered. This can help relieve fears of abandonment. If a patient or family reacts negatively to the suggestion for a consultation, explore their concerns. Someone may have mentioned palliative care and this may have negative connotations to them. Ask, What experience do you have with hospice/palliative care? What are your concerns? It may be important to discuss that palliative care is compatible with aggressively treating the underlying disease. Emphasize the positive aspects of what palliative care can do, rather than focusing on how the palliative care team will help them accept death and dying. After all, the goal of palliative care is to achieve the best possible quality of life through relief of suffering, control of symptoms and restoration of functional capacity, while remaining sensitive to the patient and family's values. Palliative Care guides the patient and family as they face disease progression and changing goals of care, and helps those who wish to address issues of life completion and life closure.

References

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Fast Facts and Concepts are edited by Drew A. Rosielle MD, Palliative Care Center, Medical College of Wisconsin. For more information write to: drosiell@mcw.edu. More information, as well as the complete set of Fast Facts, are available at EPERC: <u>www.eperc.mcw.edu.</u>

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ACGME Competencies: Interpersonal and Communication Skills, Patient Care, System-Based Practice

Keyword(s): Communication, Psychosocial and Spiritual Experience: Patients, Families, and Clinicians

Pocket Guides for Clinicians

There are several pocket guides for clinicians to use, made available by the Center to Advance Palliative Care and developed by the Medical College of Wisconsin. The following two guides assist clinicians with family-patient communication issues and are

helpful in determining how to approach family meetings and provide/receive information from families and patients. This tool is available at the <u>CAPC</u> website.

Communication Phrases in Palliative Care (Pocket Guide)

Advance Care Planning

- I'd like to talk with you about possible health care decisions in the future. This is something I do with all my patients so I can be sure that I know and can follow your wishes. Have you ever completed an Advance Directive?
- What do you understand about your health situation?
- If you were unable to make your own medical decisions, who would like to make them for you? Have you spoken to this person?
- When you think about dying, have you thought about what the end would be like or how you would like it to be?
- Have you discussed your wishes with your family?

Determining Decision Making Capacity

- Will you describe your current condition? What the doctors have told you?
- Tell me the options for treating "X" that we have just discussed.
- Explain to me why you feel that way?

Breaking Bad News

- What do you understand about your condition?
- I'm afraid I have some bad news. I wish things were different, but the test results are not good. The (test name) showed <u>X</u>.
- Address emotional reaction (see back page)
- I want to be sure you understand what we have talked about; can you summarize for me what we have discussed?
- Write down any questions that come to mind, let's to plan to meet again (time/date).

Quality of Life -phrases that will help you understand the illness's impact

- How has your disease interfered with your daily activities; your family and friends?
- Have you been feeling worried or sad about your illness?
- What symptoms bother you the most? What concerns you the most?
- How have your religious beliefs been affected by your illness?
- Many patients wonder about the meaning of all this—do you?

Prognosis

- Tell me how you spend your day; how much time do you spend laying down or resting—is it more or less than 50% of the time; has this changed recently?
- Has anyone talked to you about what to expect?
- Do you have any a sense of how much time is left? Is this something you would like to talk about?
- Although I can't give you an exact time, in general, patients with your condition live _____wks/months to ____ wks/months.
- Based on what you have told me, and what I see, I believe you are dying.

Goal Setting

- Knowing that time is short, what goals do you have for the time you have left—what is important to you? What do you need to do?
- What are your goals for this last phase of your life?

Talking with Surrogate Decision Makers

- These decisions are very hard; if <u>(resident's name)</u> were sitting with us today, what do you think he/she would say?
- Can you tell me why you feel that way?
- How will the decision affect you and other family members?
- I believe that (<u>resident's name</u>) is dying.

Discussing Artificial Feeding/Hydration

- What do you know about artificial ways to provide food?
- All dying patients lose their interest in eating in the days to weeks leading up to death. This is the body's signal that death is coming.
- I am recommending that the (tube feedings, hydration, etc.) be discontinued (or not started) as these will not improve his/her living; these treatments, if used, may only prolong his/her dying.
- Your (relation) will not suffer; we will do everything necessary to ensure comfort.
- Your (relation) is dying from (disease); he/she is not dying from dehydration or starvation.

Cross-Cultural – Understanding others views of illness

- I know different people have very different ways of understanding illness...Please help me understand how you see things.
- What do you call the problem? Tell me what you think the illness does? What do you think the natural course of the illness is? What do you fear?
- Who do you turn to for help? Who should be involved in decision making?
- How do you think the sickness should be treated? How do want us to help you?
- Some people like to know everything about their disease and be involved in all decision making. Others do not want all the news and would rather the doctor talk to XX? Which kind of person are you? How involved do you want to be in these decisions?

Discussing Palliative Care or Hospice Referral

- To meet the goals we've discussed (summarize goals) I've asked the Palliative Care Team to visit with you; they are experts in treating the symptoms you are experiencing. They can help your family deal with the changes brought on by your illness.
- You've told me you want to be as independent and comfortable as possible. Hospice care is the best way I know to help you achieve those goals. Hospice is a program that helps the patient and family achieve the goals you've just describe, it's a team of people that help meet the patient's and family's physical, psychological, social and spiritual needs.

Death Pronouncement

- I wish there is more we could have done; I'm very sorry for your loss. This must be very difficult for you; is there anyone I can call for you?
- In the days to weeks to come, please contact me if I can answer any questions about your (insert relation) illness.

DNR ORDERS

Note: Only discuss CPR/DNR following a Goal Setting discussion

A. When CPR is not medically indicated **

• You have told me that your goals are ______. With this in mind, I do not recommend the use of artificial or heroic means to keep you alive. If you agree with this, I will write an order in the chart that when you die, no attempt to resuscitate you will be made, is this acceptable (ok)?

B. When CPR is medically indicated if consistent with patient goals/wishes

- We have discussed your current illness, have you given any thought to how you would like to be cared for at the time of death? Sometimes when people die, or are near death, especially from a sudden illness, life support measures are used to try and 'bring them back', alternatively, we could focus solely on keeping you comfortable, How do you feel about this?
- C. Sustained requests for CPR when it is not medically appropriate/indicated
 - What do you know about CPR?
 - This decision seems very hard for you. I want to give you the best medical care possible; can you tell me more about your decision?
 - What do you expect will happen? What do you think would be done differently, after the resuscitation, that wasn't being done before?
 - **NOTE: if you will honor the request for CPR**. I understand your desire for CPR, but I will need some direction if you survive, since you will almost certainly be on a breathing machine in an ICU. It is very likely that you will not be able to make decisions for yourself. Who do you want to make decisions for you? Can you give me some sense of how long we should continue life support if you are not able to make decisions and there is no improvement in your condition.
 - NOTE: if participating in CPR violates your professional judgment. I understand your desire for CPR, but in my medical judgment, performing CPR would only increase your suffering and not prevent your dying. Although I would like to continue caring for you, I am unwilling to participate in CPR; it may be appropriate for you to find another physician to provide your care.

** Expected death, caused by chronic life-limiting diseases: advanced metastatic cancer with poor and declining functional status, renal failure on dialysis, multi-organ failure; advanced dementia; end stage liver or cardiac disease, etc.

RESPONDING TO EMOTION

1. Reflect thoughts, emotions or behavior

- It seems like you are having a hard time deciding between ____ and ____...
- You have been feeling ____...
- I see that you are crying...
- You seem very ...
- 2. Affirmation & respect
 - Thank you for describing your feelings and thoughts.
 - I can do a better job as your doctor when I know how you are feeling.
 - Please tell me more about the sadness you are feeling.

3. Summarize/paraphrase

- We have been talking for a while about how things are going for you. Let me see if I can summarize what you have said, then you can let me know if I'm on track ...
- 4. Make a plan
 - How can I help? or, What, if anything, would make a difference for you?
 - I would like to check in with you next week and see how things are going. In the meantime, please let me know if you need to talk before then.

5. Dealing with Anger

- It sounds/appears that you are angry?
- You appear angry; can you tell me what is upsetting you?
- So, you are telling me that you are angry about _____, is that correct?
- I wish things were different, how can we move forward? How can I help?

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Susan Block, MD; personal communication

Prognosis Discussion Tool

One facility participating in the Nursing Home Palliative Care Collaborative of Rhode Island developed a tool for the nursing staff to assess a resident's understanding of their prognosis/diagnosis. This tool was reported to be empowering for the nursing staff as it encouraged their involvement with these discussions and facilitated nurse communication with physician partners and residents. The elements of tool are included here:

Problem:

Knowledge deficit related to prognosis/treatment plan as evidenced by....

□ New condition(s)/treatment(s)/procedure(s)

Complexity of treatment

- Cognitive/physical limitation
- Emotional state affecting learning (anxiety/depression/denial)

Goal:

Resident/family/caregiver etc. will verbalize understanding of prognosis/treatment plan within first 14 days of admission

Interventions:

- Identify learners
- □ Assess motivation/ability to learn
- □ Identify previous education and misconceptions
- Determine pertinent cultural influences on health teaching
- Determine learning style and plan teaching based on individual learning style
- Determine self-efficacy (confidence) to learn and apply new knowledge
- □ Provide comfortable environment for learner(s) that exhibits an atmosphere of respect, openness, trust and collaboration
- Establish goals for learning at beginning of session
- Explore attitudes of learner(s)
- Give clear, thorough explanations/demonstrations as indicated
- Encourage questions
- Document progress of teaching and learning
- □ Explore community resources if appropriate

The Family Goal Setting Conference (Pocket Guide)

- 1. Preparation
 - > Review chart—know all med issues: treatment course, prognosis, options
 - Review Advance Care planning documents (e.g. POAHC)
 - > Review/obtain family psychosocial issues; keep open mind re: reported conflicts
 - Coordinate medical opinions among consultant physicians
 - Clarify your goals for the meeting (what decisions are you hoping to achieve)
 - Decide who you want to be present from the medical team.
 - Check your own emotions
- 2. Establish proper setting
 - > Private, comfortable
 - Everyone seated--circle seating if possible
- 3. Introductions/Goals/Relationship
 - > Allow everyone to state name and relationship to patient
 - Identify if there is legal decision-maker (POA, Guardian)
 - State your goals for the meeting; ask family if they have other goals.
 - Ask non-medical question about patient to build relationship: Can you tell me something about your father?
- 4. Family understanding of condition
 - > Tell me your understanding of the current medical condition
 - Encourage all present to respond
 - For patients with a chronic illness, ask for a description of changes in function (activity, eating, sleep, mood) observed over past weeks/months
- 5. Medical review/summary
 - Summarize "big picture" in few sentences—use "dying" if appropriate
 - Respond to specific medical queries if asked.
- 6. Silence/reactions
 - > Respond to emotional reactions; Be prepared for common questions:
 - How long? What do we do now? How can you be sure?
- 7. Prognostication
 - If appropriate/necessary, provide prognostic information using ranges
 - Allow silence; respond to emotional reactions
- 8. Decision-Making (go to 9. if no decisions need to be made)
 - Review options, make a recommendation, and assess reaction.
 - Decisional Patient: "What decision(s) are you considering?"
 - Non-Decisional Patient: "What do you believe the patient would choose if s/he were here?"
 - > If consensus is reached, summarize and confirm
 - > If no consensus, mutually decide on specific time-limited goals

- 9. Goal setting (go to 10. if goals were established in 8.)
 - Allow family/patient to state their goals; Knowing that time is short, what is important in the time that is left?
 - Review all current and planned interventions—make recommendations to continue or stop. If appropriate, discuss artificial hydration/feeding/DNR orders etc. with clear recommendations.
 - Summarize all decisions made
- 10. Document and discuss
 - > Who was present and what decisions were made and follow-up plan
 - > Discuss with relevant team members (consultants, nurse, etc.)
 - Check your emotions

The Palliative Response – Full Text and Pocket Guides

F. Amos Bailey, MD author of The Palliative Response (Copyright 2005) makes the full text of his book and pocket guides for clinicians available online at the <u>University of Alabama</u> <u>School of Medicine</u> website.

Resident and Family Communication Summary (Sample)

Resident Name:	Room #/Unit:
DOB:	_ MR#

Care Plan or Family Meeting Date:_____

Persons Present:

Facility Staff	Resident/Family/Community Members
1.	1.
2.	2.
3.	3.
4.	4.

Are two disciplines represented: \Box Yes \Box No

Were the following Discussion Points completed?

1. Proxy Decision Maker Identified: □ Yes □ No	1.	Proxy Decision	Maker	Identified:	
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Comments:

2. Pain Assessment Discussed:	□ Yes □ No		
Comments:			
Resident's Prognosis Discussed: Yes N Comments:	10		
3. Advance Care Planning Discussed: Comments:	□ Yes □ No		
4. Resident's goals for care discussed: Comments:	□ Yes □ No		
 Spiritual needs of resident explored: □ Yes □ No Comments: 			

*Adapted from RI ICU Collaborative Palliative Care Collaborative

Family Conference Checklist*

Preparation:

- 1. Chart Reviewed:
 - Diagnoses
 - Treatment course
 - Prognosis
 - Options
 - Advanced Directive
 - Surrogate Decision Maker
 - Know state laws, institutional policy
- 2. Family psychosocial issues identified:
- 3. Family instruction given:
- 4. Medical team:
 - Identified, invited
 - Consensus reached re: goals/questions
- 5. Meeting plan:
 - Leader
 - Attendees
 - Scheduling
 - Room reserved & arranged
 - Draw a seating chart
 - Kleenex
 - Pagers/ cell phones

6. Check your emotions:

Meeting:

- 7. Introductions:
 - Names
 - Relationship to patient
 - Pass out business cards
- 8. Goals of Meeting:
 - Team goals
 - Family goals
- 9. Telling the story: Family
 - Ask before you tell
 - Give everyone a turn
 - Gauge level of medical sophistication
 - Assess psychosocial content, emotional state
 - Identify & address misconceptions
 - Clarify expectations

10. Telling the story: Team

- Summarize big picture in a few sentences
- Use "dying" if appropriate
- No TLA's!

- Appropriate use of silence, empathy
- Respond to emotions and specific questions
 - Check for understanding
- 11. Prognostication:
 - Fire a warning shot
 - Acknowledge uncertainty & fluid nature of prediction
 - Use ranges
 - Allow time to digest
 - Respond to emotions, check for understanding
- 12. Goal Setting:
 - Allow patient & family to state their goals
 - Emphasize living vs. dying (rest of life vs. end of life)
 - "What is important for the time that is left?"
 - "What are your hopes for the time that is left?"
 - Look to the advance directive
 - Role of surrogate as patient's voice rather than independent decision maker
 - "If pt were here, what do you think he/she would say?"
 - Don't rush; may take more than one meeting
 - Reinforce with family that nothing is final
- 13. Summarize:
 - Restate key points of understanding
 - Include things that are agreed upon and topics of ongoing discussion:
 - Review goals & plans of care:
 - Clarify the next step (meetings, appointments)
 - Clarify options for contact:
 - Arrange follow up

Afterward:

14. Write a Note:

- Date, time, length of meeting, attendees
- Key points discussed
- Decisions Made
- Plan

15.Debrief

- Check your emotions
- Debrief with the team

*Adapted from Department of Geriatric Medicine, John A. Burns School of Medicine, University of Hawaii

Spiritual Care Tools SPIRITUAL CARE ASSESSMENT (Sample)

Faith (roupParticular Affiliation		
Pastor	Phone:		
Patien	familygives consent for chaplain to contact Pastor: Yes No		
Areas To Address			
1.	What is the patient's/family's source of strength?		
2.	What relationship/s has been significant in the past and at this time?		
3.	What group or organization has been important for providing strength?		
4.	What network will be available at home?		
5.	What are the spiritual needs at this time and how can the chaplain be of help?		
Theological Issues			
1.	mage of God:		
2.	Relationship with God:		
3.	mportant spiritual resources:		
	Prayer 🛯 Scripture 🖵 Sacraments 🖵 Worship 🖵 Other		
Spiritual issues to address (use back of form if necessary):			

Proposed spiritual component of Care Plan (use back of form if necessary):

Signature of Chaplain:	Date:
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^{*}Policies and Tools for Hospital Palliative Care Programs: A Crosswalk of National Quality Forum Preferred Practices. Available at <u>NQF</u> website.

Why Call A Chaplain? (Provided by Rhode Island Hospital Chaplains)

A chaplain assists patients:

- Who come from a wide variety of faith traditions and no faith tradition as the chaplain honors and responds within the beliefs and values of the patient
- Who are experiencing apprehension about an upcoming medical procedure
- Who are feeling overwhelmed by their illness, its diagnosis and/or prognosis
- Who are expressing feelings of loneliness and isolation, despair or discouragement, or a sense of helplessness and hopelessness
- Who are struggling with the meaning of life and/or the possibility of death in the face of illness
- Who are experiencing conflict with family members and/or staff
- Who are expressing a sense of God's absence in their lives
- Who want to explore their personal beliefs and spiritual resources for coping
- Who would benefit from the comfort of prayer and/or spiritual support from a multifaith perspective
- Who have expressed a desire to receive the Sacraments (Baptism, Communion, Reconciliation, Anointing of the Sick)
- Who would like a clergy person or religious leader from their faith tradition to be contacted

A chaplain assists the family members of patients:

- Who are experiencing apprehension about a loved one's upcoming medical procedure
- Who are feeling overwhelmed by the illness of their loved one, its diagnosis and/or prognosis
- Who are facing change and loss as a result of the illness of their loved one
- Who are grappling with questions about life and death as a result of the loved one's illness
- Who are experiencing conflict with the patient and/or staff
- Who are in need of support in deciding changes in code status or defining goals of care for a loved one
- Who are working through the loss of a loved one
- Who are facing ethical dilemmas as a result of the illness of a loved one

A chaplain assists the staff:

- By responding to Code Blue or other crisis situations to offer emotional and spiritual support
- By attending family meetings and assisting patients and/or their families with defining goals of care
- When a death of a patient is imminent or has occurred
- By providing support to staff who have grappled with particularly traumatic, difficult or challenging patient situations
- Offering support when a staff person is dealing with a difficult personal/family situation

Resources for Developing/Improving a Chaplain Program in Long Term Care

Many nursing homes may want to explore the current status of their spiritual care program. The following tools may be helpful in assessing and improving access to spiritual care.

Standards of Practice for Long Term Care Chaplains

This tool shows the standards of practice for chaplains specific to the long term care setting. It is available through the <u>National Association of Professional Chaplains</u>.

Evaluating Your Spiritual Care Assessment Process

Spiritual Assessment

REVIEWING JOINT COMMISSION STANDARDS FOR SPIRITUAL ASSESSMENT (QUESTIONS/ANSWERS), MORE INFORMATION AVAILABLE AT FULL WEBSITE, THE FOLLOWING IS ONE QUESTION/ANSWER:

Available on the <u>Joint Commission</u> website.

Revised | November 24, 2008

Q: Does the Joint Commission specify what needs to be included in a spiritual assessment?

A: No. Your organization would define the content and scope of spiritual and other assessments and the qualifications of the individual(s) performing the assessment. Examples of elements that could be but are not required in a spiritual assessment include the following questions directed to the patient or his/her family:

- Who or what provides the patient with strength and hope?
- Does the patient use prayer in their life?
- How does the patient express their spirituality?
- How would the patient describe their philosophy of life?
- What type of spiritual/religious support does the patient desire?
- What is the name of the patient's clergy, ministers, chaplains, pastor, rabbi?
- What does suffering mean to the patient?
- What does dying mean to the patient?
- What are the patient's spiritual goals?
- Is there a role of church/synagogue in the patient's life?
- How does your faith help the patient cope with illness?
- How does the patient keep going day after day?
- What helps the patient get through this health care experience?
- · How has illness affected the patient and his/her family

Article Authored by the Joint Commission

This article housed on a website for the Association of Professional Chaplains explains the Joint Commission's expectations regarding the spiritual care assessment process.

Joint Commission: The Source, February 2005, Volume 3, Issue 2 Copyright 2005 Joint Commission on Accreditation of Healthcare Organizations:

Available through the National Association of Professional Chaplains

Hope Spiritual Assessment Tool

This article reviews the use of the HOPE tool for spiritual assessment during a medical interview. The acronym HOPE is designed to be a simple tool for medical providers to remember questions to ask that relate to spiritual care needs.

- H: Sources of Hope
- **O**: **O**rganized Religion
- P: Personal spirituality and practices
- E: Effects on medical care and end-of-life issues

Access the article through the American Association of Family Physicians.

FICA Spiritual Assessment Tool

The FICA tool was designed by Christina Pulchaski, MD, an expert in the field of spiritual care and medicine. This is an evidence based tool using a simple acronym to spark questions related to a patient's spiritual care needs.

- F: Faith or beliefs
- I: Importance and Influence
- **C**: **C**ommunity
- A: Address

Specific questions to ask for each assessment segment include:

F: What is your faith or belief?

Do you consider yourself spiritual or religious?

What things do you believe in that give meaning to your life?

I: Is it important in your life?

What influence does it have on how you take care of yourself?

How have your beliefs influenced in your behavior during this illness??

What role do your beliefs play in regaining your health?

C: Are you part of a spiritual or religious community?

Is this of support to you and how?

Is there a person or group of people you really love or who are really important to you?

A: How would you like me, your healthcare provider to address these issues in your

To access the tool in more depth, go to the <u>George Washington University School of</u> <u>Medicine and Health Sciences</u> website.

Fast Facts for Clinicians

These are one or two page briefs for clinicians on various topics around end of life and palliative care. This tool is available at <u>Medical College of Wisconsin</u> website.

FAST FACT: Spiritual History

Fast Facts for Clinicians: Taking a Spiritual History, 2nd edition

Author(s): Bruce Ambuel PhD

Background: Illness raises fundamental questions – For what may I hope? Why do I suffer? Does my suffering have meaning? What happens after I die? When a physician stands with a patient as they face death, the physician inevitably plays a role in supporting the patient's inquiry into these spiritual questions. In addition some patients have specific preferences or needs regarding medical care, death and dying that are based upon their religious beliefs. The physician often plays an important role in supporting a patient's exploration of these issues. Taking a spiritual history is one way to support the patient in this exploration. Maugans (1997) presents a framework for taking a spiritual history; the interview below comes primarily from Maugans' article with some modification based upon the other sources cited.

Taking a Spiritual History

Spiritual belief system

- Do you have a formal religious affiliation? Can you describe this?
- Do you have a spiritual life that is important to you?
- What is your clearest sense of the meaning of your life at this time?

Personal spirituality

- Describe the beliefs and practices of your religion that you personally accept.
- Describe those beliefs and practices that you do not accept or follow.
- In what ways is your spirituality/religion meaningful for you?
- How is your spirituality/religion important to you in daily life?

Integration with a spiritual community

- Do you belong to any religious or spiritual groups or communities?
- How do you participate in this group/community? What is your role?
- What importance does this group have for you?
- In what ways is this group a source of support for you?
- What types of support and help does or could this group provide for you in dealing with health issues?

Ritualized practices and restrictions

- What specific practices do you carry out as part of your religious and spiritual life (e.g. prayer, meditation, services, etc.)
- What lifestyle activities or practices do your religion encourage, discourage or forbid?
- What meaning do these practices and restrictions have for you? To what extent have you followed these guidelines?

Implications for medical care

- Are there specific elements of medical care that your religion discourages or forbids? To what extent have you followed these guidelines?
- What aspects of your religion/spirituality would you like to keep in mind as I care for you?
- What knowledge or understanding would strengthen our relationship as physician and patient?
- Are there barriers to our relationship based upon religious or spiritual issues?
- Would you like to discuss religious or spiritual implications of health care?

Terminal events planning

- Are there particular aspects of medical care that you wish to forgo or have withheld because of your religion/spirituality?
- Are there religious or spiritual practices or rituals that you would like to have available in the hospital or at home?
- Are there religious or spiritual practices that you wish to plan for at the time of death, or following death?
- From what sources do you draw strength in order to cope with this illness?
- For what in your life do you still feel gratitude even though ill?
- When you are afraid or in pain, how do you find comfort?
- As we plan for your medical care near the end of life, in what ways will your religion and spirituality influence your decisions?

References:

Maugans TA. The SPIRITual History. Arch Fam Med. 1997; 5:11-16.

Ambuel B, Weissman DE. Discussing spiritual issues and maintaining hope. In: Weissman DE, Ambuel B, eds. Improving End-of-Life Care: A Resource Guide for Physician Education, 2nd Edition. Milwaukee, WI: Medical College of Wisconsin; 1999.

Griffith JL, Griffith ME. Hope in suffering/pain in health: Talking with patients about spiritual issues. Presented at The 18th Forum for the Behavioral Sciences in Family Medicine, Chicago, Illinois, October 1997.

Fast Facts and Concepts: are edited by Drew A. Rosielle MD, Palliative Care Center, Medical College of Wisconsin. For more information write to: drosiell@mcw.edu. More information, as well as the complete set of Fast Facts, are available at EPERC: www.eperc.mcw.edu.

Version History: This Fast Fact was originally edited by David E Weissman MD. 2nd Edition published August 2005. Current version re-copy-edited March 2009.

Copyright/Referencing Information: Users are free to download and distribute Fast Facts for educational purposes only. Ambuel B. Taking a Spiritual History, 2nd Edition. Fast Facts and Concepts. August 2005; 19. Available at: www.eperc.mcw.edu/EPERC/FastFactsIndex/ff_019.htm.

Disclaimer: Fast Facts and Concepts provide educational information. This information is not medical advice. Health care providers should exercise their own independent clinical judgment. Some Fast Facts cite the use of a product in a dosage, for an indication, or in a manner other than that recommended in the product labeling. Accordingly, the official prescribing information should be consulted before any such product is used.

ACGME Competencies: Interpersonal and Communication Skills

Keyword(s): Communication, Psychosocial and Spiritual Experience: Patients, Families, and Clinicians

Promoting Excellence in End-of-Life Care

Promoting Excellence in End-of-Life Care was a national program of the <u>Robert Wood</u> <u>Johnson Foundation</u> dedicated to long-term changes to improve health care for dying people and their families. Several of their workgroups and demonstration projects developed spiritual care assessment tools. These tools are available at the <u>Promoting</u> <u>Excellence</u> website.

Assessing Staff Beliefs Regarding Spiritual Care

There are staff assessments that may provide insight and understanding regarding attitude and beliefs around spiritual care. One tool that is considered a reliable source and has been widely used was developed in England. The Spirituality and Spiritual Care Rating Scale (SSCRS) questionnaire asks respondents about their beliefs around spiritual care and the direct practice of nursing. A report by the Royal College of Nursing on members' views on spirituality and spiritual care in nursing practice is available and includes a copy of the SSCRS tool in the appendix.

View this report on the <u>Royal College of Nursing</u> website.

Pain Assessment Tool

Use of the MDS RAI

Section J of the MDS 3.0 requires staff to be assessing for pain and pain management over the last 5 days. This portion of the assessment can trigger a need to respond in Section V Care Area for Pain. This requires further intervention and follow up and development of an individualized Care Plan Decision. Each facility will manage this independently but this may be a trigger for further pain assessment within the facility, a referral for further consultation from outside sources such as a palliative care provider or pain clinic.

Excerpt from CMS's RAI Manual:

CMS's RAI Version 3.0 Manual CH 3: MDS Items [J] Page1 J-1 and J-2

J0100: Pain Management (5-Day Look Back)

Item Rationale

Health-related Quality of Life

- Pain can cause suffering and is associated with inactivity, social withdrawal, depression, and functional decline.
- Pain can interfere with participation in rehabilitation.
- Effective pain management interventions can help to avoid these adverse outcomes.

Planning for Care

- Goals for pain management for most residents should be to achieve a consistent level of comfort while maintaining as much function as possible.
- Identification of pain management interventions facilitates review of the effectiveness of pain management and revision of the plan if goals are not met.
- Residents may have more than one source of pain and will need a comprehensive, individualized management regimen.
- Most residents with moderate to severe pain will require **REGULARLY** dosed pain medication, and some will require additional PRN (as-needed) pain medications for breakthrough pain.
- Some residents with intermittent or mild pain may have orders for PRN dosing only.
- Non-medication (non-pharmacologic) interventions for pain can be important adjuncts to pain treatment regimens.
- Interventions must be included as part of a care plan that aims to prevent or relieve pain and includes monitoring for effectiveness and revision of care plan if stated goals are not met. There must be documentation that the intervention was received and its effectiveness was assessed. It does not have to have been successful to be counted.

The Wong-Baker FACES Pain Rating Scale

This pain scale can be used for cognitively intact, non-verbal or non-English speaking patients. The website has multiple language versions of this scale available for download. The tool is available at the <u>Wong-Baker FACES</u> website.



The FLACC Scale

This behavioral scale is used to assess pain for cognitively impaired residents or those unable to communicate. This tool is available at the <u>WPS Prenhall</u> education site.

University of Pennsylvania School of Nursing Pain Assessment Tool (Copyright Genesis Health Care)

This pain assessment tool provides additional information not obtained via the MDS 3.0 in terms of location, type of pain, and what helps/does not help with the pain. This tool is available on the <u>Promoting Excellence</u> website.

Chart of Non-Pharmacological Interventions for Physical, Spiritual and Psychological Pain

Ireland Cancer Center and Case Western Reserve University developed this chart through a project titled Project Safe Conduct - Pain Protocol. This is a flow chart for how different disciplines can be involved in pain relief from a non-pharmacological perspective. There are multiple other tools available from this project as well. This tool is available on the <u>Promoting Excellence</u> website.

In-ServiceTraining to Understand Pain

The National Hospice and Palliative Care Association has a PowerPoint presentation available for use as an in-service training for an interdisciplinary team. The presentation reviews assessing and managing pain and understanding different types of pain. This PowerPoint is ready to use and can be downloaded from the Association's consumer website <u>Caring Info</u>.

Advance Care Planning Tools

Advance Care Planning: An Introduction for Public Health and Aging Services Professionals

This free online course is offered by the Centers for Disease Control and Prevention. The target audience includes aging services professionals in a long term care setting. The course is divided into three modules that cover:

- What advance care planning is and why it's needed
- How to initiate difficult but essential conversations and document personal values and preferences
- What public health and aging services professionals can do to leverage their unique position in the community to assist clients and constituents with advance care planning
- Where to find reliable guidance and resources.

Each module is self-paced but designed to take approximately 1 hour to complete. This tool is available on the <u>CDC</u> website.

Advance Care Planning in Rhode Island

Healthcentric Advisors has provided access to both healthcare providers and consumers access to information about advance care planning and the Rhode Island Durable Power of Attorney form. This website offers two choices, one labeled "Information For Everyone" and also a section specific for "Healthcare Provider". Providers can access additional tools to learn about advance care planning and supporting their residents/patients. Providers also have the opportunity to add a widget to their website, providing a direct link to the consumer materials. This information is available on the <u>Healthcentric Advisors</u> website.

Rhode Island Legal Forms

Rhode Island laws provide legal protection to residents through Living Wills and a Durable Power of Attorney for Health Care. Healthcare providers and consumers can access a PDF version of these two forms as well as links to the laws (Rights of the Terminally III Act and the Health Care Power of Attorney law) through the Rhode Island Department of Health. More information is available in this Toolkit, Section 7: Rhode Island Resources. The information is available on the <u>Rhode Island Department of Health</u> website.

In addition, Rhode Island passed legislation regarding MOLST (Medical Orders for Life Sustaining Treatment) in 2013. More information regarding healthcare provider's expectations and the MOLST form is also available through the <u>MOLST page</u> on the Department of Health's website.

The Conversation Project

The Conversation Project is an effort of several healthcare professionals from across disciplines that joined forces to help individual patients relay their wishes regarding how they want to live and be cared for at end of life. The project encourages families to have

conversations about their wishes and then to document those wishes. Providers and consumers can easily download the starter kit and offer this to residents and family members or encourage family members to complete the kit from the <u>Conversation Project</u> website.

The Institute *for* Healthcare Improvement (IHI) offers a free, four-hour online course on The Conversation Project through their <u>IHI Open School</u>. This course is designed to help providers shift the culture in their organization and be empowered to talk with their consumers around how each individual wants to live and be cared for at end of life.

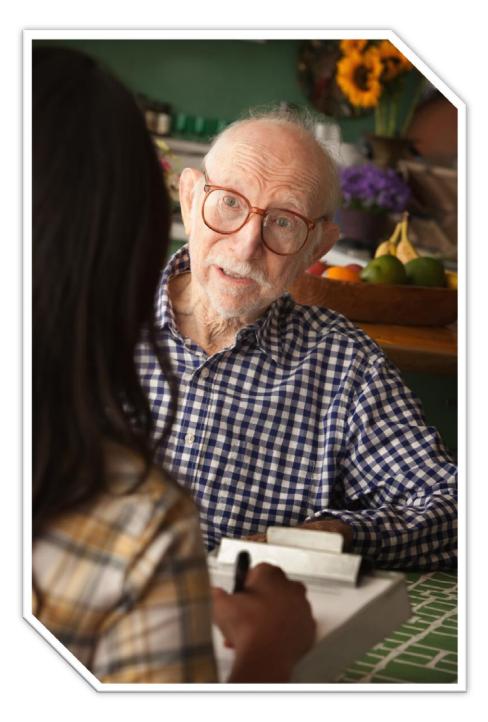
Respecting Choices

Respecting Choices is an advance care planning training and certification program available through <u>Gundersen Health System</u>®. It is an evidence based approach to advance care planning for health care professionals. For information, view the <u>YouTube</u> video and visit their website.

Thoughtful MOLST Discussions – YouTube Video

This 43 minute video shows a family meeting in a hospital setting using the eight (8) action principles of MOLST in New York. Despite the hospital and state specific setting, this <u>YouTube</u> video has principles that can be applicable to all healthcare settings and states.

7 RESIDENT AND FAMILY EDUCATION AND INFORMATION RESOURCES



General Palliative Care Information

What is Palliative Care? (Video)

This six-minute video is designed to educate nursing home residents and family members about palliative care in the nursing home setting. It uses a resident story, caregiver story and a palliative care physician to explain palliative care. This tool is available at <u>YouTube</u>.

Palliative Care: What You Should Know

A one page flyer produced by the Center to Advance Palliative Care, available at their companion website directed towards consumers and family members. This flyer defines palliative care and goes through 7 commonly asked questions such as "Where do I receive palliative care?" This tool is available at <u>CAPC's consumer website</u>.

On the "What is Palliative Care" page, click the highlighted word "handout" on the screen to be directed to this PDF file that can be printed and distributed.

Online Quiz "Is it Right for You"

The Center to Advance Palliative Care hosts a site with a questionnaire for consumers to answer to determine if palliative care may be right for them. Consumers or their loved ones can click the "Is it Right for You" tab to pull up a 5 question survey that will return a response to seek a palliative care consult or further information about palliative care if the answer is "yes" on 2 or more questions. This tool is available at <u>CAPC's consumer</u> website.

How Can Palliative Care Help Me?

What is Palliative Care?

These two page flyers are available through the companion website for the National Hospice and Palliative Care Organization (NHPCO). This website has brochures and information geared directly for the consumer and family members. Some brochures are available in Mandarin and Spanish. These tools are available on the <u>consumer website</u> for the NHPCO. (Click the brochures tab to view the selection and topics).

What is Palliative Care?

This two page informational document produced by U.S. National Library of Medicine answers general questions and includes an explanation of the difference between hospice and palliative care. This tool is available through the <u>U.S. National Library of Medicine</u> website.

Palliative Care: The Relief You Need When You're Experiencing the Symptoms of Serious Illness

This 13 page booklet is produced by the National Institute of Nursing Research (NINR). It defines the team approach in palliative care and explains how it is different from hospice. It is available in both English and Spanish versions. This tool is available on the <u>NINR</u> website.

Palliative Care Flyer

This flyer was developed by Healthcentric Advisors, the Quality Improvement Organization for Rhode Island for the Nursing Home Palliative Care Collaborative. The flyer is written to a sixth grade reading level and explains palliative care to nursing home residents and family members. There is room on the flyer for branding by individual facilities.





Palliative

IMPROVING QUALITY OF LIFE FOR OUR RESIDENTS A PLAN OF CARE DECIDED BY YOU AND YOUR FAMILY WORKING TOGETHER WITH YOUR DOCTOR AND THE TEAM THAT CARE FOR YOU

What is palliative care?

Palliative care helps decrease suffering and improves comfort for individuals with chronic or serious illness. It is care that treats symptoms of illness to help your quality of life. Palliative care keeps your comfort and goals at the center of all care.

How can it help me achieve my goals for care?

It is important that you understand your illness. Your care team will work with you to ensure you understand your medical condition and develop goals for your care. With palliative care, the team will work to decrease your symptoms such as pain, trouble breathing or trouble sleeping. Palliative care can also help with emotional or spiritual comfort.

Your care team will talk to you about making care choices and decisions about future care. Your care team will give you information to help you decide what types of treatment you may or may not want. The nursing home will help you with legal documents such as a living will or a durable power of attorney for healthcare.

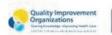




How do I get palliative care?

Palliative care is provided right here at the nursing home as part of your services. It does not increase the cost of your care. You do not need a new doctor to get palliative care. Your care team will work with your doctor.

If you need a specialist, your care team will review insurance options to pay for the consultation services.





Talk to a member of your care team today.

This material was prepared by Healthcentric Advisors, the Medicare Quality Improvement Organization for Rhode Island, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy. Publication # 10SoW-RI-GEN-112013-957

End of Life Care

End of Life: Helping with Comfort and Care

This 70 page booklet helps family caregivers and consumers cope with all aspects of end of life care with sensitivity. It is printed by the National Institutes of Health and the National Institute on Aging. It is available in a PDF download or print copies can be ordered through the <u>National Institute on Aging</u>.

Gone From my Sight: The Dying Experience

This booklet helps families understand the dying process and what to expect during this difficult time. It has been widely recognized and used by hospice providers for many years. It can be purchased directly from the <u>author's website</u> with discounts for bulk purchases.

Advance Care Planning

...Are You Traveling Without a Map? A Layperson's Guide to Advance Care Planning

This two page flyer explains the need for advance care planning directly to consumers or family members. It is available through the companion website for the National Hospice and Palliative Care Organization (NHPCO). This website has brochures and information geared directly for the consumer and family members. Some brochures are available in Mandarin and Spanish. These tools are available on the consumer website for the NHPCO. Click the Planning Ahead tab to view list of educational flyers.

AgePage: Getting Your Affairs in Order

The National Institute on Aging produces multiple AgePage brochures on various topics. This brochure can assist individuals with understanding what steps to take to get legal and financial papers organized. It is available in multiple versions. A booklet with all the AgePage brochures and <u>NIA publications</u> is available for review.

Advance Care Planning

This two page document was developed by the National Institute of Health (NIH) to assist consumers in understanding why they need to complete advance care planning and how to get started. A printer friendly version can be printed from the <u>NIH</u> website.

5 Easy Steps for Advance Care Planning

This 15 minute YouTube video walks through 5 steps of advance care planning and is weaved together with consumers' and family members' personal stories. It was developed by Compassion and Support. This tool is available on <u>YouTube</u>.

Consumer's Tool Kit for Health Care Advance Planning

The American Bar Association makes this tool kit available on its website for consumers. There are 10 printable tools available in the tool kit, including "How to Select Your Health Care Agent or Proxy" and "Personal Priorities and Spiritual Values Important to Your Medical Decisions". This tool kit is available on the <u>American Bar</u> website.

Resident – Facility Communication

Nursing Home Checklist

This checklist is designed for those reviewing potential nursing homes. However, it also has a "Words to Know" section that can help residents and family members understand the terminology and descriptions used during care plan meetings. It was developed by the Alliance for Better Long Term Care. This tool is available on the <u>Alliance</u> website.

Assessment and Care Planning: The Key to Quality Care

This two page fact sheet can be printed and provided to residents or family members. It describes the assessment and care planning process in long term care settings. It provides a checklist of how to prepare and what to ask/explain during a care plan meeting. This fact sheet encourages the consumers and families to be active participants in the Care Planning process. It was developed by The National Consumer Voice for Quality Long Term Care, an advocacy and educational organization for long term care residents. This tool is available on the <u>Consumer Voice</u> website.

Encouraging Comfort Care: A Guide for Families of People with Dementia Living in Care Facilities

This 21 page booklet was developed by the Alzheimer's Association – Greater Illinois Chapter. It can be downloaded and is designed to help family members understand dementia and the care that can be provided in the long term care setting. It defines comfort care and includes a checklist for family members to review with the facility staff. The Association states that this useful information is particularly helpful around care issues in the late and final stages of dementia. This tool is available on the <u>Greater Illinois Chapter</u> website.

Family Involvement in Nursing Home Care

This two page flyer developed by the National Citizens' Coalition for Nursing Home Reform provides family members of residents with an understanding of the role they have in their loved one's care. It gives family members tips on understanding the care plan process, visiting the resident and advocating for the resident. This tool is available on the <u>Consumer</u> <u>Voice</u> website.

8 RHODE ISLAND SPECIFIC RESOURCES



Rhode Island Hospice and Palliative Care Providers

The Department of Health has licensed eight providers of Hospice services in the State of Rhode Island. These providers also provide palliative care services. Their ability to provide palliative care services for non-hospice patients will vary from agency to agency and may be dependent on insurance reimbursement, staffing availability, and diagnosis of the patient. Many of the providers offer a "bridge" type program of palliative care prior to a patient becoming hospice eligible. In addition, many of these providers will offer palliative care consulting and education to nursing home staff.

When contracting for services with a nursing home, providers may use different approaches and models for care. These models may include use of a Nurse Practitioner, providing different models of nursing support, and/or bringing in other disciplines as needed. The provider is always acting in the role as a consultant and will be working with the resident's primary care physician. All of these consulting providers should be recognized as a part of the resident's care team and be included in the care planning and resident goal setting discussions.

Department of Health Licensed Providers

Beacon Hospice, an Amedisys Company 1 Catamore Blvd East Providence, RI 02914 800-981-8791 (East Providence Office) 800-981-4807 (North Kingstown Office) www.BEACONHOSPICE.COM Service Area: All of Rhode Island

Gentiva Hospice (formerly Odyssey Hospice) 2374 Post Road Suite 206 Warwick, RI 02886 401-738-1492 877-637-9432 <u>WWW.GENTIVA.COM</u> Service Area: All of Rhode Island

Home and Hospice Care of Rhode Island 1085 North Main Street Providence, RI 02904 401-415-4200 Referral: 800-338-6555 <u>WWW.HHCRI.NET</u> Service Area: All of Rhode Island

Nursing Placement, Inc 334 East Avenue Pawtucket, RI 02860 401-728-6500 WWW.NURSINGPLACEMENT.COM Service Area: Offices in Pawtucket, Cumberland and WarwickSouthcoast Visiting Nurse Association 1676 East Main Road Portsmouth, Rhode Island 02871 1-800-698-6877

WWW.SOUTHCOASTVNA.ORG

Service Area: Portsmouth, Middletown, Newport, Tiverton, Little Compton

Visiting Nurse Services of Newport and Bristol Counties 1184 East Main Road, Portsmouth, RI 21 Chapel Street, Newport, RI 1162 GAR Highway, Swansea, MA 624 Main Street, Warren, RI 401-682-2100 800-456-1195

WWW.VNSRI.ORG

Service Area: Barrington, Warren, Bristol, Tiverton, Adamsdale, Portsmouth, Middletown, Little Compton, Newport, Jamestown, Prudence Island

VNA of Care New England 51 Health Lane Warwick, RI 02886 401-737-6050 <u>www.vNACARENEWENGLAND.ORG</u> Service Area: All of Rhode Island

VNA of Rhode Island 475 Kilvert Street Warwick, RI 02886 401-574-4900 <u>www.Hospicevnari.org</u>

Service Area: All of Rhode Island

Rhode Island Laws, Rights, Rules and Regulations Pertaining to Palliative Care

Durable Power of Attorney for Health Care

Chapter 23-4.10 is the RI General Law for Health Care Power of Attorney. This law, amongst other things, provides RI residents the opportunity to legally appoint and give power to an agent (as proxy) to make health care decisions for them when they are no longer able to participate actively in those decisions.

Click here to access a PDF version of the law.

To access the document approved by the State (English and Spanish available), go to the <u>Rhode Island Department of Health</u> website.

The Durable Power of Attorney for Health Care document is an advance care directive. This document walks the consumer through what decisions the appointed agent (as proxy) health care decision maker can make. There is a section on Health Care Instructions that is optional but allows the consumer to relay their wishes around pain management, spiritual needs, life support issues, and organ donation. This form, when used, must be witnessed and signed by two "qualified" individuals or one Notary Public.

Rights of the Terminally III Act

Chapter 23-4.11, is the General Law that provides RI residents with the legal right to make a written declaration instructing their physician(s) to withhold or withdraw life sustaining procedures that merely prolong the dying process and are not necessary to comfort or to alleviate pain in the event they are diagnosed with a terminal condition and are unable to make decisions regarding their own medical treatment.

Click here to access a PDF version of the law.

To access the PDF document approved by the State (English, Spanish, Portuguese and French available), go to the <u>Rhode Island Department of Health</u> website.

The Instructions to Living Will is considered an advance care directive. This document provides a place for the consumer to document specifically, the option to stop or withhold artificially administered nutrition and hydration (food and water). There is no additional space to document explanations related to this decision or to outline wishes.

Rules and Regulations Pertaining to Medical Orders for Life Sustaining Treatment (MOLST)

Chapter 23-4.11 is also the RI General Law that via Section 23-4.11-3.1, gives the RI Department of Health authority to promulgate and establish procedures for MOLST and the structure and content of MOLST forms. 3.1.

Click here to access a PDF this section of the law.

<u>Click here</u> to access the PDF version Rules and Regulations pertaining to MOLST, go to:

Click here to access a PDF version of the MOLST form.

This Rules and Regulations Pertaining to MOLST document sets out the MOLST form, instructions and certain related procedures and requirements developed by the RI Department of Health.

н	PAA PERMITS DISCLOSURE OF MOLST TO OTHER HE		
		IS REQUIRED TO COMPLETE A MOLST FORM.	
CH21	V6	Life Sustaining Treatment (MOLST Patient's Last Name)
ŝ.	First follow these orders, then contact MOLST	Order	_
1 2 5	🔨 🐂 👙 Sheet, based upon the person's current medical con	dition M	F
24	without a section not completed implies full treatment of the MOLST remains in effect unlose revised.	nent. Patient's Date of Birth Date/Time Form Prepared	
Α		(CPR): Person has no pulse and is not breathing.	
Check	Attempt Resuscitation/CPR Do N	ot Attempt Resuscitation/DNR (Allow Natural Death))
One	No defibrillator (including automated external defibrillators) should be used on a person who has chosen "Do Not Attempt Resuscitation."		
	When not in cardiopulmonary arrest, follow ord	ers in B and C.	
в	MEDICAL INTERVENTIONS:	Person has pulse and/or is breathing.	
Check One		by any route, positioning, wound care and other measures to n and manual treatment of airway obstruction as needed for	,
		es care described above. Use medical treatment, tubate. May use non-invasive positive ainway pressure.	
	mechanical ventilation, and defibrillation/cardio Includes intensive care.	ove. Use intubation, advanced airway interventions, wersion as indicated. Transfer to hospital if indicated.	
C	TRANSFER To HOSPITAL Do Not Transfer to hospital for medical interven	tions. Transfer if comfort needs cannot be met in current location.	
000			_
D	ARTIFICIALLY NUTRITION (FOR EXAMPLE-A FE No artificial nutrition.	EDING TUBE): Offer food by mouth if feasible and desired. Defined trial period of artificial nutrition.	
One	 Long-term artificial nutrition, if needed. 	Artificial nutrition until not beneficial or burden to patient.	
E	ARTIFICIALLY HYDRATION: Offer fluid/nutr		
Check	 No artificial hydration. 	 Defined trial period of artificial hydration. 	
One	 Long-term artificial hydration, if needed. 	 Artificial hydration until not beneficial or burden to patient 	t.
F	ADVANCE DIRECTIVE (If any) Check all advance dree Durable Power of Health Care D Health Care Proc		
Check	Discussed with:	xy DLiving Will Documentation of Oral Advance Directive	•
One	Patient Health Care Decision Maker Parent/Gu	ardian of Minor 🔲 Court Appointed Guardian 🗌 Other:	_
G		R HEALTH CARE (Physician, RNP, APRN, and PA): ese orders are consistent with the person's medical condition and preference	×
Check	Signature (Required)	Phone Number Date/Time	
	Print Name	License #	-
	Signature of Patient, Decision Maker, Parent/Guardian of Minor, or Guardian By signing this form, the legally recognized decision maker acknowledges that this request regarding resuscitative measures is consistent with		
	the known desires of, and with the best interest of, the individual Signature (Required) Phone	who is the subject of the form. Relationship (if patient, write	self)
	Print Name and Address		_
		ENEVER TRANSFERRED OR DISCHARGED.	
	Rhode Island General Laws §23-4.11-3.1	authorizes this MOLST Form. (Rev. 9-201	13)

Palliative Care and Quality of Life Act

This Act was signed by the Governor on July 15, 2013. This Act requires the Department of Health to create "The Rhode Island Palliative Care and Quality of Life Interdisciplinary Advisory Council." It also requires the Department of Health to establish a palliative care consumer and professional information and education program. It requires all licensed healthcare organizations to "consult with the organization's physicians to educate them on

how to provide information about appropriate palliative care services for those patients or residents with serious illness, who, in their professional opinion, would benefit from them."

To review the Act visit the Rhode Island General Assembly website.

Rights of Residents

RI General Laws Chapter 23-17.5 outlines the Rights of Nursing Home Patients. Some sections are pertinent to palliative care, including:

<u>Section 23-17.5-6 Care by Physician-Disclosure of patient's medical condition</u> –(b) Each patient shall be informed by a physician of his or her medical condition unless medically contraindicated, as documented by a physician in his or her medical record, and shall be afforded the opportunity to participate in the planning of his or her medical treatment.

<u>Section 23-17.5-28 Pain Assessment</u> – A patient shall have the right to have his or her pain assessed on a regular basis.

To access the law, go to the <u>Rhode Island General Assembly</u> website.

COMFORT ONE Bracelet

The Comfort One program is a way for emergency medical services personnel to honor the wishes stated in a patient's legally executed Living Will, Durable Power of Attorney for Health Care or Do Not Resuscitate (DNR) order in the out-of-hospital setting. The presence of the COMFORT ONE bracelet informs emergency medical personnel not to initiate resuscitation efforts. A resident must request this bracelet through their physician who will file the DNR orders with the Department of Health.

To access the COMFORT ONE Administrative Handbook, go to the <u>Rhode Island</u> <u>Department of Health</u> website.

Rules and Regulations Related to Pain Assessment

The Rhode Island Department of Health has established Rules and Regulations Related to Pain Assessment (R5-37.6-PAIN). Section 2.0 of these Rules and Regulations outline the healthcare provider's responsibilities around pain assessment. Appendix A of these Rules and Regulations outline pain assessment tools that meet the standards set forth. The Appendix and Section 2.0 are excerpted on the following pages. The full content of these rules and regulations can be accessed online at the Department of Health website, under the Current Regulations tab.

<u>Click here</u> to access a PDF version of The Rules and Regulations Related to Pain Assessment.

Section 2.0 General Requirements: Pain Assessment

- 2.1 Health care facilities and health care providers, as defined herein, shall conduct an assessment of pain experienced by a patient on a regular basis, according to a written protocol established by the health care facility or health care provider, respectively.
- 2.2 Pain shall be assessed in all inpatients upon admission, using a combination of patient's self-report, a health care provider's assessment, and/or a pain intensity tool. Pain assessment shall provide for an evaluation of, and /or further testing to collect additional information to determine any underlying causes or reasons for, the identified presence and severity of pain. As appropriate, assessments shall utilize a pain intensity tool and address the location, duration, onset, and characteristics of pain, the patient's goals, and alleviation of causative factors. Physical examination shall be conducted as indicated.
- 2.3 Pain shall be assessed in all outpatients upon intake or initial evaluation using a combination of patient's self-report, a health care provider's assessment, and/or a pain intensity tool. Pain assessment shall provide for an evaluation of, and/or further testing to collect additional information to determine any underlying causes or reasons for, the identified presence and severity of pain. As appropriate, assessments shall utilize a pain intensity tool and address the location, duration, onset, and characteristics of pain, the patient's goals, and alleviation of causative factors. Physical examination shall be conducted as indicated.

Outpatients presenting for diagnostic tests only (e.g., laboratory studies, radiological examinations) shall be exempted from the pain assessment requirements herein.

- 2.4 On a regular basis, all patients shall be re-assessed for pain according to a written protocol established by the health care facility or health care provider.
- 2.5 All pain assessments and re-assessments shall be documented in the patient's clinical record.
- 2.6 More than one pain intensity tool may be used by the health care facility or health care provider. Provided, however, the same pain intensity tool shall be utilized consistently in assessing the same patient and provided the tool is, and continues to be, appropriate for the patient.
- 2.7 At least annually, health care facilities shall ensure competency in pain assessment among appropriate clinicians as designated by the health care facility.

APPENDIX A

Pain Intensity Tools

Visual Analogue Scale

