

Department of Health Care Finance & Comagine Health  
Nursing Facility Quality Improvement Collaborative

# Nursing Facility Palliative Care Toolkit

February 2020

Adapted by Comagine Health, the Medicare Quality Innovation Network - Quality Improvement Organization (QIN-QIO) for Idaho, Nevada, New Mexico, Oregon, Utah and Washington, from materials provided by Healthcentric Advisors, and prepared 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. Original Publication #10SoW-RI-GEN-102013-927

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# Section 1: Acknowledgements

Welcome to Year Two of the Department of Health Care Finance and Comagine Health Nursing Facility Quality Improvement Collaborative. The overall aim of the Year Two Collaborative is to develop and implement quality, person-centered End of Life care that is consistent with residents' wishes.

Many organizations and individuals contributed to the development of this Collaborative Toolkit. We would like to recognize the following organizations and individuals for providing direction, funding, and expertise.

## **Healthcentric Advisors**

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.

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. Comagine Health has edited the Toolkit (with permission from Healthcentric Advisors) for use in the Department of Health Care Finance & Comagine Health Nursing Facility Quality Improvement Collaborative.

## **Department of Health Care Finance (DHCF) District of Columbia**

### **Comagine Health**

Comagine Health is contracted by DHCF to lead the Nursing Facility Quality Improvement Collaborative.

### **The Institute for Healthcare Improvement (IHI)**

IHI-developed the Breakthrough Series Collaborative learning methodology including the Model for Improvement.

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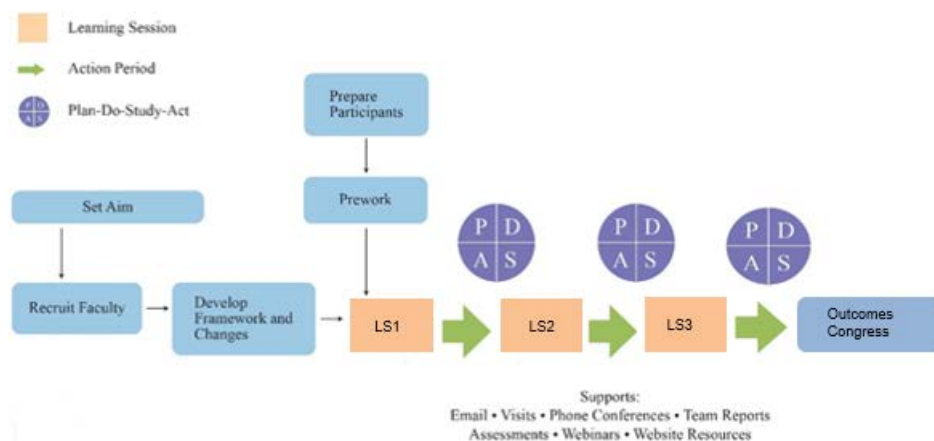
## Section 2: Introduction

**The Nursing Facility Quality Improvement (NFQI) Collaborative** involves 17 long term care nursing facilities in the District of Columbia, working together to individually test system changes aimed at improving quality and building tools for successful participation in pay-for-performance programs. A primary focus of the Collaborative is to collectively share learnings. The four main components of the Collaborative are prework activities, learning sessions, action periods, and the outcomes congress.

**The Nursing Facility Quality Improvement Collaborative** is structured to focus on one-year topic cycles, over a five-year period. The Collaborative structure is designed to focus on a limited number of improvement goals over a relatively short time frame to develop skills in rapid process improvement. New priorities will be assessed each year to determine new topics, evidence-based practices and support to bridge care gaps and ensure the success of nursing facilities in the pay for performance environment.

**Collaborative Year One (November 2018 – October 2019)** focused on the topic of bowel and bladder incontinence. Providers also had the option to select their own topic(s) of interest (e.g., falls, pressure ulcers, MDS training, staffing, etc.) based on assessments and baseline data collected by DHCF to improve Nursing Facility Quality Improvement (NFQIP) Program. **End of Life Care** has been selected as the primary topic for **Collaborative Year Two** (November 2019 – October 2020) with the overall aim of developing and implementing quality, person-centered End of Life care that is consistent with residents' wishes. This **Nursing Facility Palliative Care Toolkit** supports learning quality improvement methodology and rapid cycle improvement and resources for the End of Life **Collaborative**.

### Collaborative Year Two Model



**Prework** is the period between receipt of the Prework Packet and Learning Session 1 (February 2020). During this time, the nursing facility has several important tasks to accomplish in order to prepare for the first Learning Session.

**Learning Sessions** are the major interactive events of the Collaborative. Through plenary sessions, small group discussions, and team meetings, attendees can:

- learn from expert faculty and colleagues,
- receive individual coaching and technical assistance,
- gather knowledge on the subject matter and on process improvement,
- share experiences, learn from peers and collaborate on improvement plans, and
- problem solve barriers to improve care and decide on next steps.

**Action Periods** are the times between Learning Sessions. During action periods, nursing facility teams work within their organizations to test and implement small gradual changes using the Plan, Do, Study, Act (PDSA) model of continuous cycles of improvement, aimed at improving specific clinical and organizational quality indicators. Teams share the results of their improvement efforts in monthly senior leader reports and participate in shared learning through an email distribution list, conference calls, and webinars. Participation in action periods is not limited to those who attend the Learning Sessions; we encourage and expect the participation of other team members and supporters in the nursing facility.

**Outcomes Congress** The Collaborative will share its findings and achievements at an annual outcomes congress that will highlight the accomplishments of the teams and present effective models of improving care for nursing home residents.

**Collaborative Schedule** The sequence of events for Collaborative Year Two is as follows:

<b>Pework</b>	November 2019 – February 2020 <ul style="list-style-type: none"> <li>• Site visits to be scheduled with each facility</li> </ul>
<b>Learning Session 1</b>	February 27, 2020 (8:30am - 12:30pm)
<b>Action Period 1</b> <ul style="list-style-type: none"> <li>• Technical Assistance (TA)</li> <li>• Webinar #1</li> </ul>	February – April 2020 <ul style="list-style-type: none"> <li>• To be scheduled with each facility</li> <li>• April 13, 2020 (1:00 – 2:00pm)</li> </ul>
<b>Learning Session 2</b>	May 21, 2020 (8:30am - 12:30pm)
<b>Action Period 2</b> <ul style="list-style-type: none"> <li>• TA</li> <li>• Webinar #2</li> </ul>	May – July 2020 <ul style="list-style-type: none"> <li>• To be scheduled with each facility</li> <li>• July 16, 2020 (1:00 – 2:00pm)</li> </ul>
<b>Learning Session 3</b>	August 20, 2020 (8:30am – 12:30pm)
<b>Action Period 3</b> <ul style="list-style-type: none"> <li>• TA</li> <li>• Webinar #3</li> </ul>	August – October 2020 <ul style="list-style-type: none"> <li>• To be scheduled with each facility</li> <li>• September 17, 2020 (1:00 – 2:00pm)</li> </ul>
<b>Outcomes Congress</b>	October 29, 2020 (8:30am - 12:00pm)

## Background

### Palliative Care in Nursing Facilities

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 <sup>(1)</sup>. 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 facilities by the year 2030<sup>(2)</sup>. Whether a nursing facility 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<sup>(3)</sup>. Research has shown that many nursing facilities 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 facility. These transitions lead to concerns around communication between providers regarding care plans, potential medication errors and increased discomfort for the resident <sup>(4)</sup>.

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

The very reason that residents are admitted to long term care settings, 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<sup>(7)</sup>.

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 facilities have formal palliative care programs although care practices include elements of palliative care<sup>(8)</sup>. The Center to Advance Palliative Care's review of research shows that most nursing facilities 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 facilities include poor transitions between care settings, understaffing at the majority of US nursing facilities, and the training and educational needs of staff <sup>(9)</sup>. The current payment structure for nursing facilities 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 <sup>(10)</sup>. 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 <sup>(11)</sup>.

In essence, the residents of nursing facilities 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<sup>(12)</sup>

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

## References

<sup>1</sup>National Consensus Project for Quality Palliative Care (2013). *Clinical Practice Guidelines for Quality Palliative Care, Third Edition*. Pittsburgh, PA [www.nationalconsensusproject.org](http://www.nationalconsensusproject.org).

<sup>2</sup>*Improving Palliative Care in Nursing Homes*. Rep. New York: Center to Advance Palliative Care, 2008. [www.capc.org](http://www.capc.org) Center to Advance Palliative Care. Web. 08 July 2013.

<sup>3</sup>*National Quality Forum*. *National Quality Forum*, Web. 08 July 2013. [www.nationalqualityforum.org](http://www.nationalqualityforum.org).

<sup>4</sup>*Improving Palliative Care in Nursing Homes*. Rep. New York: Center to Advance Palliative Care, 2008. [www.capc.org](http://www.capc.org) Center to Advance Palliative Care. Web. 08 July 2013.

<sup>5</sup>Meier, Diane E., Stephen L. Isaacs, and Robert G. Hughes. *Palliative Care: Transforming the Care of Serious Illness*. San Francisco: Jossey-Bass, 2010. Print.

<sup>6</sup>Ibid

<sup>7</sup>*Palliative Care Best Practices*. Rep. Denver: Center for Improving Value in Health Care, 2012. [www.civhc.org](http://www.civhc.org) Center for Improving Value in Health Care. Web. 08 July 2013

<sup>8</sup>*Improving Palliative Care in Nursing Homes*. Rep. New York: Center to Advance Palliative Care, 2008. <http://www.capc.org> Center to Advance Palliative Care. Web. 08 July 2013.

<sup>9</sup>Ibid

<sup>10</sup>Stefanacci, Richard G. "Urgent Care in the Nursing Home: Aligning the Incentives." *Clinical Geriatrics* 19.2 (2011): 22-24. Print.

<sup>11</sup>*Improving Palliative Care in Nursing Homes*. Rep. New York: Center to Advance Palliative Care, 2008. <http://www.capc.org> Center to Advance Palliative Care. Web. 08 July 2013.

<sup>12</sup>Lynn, Joanne, Ekta Chaudhry, Lin Noyes Simon, Anne M. Wilkinson, and Janice Lynch Schuster. *The Common Sense Guide to Improving Palliative Care*. Oxford: Oxford UP, 2007. Print.



## Section 3: General Team Resources

Forming a team is an essential component to achieving quality improvement initiative success. Please refer to the DC NF Collaborative Prewrite Packet section “Forming a Team.” The following team resource templates support specific palliative care team rosters, meeting agenda structure and a work plan to achieve palliative care improvements.

### Nursing Facility Palliative Care Team Resources Contact List

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

## Nursing Facility Palliative Care One Year Work Plan

Activity	References and Resources	Completion Date
Seek palliative care team members and gain their commitment to champion palliative care.	DC NF Collaborative Prewrite Packet section Forming a Team Lynn, J, et al. <i>The Common Sense Guide to Improving Palliative Care</i> . New York; Oxford University Press; 2007 (Chapter 2, Basics of Quality Improvement: Establishing a Good Team)	
Gather research and information regarding the need for palliative care improvement in your facility.	Nursing Facility Palliative Care Toolkit, (Section 2, Introduction and Section 3, General Team Resources)	
Seek leadership approval and support to focus on palliative care improvement, select and develop co- leaders and staff that are accountable for the EOL care team.	Lynn, J, et al. <i>The Common Sense Guide to Improving Palliative Care</i> . New York; Oxford University Press; 2007 (Chapter 2, Basics of Quality Improvement: Establishing a Good Team)	
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.	
If no external providers are on your team, partner with local academic organizations and community hospice and palliative care programs 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 <a href="https://dchealth.dc.gov/service/hospice-facilities-directory">District of Columbia Hospice Directory</a> ( <a href="https://dchealth.dc.gov/service/hospice-facilities-directory">https://dchealth.dc.gov/service/hospice-facilities-directory</a> ) or <a href="https://www.nhpco.org/">National Hospice and Palliative Care Organization</a> ( <a href="https://www.nhpco.org/">https://www.nhpco.org/</a> ) websites to search list of providers in your area	
Have first collaborative interdisciplinary palliative care team meeting and establish a mission and vision for EOL care.	Nursing Facility Palliative Care Toolkit, (Section 3, General Team Resources)	
Determine how the team plans to measure success. Review process measures and outcome measures.	Nursing Facility Palliative Care Toolkit (Section 6, Data Collection and Measurement)	
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	
Review Model for Improvement as a team.	Nursing Facility Palliative Care Toolkit (Section 4, Quality Improvement)	

Activity	References and Resources	Completion Date (Months 1-9)
<b>Complete an interdisciplinary palliative care in-service for staff using internal or external palliative care subject matter experts.</b>	Seek external partners with palliative care expertise to provide curriculum, review Nursing Facility Palliative Care Toolkit ( <a href="#">Appendix A On-Line Resource Links</a> for programs with established curricula such as EPEC: Education in Palliative and End-of-Life Care and End of Life Nursing Education Consortium (ELNEC) courses as needed <a href="https://www.aacnnursing.org/ELNEC/Courses">https://www.aacnnursing.org/ELNEC/Courses</a> )	
<b>Determine areas of need for change in your facility through review of staff education needs assessment and interdisciplinary team discussion.</b>	Nursing Facility Palliative Care Toolkit ( <a href="#">Sections 5, Change Idea Sheets</a> )	
<b>At a team meeting, develop an aim statement and establish a PDSA cycle to implement a change process</b>	Nursing Facility Palliative Care Toolkit ( <a href="#">Section 4, Quality Improvement</a> )	
<b>Implement the first PDSA cycle</b>	Nursing Facility Palliative Care Toolkit ( <a href="#">Section 4, Quality Improvement</a> )	
<b>At team meeting, review results of first PDSA cycle and determine whether to adopt the change, adapt the change or abort the change</b>	Nursing Facility Palliative Care Toolkit ( <a href="#">Section 4, Quality Improvement</a> )	
<b>Use first PDSA results and initial needs assessment to determine next PDSA cycle</b>	Nursing Facility Palliative Care Toolkit ( <a href="#">Section 4, Quality Improvement</a> )	
<b>At team meeting, develop and implement additional PDSA cycles until achievement of the goal and evidence of a sustained process. Review results of each PDSA cycle to determine whether to adopt the change, adapt the change or abort the change.</b>	Nursing Facility Palliative Care Toolkit ( <a href="#">Section 4, Quality Improvement</a> )	
<b>At team meeting, review the ongoing effectiveness of the changes implemented through the multiple PDSA cycles. If the facility has not sustained the improvements, complete a root cause analysis and reassess process.</b>	Nursing Facility Palliative Care Toolkit ( <a href="#">Section 4, Root Cause Analysis</a> and <a href="#">Section 7 Intervention Tools</a> )	

Activity	References and Resources	Expected Completion
Use outcome of root cause analysis to support the facility in sustaining the positive changes made through the multiple PDSA cycles.	Lynn, J, et al. <i>The Common Sense Guide to Improving Palliative Care</i> . New York; Oxford University Press; 2007 (Chapter 2, Basics of Quality Improvement: Making the changes stick)	
If achievement of the goal and evidence of a sustained process is achieved, determine your facility's plan to sustain all positive changes.	Lynn, J, et al. <i>The Common Sense Guide to Improving Palliative Care</i> . New York; Oxford University Press; 2007 (Chapter 2, Basics of Quality Improvement: Making the changes stick)	
Develop a new aim statement to improve additional processes via various palliative change ideas. Repeat PDSA cycle as outlined in earlier workplan steps.	Nursing Facility Palliative Care Toolkit (Section 4, Introduction to Quality Improvement)	
Review palliative care team infrastructure, vision and mission to ensure your team meetings and PDSA cycles are supporting the original intent of your aim.		
Complete a six-month review of efforts and complete a storyboard to share results with staff, residents, families, facility visitors and/or leadership. Be sure to evaluate your facility performance using the original determinants of success outlined during the initial months of the work plan	Nursing Facility Palliative Care Toolkit (Section 4, Sharing Results and Section 6 Data Collection and Measurement)	
Update your story board to include the successes of months six through nine. Share results with staff, facility visitors, external partners.	Nursing Facility Palliative Care Toolkit (Section 4, Sharing Results)	
<p><i>Note: Rapid change is achieved by frequent PDSA cycles with adopt, adapt or abort determinations to inform the next PDSA cycle. The examples of cycles of PDSAs and timelines in the workplan above over 9 months is illustrative of the <u>general</u> process. Multiple PDSA cycles can be achieved within a week or a month. An aim statement remains relevant through several PDSA cycles until achievement of the goal and evidence of a sustained process. A new aim statement is developed as the team turns its focus to improving additional processes via various palliative care change ideas.</i></p>		

## Palliative Care Team Meeting Agenda Template

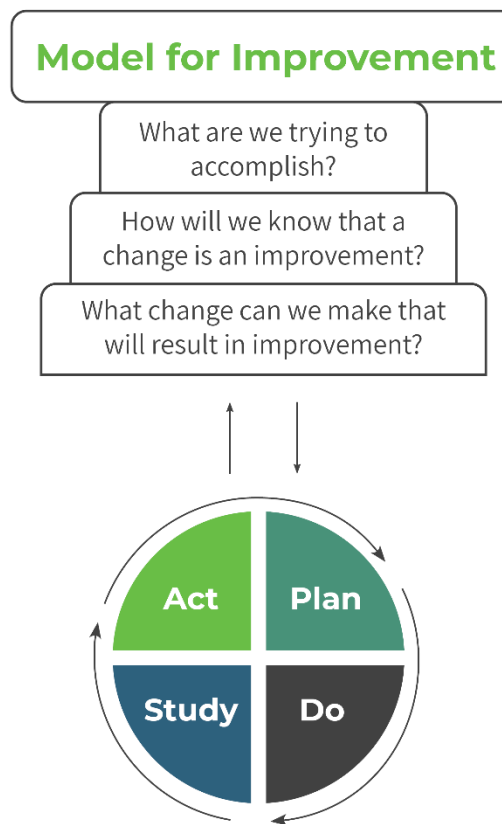
Agenda Item	Facilitator	Time Allocation
1. Action items from previous meetings		
2. Engagement Activity (Updates on team composition, multi-disciplinary champions and additional outreach efforts)		
3. Education Activity (Review the KSA grids; change idea sheets; root cause analysis results, to determine 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)		

## Section 4: Quality Improvement

When implementing a change process, there are several models of change and learning from which to choose. For this Collaborative we are using the Model for Improvement. The **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 and in the DC NH Collaborative Prewrite Packet.

### 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.

## Palliative Care Best Practice AIM Worksheet (Template)

Nursing Facility: \_\_\_\_\_

### 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 Facility 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, 2020

### **By how much?**

**This is the target performance measurement that the team has identified.**

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

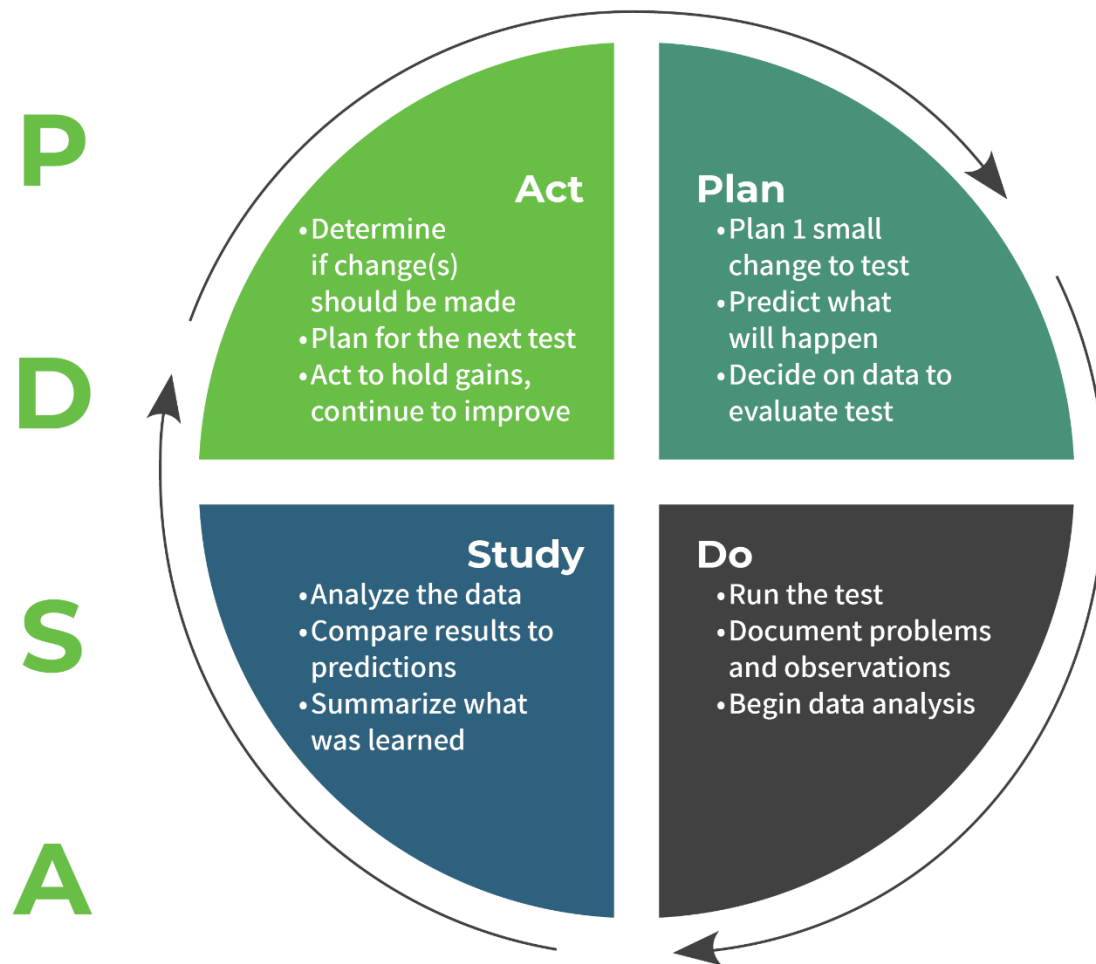
### **Complete AIM Statement:**

Identification and documentation of proxy decision maker within 14 days of admission to the nursing home improves from 50% to 75% by November 15, 2020.



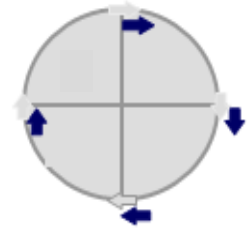
## Making the Change:

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.



## PDSA Worksheet (Template)

<b>Palliative Care PDSA Worksheet</b> (Template)	Team Name: _____ Cycle start date: _____ Cycle end date: _____
<p><b>PLAN:</b> Area to work on:</p> <p>Describe the change you are testing and state the question you want this test to answer (If I do x will y happen?)</p> <p>What do you predict the result will be?</p> <p>What measure will you use to learn if this test is successful or has promise?</p> <p>Plan for change or test: who, what, when, where</p> <p>Data collection plan: who, what, when, where</p>	
<p><b>DO:</b> Report what happened when you carried out the test. Describe observations, findings, problems encountered, special circumstances.</p>	
<p><b>STUDY:</b> Compare your results to your predictions. What did you learn? Any surprises?</p>	
<p><b>ACT:</b> Modifications or refinements for the next cycle; what will you do next?</p>	



## PDSA Worksheet (Sample)

<b>Proxy Decision Maker PDSA Worksheet (sample)</b>	Team Name: Quality Nursing & Rehab Center Cycle start date: 9/15/19 Cycle end date: 9/23/19
<p><b>PLAN: Area to work on</b></p> <p><b>Describe the change you are testing and state the question you want this test to answer (If I do x will y happen?)</b></p> <p>We want to improve use of the Proxy Decision-Maker field in the electronic medical record.</p> <p><b>Test:</b> 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.</p> <p>What do you predict the result will be?</p> <p>Predict that identification and documentation of proxy decision-maker improves by at least 25% at time of admission.</p> <p>What measure will you use to learn if this test is successful or has promise?</p> <p>measure = <u># of Residents whose EMR field is completed within 14 days of admission</u></p> <p style="padding-left: 40px;">All residents Admitted to Rehab Unit during the Sept 15-23 timeframe</p> <p>Plan for change or test: who, what, when, where</p> <p><b>Who:</b> 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.</p> <p><b>What:</b> 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.</p> <p><b>When:</b> September 15-Sept 23</p> <p><b>Where:</b> Rehabilitation Unit</p> <p>Data collection plan: who, what, when, where</p> <p><b>Who:</b> Jane Doe, QA Coordinator</p> <p><b>What:</b> Review the utilization of the EMR field "Proxy Decision-Maker" on admitted residents from September 15- September 23 and collect data</p> <p><b>When:</b> September 23-October 7 (allowing for the 14-day window)</p> <p><b>Where:</b> Electronic Medical Record</p>	
<p><b>DO: Report what happened when you carried out the test. Describe observations, findings, problems encountered, and special circumstances.</b></p> <p>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.</p>	
<p><b>STUDY: Compare your results to your predictions. What did you learn? Any surprises?</b></p> <p>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.</p>	
<p><b>ACT: Modifications or refinements for the next cycle; what will you do next?</b></p> <p>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.</p>	

## Knowledge, Skills and Attitudes (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”
- **Attitudes:** The state of mind, feelings or beliefs

### Competency Grids

Competency: Identifying a Proxy Decision-Maker	K	S	A
1. Understand the importance for each resident to have an identified proxy decision-maker	X		
2. Believe that having a proxy decision-maker identified is beneficial to the resident			X
3. Develop a tool for recording this information in the record both on paper and electronically		X	
4. Feel comfortable and confident in posing questions to residents about care scenarios that may involve a proxy-decision maker			X
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	X		
7. Recognize cultural issues and how this may intersect with identifying proxy decision-makers	X		
8. Have a pre-defined script for discussing proxy-decision makers with residents.	X		
9. Be able to adapt the script in the moment to given situations and conversations as they arise		X	
10. Document the identified proxy-decision maker		X	
11. Assess whether further follow up will be required (i.e. legal documents, referrals) and act on that assessment		X	

<b>Competency: Advance Care Planning Discussion with Residents</b>	<b>K</b>	<b>S</b>	<b>A</b>
1. Recognize the value of having discussions around choices in care prior to needing that care			X
2. Understand the scope and content of an Advance Care Planning discussion	X		
3. Have thorough knowledge of the state's legally accepted documents and how to obtain/complete them	X		
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		X	
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			X
7. Recognize cultural issues and how this may intersect with an Advance Care Planning discussion	X		
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)		X	
9. Have presence of self and understand if one's own bias is interfering with the discussion	X		
10. Assess whether further follow up will be required (i.e. legal documents, referrals) and act on that assessment		X	
11. Document the discussion and resulting care choices		X	

<b>Competency: Have Discussion of Resident Prognosis or Illness Trajectory with Resident/Family</b>	<b>K</b>	<b>S</b>	<b>A</b>
1. Identify prognosis or change in illness trajectory	X		
2. Value the importance of a resident's or designated decision-maker's right to know the diagnosis, and illness trajectory			X
3. Determine most appropriate team member to have discussion of prognosis or illness trajectory with resident/family		X	
4. Assess for each resident individually the most appropriate manner in which to have a discussion of prognosis or illness trajectory		X	
5. Develop a tool for documenting this discussion with resident/family both electronically and on paper		X	
6. Have an understanding of how certain phrases and terminology can help residents understand and accept their prognosis or illness trajectory	X		
7. Prepare for discussion by reviewing all test results, diagnostic indicators, physical and psychosocial history for the resident		X	
8. Have presence of self to determine if personal history or concerns may influence your participation in this discussion	X		
9. During discussion, assess resident/family's understanding of prognosis or illness trajectory and alter course of conversation according to their health literacy and ability to process information		X	

<b>Competency: Have Discussion of Resident Prognosis or Illness Trajectory with Resident/Family</b>	<b>K</b>	<b>S</b>	<b>A</b>
10. Assess need for follow up discussion in order to accurately relay all information the resident and family must have		X	
11. Assess the need for further follow-up by other professionals (i.e. spiritual or mental health counseling) and act on that assessment		X	
12. Document the discussion and any outcomes		X	

<b>Competency: Have a Discussion with Resident/Family about Goals for Care</b>	<b>K</b>	<b>S</b>	<b>A</b>
1. Recognize the importance of understanding a resident's goals for care			X
2. Understand the importance of the resident having a full understanding of his/her prognosis or illness trajectory in order to formulate care goals based on appropriate information			X
3. Develop a model for including the opportunity for residents to share their goals for care during all care discussions		X	
4. Develop a system for documenting a resident's care goals both in paper record and electronic record		X	
5. 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	X		
7. Assess whether the resident or decision-maker understands the resident's prognosis or illness trajectory prior to forming care goals		X	
8. Recognize how cultural factors may influence a resident's care goals	X		
9. Be able to process a resident's care goals without judgment based on personal beliefs		X	
10. Have presence of self to understand if personal beliefs interfere with acceptance and execution of resident's care goals	X		
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		X	
12. Assess whether resident's stated care goals require a change in the current plan of care, necessitating further team action		X	
13. Document discussion and resident goals for care		X	

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

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

Competency: Completing a Pain Assessment			
	K	S	A
11. Develop a system to document the pain assessment and resulting change/recommendations		X	
12. Document the pain assessment and resulting change/recommendation or resulting actions		X	
13. Act on changes in orders to treat pain		X	
14. Ensure that all staff have information needed to act on changes in orders		X	
15. Determine the protocol for reassessing pain after implementing the pain management regimen		X	
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		X	



## Root Cause Analysis

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. Conducting a root cause analysis allows facility teams to complete an in-depth breakdown of a problem and focus on the changes they need to make. 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.

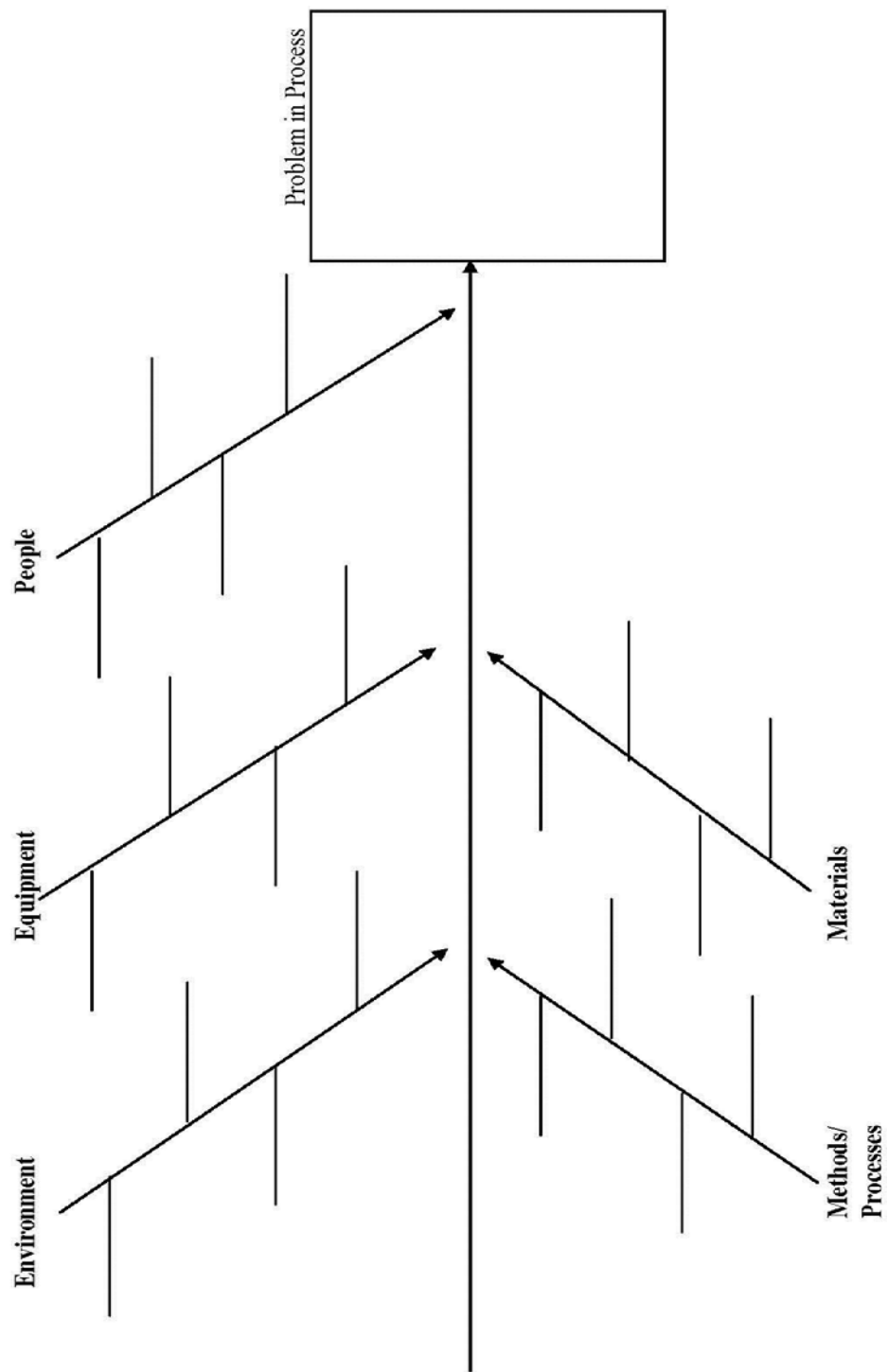
An effective method is called the: “**Five Whys**”. State the problem, ask “why”, answer and then ask “why” again. An example of this method may look like:

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 cause-effect 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 earlier in this section.

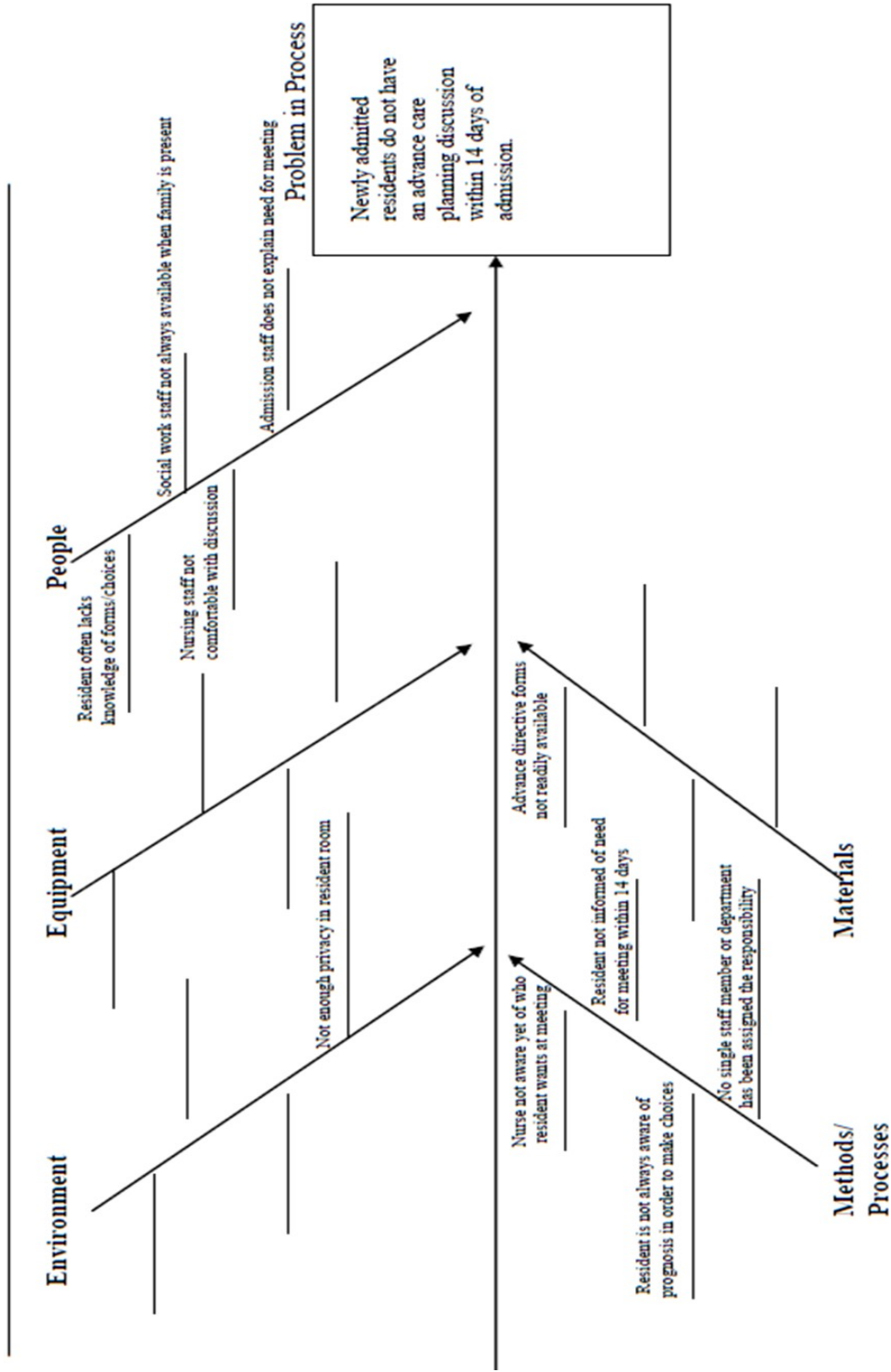
## Fishbone Diagram Template

Goal: \_\_\_\_\_



## Sample Fishbone Diagram

Goal: Every newly admitted resident has an advance care planning discussion within 14 days of admission.



## 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 details:

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.

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Storyboard Guide for Performance Improvement Projects: <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/QAPI/downloads/PIPStoryBdGuide.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 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 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.

## Section 5: Change Ideas

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

### Change Idea #1: 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 Facility 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 facility. 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.

**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 illness trajectory. 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 and illness trajectory, 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 pre-meeting 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 at the End of Life 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 meeting.

## Regulatory Support:

There is much regulatory support around the need to assist residents in the creation of advance directives. **F578 Request/Refuse/Discontinue Treatment; Formulate Advance Directives** states “the resident has the right to refuse treatment, to refuse to participate in experimental research, and to formulate an advance directive...” In addition, **F578 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.

**F551 Rights Exercised by Representative** states in the case of a resident who has not been adjudged incompetent by the state court, the resident has the right to designate a representative, in accordance with State law and any legal surrogate so designated may exercise the resident’s rights to the extent provided by state law. The resident representative has the right to exercise the resident’s rights to the extent those rights are delegated to the representative. The resident retains the right to exercise those rights not delegated to a resident representative, including the right to revoke a delegation of rights, except as limited by State law.

In addition, **F561 Self-Determination** 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 **F561 Self-Determination** charges the nursing facilities with actively seeking information to understand a resident’s preferences and choices for care. **F656 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.

**F684 Quality of Care** further supports residents during end of life situations. Guidelines state that the resident must receive a comprehensive assessment to provide direction for the development of the resident’s care plan to address the choices and preferences of the resident who is nearing the end of life. In addition, 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 resident’s attending physician/practitioner, should, to the extent possible:

- Identify the resident’s prognosis and the basis for that prognosis; and
- Initiate discussions/considerations regarding advance care planning and resident choices to clarify goals and preferences regarding treatment including pain management and symptom control, treatment of acute illness, and choices regarding hospitalization.

The guidelines further state that the care plan must be based upon the resident assessment, choices and advance directives, if any. As the resident’s status changes, the facility, attending practitioner and the resident representative, to the extent possible, must review and/or revise care plan goals and treatment choices.

Care plan interventions for activities must be based on the resident's assessment and include the resident's choices, personal beliefs, interests, ethnic/cultural practices and spiritual values, as appropriate.

The interpretative guideline for **F678 Cardio-Pulmonary Resuscitation (CPR)** ensures personnel provide basic life support, including CPR, to a resident requiring emergency care prior to the arrival of emergency medical personnel and subjected to related physician's orders DNRs, and the resident's advance directives.

#### References and Resources:

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<<http://www.annalsoflongtermcare.com/content/advance-care-planning-transitions-care-challenges-opportunities-and-benefits>>.
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6. Waldrop, D, Meeker, M. "Communication and advanced care planning in palliative and end-of-life care." *Nursing Outlook* 60(2012):365-369. Print.
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](http://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  
[www.theconversationproject.org](http://www.theconversationproject.org).
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 <https://compassionandsupport.org/advance-care-planning/cccc/> or You Tube at <http://www.youtube.com/watch?v=w95MzkQnp2g>

## Change Idea #2: Completing a Pain Assessment in Nursing Facilities

**Definition:** Completing a pain assessment is the first step in enacting a comprehensive pain care program for nursing facility 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 Facility 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.

### 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 recommendations listed in the F697 Pain Management interpretive guidelines. 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 facility.
- ☐ 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 wear 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.

## Regulatory Support:

There is extensive regulatory support around the issues of pain assessment and management for nursing facility 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 **F684 Quality of Care** has a strong focus on managing residents’ preferences for care, including controlling pain. **F697 Pain Management** interpretive guidelines state that Nursing Facility residents are at high risk for having pain that may affect function, impair mobility, impair mood, or disturb sleep, and diminish quality of life. It is important, therefore, that a resident’s reports of pain, or nonverbal signs suggesting pain, be evaluated. The resident’s needs and goals as well as the etiology, type, and severity of pain are relevant to developing a plan for pain management. It should be noted that while analgesics can reduce pain and enhance the quality of life, they do not necessarily address the underlying cause of pain. It is important to consider treating the underlying cause, where possible. **F697 Pain Management** guidance recommends the following strategies for the prevention and management of pain may include but not limited to the following:

- Assessing the potential for pain, recognizing the onset, presence and duration of pain, and assessing the characteristics of the pain; Addressing/treating the underlying causes of the pain, to the extent possible;
- Developing and implementing both non-pharmacological and pharmacological interventions/approaches to pain management, depending on factors such as whether the pain is episodic, continuous, or both;
- Identifying and using specific strategies for preventing or minimizing different levels or sources of pain or pain-related symptoms based on the resident-specific assessment, preferences and choices, a pertinent clinical rationale, and the resident’s goals and; using pain medications judiciously to balance the resident’s desired level of pain relief with the avoidance of unacceptable adverse consequences;
- Monitoring appropriately for effectiveness and/or adverse consequences (e.g., constipation, sedation) including defining how and when to monitor the resident’s symptoms and degree of pain relief; and
- Modifying the approaches, as necessary

## References and Resources:

1. 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 [www.promotingexcellence.org](http://www.promotingexcellence.org) and

- [www.npcrc.org](http://www.npcrc.org). In addition, different states may have specific tools required or encouraged through regulations or guidelines. Check with your state's governing agencies.
2. Agency for Healthcare Research and Quality, Pain Management Guideline (NGC- 5217) available through the website of the developer, Health Care Association of New Jersey at <http://www.hcanj.org>.
  3. Hughes RG, editor. Patient Safety and Quality: An Evidence-Based Handbook for Nurses. Rockville (MD): Agency for Healthcare Research and Quality (US); 2008 Apr. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK2651/>(Chapter 17. Improving the Quality of Care Through pain Assessment and Management by Nancy Wells, Chris Pasero, Margo McCaffery)
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  5. "Core Principles of Pain Assessment for Providers." *Center for Nursing Excellence in Long Term Care*. Web. 22 Sept. 2013. <[www.geriatricpain.org](http://www.geriatricpain.org)>.
  6. Fink, Regina, PhD, AOCN. "Pain Assessment: The Cornerstone to Optimal Pain Management." Baylor University Medical Center Proceedings, Web. 22 Sept. 2013.
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## Change Idea #3: Having Discussions with Residents Regarding Prognosis and/or Illness Trajectory and Goals of Care

**Definition and Background:** Discussions with nursing facility residents regarding their prognosis and/or illness trajectory and their goals of care would seem to be a necessary and integral part of providing care in a nursing facility 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 and/or illness trajectory should occur at regularly scheduled intervals and at times of change or decline in health. In addition, these discussions with residents 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 facility 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 illness trajectory 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 facility 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, 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 illness trajectory 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 illness trajectory information being provided.

**Barriers:** Research shows that there are several reasons why clinicians do not have goals of care discussions with nursing facility 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 facilities 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.

**Goals:**

- To ensure that all residents and appropriate family members understand their illness trajectory, 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 illness trajectory 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, illness trajectory 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 illness trajectory 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 illness trajectory and care goals improve the care staff provide?
- ☐ How will discussions of illness trajectory 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 illness trajectory and goals of care. These champions can lead improvement efforts and build excitement for making positive changes.
- ☐ Have illness trajectory 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 illness trajectory 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 illness trajectory or the need to develop goals of care.
- ☐ Review your facility's current policies on having discussions regarding illness trajectory 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 illness trajectory 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 illness trajectory.
- ☐ Review the interpretive guidelines for **F684 Quality of Care and F578 Request/Refuse/Discontinue Treatment; Formulate Advance Directives** 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 teamwork. 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 illness trajectory/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?

## Regulatory Support:

There is much regulatory support around the need to engage residents in discussions regarding illness trajectory and goals. **Under F552 Resident Rights To Be Informed/Make Treatment Decisions**, 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, **F578 Request/Refuse/Discontinue Treatment; Formulate Advance Directives** states that the resident has the right to accept or refuse treatment and to formulate an advance directive. **F578 interpretive guidelines** state: "The ability of a dying person to control decisions about medical care and daily routines has been identified as one of the key elements of quality care at the end of life. The process of advance care planning is ongoing and affords the resident, family, and others on the resident's interdisciplinary health care team an opportunity to reassess the resident's goals and wishes as the resident's medical condition changes. Advance care planning is an integral aspect of the facility's comprehensive care planning process and assures re-evaluation of the resident's desires on a routine basis and when there is a significant change in the resident's condition. The process can help the resident, family and interdisciplinary team prepare for the time when a resident becomes unable to make decisions or is actively dying."

**F578** states requirements related to care planning and advance directives includes the following related to illness trajectory and goal setting:

- Determining on admission whether the resident has an advance directive and, if not, determining whether the resident wishes to formulate an advance directive;
- Providing information in a manner easily understood by the resident or resident representative about the right to refuse medical or surgical treatment and formulate an advanced directive. Defining and clarifying medical issues and presenting the information regarding relevant health care issues to the resident or his or her representative, as appropriate;
- Identifying, clarifying, and periodically reviewing, as part of the comprehensive care planning process, the existing care instructions and whether the resident wishes to change or continue these instructions;
- Identifying situations where health care decision-making is needed, such as a significant decline or improvement in the resident's condition;
- Establishing mechanisms for documenting and communicating the resident's choices to the interdisciplinary team and to staff responsible for the resident's care; and;

Additional regulatory support for having discussions with residents regarding prognosis and goals of care is written into **F765 Quality of Life**. 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. **F561 Self Determination** expounds the resident’s right to “choose activities, schedules and health care consistent with his or her interests, assessments and care plans.”

The interpretative guideline for **F684 Quality of Care** state that quality of care is a fundamental principle that applies to all treatment and care provided to facility residents. Based on the comprehensive assessment of a resident, the facility must ensure that residents receive treatment and care that are resident centered, in accordance with the resident’s preferences, goals of care and professional standards of practice that will meet each resident’s physical, mental, and psychosocial needs. Review of a resident at or approaching End of Life and/or receiving hospice care and services are covered under this F-tag, the resident must receive a comprehensive assessment for the development of the resident’s care plan to address the choices and preferences of the resident who is nearing the end of life. In addition, 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 resident’s attending physician/practitioner, should to the extent possible: Identify the resident’s prognosis and the basis for the prognosis, and initiate discussions/considerations regarding advance care planning and resident choices to clarify goals and preferences regarding treatment including pain management and symptom control, treatment of acute illnesses, and choices regarding hospitalization. The care plan must be based on the resident assessment, choices and advance directives, if any. As the resident’s status changes, the facility, attending practitioner and the resident representative, to the extent possible, must review and/or revise care plan goals and treatment choices. In addition, if the facility has a written agreement with a Medicare-certified hospice, the policies must identify ongoing collaboration and communication processes established by the nursing facility and hospice (refer to **F841 Medical Director**, for the written agreement, and to **F849 Hospice Services**).

#### References and Resources:

1. EPEC: Education in Palliative and End-of-Life Care  
<https://www.bioethics.northwestern.edu/programs/epec/curricula/core.html> (an online learning program that includes 16 modules that consist of information, video, cases, and discussion boards on the topic of Legal Issues, Whole Patient Assessment, Goals of Care, Advance Care Planning, Communicating Bad New, Pain Management, and Medical Futility).
2. Fast Facts for Clinicians: One to two-page briefs on various topics around end of life care and palliative care. Available at  
[https://www.mywhatever.com/cifwriter/library/eperc/fastfact/ff\\_index.html](https://www.mywhatever.com/cifwriter/library/eperc/fastfact/ff_index.html) or  
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11. Peereboom, Karen, BSN, RN, and Nessa Coyle, PhD, ACHPN, FAAN. "Facilitating Goals-of-Care Discussions for Patients with Life-Limiting Disease - Communication Strategies for Nurses." *Journal of Hospice & Palliative Nursing* 14.4 (2012): 251-58. Print.
12. 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 #4: Spiritual Care for Nursing Facility 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 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).

### 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). 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 aware of one’s 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 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.

## Regulatory Support:

There is some regulatory support for the provision of spiritual care within nursing facilities. **F679 Activities** states that “the facility must provide, based on a comprehensive assessment and care plan and the preferences of each resident, an ongoing program to support residents in their choice of activities, both facility sponsored group and individual activities designed to meet the interest of and support of the physical, mental and psychosocial well-being of each resident, encouraging both independent and interaction in the community”. Facilities must implement ongoing resident-centered activities program that incorporates the resident’s interest, hobbies, and cultural preferences, which is integral to the maintaining and or improving a resident physical, mental and psychosocial well-being and

independence to create opportunities for each resident to have a meaningful life by supporting his/her domains of wellness (security, autonomy, growth, connectedness, identify, joy and meaning). This indicates the activities program must incorporate the residents' individual needs and interests, including cultural and spiritual preferences. The guidelines explain that the activity assessment must gather information regarding a resident's spirituality and activities. Care planning must include connections to the community including places of worship. Other regulations incorporate assessment of and ongoing support of social, spiritual and religious preferences in achieving whole person care.

The interpretive guideline for **F675 Quality of Life** states that quality of life is a fundamental principle that applies to all care and services provided to facility residents. Each resident must receive and, the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and psycho-social well-being, consistent with the resident's comprehensive assessment and plan of care. The intent of this requirement is to ensure that the care and services provided are person-centered, and honor and support each resident's preferences, choices, values and beliefs. **F684 Quality of Care** states that the facility in collaboration with the medical director must develop and implement resident care policies that are consistent with the current professional standards of practice for not only pain management and symptom control, but for assessing resident's physical, intellectual, emotional, social, and spiritual needs as appropriate.

#### References and Resources:

- Cavendish R, et al. (2003) Spiritual care activities of nurses using Nursing Interventions Classification (NIC) labels. *Intl J Nurs Term Class.*, 14(4), 113-124.
- Conger J. (1994). *Spirit at work: Discovering the spirituality in leadership*. San Francisco: Josey-Bass.
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- The George Washington Institute for Spirituality and Health. *Palliative and Spiritual Care Resources* – Available on the [George Washington University website](https://smhs.gwu.edu/gwish/resources/online) (<https://smhs.gwu.edu/gwish/resources/online>).
- Puchalski CM. Spirituality and the care of patients at the end-of-life: an essential component of care. *Omega (Westport)*, 56(1):33-46.
- Puchalski CM. Spirituality in the Cancer Trajectory. *Annals of Oncology.* 2012;23 Suppl 3:49-55.
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- Watson Caring Science Institute & International Caritas Consortium. *Caring Science (Definitions, Processes and Theory)*. Available on the [Watson Caring Science website](https://www.watsoncaringscience.org/jean-bio/caring-science-theory/) (<https://www.watsoncaringscience.org/jean-bio/caring-science-theory/>). The Association of Professional Chaplains <http://www.professionalchaplains.org> has educational resources as well as professional standards for long term care chaplains

# Section 6: Data Collection and Measurement

## 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/illness trajectory. This will provide a baseline measurement that will help facilities determine their focus area for a PDSA cycle (see Section 4 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 residents' 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 7 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 facility 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:
  - 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 7: Intervention Tools: Pain Assessment Tools.

3. Have an Advance 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 Section 7: Intervention Tools: Advance Care Planning Tools and Section 8: District of Columbia Specific Resources for local advance care planning information.

4. Discussion of resident illness trajectory 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 illness trajectory 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 Section 7: Intervention Tools: Resident-Family Communication Tools

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:** 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 Medical Orders for Scope of Treatment (MOST).

**Tools:** Refer to toolkit Section 7: Intervention Tools: Resident-Family Communication Tools and Advance Care Planning Tools.

6. Assessment for resident's need for spiritual care and support is completed 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:

- 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 through the patient's own clergy relationships.



**Tools:** Refer to toolkit Section 7: 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 through the patient's own clergy relationships

#### **References and Resources**

[A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A National Quality Forum Consensus Report. December 2006](https://www.qualityforum.org/Publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx)  
[https://www.qualityforum.org/Publications/2006/12/A\\_National\\_Framework\\_and\\_PREFERRED\\_Practices\\_for\\_Palliative\\_and\\_Hospice\\_Care\\_Quality.aspx](https://www.qualityforum.org/Publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx) (See Addendum C)

## 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	<input type="checkbox"/> YES <input type="checkbox"/> NO
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)	<input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> N/A
Information gathered as to whether decision maker is legally appointed or resident's choice without legal documentation ( <i>N/A is appropriate if a resident refuses to identify a proxy decision maker</i> )	<input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> N/A
All information documented (both presence or absence of proxy decision maker) in both electronic and hard copy chart in a readily identifiable location	<input type="checkbox"/> YES <input type="checkbox"/> NO
Identified and documented within 14 days of admission or assessed change in diagnosis/prognosis indicating a significant decline in health	<input type="checkbox"/> YES <input type="checkbox"/> NO
<p>Data Entry for this measure should be:</p> <p><input type="checkbox"/> YES (all aspects of measure met with a YES or N/A response)</p> <p><input type="checkbox"/> NO (one or more aspects of measure unmet)</p>	

Pain Assessment Completed	Yes or No
Pain assessment completed and documented using standardized tool that is 1) consistently used according to nursing facility policy and 2) a validated tool such as the 0-10 scale, Wong-Baker FACES Pain Rating Scale, FLACC behavioral scale	<input type="checkbox"/> YES <input type="checkbox"/> NO
Documentation is recorded by MD, NP, PA, RN, or LPN	<input type="checkbox"/> YES <input type="checkbox"/> NO
Completed and documented within 24 hours of admission or assessed change in diagnosis/prognosis indicating a significant decline in health	<input type="checkbox"/> YES <input type="checkbox"/> NO
Data Entry for this measure should be: <input type="checkbox"/> YES (all aspects of measure met with a YES response) <input type="checkbox"/> NO (one or more aspects of measure unmet)	

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

Prognosis or Illness Trajectory Discussion with Resident Completed	Yes or No
Discussion occurred with resident and family per resident choice and includes clear information on resident's prognosis or illness trajectory	<input type="checkbox"/> YES <input type="checkbox"/> NO
Information presented to resident/family with opportunity to ask questions and seek clarification	<input type="checkbox"/> YES <input type="checkbox"/> NO
Discussion occurred within 14 days of admission or assessed change indicating a significant decline in health	<input type="checkbox"/> YES <input type="checkbox"/> NO
At least two members of the care team were present at the discussion	<input type="checkbox"/> YES <input type="checkbox"/> NO
Documentation of discussion includes who was present, prognosis discussed and is recorded by MD, NP, PA, RN, LPN or SW	<input type="checkbox"/> YES <input type="checkbox"/> NO
Data Entry for this measure should be: <input type="checkbox"/> YES (all aspects of measure met with a YES response) <input type="checkbox"/> 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	<input type="checkbox"/> YES <input type="checkbox"/> NO
At least two members of the care team were present for the discussion	<input type="checkbox"/> YES <input type="checkbox"/> NO
Documentation includes who was present, outline of goals relayed by resident/family/ and is recorded by MD, NP, PA, RN, LPN or SW	<input type="checkbox"/> YES <input type="checkbox"/> NO
Discussion occurred within 14 days of admission or assessed change in prognosis/diagnosis indicating a significant decline in health	<input type="checkbox"/> YES <input type="checkbox"/> NO
Data Entry for this measure should be: <input type="checkbox"/> YES (all aspects of measure met with a YES response) <input type="checkbox"/> 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	<input type="checkbox"/> YES <input type="checkbox"/> NO
Assessment occurs that identifies whether further spiritual support is wanted or needed	<input type="checkbox"/> YES <input type="checkbox"/> NO
Assessment is completed within 14 days of admission or assessed change in prognosis/diagnosis indicating a significant decline in health	<input type="checkbox"/> YES <input type="checkbox"/> NO
Individual responsible to make further referral for support is identified (if spiritual care is not requested, N/A is the appropriate response)	<input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> N/A
Individual/entity to whom referral will be made is identified (if spiritual care is not requested, N/A is the appropriate response)	<input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> N/A
Data Entry for this measure should be: <input type="checkbox"/> YES (all aspects of measure met with YES or N/A Response) <input type="checkbox"/> 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 spiritual care was not requested or identified as a need during the assessment</i> )	<input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> N/A
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)	<input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> N/A
Referral for care documented and confirmation that it was provided documented in medical record by MD, NP, PA, RN, LPN or SW. ( <i>N/A is the appropriate response if spiritual care was not requested or identified as a need during the assessment</i> )	<input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> N/A
Data Entry for this measure should be: <input type="checkbox"/> YES (all aspects of measure met with YES Response) <input type="checkbox"/> NO (one or more aspects of measure unmet) <input type="checkbox"/> N/A (measure unnecessary as spiritual care was not requested or identified as a need during the assessment)	

## PROCESS MEASURES TABLE

Measure	Requirements	Rationale	Preferred Practice	Tools	Metrics
<b>Identify a proxy decision-maker</b> 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.	<p>This measure requires the following within 14 days:</p> <ul style="list-style-type: none"> <li>Proxy decision-maker is identified by the resident</li> <li>Contact information for decision maker is gathered</li> <li>Information as to whether this decision-maker has been legally designated or is the resident's choice without legal documentation in place.</li> <li>This information is documented in both the electronic and hard copy chart in a readily available location and in an easily identifiable way.</li> <li>Documentation of this information is recorded by a MD, NP, PA, RN, LPN or SW.</li> </ul>	National Framework and Preferred Practices for Palliative and Hospice Care Quality*	<b>Preferred Practice #32:</b> 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	Refer to toolkit <a href="#">Section 7 Intervention Tools</a> : Advance Care Planning Tools and Resident-Family Communication Tools	<p><b>Numerator:</b> Number of residents with healthcare decision-maker documented according to guidelines</p> <p><b>Denominator:</b> Number of eligible residents</p>
Have an <b>Advanced Care Planning discussion</b> 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.	<p>The measure requires the following within 14 days:</p> <ul style="list-style-type: none"> <li>Discussion with resident (and family per resident choice) occurs</li> <li>Assessment completed of whether resident already has an advance directive document</li> <li>Assessment completed of whether resident would like to create such a document, relay specific wishes, or edit an existing document</li> <li>Documentation is recorded in the medical record by the MD, NP, PA, RN, LPN or SW</li> </ul>	National Framework and Preferred Practices for Palliative and Hospice Care Quality*	<p><b>Preferred Practice #10:</b> 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.</p> <p><b>Preferred Practice #18:</b> 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.</p> <p><b>Preferred Practice #35:</b> 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.</p>	Refer to toolkit <a href="#">Section 7: Intervention Tools</a> : Advance Care Planning Tools and <a href="#">Section 8: District of Columbia Specific Resources</a> for local advance care planning information.	<p><b>Numerator:</b> Number of residents with Advance Care Planning discussion according to guidelines</p> <p><b>Denominator:</b> Number of eligible residents</p>

Measure	Requirements	Rationale	Preferred Practice	Tools	Metrics
<b>Pain assessment</b> 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	<p>This measure requires the following within 24 hours:</p> <ul style="list-style-type: none"> <li>Pain assessment and documentation reflects the policy that each nursing facility has established regarding initial assessment and reassessment.</li> <li>Methods of assessment include but not limited to: patient self-report, physical examination, observation of patient, behavior, family member's report and physiological cues</li> <li>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.</li> <li>Measure of pain intensity tool that is utilized must be consistent and validated, such as: <ul style="list-style-type: none"> <li>0-10 scale for cognitively intact patients</li> <li>The Wong-Baker FACES Pain Rating Scale for cognitively intact, nonverbal or non-English speaking patients</li> <li>FLACC behavioral scale for cognitively impaired or patients unable to communicate</li> </ul> </li> <li>Documentation is recorded by MD, NP, PA, RN or LPN.</li> </ul>	National Framework and Preferred Practices for Palliative and Hospice Care Quality*	<p><b>Preferred Practice #12:</b> Measure and document pain, dyspnea, constipation and other symptoms using available standardized scales.</p> <p><b>Preferred Practice #13:</b> 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.</p>	Refer to toolkit <b>Section 7: Intervention Tools:</b> Pain Assessment Tools.	<p><b>Numerator:</b> Number of residents with pain assessments according to guidelines</p> <p><b>Denominator:</b> Number of eligible residents</p>
<b>Discussion of resident prognosis/illness trajectory</b> 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.	<p>The measurement requires the following within 14 days:</p> <ul style="list-style-type: none"> <li>Discussion that includes clear information about the resident's prognosis occurs with the resident (and family per resident choice)</li> <li>Information must be presented in a way that resident and/or family understand and with an opportunity for questions</li> <li>At least two members of the care team are present at the meeting</li> <li>Documentation includes who was present and prognosis discussed and is recorded by MD, NP, PA, RN, LPN or SW</li> </ul>	National Framework and Preferred Practices for Palliative and Hospice Care Quality*	<p><b>Preferred Practice #10:</b> 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.</p> <p><b>Preferred Practice #18:</b> 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.</p>	Refer to toolkit page <b>Section 7: Intervention Tools:</b> Resident-Family Communication Tools.	<p><b>Numerator:</b> Number of residents with prognosis discussions completed according to guidelines</p> <p><b>Denominator:</b> Number of eligible residents</p>

Measure	Requirements	Rationale	Preferred Practice	Tools	Metrics
<b>Discussion of resident goals around care and treatment</b> occurs and is documented within 14 days of admission, within 14 days of change of diagnosis/prognosis indicating a significant decline in overall health.	<p>The measurement requires the following within 14 days:</p> <ul style="list-style-type: none"> <li>Discussion with resident (and family per resident choice) outlining the resident's goals for care, treatment, and quality of life issues occurs</li> <li>At least two members of the care team are present at the meeting</li> <li>Documentation includes who was present, outline of goals relayed by resident/family, and is recorded by MD, NP, PA, RN or SW</li> </ul>	National Framework and Preferred Practices for Palliative and Hospice Care Quality*	<p><b>Preferred Practice #6:</b> 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.</p> <p><b>Preferred Practice #18:</b> 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.</p> <p><b>Preferred Practice #28:</b> 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.</p> <p><b>Preferred Practice #34:</b> 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.</p>	Refer to toolkit <b>Section 7: Intervention Tools:</b> Resident-Family Communication Tools and Advance Care Planning Tools.	<p><b>Numerator:</b> Number of residents with goals for care conversations completed according to guidelines</p> <p><b>Denominator:</b> Number of eligible residents</p>

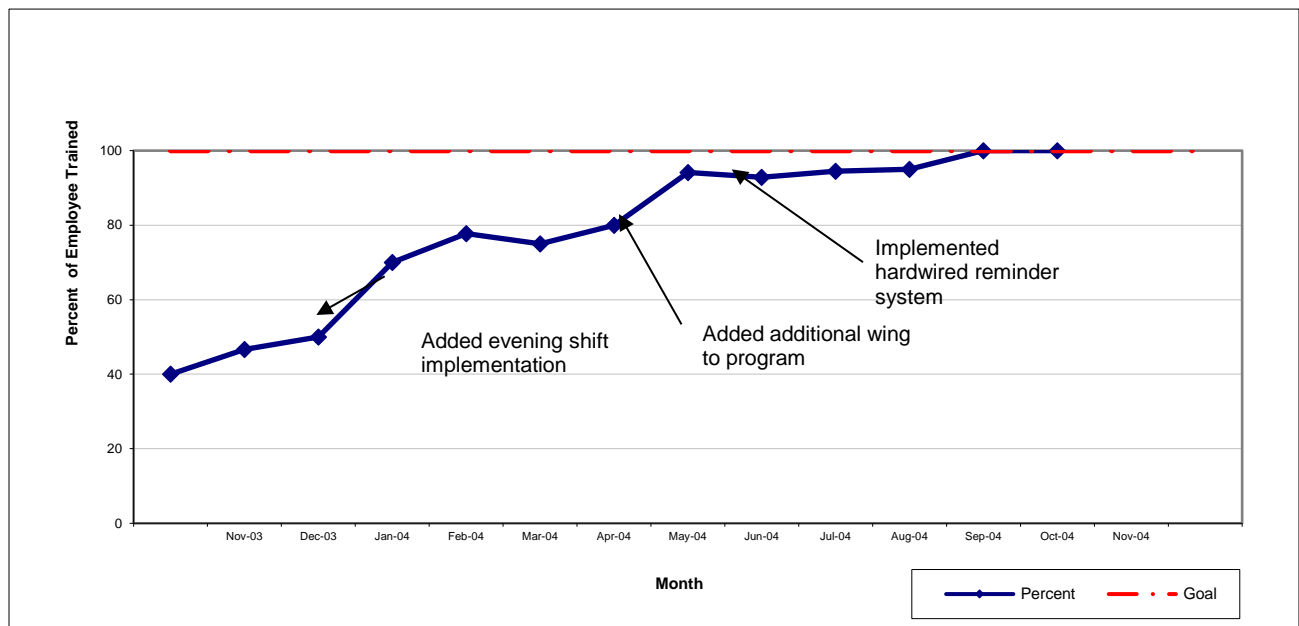


Measure	Requirements	Rationale	Preferred Practice	Tools	Metrics
<b>Assessment for resident's need for spiritual care and support</b> is completed 14 days of admission, within 14 days of change of diagnosis/prognosis indicating a significant decline in overall health.	The measure requires the following within 14 days: <ul style="list-style-type: none"> <li>Assessment occurs that identifies the resident's religious, spiritual and/or cultural preferences, assessment is documented in medical record</li> <li>Resident's preference regarding whether referral for further spiritual support is wanted or needed is identified and documented,</li> <li>Individual (resident, family, or staff) who will make referral for further spiritual support is identified and documented.</li> <li>Individual and/or religious entity to whom this referral will be made is identified and documented.</li> </ul>	National Framework and Preferred Practices for Palliative and Hospice Care Quality*	<b>Preferred Practice # 20:</b> 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. <b>Preferred Practice #21:</b> 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.	Refer to toolkit <b>Section 7 Intervention Tools:</b> Spiritual Care Tools.	<b>Numerator:</b> Number of residents with spiritual care assessed according to guidelines  <b>Denominator:</b> Number of eligible residents
For those residents who expressed a desire or need for spiritual care, that <b>spiritual care is provided</b> within 3 days of having identified this need.	The measure requires the following: <ul style="list-style-type: none"> <li>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</li> <li>The requested spiritual care is then provided within 3 days</li> <li>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.</li> </ul>	National Framework and Preferred Practices for Palliative and Hospice Care Quality*	<b>Preferred Practice # 20:</b> 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. <b>Preferred Practice #21:</b> 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	Refer to toolkit <b>Section 7: Intervention Tools:</b> Spiritual Care Tools.	<b>Numerator:</b> Number of residents with spiritual care provided according to guidelines  <b>Denominator:</b> Number of residents with spiritual care assessed as a need

## Annotated Run Chart

A run chart is a line graph of data plotted over time. By collecting and charting data over time, you can find trends or patterns in the process and assess whether the changes you are making are leading to improvement. The minimum standard for monitoring the progress of your team throughout the Collaborative is an annotated run chart of the process measures selected. Data points should be plotted monthly on a run chart and submitted with senior leader reports. Run charts can be constructed via a run chart template provided to Collaborative members. The following run chart is one example of appropriate presentation of a prompted voiding process measure for the Collaborative:

Annotations on the run chart should include changes that are being evaluated or implemented as well as other circumstances that could impact Collaborative measures



# Section 7: 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 [National Hospice and Palliative Care Organization](https://www.nhpco.org/education/tools-and-resources) <https://www.nhpco.org/education/tools-and-resources> /and is available on their website.

National Hospice and Palliative Care  
Organization



Interdisciplinary Team Competency Grid

COMPETENCY	NOVICE	PROFICIENT	EXPERT
TEAM FUNCTION	<ul style="list-style-type: none"> <li>Defines the interdisciplinary team</li> </ul>	<ul style="list-style-type: none"> <li>Collaborates with the interdisciplinary team to identify and meet patient/family identified needs</li> </ul>	<ul style="list-style-type: none"> <li>Models and teaches interdisciplinary team process and function to new team members</li> </ul>
	<ul style="list-style-type: none"> <li>Explains the difference between the medical model and the hospice philosophy of care</li> </ul>	<ul style="list-style-type: none"> <li>Assesses patient/family needs using patient/family-centered, holistic approach</li> </ul>	<ul style="list-style-type: none"> <li>Advocates for reframing the focus of care cooperatively with medical model practitioners/organizations</li> </ul>
	<ul style="list-style-type: none"> <li>Describes the purpose and value of the interdisciplinary team to hospice care</li> </ul>	<ul style="list-style-type: none"> <li>Articulates the purpose and value of the interdisciplinary team to patients and families, fellow team members and community</li> </ul>	<ul style="list-style-type: none"> <li>Serves as a role-model for interdisciplinary care, demonstrates expertise in utilizing the strengths of each discipline/perspective and recognizing their limitations</li> </ul>
	<ul style="list-style-type: none"> <li>Describes the purpose and value of the interdisciplinary team meeting</li> </ul>	<ul style="list-style-type: none"> <li>Participates in the interdisciplinary team meeting and considers the perspectives of all disciplines in the care planning process</li> </ul>	<ul style="list-style-type: none"> <li>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</li> </ul>
	<ul style="list-style-type: none"> <li>Identifies interdisciplinary team related regulations and complies with them</li> </ul>	<ul style="list-style-type: none"> <li>Demonstrates compliance by putting regulations into context/practice</li> </ul>	<ul style="list-style-type: none"> <li>Keeps abreast of and educates colleagues about regulatory changes and assists in the development of organizational policy and process to ensure compliance</li> </ul>
	<ul style="list-style-type: none"> <li>Describes ethical practice in end-of-life care</li> </ul>	<ul style="list-style-type: none"> <li>Participates in discussion of ethical issues and problem-solving</li> </ul>	<ul style="list-style-type: none"> <li>Models ethical practice, is skilled in leading discussions about ethical issues and leads the problem-solving and resolution process</li> </ul>
	<ul style="list-style-type: none"> <li>Identifies the elements of team process/team development (using B. Tuckman's [1965] "forming, storming, norming, performing" or other model of group development)</li> </ul>	<ul style="list-style-type: none"> <li>Describes the relevance of and applies group process/development to his/her interdisciplinary team</li> </ul>	<ul style="list-style-type: none"> <li>Observes group process and the development of his/her interdisciplinary team and reflects observations back to the group in efforts to further its development</li> </ul>
	<ul style="list-style-type: none"> <li>Describes team discussion, team meeting, collaborative practice, evaluation, support, memorial and team activities</li> </ul>	<ul style="list-style-type: none"> <li>Participates in team discussion, team meeting, collaborative practice, support, memorial and team activities</li> </ul>	<ul style="list-style-type: none"> <li>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</li> </ul>

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## Palliative Care Screening Tools

### Use of the MDS Section V: Care Assessment Summary

The MDS is a preliminary assessment to identify potential resident problems, strengths, and preferences. Care Areas are triggered by MDS item responses that indicate the need for additional assessment based on problem identification, known as “triggered care areas,” which form a critical link between the MDS and decisions about care planning. The CAA process provides for further assessment of the triggered areas by guiding staff to look for causal or confounding factors that may need to be addressed in the Care Plan.

Nursing facilities 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 October 2019 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 University of Colorado Medical School <https://medschool.cuanschutz.edu/health-care-policy-and-research/palliative-care/mortality-prediction-toolswebsite>.

## 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 Score	MDS Section G1. See Chart Below	If Summary functional 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 J1I	If has shortness of breath, score 2.08.	
Swallowing Problems	MDS Section K1b, K5c, also see diet order for special texture	If has swallowing problems, score 1.81.	
Male Sex	MDS Section AA2	If Male, Score 1.76.	
Body Mass Index	MDS Section K2 – Use BMI Chart	If BMI is less than 22 kg/m <sup>2</sup> , score 1.75.	
Congestive Heart Failure	MDS Section I1f	If has CHF, score 1.57.	
Age > 88 Years	DOB – MDS Section AA3 or face sheet	If age greater than 88, 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 mortality-related 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 [National Palliative Care Research Center](http://www.npcrc.org/files/news/karnofsky_performance_scale.pdf) [http://www.npcrc.org/files/news/karnofsky\\_performance\\_scale.pdf](http://www.npcrc.org/files/news/karnofsky_performance_scale.pdf) and is available through this link.

### KARNOFSKY PERFORMANCE STATUS SCALE DEFINITIONS RATING (%)

#### CRITERIA

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

#### References:

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- *Oxford Textbook of Palliative Medicine*, Oxford University Press. 1993;109.
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## General Palliative Care 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” \(https://getpalliativecare.org\)](https://getpalliativecare.org).

**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



# 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 website <https://www.mypcnow.org/fast-facts/>.

*# 042 Broaching the Topic of a Palliative Care Consultation with Patients and Families, 3rd 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 and Resources

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- Fast Facts and Concepts are edited by Sean Marks MD (Medical College of Wisconsin) and associate editor Drew A Rosielle MD (University of Minnesota Medical School), with the generous support of a volunteer peer-review editorial board, and are made available online by the Palliative Care Network of Wisconsin (PCNOW); the authors of each individual Fast Fact are solely responsible for that Fast Fact's content. The full set of Fast Facts are available at Palliative Care Network of Wisconsin with contact information, and how to reference Fast Facts.

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Disclaimer: Fast Facts and Concepts provide educational information for health care professionals. This information is not medical advice. Fast Facts are not continually updated, and new safety information may emerge after a Fast Fact is published. Health care providers should always exercise their own independent clinical judgment and consult other relevant and up-to-date experts and resources. 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.

## Family Conference Checklist\*

<p><b><u>PREPARATION</u></b></p> <p>1. Chart Reviewed:</p> <ul style="list-style-type: none"> <li>• Diagnoses</li> <li>• Treatment course</li> <li>• Prognosis</li> <li>• Options</li> <li>• Advanced Directive</li> <li>• Surrogate Decision Maker</li> <li>• Know state laws, institutional policy</li> </ul> <p>2. Family psychosocial issues identified</p> <p>3. Family instruction given</p> <p>4. Medical team:</p> <ul style="list-style-type: none"> <li>• Identified, invited</li> <li>• Consensus reached re: goals/questions</li> </ul> <p>5. Meeting plan:</p> <ul style="list-style-type: none"> <li>• Leader</li> <li>• Attendees</li> <li>• Scheduling</li> <li>• Room reserved &amp; arranged</li> <li>• Draw a seating chart</li> <li>• Kleenex</li> <li>• Pagers/ cell phones</li> </ul> <p>6. Check your emotions</p> <p><b><u>MEETING:</u></b></p> <p>7. Introductions</p> <ul style="list-style-type: none"> <li>• Names</li> <li>• Relationship to patient</li> <li>• Pass out business cards</li> </ul> <p>8. Goals of Meeting</p> <ul style="list-style-type: none"> <li>• Team goals</li> <li>• Family goals</li> </ul> <p>9. Telling the story: Family</p> <ul style="list-style-type: none"> <li>• Ask before you tell</li> <li>• Give everyone a turn</li> <li>• Gauge level of medical sophistication</li> <li>• Assess psychosocial content, emotional state</li> <li>• Identify &amp; address misconceptions</li> <li>• Clarify expectations</li> </ul>	<p>10. Telling the Story: Team</p> <ul style="list-style-type: none"> <li>• Summarize big picture in a few sentences</li> <li>• Use “dying” if appropriate</li> <li>• No TLA’s! (three letter abbreviations)</li> <li>• Appropriate use of silence, empathy</li> <li>• Respond to emotions and specific questions</li> <li>• Check for understanding</li> </ul> <p>11. Prognostication:</p> <ul style="list-style-type: none"> <li>• Fire a warning shot</li> <li>• Acknowledge uncertainty &amp; fluid nature of prediction</li> <li>• Use ranges</li> <li>• Allow time to digest</li> <li>• Respond to emotions, check for understanding</li> </ul> <p>12. Goal Setting</p> <ul style="list-style-type: none"> <li>• Allow patient &amp; family to state their goals</li> <li>• Emphasize living vs. dying (rest of life vs. end of life)</li> <li>• “What is important for the time that is left?”</li> <li>• “What are your hopes for the time that is left?”</li> <li>• Look to the advance directive</li> <li>• Role of surrogate as patient’s voice rather than independent decision maker</li> <li>• “If resident were here, what do you think he/she would say?”</li> <li>• Don’t rush; may take more than one meeting</li> <li>• Reinforce with family that nothing is final</li> </ul> <p>13. Summarize</p> <ul style="list-style-type: none"> <li>• Restate key points of understanding</li> <li>• Include things that are agreed upon and topics of ongoing discussion:</li> <li>• Review goals &amp; plans of care:</li> <li>• Clarify the next step (meetings, appointments)</li> <li>• Clarify options for contact:</li> <li>• Arrange follow up</li> </ul> <p><b><u>AFTERWARD:</u></b></p> <p>14. Write a Note:</p> <ul style="list-style-type: none"> <li>• Date, time, length of meeting, attendees</li> <li>• Key points discussed</li> <li>• Decisions Made</li> <li>• Plan</li> </ul> <p>15. Debrief</p> <ul style="list-style-type: none"> <li>• Check your emotions</li> <li>• Debrief with the team</li> </ul>
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\*Adapted from Department of Geriatric Medicine, John A. Burns School of Medicine, University of Hawaii

## Spiritual Care Tools

### Spiritual Care Assessment (Sample)

Faith Group \_\_\_\_\_ Particular Affiliation \_\_\_\_\_

Pastor: \_\_\_\_\_ Phone: \_\_\_\_\_

Patient/family \_\_\_\_\_ gives consent for chaplain to contact Pastor: Yes ☐ No ☐

#### Areas to Address

1. What is the resident'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. Image of God: \_\_\_\_\_
2. Relationship to God: \_\_\_\_\_
3. Important 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: \_\_\_\_\_

\*Policies and Tools for Hospital Palliative Care Programs: A Crosswalk of National Quality Forum Preferred Practices. Available at CAPC website. <https://www.capc.org/forums/>

## Evaluating Your Spiritual Care Assessment Process

Review Joint Commission Standards for Spiritual Assessment (Questions/Answers). More information available at full website: [Joint Commission](https://www.jointcommission.org/standards_information/jcfaqdetails.aspx?StandardsFaqId=1492&ProgramId=46)  
[https://www.jointcommission.org/standards\\_information/jcfaqdetails.aspx?StandardsFaqId=1492&ProgramId=46](https://www.jointcommission.org/standards_information/jcfaqdetails.aspx?StandardsFaqId=1492&ProgramId=46)

**The following is one question/answer:**

**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

Source: 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](#)

## Assessing Staff Beliefs Regarding Spiritual Care

The Spirituality and Spiritual Care Rating Scale (SSCRS) is a questionnaire to ask 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 on the [Royal College of Nursing](https://www.rcn.org.uk/professional-development/publications/pub-003861) website. <https://www.rcn.org.uk/professional-development/publications/pub-003861>

## 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:** Organized 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](https://www.aafp.org/afp/2001/0101/p81.pdf) (<https://www.aafp.org/afp/2001/0101/p81.pdf>).

## 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:** Community

**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 healthcare?

\*To access the tool in more depth, go to the [George Washington University School of Medicine and Health Sciences website](https://smhs.gwu.edu/gwish/clinical/fica) (<https://smhs.gwu.edu/gwish/clinical/fica>).

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

Many nursing facilities 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 [National Association of Professional Chaplains](http://www.professionalchaplains.org/files/professional_standards/standards_of_practice/sop_longtermcare.pdf) ([http://www.professionalchaplains.org/files/professional\\_standards/standards\\_of\\_practice/sop\\_longtermcare.pdf](http://www.professionalchaplains.org/files/professional_standards/standards_of_practice/sop_longtermcare.pdf)).

### 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 [Medical College of Wisconsin website](https://www.mypcnow.org/fast-facts). <https://www.mypcnow.org/fast-facts>

*FAST FACT: Spiritual History*

**Fast Facts for Clinicians: Taking a Spiritual History #19, 3rd 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

##### **S**piritual 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?

##### **P**ersonal 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 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

### 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 and Resources:

- 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.
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## Promoting Excellence in End-of-Life Care: Spiritual Care Assessments

*Promoting Excellence in End-of-Life Care* was a national program of the [Robert Wood Johnson Foundation](https://www.rwjf.org/) (<https://www.rwjf.org/>) 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 [Promoting Excellence](http://promotingexcellence.growthhouse.org/tools/spiritual.html) (<http://promotingexcellence.growthhouse.org/tools/spiritual.html>) website.

## Pain Assessment Tools

### Use of the MDS RAI

Section J of the MDS 3.0 requires staff to assess 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 [Wong-Baker FACES](http://wongbakerfaces.org/) (<http://wongbakerfaces.org/>) 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 [WPS Prenhall](http://wps.prenhall.com/wps/media/objects/3103/3178396/tools/flacc.pdf) (<http://wps.prenhall.com/wps/media/objects/3103/3178396/tools/flacc.pdf>) education site.

## 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 [Promoting Excellence](http://www.promotingexcellence.org/tools/pe5704.html) (<http://www.promotingexcellence.org/tools/pe5704.html>) website.

## University of Iowa College of Nursing Geriatric Pain Resources

The Geriatric Pain website was initially created to provide nurses and other staff working in long term care environments and informal caregivers with access to free evidence-based pain assessment tools, pain management strategies, and resources to help identify and manage pain in older adults. Tools include assessing, documenting and monitoring pain in cognitively intact and cognitively impaired older adults. The site is supported by the Barbara and Richard Csomay Center for Gerontological Excellence at The University of Iowa College of Nursing. <https://geriatricpain.org/>.

## 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 [CDC](https://www.cdc.gov/aging/advancecareplanning/care-planning-course.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Faging%2Fadvancecareplanning%2Fcare-planning-course.htm) ([https://www.cdc.gov/aging/advancecareplanning/care-planning-course.html?CDC\\_AA\\_refVal=https%3A%2F%2Fwww.cdc.gov%2Faging%2Fadvancecareplanning%2Fcare-planning-course.htm](https://www.cdc.gov/aging/advancecareplanning/care-planning-course.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Faging%2Fadvancecareplanning%2Fcare-planning-course.htm)) website.

## Advance Care Planning and Legal Forms in the District of Columbia

**District of Columbia Medical Orders for Scope of Treatment (MOST).** The MOST is a set of medical orders intended to guide medical treatment based on a person's current medical conditions and goals. Completing a MOST form is always voluntary. The [MOST form](https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page_content/attachments/2019-07-22%20MOST%20Fillable%20Form.pdf) ([https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page\\_content/attachments/2019-07-22%20MOST%20Fillable%20Form.pdf](https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page_content/attachments/2019-07-22%20MOST%20Fillable%20Form.pdf)) is divided into four (4) sections (A-D), simplifying patient preferences for life-sustaining treatments, including: Cardio-Pulmonary Resuscitation (CPR), Medical Interventions/Treatment Options, Antibiotics, and Medically-Assisted Nutrition. Any incomplete section of the MOST form implies full treatment for that section. The form must be completed by the patient or their authorized representative and an authorized DC licensed healthcare provider to be considered valid. The MOST form does not replace an advance directive. HIPPA permits disclosure of MOST to other health care providers as necessary.

**District of Columbia Advance Health Care Directive.** <https://www.nhpco.org/wp-content/uploads/DistrictofColumbia.pdf>.

### 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 [Conversation Project](https://www.theconversationproject.org/) (<https://www.theconversationproject.org/>) website.

### Institute for Health Care Improvement (IHI)


IHI offers a free four-hour online course on The Conversation Project through their [IHI Open School](http://app.ihl.org/lms/home.aspx?CatalogGUID=debbdb58-726f-4a20-ac4a-7796b7d94d37) (<http://app.ihl.org/lms/home.aspx?CatalogGUID=debbdb58-726f-4a20-ac4a-7796b7d94d37>). 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 [Gundersen Health System](https://respectingchoices.org/)® (<https://respectingchoices.org/>). It is an evidence based approach to advance care planning for health care professionals. For information, view the [YouTube](https://www.youtube.com/watch?v=qbgynMo9OGc) (<https://www.youtube.com/watch?v=qbgynMo9OGc>) 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 State. Despite the hospital and state specific setting, this [YouTube](https://www.youtube.com/watch?v=qbgynMo9OGc) (<https://www.youtube.com/watch?v=qbgynMo9OGc>) video has principles that can be applicable to all healthcare settings and states.



**PREPARE** (<https://www.prepareforyourcare.org/>) is an advance care plan web site with videos that focus on preparing patients for communication and decision making.

**ACP Decisions** (<http://www.acpdecisions.org>) presents advance care planning videos describing how overall goals of care, CPR, and mechanical ventilation can influence patients' and surrogates' preferences for end of life care.

**The GO WISH Card Game** ([www.gowish.org](http://www.gowish.org)), a set of cards that describe potential quality-of-life values, may facilitate conversations among older adults with cognitive impairment.

## Section 8: District of Columbia Specific Resources

### District of Columbia Hospice and Palliative Care Providers

The Department of Health lists three licensed providers of Hospice services in the District of Columbia. Most hospice agencies also provide palliative care services. The 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 hospice 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 facility staff.

When contracting for services with a nursing facility, hospice 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.

#### [DC Health Hospice Directory](https://dchealth.dc.gov/sites/default/files/dc/sites/doh/service_content/attachments/DCHospice%20Directory%20Updated%2012-5-19.pdf)

([https://dchealth.dc.gov/sites/default/files/dc/sites/doh/service\\_content/attachments/DCHospice%20Directory%20Updated%2012-5-19.pdf](https://dchealth.dc.gov/sites/default/files/dc/sites/doh/service_content/attachments/DCHospice%20Directory%20Updated%2012-5-19.pdf)): PDF (revised 12/5/2019) provides hospice names, addresses and contact information.

#### **DC.Gov Department of Aging and Community Living Hospice and End of Life Care webpage**

describes hospice care and links to Medicare Hospice benefit information.

<https://dcoa.dc.gov/book/how-should-you-or-your-loved-one-be-cared/hospice-end-life-care>

#### **Medicare.Gov Hospice Compare:** <https://www.medicare.gov/hospicecompare/>

Find hospices that serve your area and compare them based on the quality of care they provide. Hospice agencies most often provide services at home, an assisted living facility, or a nursing facility. This site also has information on how Medicare covers hospice services.

## **District of Columbia Laws, Rights, Rules and Regulations Pertaining to Palliative Care**

### **Durable Power of Attorney for Health Care and Advance Care Planning**

A Durable Power of Attorney for Health Care Living Will and Other Wishes document has been prepared and distributed as an informational service of the District of Columbia Hospital Association.

<https://www.everplans.com/articles/washington-dc-district-of-columbia-advance-directive-form>.

A DC Durable Power of Attorney for Healthcare and Living Will is provided by the National Hospice and Palliative Care Organization <https://www.nhpco.org/wp-content/uploads/DistrictofColumbia.pdf>

### **District of Columbia Death with Dignity Act of 2016, D.C. Law 21-182**

This act provides procedures and requirements regarding the request for and dispensation of covered medications to qualified patients seeking to die in a humane and peaceful manner, to define the duties of attending physicians and consulting physicians, to provide for counseling of patients and family notification, to require informed decision-making and waiting periods, to require reporting from the Department of Health, to outline the effect of the act on contracts, wills, insurance, and annuity policies, to provide for immunities, liabilities, and exceptions, to provide an opt-out provision for health care providers, to provide for claims against a qualified patient's estate for costs incurred by the District government when a qualified patient ingests a covered medication in public, and to establish criminal penalties.

### **Guidelines for Chronic Use of Opioid Analgesics**

Guidelines for chronic use of opioid analgesics are on the District of Columbia Department of Health website:

[https://dchealth.dc.gov/sites/default/files/dc/sites/doh/service\\_content/attachments/opioid\\_guidelines\\_as\\_adopted\\_april-2017\\_final.pdf](https://dchealth.dc.gov/sites/default/files/dc/sites/doh/service_content/attachments/opioid_guidelines_as_adopted_april-2017_final.pdf). Guidelines were adopted as policy by the Federation of State Medical Boards April 2017. The goal of this Model Policy is to provide state medical and osteopathic boards with an updated guideline for assessing a clinician's management of pain, so as to determine whether opioid analgesics are used in a manner that is both medically appropriate and in compliance with applicable state and federal laws and regulations.

### **District of Columbia Medical Orders for Scope of Treatment (MOST) Program**

Specific DC Health page with information on MOST, screen print of form, sample of filling out form, link to download form, instructions (including a Spanish version), and a list of resources:

<https://dchealth.dc.gov/node/1354936>

HIPAA PERMITS DISCLOSURE OF THIS DOCUMENT TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

## DC Medical Orders for Scope of Treatment (MOST)

Patient Last Name / First Name / Middle Initial

Address

City/State/Zip Code

Date of Birth (MM/DD/YYYY)

Last 4 Digits of SSN (optional)

☐ Male

☐ Female

☐ Transgender

☐ Other

Medical Conditions/Patient Goals:

### Instructions for Responding Providers:

FIRST follow these orders, THEN contact physician or nurse practitioner. The MOST is a set of medical orders intended to guide medical treatment based on a person's current medical condition and goals. Any section not completed implies full treatment for that section. Completing a MOST form is always voluntary. Everyone shall be treated with dignity and respect. PLEASE email completed form as a PDF document to [DC.MOST@dc.gov](mailto:DC.MOST@dc.gov) or fax to 202-671-0707. To print the DC MOST form, go to: [dchealth.dc.gov/most](http://dchealth.dc.gov/most)

**A**

Check One

### Cardio-Pulmonary Resuscitation (CPR): Person has no pulse and is not breathing.

☐ Attempt Resuscitation/CPR

When not in cardiopulmonary arrest, go to part B.

☐ Do Not Attempt Resuscitation (DNAR) / Allow Natural Death (AND)

Choosing DNAR will include appropriate comfort measures.

**B**

Check One

### Medical Interventions: Person has pulse and/or is breathing.

☐ FULL TREATMENT - primary goal of prolonging life by all medically effective means.

Includes care described below. Use intubation, advanced airway interventions, mechanical ventilation and cardioversion as indicated. Transfer to hospital if indicated. Includes intensive care.

☐ SELECTIVE TREATMENT - goal of treating medical conditions while avoiding burdensome measures. Includes care described below. Use medical treatment, IV fluids and cardiac care as indicated. Do not intubate. May use less invasive airway support (e.g. CPAP, BiPAP). Transfer to hospital if indicated. Avoid intensive care if possible.

☐ COMFORT FOCUSED TREATMENT - primary goal of maximizing comfort.

Relieve pain and suffering with medication by any route as needed. Use oxygen, oral suction and manual treatment of airway obstruction as needed for comfort. Patient prefers no hospital transfer: EMS consider contacting medical control to determine if transport is indicated to provide adequate comfort.

Additional Orders: (e.g. dialysis)

**C**

Check One

### Medical Treatment Preferences:

Medically-assisted Nutrition:

(Always offer food and liquids by mouth if feasible.)

☐ Trial period of medically-assisted nutrition by tube.

(Goal: \_\_\_\_\_)

☐ No medically-assisted nutrition by tube.

☐ Long-term medically-assisted nutrition by tube.

### Antibiotics:

☐ Use antibiotics for prolongation of life.

☐ Do not use antibiotics except when needed for symptom management

Additional orders: (e.g. dialysis, blood products, implanted cardiac devices. Attach additional orders if necessary.)



**D Signatures:** The signatures below verify that these orders are consistent with the patient's medical condition, known preferences and best known information. If signed by an authorized representative, the patient must be mentally incapacitated and the person signing is the legal authorized representative.

Discussed with: <input type="checkbox"/> Patient <input type="checkbox"/> Parent of Minor <input type="checkbox"/> Guardian with Health Care Authority <input type="checkbox"/> Spouse/Domestic Partner <input type="checkbox"/> Health Care Agent (Durable Power of Attorney for Healthcare) <input type="checkbox"/> Adult child of patient	PRINT — MD/DO/APRN Name (required)	Phone Number
	X MD/DO/APRN Signature (required)	Date (required)
	MD/DO/APRN License Number (required)	
PRINT — Patient or Legal Authorized Representative Name		Phone Number
X Patient or Legal Authorized Representative Signature (required)		Date (required)

Person has: ☐ Health Care Directive (Living Will) ☐ Durable Power of Attorney for Health Care

Encourage all advance care planning documents to accompany MOST

## KFFP ORIGINAL DC MOST FORM WITH PATIENT'S MEDICAL RECORDS

<b>Health Care Professional Information:</b>  <b>Completing MOST</b> <ul style="list-style-type: none"> <li>Completing a MOST form is always voluntary.</li> <li>Treatment choices documented on this form should be the result of shared decision-making by an individual or their authorized representative and medical provider based on the person's preferences and medical condition.</li> <li>MOST must be signed by a MD/DO/APRN and patient, or their authorized representative, to be valid. Verbal orders are acceptable with follow-up signature by a MD/DO/APRN in accordance with facility/community policy.</li> </ul> <b>Using MOST</b> <ul style="list-style-type: none"> <li>Any incomplete section of MOST implies full treatment for that section.</li> <li>This MOST is valid in all care settings including hospitals until replaced by new physician orders.</li> <li>The MOST is a set of medical orders.</li> <li>The MOST does not replace an advanced directive.</li> <li>An advance directive is encouraged for all competent adults regardless of their health status. An advance directive allows a person to document in detail his/her future health care instructions and/or name an authorized representative decision maker to speak on his/her behalf. When available, all documents should be reviewed to ensure consistency, and the forms updated appropriately to resolve any conflicts.</li> </ul>	<b>NOTE:</b> A person with capacity may always consent to or refuse medical care interventions, regardless of information represented on any document, including this one.  <b>SECTIONS A, B and C:</b> <ul style="list-style-type: none"> <li>No defibrillator should be used on a person who has chosen "Do Not Attempt Resuscitation"</li> <li>When comfort cannot be achieved in the current setting, the person should be transferred to a setting able to provide comfort (e.g., treatment of a hip fracture).</li> <li>An IV medication to enhance comfort may be appropriate for a person who has chosen "Comfort-Focused Treatment".</li> <li>Treatment of dehydration is a measure which may prolong life. A person who desires IV fluids should indicate "Selective" or "Full Treatment".</li> <li>Oral fluids and nutrition must always be offered if medically feasible.</li> </ul> <b>SECTION D:</b> <ul style="list-style-type: none"> <li>Patient/Authorized Representative and MD/DO/APRN signatures.</li> </ul> <b>Reviewing MOST</b> This MOST should be reviewed periodically whenever: 1. The person is transferred from one care setting or care level to another, or 2. There is a substantial change in the person's health status, or 3. The person's treatment preferences change.  <b>To void this form, draw a line through "Medical Orders" and write "VOID" in large letters. Any changes require a new MOST.</b>
---	---

Review of this MOST Form			
Review Date	Reviewer	Location of Review	Review Outcome
			<input type="checkbox"/> No Change <input type="checkbox"/> Form Voided <input type="checkbox"/> New form completed
			<input type="checkbox"/> No Change <input type="checkbox"/> Form Voided <input type="checkbox"/> New form completed

Version 4.29.19

Photocopies and faxes of signed MOST forms are legal and valid. May make copies for records.

899 North Capitol Street, NE, Suite 570; Washington, DC 20002 | P 202-671-4222 | F 202-671-0707 | dchealth.dc.gov



## **DC Frequently Asked Questions about EMS Comfort Care Program**

[https://dchealth.dc.gov/sites/default/files/dc/sites/doh/service\\_content/attachments/Comfort%20care%20form%20brochure.pdf](https://dchealth.dc.gov/sites/default/files/dc/sites/doh/service_content/attachments/Comfort%20care%20form%20brochure.pdf)

## **DC Places of Worship Advisory Board (POWAB)**

[https://dchealth.dc.gov/sites/default/files/dc/sites/doh/service\\_content/attachments/POWAB%20History%202008-2019.pdf](https://dchealth.dc.gov/sites/default/files/dc/sites/doh/service_content/attachments/POWAB%20History%202008-2019.pdf)

## Section 9: Resident & Family Education, Tools & Resources

### What is Palliative Care? (Video)

This six-minute video is designed to educate nursing facility residents and family members about palliative care in the nursing facility setting. It uses a resident story, caregiver story and a palliative care physician to explain palliative care. This tool is available at [YouTube \(https://www.medicare.gov/hospicecompare/\)](https://www.medicare.gov/hospicecompare/).

### 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 [CAPC’s consumer website \(https://getpalliativecare.org/\)](https://getpalliativecare.org/)

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 [CAPC’s consumer website \(https://getpalliativecare.org/\)](https://getpalliativecare.org/).

### How Can Palliative Care Help Me?

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 [consumer website for the NHPCO \(https://www.nhpco.org/patients-and-caregivers/\)](https://www.nhpco.org/patients-and-caregivers/). (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.S. National Library of Medicine \(https://medlineplus.gov/palliativecare.html\)](https://medlineplus.gov/palliativecare.html) 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 [NINR website \(https://www.ninr.nih.gov/newsandinformation/what-is-palliative-care\)](https://www.ninr.nih.gov/newsandinformation/what-is-palliative-care).

## Palliative Care Flyer

This flyer was developed by Healthcentric Advisors for the Nursing Home Palliative Care Collaborative. The flyer explains palliative care to nursing home residents and family members.



# Palliative Care

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.**

## **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 [National Institute on Aging \(https://order.nia.nih.gov/publication/end-of-life-helping-with-comfort-and-care\)](https://order.nia.nih.gov/publication/end-of-life-helping-with-comfort-and-care).

## **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 author's website Barbara Karnes (<https://bkbooks.com/collections/frontpage/products/gone-from-my-sight-the-dying-experience>) 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) (<https://www.uclahealth.org/palliative-care/Workfiles/Are-You-Traveling-Without-map.pdf>). 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 (<https://www.nhpc.org/patients-and-caregivers/>). 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 NIH publications (<https://www.nia.nih.gov/health/getting-your-affairs-order>) 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 NIH (<https://www.nia.nih.gov/health/advance-care-planning-healthcare-directives#what>) website. You can also order publications from National Institute on Aging (<https://order.nia.nih.gov/publication/advance-care-planning>).

## **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 [YouTube \(https://www.youtube.com/watch?v=w95MzkQnp2g\)](https://www.youtube.com/watch?v=w95MzkQnp2g).

## **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 [American Bar Association website \(https://www.americanbar.org/groups/law\\_aging/resources/health\\_care\\_decision\\_making/consumer\\_s\\_toolkit\\_for\\_health\\_care\\_advance\\_planning/\)](https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning/).

## **Resident – Facility Communication - Nursing Facility Checklist**

This checklist is designed for those reviewing potential nursing facilities. 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 [Alliance website](http://alliancebltc.com/page12.php) (<http://alliancebltc.com/page12.php>).

## **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 Consumer Voice [https://theconsumervoice.org/uploads/files/issues/assessment\\_care\\_planning-final.pdf](https://theconsumervoice.org/uploads/files/issues/assessment_care_planning-final.pdf)

## **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 for care issues in the late and final stages of dementia. This tool is available on the [Greater Illinois Chapter website](https://www.alzheimers-illinois.org/pti/comfort_care_guide.asp) ([https://www.alzheimers-illinois.org/pti/comfort\\_care\\_guide.asp](https://www.alzheimers-illinois.org/pti/comfort_care_guide.asp)).



## APPENDIX A: On-Line Resource Links

### [American Academy of Hospice and Palliative Care Medicine \(http://aahpm.org/\)](http://aahpm.org/)

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 \(CAPC\) \(https://www.capc.org/\)](https://www.capc.org/)

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 \(https://getpalliativecare.org/\)](https://getpalliativecare.org/)

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 [Palliative Care Provider Directory of Hospitals \(https://getpalliativecare.org/howtoget/\)](https://getpalliativecare.org/howtoget/), 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 \(https://getpalliativecare.org/resources/\)](https://getpalliativecare.org/resources/)

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

### [CAPC Leadership Centers \(https://www.capc.org/palliative-care-leadership-centers/palliative-care-training-locations/\)](https://www.capc.org/palliative-care-leadership-centers/palliative-care-training-locations/)

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 \(CIVHC\) \(https://www.civhc.org/\)](https://www.civhc.org/)

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.

### [EPEC: Education in Palliative and End-of-Life Care](https://www.bioethics.northwestern.edu/programs/epec/curricula/core.html)

[\(https://www.bioethics.northwestern.edu/programs/epec/curricula/core.html\)](https://www.bioethics.northwestern.edu/programs/epec/curricula/core.html)

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

### [Five Wishes \(https://fivewishes.org/\)](https://fivewishes.org/)

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 \(https://advancingexpertcare.org/\)](https://advancingexpertcare.org/)

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 \(EPERC\)](https://www.bioethics.northwestern.edu/programs/epec/curricula/core.html) (<https://www.bioethics.northwestern.edu/programs/epec/curricula/core.html>)

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](https://www.nationalcoalitionhpc.org/) (<https://www.nationalcoalitionhpc.org/>)

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](https://www.nationalcoalitionhpc.org/) (<https://www.nationalcoalitionhpc.org/>)

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 \(POLST\) \(https://polst.org/\)](https://polst.org/)

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 \(http://www.growthhouse.org/spirit/\)](http://www.growthhouse.org/spirit/)

Hillel Bodek, MSW, LCSW-R, BCD, Chairperson of the Committee on Palliative and End- of-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 \(http://www.growthhouse.org/stanford/index.html\)](http://www.growthhouse.org/stanford/index.html)

With support from the Robert Wood Johnson Foundation, The Stanford Faculty Development Center (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 \(https://www.ipfcc.org/index.html\)](https://www.ipfcc.org/index.html)

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 \(http://depts.washington.edu/eolcare/\)](http://depts.washington.edu/eolcare/)

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 \(GSF\) \(http://www.goldstandardsframework.org.uk/\)](http://www.goldstandardsframework.org.uk/)

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."

## **Palliative Care Provider Education**

"Palliative Care in Long-Term Care: Clinical and Ethical Considerations". The American Medical Director's Association has a training program available for purchase. Medical Directors can utilize this program to present practical approaches to communication, advance care planning, and assessment and control of pain and other distressing symptoms experienced by patients in post-acute and long term care. This tool is available through this link: <https://paltc.org/product-store/palliative-care-long-term-care-clinical-and-ethical-considerations>.

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 **EPEC: Education in Palliative Care and End-of-Life Care** This tool is available at Programs for Elderly website:


<https://www.bioethics.northwestern.edu/programs/epec/Distance%20Learning/index.html>.

**INTERACT® (Interventions to Reduce Acute Care Transfers)** is a quality improvement program that focuses on the management of acute change in resident condition. It includes clinical and educational tools and strategies for use in everyday practice in long term care facilities. Tools applicable to palliative care include Identifying Residents Appropriate for Hospice, Communication Guide, Comfort Care Orders, Advance Care Planning Tracking Form, Education for Residents about Going to the Hospital, CPR, Tube Feeding, Care Paths, Review Acute Care Transfers Form and Acute Change in Condition File Cards.

<https://pathway-interact.com>.

## APPENDIX B: List of Revised F-Tags

(<https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/Downloads/List-of-Revised-FTags.pdf>)

Long-Term Care Rule   F-Tag: Job Aid			
Federal Regulatory Groups for Long Term Care Facilities			
* Substandard quality of care = one or more deficiencies with s/s levels of F, H, I, J, K, or L in Red			
F540 Definitions	483.12 Freedom from Abuse, Neglect, and Exploitation	483.24 Quality of Life	
483.10 Resident Rights	F600 *Free from Abuse and Neglect	F675 *Quality of Life	
F550 *Resident Rights/Exercise of Rights	F602 *Free from Misappropriation/Exploitation	F676 *Activities of Daily Living (ADLs)/ Maintain Abilities	
F551 Rights Exercised by Representative	F603 *Free from Involuntary Seclusion	F677 *ADL Care Provided for Dependent Residents	
F552 Right to be Informed/Make Treatment Decisions	F604 *Right to be Free from Physical Restraints	F678 *Cardio-Pulmonary Resuscitation (CPR)	
F553 Right to Participate in Planning Care	F605 *Right to be Free from Chemical Restraints	F679 *Activities Meet Interest/Needs of Each Resident	
F554 Resident Self-Admin Meds-Clinically Appropriate	F606 *Not Employ/Engage Staff with Adverse Actions	F680 *Qualifications of Activity Professional	
F555 Right to Choose/Be Informed of Attending Physician	F607 *Develop/Implement Abuse/Neglect, etc. Policies		
F557 Respect, Dignity/Right to have Personal Property	F608 *Reporting of Reasonable Suspicion of a Crime	483.25 Quality of Care	
F558 *Reasonable Accommodations of Needs/Preferences	F609 *Reporting of Alleged Violations	F684 *Quality of Care	
F559 *Choose/Be Notified of Room/Roommate Change	F610 *Investigate/Prevent/Correct Alleged Violation	F685 *Treatment/Devices to Maintain Hearing/Vision	
F560 Right to Refuse Certain Transfers	483.15 Admission, Transfer, and Discharge	F686 *Treatment/Svcs to Prevent/Heal Pressure Ulcers	
F561 *Self Determination	F620 Admissions Policy	F687 *Foot Care	
F562 Immediate Access to Resident	F621 Equal Practices Regardless of Payment Source	F688 *Increase/Prevent Decrease in ROM/Mobility	
F563 Right to Receive/Deny Visitors	F622 Transfer and Discharge Requirements	F689 *Free of Accident Hazards/Supervision/Devices	
F564 Inform of Visitation Rights/Equal Visitation Privileges	F623 Notice Requirements Before Transfer/Discharge	F690 *Bowel/Bladder Incontinence, Catheter, UTI	
F565 *Resident/Family Group and Response	F624 Preparation for Safe/Orderly Transfer/Discharge	F691 *Colostomy, Urostomy, or Ileostomy Care	
F566 Right to Perform Facility Services or Refuse	F625 Notice of Bed Hold Policy Before/Upon Transfer	F692 *Nutrition/Hydration Status Maintenance	
F567 Protection/Management of Personal Funds	F626 Permitting Residents to Return to Facility	F693 *Tube Feeding Management/Restore Eating Skills	
F568 Accounting and Records of Personal Funds	483.20 Resident Assessments	F694 *Parenteral/IV Fluids	
F569 Notice and Conveyance of Personal Funds	F635 Admission Physician Orders for Immediate Care	F695 *Respiratory/Tracheostomy care and Suctioning	
F570 Surety Bond - Security of Personal Funds	F636 Comprehensive Assessments & Timing	F696 *Prostheses	
F571 Limitations on Charges to Personal Funds	F637 Comprehensive Assmt After Significant Change	F697 *Pain Management	
F572 Notice of Rights and Rules	F638 Quarterly Assessment At Least Every 3 Months	F698 *Dialysis	
F573 Right to Access/Purchase Copies of Records	F639 Maintain 15 Months of Resident Assessments	F699 *(PHASE-3) Trauma Informed Care	
F574 Required Notices and Contact Information	F640 Encoding/Transmitting Resident Assessment	F700 *Bedrails	
F575 Required Postings	F641 Accuracy of Assessments	483.30 Physician Services	
F576 Right to Forms of Communication with Privacy	F642 Coordination/Certification of Assessment	F710 Resident's Care Supervised by a Physician	
F577 Right to Survey Results/Advocate Agency Info	F644 Coordination of PASARR and Assessments	F711 Physician Visits- Review Care/Notes/Order	
F578 Request/Refuse/Discontinue Treatment/Formulate Adv Di	F645 PASARR Screening for MD & ID	F712 Physician Visits-Frequency/Timeliness/Alternate NPPs	
F579 Posting/Notice of Medicare/Medicaid on Admission	F646 MD/ID Significant Change Notification	F713 Physician for Emergency Care, Available 24 Hours	
F580 Notify of Changes (Injury/Decline/Room, Etc.)	483.21 Comprehensive Resident Centered Care Plans	F714 Physician Delegation of Tasks to NPP	
F582 Medicaid/Medicare Coverage/Liability Notice	F655 Baseline Care Plan	F715 Physician Delegation to Dietitian/Therapist	
F583 Personal Privacy/Confidentiality of Records	F656 Develop/Implement Comprehensive Care Plan	483.35 Nursing Services	
F584 *Safe/Clean/Comfortable/Homelike Environment	F657 Care Plan Timing and Revision	F725 Sufficient Nursing Staff	
F585 Grievances	F658 Services Provided Meet Professional Standards	F726 Competent Nursing Staff	
F586 Resident Contact with External Entities	F659 Qualified Persons	F727 RN 8 Hrs/7 days/Wk, Full Time DON	
	F660 Discharge Planning Process	F728 Facility Hiring and Use of Nurse	
	F661 Discharge Summary	F729 Nurse Aide Registry Verification, Retraining	

## Federal Regulatory Groups for Long Term Care Facilities

\* Substandard quality of care = one or more deficiencies with s/s levels of F, H, I, J, K, or L in Red

F730 Nurse Aide Perform Review – 12Hr/Year In-service	F806 Resident Allergies, Preferences and Substitutes	483.85 {PHASE-3} Compliance and Ethics Program
F731 Waiver-Licensed Nurses 24Hr/Day and RN Coverage	F807 Drinks Avail to Meet Needs/Preferences/ Hydration	F895 {PHASE-3} Compliance and Ethics Program
F732 Posted Nurse Staffing Information	F808 Therapeutic Diet Prescribed by Physician	
<b>483.40 Behavioral Health Services</b>	F809 Frequency of Meals/Snacks at Bedtime	
F740 Behavioral Health Services	F810 Assistive Devices - Eating Equipment/Utensils	<b>483.90 Physical Environment</b>
F741 Sufficient/Competent Staff-Behav Health Needs	F811 Feeding Asst -Training/Supervision/Resident	F906 Emergency Electrical Power System
F742 *Treatment/Svc for Mental/Psychosocial Concerns	F812 Food Procurement, Store/Prepare/Serve - Sanitary	F907 Space and Equipment
F743 *No Pattern of Behavioral Difficulties Unless Unavoidable	F813 Personal Food Policy	F908 Essential Equipment, Safe Operating Condition
F744 *Treatment /Service for Dementia	F814 Dispose Garbage & Refuse Properly	F909 Resident Bed
F745 *Provision of Medically Related Social Services	<b>483.65 Specialized Rehabilitative Services</b>	F910 Resident Room
<b>483.45 Pharmacy Services</b>	F825 Provide/Obtain Specialized Rehab Services	F911 Bedroom Number of Residents
F755 Pharmacy Svcs/Procedures/Pharmacist/Records	F826 Rehab Services- Physician Order/Qualified Person	F912 Bedrooms Measure at Least 80 Square Ft/Resident
F756 Drug Regimen Review, Report Irregular, Act On	<b>483.70 Administration</b>	F913 Bedrooms Have Direct Access to Exit Corridor
F757 *Drug Regimen is Free From Unnecessary Drugs	F835 Administration	F914 Bedrooms Assure Full Visual Privacy
F758 *Free from Unnec Psychotropic Meds/PRN Use	F836 License/Comply w/Fed/State/Local Law/Prof Std	F915 Resident Room Window
F759 *Free of Medication Error Rates of 5% or More	F837 Governing Body	F916 Resident Room Floor Above Grade
F760 *Residents Are Free of Significant Med Errors	F838 Facility Assessment	F917 Resident Room Bed/Furniture/Closet
F761 Label/Store Drugs & Biologicals	F839 Staff Qualifications	F918 Bedrooms Equipped/Near Lavatory/Toilet
<b>483.50 Laboratory, Radiology, and Other Diagnostic Se</b>	F840 Use of Outside Resources	F919 Resident Call System
F770 Laboratory Services	F841 Responsibilities of Medical Director	F920 Requirements for Dining and Activity Rooms
F771 Blood Blank and Transfusion Services	F842 Resident Records - Identifiable Information	F921 Safe/Functional/Sanitary/Comfortable Environment
F772 Lab Services Not Provided On-Site	F843 Transfer Agreement	F922 Procedures to Ensure Water Availability
F773 Lab Svcs Physician Order/Notify of Results	F844 Disclosure of Ownership Requirements	F923 Ventilation
F774 Assist with Transport Arrangements to Lab Svcs	F845 Facility closure-Administrator	F924 Corridors Have Firmly Secured Handrails
F775 Lab Reports in Record-LabName/Address	F846 Facility closure	F925 Maintains Effective Pest Control Program
F776 Radiology/Other Diagnostic Services	F849 Hospice Services	F926 Smoking Policies
F777 Radiology/Diag. Svcs Ordered/Notify Results	F850 *Qualifications of Social Worker >120 Beds	<b>483.95 Training Requirements</b>
F778 Assist with Transport Arrangements to Radiology	F851 Payroll Based Journal	F940 {PHASE-3} Training Requirements - General
F779 X-Ray/Diagnostic Report in Record-Sign/Dated	<b>483.75 Quality Assurance and Performance Improvem</b>	F941 {PHASE-3} Communication Training
<b>483.55 Dental Services</b>	F865 QAPI Program/Plan. Disclosure/Good Faith Attempt	F942 {PHASE-3} Resident's Rights Training
F790 Routine/Emergency Dental Services in SNFs	F866 {PHASE-3} QAPI/QAA Data Collection and Monitoring	F943 Abuse, Neglect, and Exploitation Training
F791 Routine/Emergency Dental Services in NFs	F867 QAPI/QAA Improvement Activities	F944 {PHASE-3} QAPI Training
<b>483.60 Food and Nutrition Services</b>	F868 QAA Committee	F945 {PHASE-3} Infection Control Training
F800 Provided Diet Meets Needs of Each Resident	<b>483.80 Infection Control</b>	F946 {PHASE-3} Compliance and Ethics Training
F801 Qualified Dietary Staff	F880 Infection Prevention & Control	F947 Required In-Service Training for Nurse Aides
F802 Sufficient Dietary Support Personnel	F881 Antibiotic Stewardship Program	F948 Training for Feeding Assistants
F803 Menus Meet Res Needs/Prep in Advance/Followed	F882 {PHASE-3} Infection Preventionist Qualifications/Role	F949 {PHASE-3} Behavioral Health Training
F804 Nutritive Value/Appear ,Palatable/Prefer Temp	F883 *Influenza and Pneumococcal Immunizations	
F805 Food in Form to Meet Individual Needs		

## APPENDIX C: 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](#)

([http://www.qualityforum.org/Publications/2006/12/A\\_National\\_Framework\\_and\\_PREFERRED\\_Practices\\_for\\_Palliative\\_and\\_Hospice\\_Care\\_Quality.aspx](http://www.qualityforum.org/Publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx)).

1. 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).
2. Provide access to palliative and hospice care that is responsive to the patient and family 24 hours a day, 7 days a week.
3. Provide continuing education to all healthcare professionals on the domains of palliative care and hospice care.
4. Provide adequate training and clinical support to assure that professional staff is confident in their ability to provide palliative care for patients.
5. Hospice care and specialized palliative care professionals should be appropriately trained, credentialed, and/or certified in their area of expertise.
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.
7. 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.
8. 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.
9. Patients and caregivers should be asked by palliative and hospice care programs to assess physicians'/healthcare professionals' ability to discuss hospice as an option.
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.
11. 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.
12. Measure and document pain, dyspnea, constipation, and other symptoms using available standardized scales.
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. 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.

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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.



## Collaborative Glossary

### **Action Period**

The time between Learning Sessions when teams work on improvement in their own facilities. Teams are supported by the Collaborative staff and faculty, and they are connected to other Collaborative team members.

### **Aim, or Aim Statement**

A written, measurable, and time-sensitive statement of the accomplishments a team expects to make from its improvement effort. The aim statement contains a general description of the work, the population of focus, the numerical goals, and a statement on spreading the changes to another population.

### **Annotated Run Chart, or Annotated Time Series**

A line graph showing results of improvement efforts plotted over time. The changes or annotations made are also noted on the chart at the time they occur, allowing the viewer to connect changes made with specific results.

### **Assessment Scale**

A numerical scale used to assess the progress of participating teams toward reaching their aim. 1 = forming team, and 5 = outstanding, sustainable improvement. In each Collaborative, Collaborative faculty assesses teams and may also ask them to evaluate their own progress using this scale. The expected level of attainment by the end of the Collaborative is a 4 (significant progress).

### **Breakthrough Series (BTS) Collaborative (see Collaborative)**

### **Change Concept**

A general idea for changing a process. Change concepts are usually at a high level of abstraction but evoke multiple specific ideas for how to change processes. “Simplify,” “reduce handoffs,” “consider all parties as part of the same system,” are all examples of change concepts.

### **Change Package**

A list of essential process changes that will help to lead a breakthrough improvement, usually created by the Collaborative faculty based on literature and their experiences.

### **Clinical Champion**

An individual in the organization who believes strongly in the improvements and is willing to try them and work with others to learn them. Teams need at least one nurse champion on their team. Champions in other disciplines who work on the process are important as well.

### **Collaborative**

A time-limited effort (usually 6–18 months) of multiple organizations that come together with faculty to learn about and to create improved processes in a specific topic area. The expectation is that the teams share expertise and data with each other; thus, “All teach, all learn.”

### **Collaborative Chair**

The leader of the Collaborative, usually an expert in the topic.

### **Collaborative Coordinator**

The noted authority in Collaborative topic. Creates a shared vision and provides intellectual leadership on the topic, helps form and guide faculty, assists the Improvement Advisor to develop the change package and measurement system, chairs and teaches at Learning Sessions, coaches and mentors organizations to achieve goals, and reviews Collaborative progress.

### **Collaborative Framework**

The Collaborative framework consists of the charter, change package, and measurement strategy. The framework provides constant direction to the teams regarding why they are doing this work, what changes they can make, and how they can use measurement to determine if they are making changes that result in improvements.

### **Collaborative Team**

All individuals from the nursing facilities, Comagine Health and DHCF that drive and participate in the improvement process. A core team of three individuals attends the Learning Sessions, but a larger team of six to eight people, often from various disciplines, participates in the improvement process in the organization.

### **Community of Practice**

Groups of people who share a concern, set of problems, mandate or sense of purpose. Communities of practice complement existing structures by promoting collaboration, information exchange, and sharing of best practices across boundaries of time, distance, and organizational hierarchies. A great deal of knowledge creation happens in these less visible but increasingly recognized and supported groups.

### **Cycle**

See PDSA cycle.

### **Day-to-Day Leader**

The person on the nursing facility's team who is responsible for driving the improvement process every day. This person manages the team, arranges meetings, and assures that tests are being completed and that data are collected.

### **Director**

The person who oversees all aspects of the Collaborative. The Director coaches and guides topic experts, facilitates Learning Sessions, teaches and coaches teams about process improvement (with the Improvement Advisor), regularly assesses Collaborative progress and institutes necessary changes to meet Collaborative aim, and supports collaborative learning throughout the Action Periods.

### **Early Adopter**

In the improvement process, the opinion leader within the organization who brings in new ideas from the outside, tries them, and uses positive results to persuade others in the organization to adopt the successful changes.

### **Early Majority/Late Majority**

The individuals in the organization who will adopt a change only after it is tested by an early adopter (early majority) or after the majority of the organization is already using the change (late majority).



### **Electronic Mailing List, or Email List**

A communication system that allows teams to stay connected with the leadership team and each other during the action periods. Sharing information, getting questions answered, and solving problems are all part of email list activity.

### **Faculty (see Subject Matter Experts)**

### **Handbook**

Pages containing a complete description of the Collaborative, along with expectations and activities to complete before the first meeting of the Collaborative.

### **IHI**

Institute for Healthcare Improvement

### **IHI Breakthrough Series**

An improvement method that relies on spread and adaptation of existing knowledge to multiple settings to accomplish a common aim.

### **Implementation**

Taking a change and making it a permanent part of the system. A change may be tested first and then implemented throughout the organization.

### **Improvement Advisor**

The expert in process improvement and measurement who assists the co-chairs and director in guiding the Collaborative's work and teaches and coaches teams on process improvement at Learning Sessions and during Action Periods.

### **Improvement Cycle**

See PDSA cycle.

### **Key Changes**

The list of essential process changes that will help lead to breakthrough improvement, usually developed by the leadership team and chair based on literature and their experiences.

### **Key Contact**

The individual on the organization team who takes responsibility for communication between the team and Comagine Health, including monthly reporting and disseminating information to team members. The key contact is often the day-to-day leader on the team.

### **Key Messenger**

The individual in the organization who can be relied on for spreading ideas to others within the organization.

### **Knowledge Management**

A method for gathering information and making it available to others.

### **Leadership Team**

The small group of experts on the topic who assist the chair and director in teaching and coaching participating teams. Usually the leadership team contains representatives from all the disciplines who are involved in the change process.

### **Learning Session**

A half day meeting during which participating organization teams meet with faculty and collaborate to learn key changes in the topic area, including how to implement changes, an approach for accelerating improvement, and a method for overcoming obstacles to change. Teams leave these meetings with new knowledge, skills, and materials that prepare them to make immediate changes.

### **Measurement System**

The key indicators that teams will use to measure improvement in their own organizations, along with suggested methods for defining variables and collecting data.

### **Measure**

A focused, reportable unit that will help a team monitor its progress toward achieving its aim.

### **Model for Improvement**

An approach to process improvement, developed by Associates in Process Improvement, which helps teams accelerate the adoption of proven and effective changes.

### **Organization Team**

The group of individuals, usually from multiple disciplines, that participates in and drives the improvement process. Typically, a core team of three individuals attends the Learning Sessions, but a larger team of six to eight people participates in the improvement process in the organization.

### **Outcome Measure**

Measures of change (or lack of change) in the well-being of a defined population. Improvement in an outcome measure reflects the health status of the resident, whereas process measure reflects the care delivery to the resident. Improvement in an outcome measure has a direct effect on mortality and morbidity.

### **Outcomes Congress**

A large public meeting at the end of the Collaborative during which the best practices in the topic area are presented to others interested in making improvements in the area.

### **PDSA Cycle**

- A structured trial of a process change. Drawn from the Shewhart cycle, this effort includes the following steps:
- Plan—a specific planning phase;
- Do—a time to try the change and observe what happens;
- Study—sometimes called “check,” an analysis of the results of the trial; and
- Act—devising next steps based on the analysis.
- This PDSA cycle will naturally lead to the “plan” component of a subsequent cycle. PDSA cycles are also called “rapid cycles” or “improvement cycles.”

### **Pilot Population**

See population of focus.

### **Pilot Site**

The clinic location where changes are tested. After implementation and refinement, the changes will be spread to additional locations.

### **Population of Focus**

A designated set of residents who will be tracked to determine whether changes have resulted in improvements. For this Collaborative, a pilot population might be defined as Medicaid residents on a particular wing or unit.

### **Pework Packet**

A collection of materials (hard copy or electronic) containing a complete description of the Collaborative, along with expectations and activities to complete prior to the first Learning Session of the Collaborative.

### **Pework Period**

The time before the first Learning Session when teams prepare for their work in the Collaborative. Pework activities include selecting team members, registering for the first Learning Session, scheduling initial meetings, preparing an aim statement, defining a pilot population, selecting measures, and initiating data collection.

### **Process Change**

A specific change in a process in an organization. More focused and detailed than a change concept, a process change describes what specific changes should occur. “Institute a pain management protocol for patients with moderate to severe pain” is an example of a process change.

### **Rapid Cycle**

See PDSA cycle.

### **Run Chart**

See “annotated time series.”

### **Sampling Plan**

A specific description of the data to be collected, the interval of data collection, and the subjects from whom the data will be collected. The sampling plan is included on all senior leader reports. It emphasizes the importance of gathering samples of data to obtain “just enough” information.

### **Senior Leader**

The executive in the organization who supports the team and controls the resources employed in the processes to be changed. This person is usually at the administrator level or higher. The senior leader works to connect the team’s aim to the organization’s mission, provides resources for the team, and promotes the spread of the team’s work to others.

### **Senior Leader Report**

The standard reporting format for monthly progress updates in a Collaborative. This concise, two-page report includes an aim statement, measures to be used, a sampling plan, a listing of the changes made,

and the results displayed graphically on run charts. The nursing facility pilot team prepares the report and sends it to the senior leader at the nursing facility, along with submitting the report to the Comagine Health Quality Improvement Advisor Lead. Reports will be reviewed and summarized in Collaborative reports.

**Spread**

The intentional and methodical expansion of the number and type of people, units, or organizations using the improvements. The theory and application of spread comes from the literature on Diffusion of Innovation (Everett Rogers, 1995)

**Staging Plan**

A plan of what populations/units will be spread to and in what order.

**System Leader**

Responsible for all Collaborative Improvement. Charters Collaborative consistent with mission, goals, and resources of their system, provides resources for Collaborative staff and faculty, and provides executive review and guidance. In the present Collaborative, this person may be the administrator or the director of nursing services.

**Subject Matter Experts (Faculty)**

Viewed as credible experts in the selected team, represent multiple disciplines and multiple organizational structures (primarily practitioners, some researches), specifies goals, high leverage changes, teams for Prewrite, teaches and coaches at Learning Sessions and during Action Periods, and advises the Chair and Director about teams' progress.

**Technical Expert**

The team member in the organization who has a strong understanding of the process to be improved and changes to be made. A technical expert may also provide expertise in process improvement, data collection and analysis, and team function.

**Test**

A small-scale trial of a new approach or a new process. A test is designed to learn if the change results in improvement and to fine-tune the change to fit the organization and patients. Tests are carried out using one or more PDSA cycles.

**Tipping Point**

In epidemiology, the concept that small changes will have little or no effect on a system until a critical.