



Palliative Care

IMPLEMENTATION GUIDE BOOK

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**Program Implementation
Materials, 1st Edition
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Introduction



Establishing a formalized Palliative Care Program involves three critical pieces: providing education, using a team approach, and assessing for the five domains of pain. All persons served by the Carmelite Sisters for the Aged and Infirm receive palliative care upon admission to a facility. This interdisciplinary method involves caring for the whole person, not just their physical needs. The holistic approach assesses and provides care for the physical, social, familial, psychiatric, and emotional pains a person may experience when faced with life altering illnesses and situations.

The Carmelite Sisters for the Aged and Infirm and their education arm, the Avila Institute of Gerontology, have collaborated to develop an implementation guide to aid in the establishment of a formalized palliative care program within long-term care facilities. The program was developed through a series of pilot studies and revisions were based on the results of these pilot studies. This program is flexible, and can be tailored to meet the needs of each facility.

“The best interests of the old people should always come first.”

— Venerable Mary Angeline Teresa McCrory, O.Carm.

What is Palliative Care?

“[Palliative care], is an expression of the properly human attitude of taking care of one another, especially of those who suffer. It bears witness that the human person is always precious, even if marked by age and sickness.”

— Pope Francis



Palliative Care Defined by the Carmelite Sisters for the Aged and Infirm

Palliative care seeks to provide relief from the five domains of pain that all persons experience when faced with a debilitating diagnosis. Palliative care is not reserved for those who are imminently dying. Palliative care allows each resident to receive the appropriate treatment that brings him/her comfort and the best possible care. Palliative care can be combined with curative care or with less aggressive care. Palliative care is not the same as hospice care or end-of-life care, which is reserved for those who are clearly dying.

Palliative Care begins upon admission.



Establishing a Palliative Care Program

The first step in implementing a Palliative Care Program within a long-term care facility is to establish a Palliative Care Steering Committee. The Palliative Care Steering Committee has many functions and is comprised of interdisciplinary team members. The committee is responsible for identifying the goals of the program and creates an action plan for education. It is critical when choosing this committee that the staff members chosen are those who display a desire to serve on the committee and a willingness to implement ongoing Palliative Care throughout the facility.

This committee is accountable in all aspects of the Palliative Care Program. Their duties consist of the following:

- Review policies and procedures
- Evaluate all aspects of the implementation of Palliative Care
- Follow through on all requests made by the Unit Teams
- Provide educational programs for staff, residents, and families

The members of the Palliative Care Steering Committee are to play an active role in establishing the program. They lead all caregivers and other staff through the implementation process. The Chairperson of the Committee is identified as the “champion.” This “champion” will be the key to the efficient operation of the program. The discussion below outlines the responsibilities of the Palliative Care Steering Committee.

Once the Palliative Steering Committee has been established, the education and training of all staff in the Palliative Care curriculum is initiated. All Nurses, Social Workers, and Spiritual/Pastoral Care staff are trained to complete pain assessments for all the domains of pain. This comprehensive assessment is for all residents admitted in the facility. Once the assessments are completed, and the pains identified, deciding an appropriate palliative care plan for each resident is critical. This plan is based on the most pressing concern identified by the assessment.

Once the appropriate interventions have been identified and evaluated they are added to the resident’s care plan under the title, “Palliative Care Plan.”

“We can never show our dear old people too much kindness and love.”

— Venerable Mary Angeline Teresa McCrory, O.Carm.

The Palliative Care Steering Committee

The Palliative Care Steering Committee is comprised of several different disciplines, and includes but is not limited to, nursing, social services, pastoral/spiritual care, and administrative services. The Palliative Care Steering Committee identifies the plan of action for implementing the Palliative Care program throughout the facility. This can take place on a broad scale (depending on the size of the home), but implementing the procedure one unit/floor/wing at a time has proven to be most successful.

Members of the Palliative Care Steering Committee must understand the importance of Palliative Care and all of its concepts. Therefore, all members are trained in Principles of Palliative Care and how to assess and manage each resident's five pains. Staff, guided by the Palliative Care Steering Committee, should have access to educational resources to help them gain knowledge of all the facets of the Palliative Care program. The committee ensures that regular training and in-services on the many aspects of Palliative Care are implemented and maintained. This training includes

meeting Palliative Care regulations and guidelines as well as understanding the teachings of the Catholic Church, the Ethical and Religious Directives for Catholic Healthcare Services and the mission of the organization.

The members of the committee will vary from facility to facility. It is up to the Chairperson of the committee and Administration to decide as to which disciplines will be most effective on the Palliative Care Steering Committee. The duties of the committee must be adopted by the entire facility. The Palliative Care Steering Committee reports to administration and the Medical Director. It will meet monthly on initial start up (or more often) and can move to a quarterly meeting once it is well established.

Once the Steering Committee is established, and a course of action for implementing the program decided upon, the Steering Committee establishes Palliative Care Unit Teams for each unit/wing/floor. The goal of the Unit Team is to ensure Palliative Care for all the residents assigned to them.

The duties of the Palliative Care Steering Committee include but are not limited to:

1. Oversee Palliative Care in the facility
2. Provide education based on trends noted
3. Serve as mentors to staff
4. Work closely with all disciplines
5. Direct implementation of Unit Teams
6. Ensure all pain assessments are being completed, and interventions are developed
7. Oversee evaluation of interventions, prior to their addition to the care plan
8. Develop performance improvement projects
9. Establish policies and procedures
10. Establish an environment of compassionate healing
11. Promote optimized symptom control and functional status when appropriate
12. Direct the establishment of bereavement programs
13. Oversee initiatives to improve pain management
14. Evaluate the program on an on-going basis
15. Develop satisfaction surveys

The Palliative Care Unit Team

The Palliative Care Unit Team is comprised of all disciplines, and includes but is not limited to, nursing, social services, pastoral/spiritual care, psychologists, therapists, residents, families, and support services. Each Palliative Care Unit Team must have a Coordinator assigned. The Unit Team meets weekly to ensure

all residents' pains are managed. The Unit Team provides detailed reports to the Palliative Care Steering Committee's Chairperson who includes plans for each resident and his/her progress. The Palliative Care Unit Team works to provide optimal holistic care to each resident.

The duties of the Coordinator of the Palliative Care Unit Team include, but are not limited to:

1. Lead efforts to provide Christ's compassionate healing mission
2. Provide Palliative Care on the unit
3. Ensure each resident is assessed upon admission for palliative care
4. Complete a comprehensive pain assessment for each resident
5. Work closely with all departments
6. Develop interventions for identified pains and optimize symptom control
7. Educate residents and family to promote understanding of the underlying disease process and the expected future course of the illness
8. Establish an environment that is comforting and healing
9. Coordinate with hospice care when a resident is actively dying, if family wishes
10. Serve as an educator and mentor for the staff
11. Promote a life lived in comfort for the resident and family
12. Report all efforts to the Palliative Care Steering Committee's Chairperson

*“To cure sometimes,
to relieve often,
to comfort always.”*

— Hippocrates

Palliative Care Training

Training is the most important aspect of Palliative Care. Direct and indirect care staff all play important roles in providing the best possible care to each resident. The strategies for training all staff on the Principles of Palliative Care and Pain Management will vary in all facilities. It is the role of the Palliative Care Steering Committee to see that all staff attend the required training. The Steering Committee Members are the mentors for staff who may struggle to understand the role Palliative Care plays in the lives of the residents they serve.

The Avila Institute of Gerontology has developed a Palliative Care curriculum, in collaboration with the End of Life Nursing Education Consortium (ELNEC) and the Carmelite Sisters for the Aged and Infirm. As a Catholic health-care provider and religious organization, it was important to include throughout the program, scripture quotes which help one reflect upon the privilege of being called to serve the aged and infirm as part of Jesus' healing mission.

Topics in the Palliative Care Curriculum

- Principles of Palliative Care
- Understanding and Assessing Physical Pain
- Understanding and Assessing Emotional, Psychiatric, Spiritual and Family Pain
- Implementing and Sustaining a Palliative Care Program
- Communication
- Spiritual Care
- Care at the Time of Death
- Ethical Issues
- Loss, Grief and Bereavement

This curriculum focuses on training caregivers to understand:

- The importance of identifying and managing different types of pain
- The important role of being an advocate for the resident
- The importance of each resident's culture and faith traditions
- The importance of an interdisciplinary approach to each resident's care
- The importance of understanding the mission

“Older people are valuable members of society until they die, and after death their memories are valuable. They deserve our respect and love at all times.”

— Venerable Mary Angeline Teresa McCrory, O.Carm.

The Palliative Care Pain Assessment

The Palliative Care Pain Assessment has been developed to identify all elements of pain and suffering experienced by a person with a life limiting disease. This assessment focuses on identifying the psychiatric, emotional, social, and familial struggles a resident may be experiencing. The goal of the assessment is to identify the root cause of the pain, so that each person can receive the care he/she deserves. When completing the assessment for the five domains of pain it is important to follow up on the pains or concerns a resident identifies. The assessments involve asking leading questions to establish a dialogue with the resident to discern the type of pain they might be experiencing. The goal is to allow them to open up about themselves and speak to what it is that is causing them pain. This may involve asking questions that are not on the assessment sheet, but can lead you to identify the pain a resident may be experiencing.

Guiding or essential questions are open-ended questions that are designed to identify who, what, when, where, how, and why. These types of question will allow care staff to identify any concerns that are raised because of the assessment. Once these concerns have been raised, it is important to develop an intervention plan to address these concerns. The Palliative Care Unit Team meets to identify the pain concern that is most prevalent for the person. An interdisciplinary approach is used to develop interventions to help prevent and monitor the pain. The effectiveness of the proposed intervention is to be reviewed at regular intervals until the resident is comfortable. When an intervention has been successful, the interventions become part of the care plan and assignment sheets.

The assessment developed by the Carmelite Sisters for the Aged and Infirm includes psychiatric, emotional, spiritual, and familial pain. Since all homes use a Physical Pain Assessment form when evaluating physical pain, we did not create another one. An explanation of the five domains of pain follows.

*“You treat a
disease,
you win,
you lose.
You treat a
person,
I guarantee you,
you’ll win,
no matter
what the
outcome.”*

— Patch Adams

The Five Domains of Pain

The **five domains** of pain consist of the physical, spiritual, psychiatric, emotional and familial. Each pain is to be assessed accurately upon admission in order for good palliative care to be initiated and maintained. Use of appropriate pain instruments is critical.

<p>1. Physical Pain</p>	<p>Physical pain is pain in the body. There are many misconceptions about pain. Most people believe aches and pains are to be expected as one ages, and elders frequently feel they should not report them. Physical pain left untreated can lead to a loss of stamina and independence. It is important that we allow each resident to express his or her physical pain and its impact on their lives.</p>
<p>2. Emotional Pain</p>	<p>Emotional pain is the most difficult to relieve. It can take on many forms of feelings: sadness, guilt, regret, and anger. A person who has broken a hip not only has the physical pain to endure, but the incident may lead him or her to an entire lifestyle change. This type of emotional pain is never easy to express. It takes time to name. Even in the naming, a person may find it is so personal that it never gets shared. We remain present so they know they are not alone.</p>
<p>3. Psychiatric Pain</p>	<p>Psychiatric Pain refers to suffering caused by alterations in cognition, mood or behavior that go beyond “normal reactions” and into the realm of psychiatric illness. These symptoms are important to identify because the associated suffering can often be much improved with proper identification and management which often requires psychotropic medication.</p> <p>Two specific psychiatric syndromes which are prevalent in nursing home patients with co-morbid medical conditions are Delirium and Major Depressive Disorder. Each of these illnesses causes significant suffering to patients and families when not properly identified and adequately treated. Competent care requires that we identify symptoms of Delirium and Depression as soon as possible so that treatment can be initiated and suffering minimized.</p>
<p>4. Spiritual Pain</p>	<p>Spiritual pain brings a feeling of a temporary loss of connection between the person and God. A person experiencing spiritual pain often feels that the meaning to his or her life is gone. The person may no longer find comfort in prayer or in his or her own faith traditions and begins to feel guilty. People who are experiencing spiritual suffering may feel spiritual concern, spiritual despair or spiritual distress. Each of these must be recognized by the caregiver in order to help bring balance to a person’s life again in the context of the new situation.</p>
<p>5. Family Pain</p>	<p>Family pain can be a lack of understanding by the family of the disease process and the situation. Expectations may be a lot higher than we can actually provide. The expectation of the resident is different as well, and can be out of sync with the families’ expectations. Often a loved one’s disease affects each family member in ways that are difficult to express to one another.</p>

*“This is how all will know
that you are my disciples, if you
have love for one another.”*

— John (13:35)

Assessment Tools

Emotional Pain Assessment	10
Psychiatric Pain Assessment	11
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Emotional Pain Assessment

Resident Name

Room

Birth Date

Assessment Completed by

Date Completed

Are you hopeful about the future?

What do you miss about home?

Are you hurting inside?

What are the things you need to look after? How can we help?

Is Emotional Pain a pressing concern? YES NO If yes, why?

Other Concerns:

Comments:

Observations

- Fearful Anguish Overly Excited Content Distracted Scared Depressed
- Angry Agitated Anxious/Nervous Frustrated Hopeful Lonely Fatigued

Other Observations:

Psychiatric Pain Assessment

Resident Name	Room	Birth Date
---------------	------	------------

Assessment Completed by	Date Completed
-------------------------	----------------

Does the resident have a history of psychiatric illness? YES NO If yes, what, when and for how long?

Have there been any recent changes in cognition, attention, behavior (restless, agitation)?
 YES NO If yes, consider formal evaluation for Delirium.

Is patient's mood significantly depressed or irritable? Has patient lost interest in things he/she formally enjoyed (reading/music/TV, etc.)? Has patient's ability to experience pleasure/joy/happiness dramatically diminished? Does patient have thoughts of suicide or wishing to be dead? If yes to any, consider formal evaluation for Depression.

Other psychiatric symptoms which might warrant formal psychiatric evaluation:

- Hallucinations
- Delusions

Other Concerns:

Comments:

Spiritual Pain Assessment

Resident Name

Room

Birth Date

Assessment Completed by

Date Completed

What gives meaning to your life?

What has been most fulfilling for you in your life?

What does your illness mean to you?

What supports/sustains you in this difficult time? What has helped you during difficult times in the past?

Has being ill made any difference in your feelings about God or the practice of your faith?

Is there anything that would give you comfort at this time?

Is Spiritual Pain a pressing concern? YES NO If yes, why?

Comments:

Familial Pain Assessment

Resident Name

Room

Birth Date

Assessment Completed by

Date Completed

Familial Pain (Check all that apply)	Resident		Family/Significant Other	
	Yes	No	Yes	No
Do you enjoy the relationships that you have with your family members/significant others?				
Are you able to communicate with your loved one?				
Have you expressed your needs and wishes regarding care?				
Does your family/loved one respect your Advance Directives?				
Does your family/significant other understand how you feel about your living situation?				
Have you expressed your needs/wishes?				

Describe familial concerns:

Is Familial Pain a pressing concern? YES NO If yes, why?

Comments:

Other Concerns:

Completing and Reporting on the Palliative Care Assessment

The goal of the assessment is to identify the root cause of the pain, so that each person can receive the care he/she deserves. Once the assessments are completed then:

1. The Coordinator of the Unit Team conducts a Unit Team meeting to develop a Palliative Care Approach. This Palliative Care Approach is developed through the input of the resident, family, caregivers; all those involved with the resident's care including support services such as environmental, dietary, etc.
2. The goal is to identify interventions utilizing the input and skills of all care disciplines. The Unit Team decides on several interventions to address the concerns raised in the assessment. The reason being that if the first intervention fails, the second can be implemented right away. Once an intervention has been identified, the Coordinator will ensure that it is added to that person's care plan.
3. The plan becomes part of the care assignment of the resident and the direct caregiver is instructed to report about the resident's pain on each shift daily until the pain is managed. Direct caregivers must be aware that the Palliative Care plan may change based on the evolving needs and preferences of the resident and family over time, recognizing that complex, competing and shifting priorities in goals of care may arise. Reassessment is performed as needed by the appropriate discipline when there is a change of condition.
4. The Coordinator of the Unit Team provides support for decision-making, develops and carries out the care plan, and communicates the plan to the resident, family, and to the involved health care professionals and providers. As the plan is implemented, all pains are reported daily on the 24-hour report indicating whether the resident's pain is in control or needs further assessing.
5. The Nurses document pain issues in a chart per procedure.
6. The Coordinator of each Unit Team attends the Palliative Care Steering Committee meetings as needed to inform them of the Palliative Care Approach decided upon for each resident. He/she must attend meetings at least quarterly to report progress, trends, and pertinent information.
7. Pain issues are to be addressed immediately and interventions should be discussed at the quarterly Care Plan meetings.

The Palliative Care Plan (PCP)

The Palliative Care Plan (PCP) is based on the Pain Assessment the Palliative Care Team completed upon admission of the resident or at a change of condition. In order to provide an accurate intervention plan for each per-

son, one must remember that each person is unique and has individual needs. The Unit Team Coordinator conducts the meeting using the palliative care unit team worksheet and following procedure.

The following information is gathered before the Team meets:

- **Relevant Diagnosis:** Any current medical/psychiatric history that may contribute to the person experiencing one of the different types of pain
- **Resident Profile:** A brief personal history of the resident summarizing important historic personal background education, work experience, and interpersonal issues, which is relevant for the pain issues identified. This info will help the team to discuss appropriate individualized interventions.
- **Personal Strengths/Resources:** Identify areas that a person may rely upon to cope with difficult situations
- **Completed Pain Assessment Tool:** Using the Pain Assessment tool the team can identify which pains are of concern and why. Highlight the areas that are to be discussed at the meeting and why.

The following is discussed at the team meeting using the information gathered from above:

- **Most Pressing Concern:** Discussion should help identify the pain concern that is most prevalent for the person
- **Proposed Interventions:** (for each pain identified): Treatments and interventions staff can do to help prevent the pain and monitor pain
- **Implementation:** (for each pain identified): Who is responsible for each intervention? Who will evaluate the efficacy of the intervention?
- **Review Period:** The effectiveness of the pain is to be reviewed daily until the resident is comfortable. All interventions are reviewed weekly.
- **Care Plan:** When interventions are successful then the interventions become part of the Care Plan and Assignment sheets.

Palliative Care Plans are reviewed and altered as needed and reviewed at every care plan meeting for efficacy unless the plan itself dictates other reviews.

All those responsible for the care should sign off on the plan and are responsible for disseminating the information to their respective departments.

Any trends noted during discussions are to be brought to the Steering Committee to provide in-services on various aspects of pain and palliative care.

Palliative Care Unit Team Worksheet

Resident Name

Room

Birth Date

Assessment Completed by

Date Completed

Relevant Diagnosis:

Resident Profile: *Include a brief personal history, including education, work history, interpersonal issues and other significant events or issues.*

Personal Strengths:

Results of Pain Assessment: *List pains and concerns identified on assessment.*

Most Pressing Concerns:

Proposed Intervention #1

Date

Discipline Responsible

Evaluation Date*

Successful: YES NO

Outcome:

* Recommended time frame for evaluation is within 21 days.

Palliative Care Unit Team Worksheet

Proposed Intervention #2			
_____	_____	_____	Successful: YES NO
Date	Discipline Responsible	Evaluation Date*	
Outcome:			

** Recommended time frame for evaluation is within 21 days.*

Proposed Intervention #3			
_____	_____	_____	Successful: YES NO
Date	Discipline Responsible	Evaluation Date*	
Outcome:			

** Recommended time frame for evaluation is within 21 days.*

Care Plan Update <i>Intervention added to the care plan</i>					
Palliative Care Plan:	<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; border-bottom: 1px solid black; text-align: center;">_____</td> <td style="width: 50%; border-bottom: 1px solid black; text-align: center;">_____</td> </tr> <tr> <td style="text-align: center;">Date Added</td> <td style="text-align: center;">Initials</td> </tr> </table>	_____	_____	Date Added	Initials
_____	_____				
Date Added	Initials				
<i>Describe</i>					

Sustaining a Palliative Care Program

The key to sustaining a Palliative Care program is to maintain the education and training. This ensures that all new staff members understand the principals of palliative care and how to manage pain, and the existing staff receives a refresher course on the materials. This continuing education allows the program to be regularly reviewed and updated as needed.

The Palliative Care program needs to be adjusted as needed to meet the care needs of residents. The program's sustainability is directly linked to the Palliative Care Steering Committee overseeing the programs implementation and the Unit Teams following through on assessments and interventions.

If the goals of the program were achieved, then the implementation process shifts to the maintenance process. This maintenance consists of continually identifying areas of improvement. If the goals of the program are not achieved in a timely manner then, re-evaluate the barriers, look through the implementation plan, and re-establish the program goals.

The Chairperson of the Palliative Care Steering Committee is the key person to making sure all areas of Palliative Care are being conducted throughout a resident's stay. This person is in a critical position and this position should be assigned to a staff member in a key discipline (i.e. nursing, social work, administration).

The Palliative Care Steering Committee and the Unit Palliative Care Teams must:

- Evaluate the effectiveness of the plans
- Continue to get feedback and troubleshoot with the staff
- Track key structural process and outcome measures
- Develop best practices with the Unit Care teams. Each person on the team should research best practices in their expertise
- Conduct training throughout the year. Each discipline may have their own training and attend the trainings of other disciplines
- Re-evaluate the program through:
 - Resident focus groups
 - Satisfaction surveys
 - Pre- and post- tests

*“Hope does not lie in a way out
but in a way through.”*

— Robert Frost