



Palliative Care for People with Dementia:

Why Comfort Matters in Long-Term Care

caringkind

The Heart of Alzheimer's Caregiving

This implementation guide was developed by CaringKind, The Heart of Alzheimer's Caregiving with the assistance of Comfort Matters®, as an outcome of the pilot project, Palliative Care for Advanced Dementia, Training and Implementation, the study of effective ways to implement the Comfort Matters® approach in three New York City nursing homes.

These guidelines may not apply to all patients in all situations and are not fixed protocols that must be followed. Rather, the recommendations made in these guidelines are intended for consideration by residential care facilities to be applied based on individual patient needs using professional judgment. Professional caregivers and families are encouraged to review the guidelines with a doctor or professional health care provider. The authors and publisher are not engaged in rendering medical, health or professional services in these guidelines. The authors and publisher specifically assume no responsibility for any outcome of applying the guidelines' contents.

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Greeting



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CaringKind, The Heart of Alzheimer's Caregiving, is proud to have initiated, convened and completed the pilot project, Palliative Care for Advanced Dementia, Training and Implementation. The project demonstrates that, as a human service and advocacy organization, we can make a meaningful contribution to the improvement of residential care for persons with dementia. As the pilot comes to a close, we are delighted with the results, including these guidelines. In the future we will continue to imbue the principles of palliative care in our work supporting persons with the disease, their family members and professional caregivers.

This has been a busy and exciting time at CaringKind. As we returned to our roots as an independent, local 501(c)(3), serving New York City's Alzheimer's and dementia community, we took a hard look at who we are, what we do best and our core principles.

We reaffirmed that our vision is a world where a diagnosis of Alzheimer's doesn't cause caregivers to retreat, but one where it is safe to reach out for help; a world where persons with dementia, and their family and professional caregivers are recognized as a whole being and treated with love, dignity and respect. A world where we can continue to deliver the high quality care we passionately believe in. Where caregivers respond to the reality of their today, while planning for tomorrow. And where family and paid caregivers are supported so they can care with confidence to make each day brighter. Most of all, a place where individuals and families affected by a dementia diagnosis have access to compassionate care. Palliative Care for Advanced Dementia embodies these core values.

In the absence of a medical cure or effective treatment, families and professional caregivers often feel helpless and hopeless. The principles behind our palliative care project offer help and the promise that we can make a residents' life better, in some cases with the simple additions of a moment of pleasure; a smile, a hug, a needed nap, a taste of chocolate, or a favorite song.

We are extremely proud of this project and hope the guidelines provide insight and motivation for residential care facilities to pursue a path of comfort for persons with dementia and those who care for them.

We are deeply grateful to everyone who made this project possible. As reflected in the acknowledgement section, work of this scope does indeed take a village. But every village needs a leader, and we are enormously grateful to our Project Manager, Ann Wyatt, for her tireless championship of this project, her deep belief in the principles and for keeping us all focused on the goal: bringing comfort to people with advanced dementia.

A handwritten signature in black ink that reads "Lou-ellen Barkan".

LOU-ELLEN BARKAN

A handwritten signature in black ink that reads "Jed A. Levine".

JED A. LEVINE

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Our appreciation as well to the three NYC hospice programs who work with these homes, and who contributed their support, time and attention to the project: Calvary Hospital Hospice; MJHS Hospice and Palliative Care, and Visiting Nurse Service of New York Hospice and Palliative Care (VNSNYHPC).

There would have been no project had we not found our way to the remarkable people at the Beatitudes Campus, who worked tirelessly over many years to find ways to bring comfort to people with advanced dementia, and in the process, identified the organizational adaptations that are necessary if such care is to be effective in residential settings. To Comfort Matters® staff Tena Alonzo, MA, Director, and Karen Mitchell, BSN, the depth of your commitment and the generosity you showed in your support and encouragement to us have been truly transformative. For all those others at Beatitudes Campus who were at all times responsive and encouraging, we are so grateful. To Carol O. Long, PhD, RN, FPLN, FAAN, Capstone Healthcare & Palliative Care Essentials, your dedication to this model, and to guiding and supporting us through our research efforts, was both inspirational and grounding, and we couldn't have done it without you. To Maribeth Gallagher, DNP, PMHNP-BC, FAAN, and Dementia Program Director, Hospice of the Valley, the collaborative example you have set with the Beatitudes Campus, and your knowledge, your skill and your passion for this work has been a gift in all ways. We also want to thank Robyn I. Stone, DrPH and Natasha Bryant, MS, from the LeadingAge Center for Applied Research, and Mark Heisler, PharmD, BCPS and Robert Hess, PhD, independent consultants, for your support and participation in our research.

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The photographs are all from our partner nursing homes, and are used with permission.

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Palliative Care for People with Dementia: Why Comfort Matters in Long-Term Care

“Ordinary, even familial things happen here, though often unwitnessed. Wounds are healed, muscles strengthened, faces washed, and hands held. Each small movement is tiny in its fruition, huge in its absence.”

- Sallie Tisdale, Harvest Moon, Portrait of a Nursing Home.

Introduction

Moving a parent, a husband, wife, sister, brother or friend to live in a nursing home is regarded by most people as one of the most difficult things they will ever have to do. Apart from the loss and sadness, there is fearfulness that the person will feel abandoned, especially if his/her dementia is irrevocably associated with suffering and distress.

Seventy-five percent of people with dementia will spend time in a nursing home, most typically in the moderate and advanced stages. Dementia is progressive and eventually terminal; the average time between diagnosis and death is 8 to 10 years, but there is extreme variability with some dementias lasting up to 20 years or more.

Typically, about 40% of time spent living with dementia means living in the advanced stages. Someone who reaches the age of 80 and does not have dementia has an approximately 5% chance of spending time in a nursing home, whereas someone who reaches the age of 80 and has dementia has an approximately 80% chance of spending time in a nursing home.

For these reasons, there can be no more important role for long-term care providers than that of bringing comfort to people with advanced dementia, and by extension, to their families and friends. Palliative care means taking active steps to discover what comforts someone and even gives them pleasure, and taking active steps to prevent or avoid unnecessary pain and suffering before they take hold. It is not about giving up. The more advanced the dementia, the more palliation has to offer. Nursing homes have much to gain from adopting a palliative approach to care for people with dementia.

Sadly palliation often isn't even considered as an option for people with dementia. Yet, unless modifications in how palliation is offered and delivered are made, it is unlikely to be effective. When someone with advanced dementia is experiencing distress, his/her actions, rather than words are most likely to communicate that distress. Unfortunately, and all too often, these behavioral expressions (moaning, calling out, striking out, grimacing) are not understood as distress, but rather they are assumed to be the inevitable consequences of the dementia itself.

Palliation cannot occur if the reason or triggers for distress are not known or understood. Anti-psychotic, anti-anxiety and sedative medications do not take away pain or distress that is non-psychosis related, nor do they comfort someone living with dementia who may be hungry, cold, too warm, tired, lonely, or frightened by noises or activity in the environment.

This book describes what we have learned in assisting three New York City nursing homes as they implement dementia-capable palliative care. We offer guidance for other homes moving toward dementia-capable comfort care.

Background

In 2012, we began an initiative focused on palliative care for people with advanced dementia. We built the program on the groundbreaking model at Beatitudes Campus, Phoenix, Arizona. Beatitudes invested time, research and training to expand knowledge and practice in residentially-based care for people with advanced dementia.

The Beatitudes Campus of Care was founded in 1962 in Phoenix, Arizona, and now includes a nursing home, assisted living units, independent apartment units, as well as a home care program. More than a decade ago, staff at Beatitudes began an intensive focus on the care offered to residents with dementia residing in their nursing home. Using a comfort approach and working with their partner, Hospice of the Valley, they identified a number of strategies specifically for people with advanced dementia living in residential settings. Care is based on knowing as much as possible about the individual with dementia, with full recognition that the resident may not be able to articulate needs which may be expressed in other ways. Beatitudes offers specific practice improvements to address needs underlying behaviors rather than the behaviors themselves.

We were most impressed by the degree to which Beatitudes identified the organizational adaptations necessary to support improved care practices for people with advanced dementia. Results of their efforts include the following: (1) liberalized diets contributing to stable weights; (2) increased toileting and reduced incontinence; (3) no use of physical restraints (including alarms); (4) almost no anti-psychotic, anxiolytic and sedative medications; (5) increase in pharmacologic and non-pharmacologic methods for treating pain; (6) decrease in total number of medications prescribed; (7) elimination of “sun-downing” symptoms; (8) improved staff knowledge, beliefs, and attitudes about palliation and end-of-life care; (9) residents receiving active comfort and even enjoyment from meaningful engagement, (10) decreased hospitalizations, (11) increased family engagement and satisfaction; (12) greatly improved staff satisfaction; and (13) almost no typical staff turnover. In recognition of Beatitudes pioneering practices and outcomes LeadingAge (a national organization of 6,000 not-for-profit organizations) awarded Beatitudes their 2010 Excellence in Research and Education award and the LeadingAge Public Trust Award in 2013.

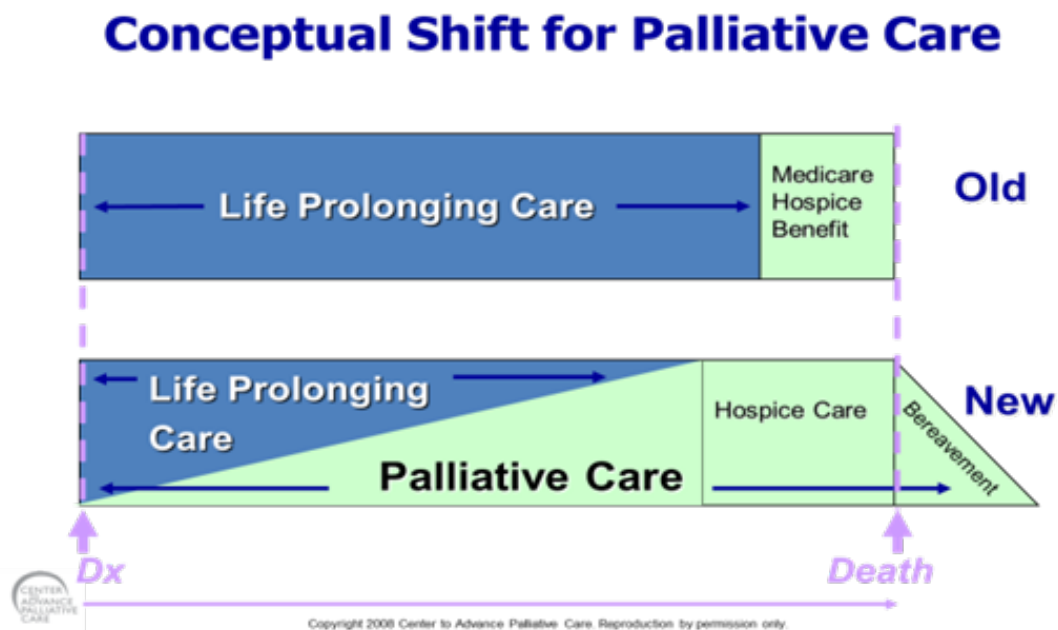
Our project began working with three nursing homes to move the Beatitudes model to New York City: Cobble Hill Health Center; Isabella Geriatric Center, and The New Jewish Home, Manhattan campus. The project involved the three hospice programs affiliated with these homes: Calvary Hospice, Metropolitan Jewish Health System (MJHS) Hospice and Palliative Care, and Visiting Nurse Service of New York Hospice and Palliative Care (VNSNYHPC). Through a 30-month process of education, piloting, spreading, and evaluation, these homes worked to implement the practice changes pioneered by Beatitudes. Our intent was to learn from the process and understand the obstacles, in hopes that our experiences could assist other homes in implementing these practices.

Dementia-Capable Palliative Care: What is it?

The fundamental premise underlying all care for people with dementia is that behavior is communication. This is not a new concept and it is an essential part of all training programs in dementia care. These behavioral expressions are almost always signs of distress, and as the disease advances, behavior rather than words become the primary mode of communication for most people living with dementia. Palliation—preventing or relieving distress—becomes a cornerstone of care for people with advanced dementia. Staff trained in dementia care is necessary but not sufficient. Organizational systems must be aligned to support a palliative approach and to insure staff efforts are effective.

In recent years there has been a shift in thinking about palliative care (see chart below). Palliation is not just for end-of-life care, but for people with chronic illnesses or people facing serious illnesses or injury, sometimes for many years. Palliative care focuses on symptom management, helping to ease stress for the person and for the family. Symptom management is about symptoms like depression, pain, anxiety, or difficulty sleeping or breathing. Some research studies suggest that this additional level of support and attention to comfort and quality of life may even prolong life. Further, a focus on personal priorities with regard to treatment and comfort can help clarify preferences for medical care directives as the disease progresses. This person-centered focus has also been shown to reduce the need for crisis hospitalizations.

Although dementia is eventually terminal, people can spend many years in the advanced stages of dementia when palliation can be most effective. As the chart suggests, palliation may be needed very little at the point of diagnosis, but palliative care assumes a growing role as the disease progresses.



Dementia-capable care practices aren't the whole story. Significant decisions must be made regarding aggressive medical treatments, traditionally used with the goal of curing. More often than not curing is not likely or appropriate for someone with advanced dementia and many of the following aggressive medical treatments are inappropriate or ineffective: (1) artificial nutrition through gastric tube feeding; (2) antibiotic therapy; (3) cardiopulmonary resuscitation (CPR); (4) hospitalization for infection.

There are further decisions about how long to continue administering various medications and over-the-counter drugs such as multivitamins. Is it necessary to continue blood-glucose level checks? Is an anti-dementia drug still helpful? What about screening tests, such as mammograms, biopsies, etc.? Both the benefits and burdens of treatment and non-treatment should be discussed so that comfort of the person with dementia is the key to every decision. These are highly individual decisions that must be made based on the person's values and best interests.

Palliative care decision points are usually reached when the person with dementia is beyond appreciating or understanding the consequences of his/her decisions. It is essential that family be involved and provided with appropriate education and help. Family members need information, understanding and support to assist them in learning what to expect and how to weigh risks and benefits of treatments. Even if the resident has advance directives, clarification about risks and benefits of specific decisions are often needed at many points during progressive dementia. If there are no directives, clarity about the potential impact on the resident of specific decisions will be essential. This means that staff must be thoroughly knowledgeable about these risks and benefits, and skilled in helping family and friends comprehend the implications of their decisions.

Again, this kind of support for families can't be accomplished without appropriate systems in place.

As Hippocrates, the Father of Medicine, wrote:
***“Cure sometimes, treat often,
comfort always.”***

Palliative Care in Action

Example 1



Sharon's husband, Anthony, was diagnosed with Alzheimer's disease in 2005. As the disease progressed, Sharon struggled to care for her husband at home. During the difficult period when Anthony wandered, he moved through ERs, private psychiatric facilities and residential care homes without available Alzheimer's units. Some facilities rejected him. Finally, three years ago Sharon was able to place him in a facility with a floor specifically for people with dementia at Isabella Geriatric Center, just at the time Isabella became a partner in our palliative care project.

When Anthony first arrived, staff had difficulties getting him to bed at night, and difficulties getting him up in the morning in time for breakfast. He was very resistive, emphatically pushing staff away. When they explored this with Sharon, they learned that it had been Anthony's habit for many, many years to stay up late (often as late as 4 am), then a snack before going to bed, often sleeping until noon or later the next day. With Sharon's encouragement, they experimented with adjusting Anthony's care plan, and now, as Sharon says, "the staff tells me that Anthony is the poster boy for letting patients sleep late." This is a great example of how to tailor dementia care to needs and preferred routines. Now Anthony sleeps until he is ready to get up. Staff know and provide the food he likes (fruit and salads especially during the day, and sandwiches, yogurt and/or cookies at night). He has good days and bad days, but staff know how to connect with him, and how to work with him."

When Anthony first arrived from a hospital psychiatric unit where he had been placed most recently, he was taking high doses of many different antipsychotic medications. Staff helped him slowly wean off and he is no longer receiving any antipsychotic medications.

Anthony's wife summarizes their experience, "Like most people, I didn't get the meaning of palliative care. Most people think it is for people with six months to live. The real meaning of palliative care is relieving and preventing suffering. If anyone thinks an Alzheimer's patient doesn't suffer...they do, in the brain. I am so relieved he is here. Even though it's an hour and a half travel each way for me, I don't care. He has blossomed with the caring people he has now. He has a better life there than he had at home with me. Once they found a way to make him comfortable, and he was no longer on so many drugs, his personality came back, his sense of humor, his pleasure in dancing, I got my husband back! Anthony has a roommate and his roommate takes care of him. He takes Anthony for a walk down the hall. My heart just bursts with joy when that happens. It brings tears to my eyes."

Anthony's story illustrates the **organizational elements** that need to be in place in order to support staff to provide appropriate care for Anthony:

1. Interaction with families as soon as someone is admitted to learn about the resident's routines and specific comforts/discomforts.
2. A care plan that specifically addresses Anthony's particular needs for flexibility insuring all staff including holiday replacements know and understand Anthony's needs.
3. Food Anthony prefers must be available in the middle of the night.
4. Food Anthony prefers must be available when he awakens in the early to mid-afternoon.
5. All three shifts need to support each other in this schedule adjustment. No one should be questioning why the night shift didn't get him up before they left.
6. Facility policies and procedures must support flexibility in waking and sleeping (including education and orientation for all staff).
7. Ongoing conversation with families about what is working and what isn't, based upon the resident's level of comfort, especially as the resident's needs change over time.

Getting Started

Bringing comfort to people with advanced dementia in a residential setting is far more than an educational process accomplished with training alone. Comfort needs to be more than a ‘project.’ Comfort must be embedded in facility expectations and reflected in the actions, attitudes and assumptions of administrators and managers, in how staff relate to each other, and in the mission, policies, procedures and protocols that set guidelines for daily practice. Department heads and managers need to be actively involved from the beginning.

Bringing comfort to people with dementia happens **through the implementation of specific care practices, and through the processes used to implement these practices.** This is an extremely important distinction. Adoption of dementia-appropriate care practices overall is key to better care, but care is always delivered one person at a time. That is, the ongoing process of matching a person’s needs with available options is pivotal. Not only will the person have difficulties communicating his/her needs, but also each person is different from others and from themselves as his/her disease progresses over time.

Practically speaking, this means **that the most effective approach** for implementing palliative care **is one which focuses simultaneously on the care planning process for individual residents,** and on the **introduction of dementia-specific care practices,** using Quality Assurance Performance Improvement (QAPI) tools to assess progress. *See Care Planning, Care Practices, and QAPI, below.*

The Basics

Because the nursing homes we worked with were large facilities, we chose to introduce palliative care to these homes using one of their dementia units as a pilot, before spreading these practices throughout each home. In most homes with a dementia unit, there are actually more people with dementia residing off the unit than on the specialized unit, so our goal was always to have practices spread to anyone who could benefit, once each home made the organizational changes needed to sustain the improved practices. It is also feasible to start with a particular practice (such as introduction of behavior-based pain assessment tools and related policies and procedures to address pain management) throughout a facility. However, while introducing new practices gradually may be the way your organization chooses to move forward, it is essential that these changes not be seen in isolation from each other: what will bring comfort to someone is how all these practices *combine* to meet the needs of the resident.

It should be clear that the purpose of this approach is not to test the efficacy of the practice improvements. These practices are well-tested. Rather, the purpose of using a pilot approach was to clarify as much as possible within each facility what specific organizational adaptations had to be in place for a given practice improvement to be embedded and sustained. These adaptations can vary slightly from one facility to the next, depending on size of the facility and the organizational structure.

Although the initial focus may be on a pilot unit, at some point sustaining that practice, even on one unit, will necessitate changes in policy and/or practice with rippling impacts on the facility as a whole. For example, improved pain assessment and pain management practices will need to be adopted for the facility overall, with

a consequent need for full staff education. It is not possible, ethical or desirable to sustain a change in practice on one unit only if residents with the same needs reside elsewhere in the facility.

A Coordinator is Essential

First, identify a staff member who will act as **Coordinator** for these change efforts. An obvious choice is a Dementia Care Coordinator, if someone is already in that role. The person who is chosen needs to be knowledgeable about both dementia and palliative care (and committed to learning more), as well as someone who has full administrative support and access. Further, the coordinator must understand that *all* disciplines and departments have a role in offering comfort to residents. Communication and group facilitation skills in this role are also extremely important.

Managerial Support Makes or Breaks a Program

The next step is determining the most feasible strategy for your facility to provide continuing **managerial oversight and support**. This means regular meetings (at least monthly) to review progress, obstacles, needed changes in policies and procedures, and resource needs. Such a meeting can either be one dedicated to this effort, or added routinely to the agenda for regular managerial meetings. Essential participants in these meetings include the Coordinator, an administrator, nursing administration, social work, recreation, dietary, the Medical Director, and as much as possible, Staff Education, and the MDS Coordinator. In addition, technical assistance for staff in designing and carrying out quality assurance/performance improvement studies will be an ongoing need. *The importance of ongoing managerial support cannot be over-emphasized.*

The MDS Coordinator is Critical

The Minimum Data Set (MDS) is information that CMS requires all nursing homes to regularly collect on each resident, and it is important to involve the MDS Coordinator from the beginning. The MDS is an essential part of the care planning process, and MDS ‘behavior’ definitions are a crucial element in effectively addressing the needs of people with advanced dementia in the nursing home setting. As is noted in the *Care Planning* section, below, there are four key items in the behavioral section, all of which are very helpful.

Teamwork is at the Heart of Change

Finally, *the most valuable tool for these improved practices is* **weekly interdisciplinary meetings on the nursing units** implementing change. These weekly team meetings should be cross-disciplinary (nursing, social work, recreation, dietary and housekeeping staff). All three of the project homes held these weekly meetings not only during the entire year of the pilot phase, but for two years since on their own. Without exception, there is agreement that these meetings are the cornerstone of this project. They should be incorporated into routine practice. The meeting facilitator must be skilled at drawing people out and open to a variety of perspectives. The facilitator must acknowledge frequently that every member of the team is important, encouraging questions and shared observations. These meetings have several objectives:

- *Education.* Although staff working on the pilot units were provided with an introduction to key concepts in palliative care for people with advanced dementia, as well as additional workshops, most learning actually occurs in the weekly meetings. Real learning takes place when resident needs are discussed, new practices are introduced, and successes and obstacles are shared. The weekly meetings provide an opportunity for managers to identify, based on staff questions, topics for additional staff education.
- *Teamwork.* These meetings have been an ideal opportunity to model both inter-disciplinary and cross-

hierarchy collaboration and problem-solving. Typically there are few opportunities for floor staff to interact in this way. The evidence of the value of these meetings in filling an unmet need is the ongoing commitment of the staff on the pilot units to continue the weekly meetings for three full years. Dietitians, nursing assistants, physicians, all staff have had the opportunity to ask questions of each other, and to share what they have learned works well and what doesn't with residents. Classic performance improvement guides acknowledge that problems can't really be solved until the people most involved participate. We demonstrated this with the weekly meetings.

- *Planning.* New practices and discussion of implementation processes are introduced at these meetings. For example, when one of the homes introduced the idea of baby dolls, there was discussion about what the dolls should look like, how big they should be, and the importance of checking with families first to gain their agreement (and comfort) with introducing the doll to their relative (with recognition that not all families are comfortable with this approach). In keeping with person-centered principles, there was considerable discussion about which residents would be most likely to benefit from having a doll.
- *Assessment.* Once a new practice is implemented, it is essential to have ongoing discussion about how it is going. For example, all three of the homes in this project use iPods with residents on their pilot units; in two of the homes, planning did not fully account for how to charge the iPod batteries. The focus was on identification of and loading each resident's preferred music but concerns about charging the batteries surfaced clearly in ongoing discussion of implementation.
- *Monitoring.* It is important for sustainability to check in regularly with staff for months after a new practice is adopted. For example, one of the facilities made changes in their snack program two and a half years ago, and yet they check routinely to be sure that (1) the right foods are delivered, and (2) it is still the right foods for residents currently living there.
- *Care Planning.* Every meeting included some time spent to focus on specific residents experiencing distress. Information and observations were shared across disciplines, potential solutions offered, and revisited the following week to make sure the solutions effectively addressed the distress.

Weekly team meetings ranged from 30 to 45 minutes, and brief minutes were kept. Because most of the 'work' happens in-between meetings, as staff try out new ideas, mini-meetings (sometimes called "huddles") are encouraged. For example, if a nursing assistant observes a resident who seems uncomfortable, she might ask the nurse to observe so they can talk through next steps. A dietitian, a nurse and nursing assistants from two different shifts might communicate about a resident who has not eaten all day to decide what might be feasible to offer the resident on the next shift.

Education for Staff

Initial educational sessions were provided on key palliative care concepts for people with advanced dementia for administrators, managers, and direct care staff (all three shifts, all disciplines). Providing comfort care to people with advanced dementia has significant organizational implications. This program requires the fully engaged support of administrators and managers. Orientation to a comfort approach is as essential for supervisors as it is for front-line staff. It is equally important to include physicians in educational and planning sessions. Educating hands-on staff on the nursing units without the active participation of managers and physicians will not achieve the desired results.

In addition to the initial orientation and educational sessions, periodic additional sessions address pain, resistance to care, and how to assure meaningful connections with people with advanced dementia. Ongoing dementia education means some education for everyone in the facility each year, and specific orientation and education for each new employee before s/he is assigned to work with people with dementia. Further, department heads and managers most likely to attend outside conferences should be encouraged to include dementia in their continuing education requirements if practice improvements are expected.

There are many sources of help and guidance for education in dementia care. CMS offers “*Hand-in-Hand: A Training Kit for Nursing Homes*” which addresses many of the care practices used in this project. CaringKind in New York City and many similar support organizations across the country offer training in dementia care, the Pioneer Network offers frequent webinars on a wide variety of topics, and there are other continuing education options listed at the back of this book.

Comfort Matters® at Beatitudes Campus

Our approach to caring for people with advanced dementia is one that Beatitudes developed and has been used to educate others for several years. Beatitudes has an expanded educational program which now includes an accreditation process. *Comfort Matters*® accreditation is granted to an organization that adopts *Comfort Matters*® principles and demonstrates program fidelity or adherence to program principles. The accreditation process supports people with dementia by incorporating organizational benchmarks and practical strategies to enhance staff practice and operational systems. The accreditation process, which generally occurs over a twelve month period, is a collaborative effort between the *Comfort Matters*® team and the participating organization. Accreditation for the program is determined through observation of *Comfort Matters*® competencies and analysis of data provided monthly by the organization. The *Comfort Matters*® team coaches and supports the organization throughout the accreditation process to maximize program success.

Comfort Matters® accreditation process assesses:

- Environmental factors which promote comfort for people with dementia
- Comfort practices
- Emergency department and hospitalization utilization
- Pain management
- Medication management

- Dementia-related behavior such as rejection of care
- Weight trends and supplement use

For more information about *Comfort Matters*® contact Tena Alonzo (talonzo@beatitudescampus.org) or Ivan Hilton (ihilton@beatitudescampus.org) at The Beatitudes Campus.

Care Planning

One of the most rewarding outcomes of our work has been the improvements to the care planning process for people with dementia.

Our first success came from learning to include not just resident problems, but resident comforts in care plans. These comforts are often the key to preventing or alleviating distress. One of the homes instituted “What Comforts Me” care plans developed at their routine care plan meetings, and adjusted as needed. While the following examples of specific interventions may seem ‘small,’ they illustrate well how ‘small’ moments have the potential to positively (or negatively, if they are left out or handled inappropriately) affect the daily experience of someone with advanced dementia:

“Staff will engage X with Bible reading, watching the NY Mets baseball, and dancing”

“Staff will only engage X in small group activities which can include puzzles and dancing, and redirect X back to room if X becomes uncomfortable with these group activities”

“Staff will offer X ice cream as a snack as much as she likes and support her decision to eat breakfast in the day room, but redirect her to her room after breakfast when that is her preference”

“Staff will assist X with wearing her makeup on a daily basis”

“Staff will receive and give hugs to X and use humor as therapeutic interventions on a daily basis”

A second aspect of our success was learning to use the MDS more effectively with people with dementia. In particular, there are four questions in the behavior section which are essential focal points when caring for people with dementia when behavior is the only means of communication. The four items are:

- E0200 A. Physical behavioral symptoms directed toward others
- E0200 B. Verbal behavioral symptoms directed toward others
- E0200 C. Other behavioral symptoms not directed toward others
- E0800 Rejection of Care (Did the resident reject evaluation or care?)

Any time one of these questions is answered in the affirmative at the mandated routine care plan meeting, the team’s attention for days, weeks or however long it takes should focus on what is causing the person’s distress, and what is the best way to alleviate that distress. “It’s the dementia” is not a sufficient answer. Otherwise, the

resident remains distressed and, when this is manifested in physical or verbal aggressiveness to others, places other residents and staff at risk. **This is an example of using the processes you already have in place to focus more effectively on the needs of people with advanced dementia.**

Behavior vs. Distress

We have learned that when we see “behavior,” we should instead label it “distress.” Typically, the term, behavior, is used to describe what someone with dementia is doing that is disconcerting or disturbing in ways we don’t understand. “Behaviors” may include calling out, taking someone else’s food, or hitting a staff member during bathing. Why does this matter so much? When we think ‘behavior,’ there is a tendency (however unconsciously) to assume the person has control over something s/he should stop. It is often hard in the moment to understand that the person doesn’t ‘know’ what or why they are behaving in such a way. Our first response is often directed to stopping the behavior. When we think ‘distress,’ we are much more likely to think that something is happening to the person that is causing him/her to feel badly. Then we are more likely to focus on getting to the root of the problem and relieving the person’s discomfort.

In this context, we have been learning to avoid the use of the terms, ‘agitation’ and ‘combative’ because they are non-specific, and don’t help us understand what is causing the person’s distress. We need to know more about potential contributing factors to the person’s discomfort...time of day, how the resident actually expressed upset (calling out, pushing away another resident or a staff member) what was going on at the time (being helped up in the morning, a fire alarm drill, another resident taking food from his/her plate).

Problem Solving

Staff should not wait for a care plan meeting if they observe a resident experiencing signs of distress. Observations of distress should trigger a search for causes of the resident’s discomfort. Beatitudes developed the following tool to help them focus specifically on what was happening for the resident, what the resident might be trying to communicate, and ideas to improve the situation from all three shifts. Example #2 illustrates there is often no one solution, but a process of trial and error before the most helpful solution(s) are identified. Discussions at the weekly interdisciplinary meetings, as well as staff ‘huddles’ in-between, to share ideas and observations, keep a focus on addressing the problem.

Beatitudes Campus Comfort Road Map



Dementia-related Behavior <i>Describe what the person is actually doing, avoid using words such as agitated or combative</i>	What is the Person Communicating <i>Consider all possible meanings of the person's actions</i>	Possible Remedies <i>Consider all possible options that could help</i>

Palliative Care in Action

Example 2

N.D. is a resident at Cobble Hill Health Center who usually sat with her peers in the dayroom. She tended to yell out constantly....it seemed as if she was yelling without a break all day long. The staff used the Beatitudes tool, “Road Mapping,” to determine why she was in distress. The tool was used at the weekly half-hour team meeting to identify the cause of N.D.’s yelling and discomfort.

Staff started by brain-storming. One team member suggested the Day Room was over-stimulating for her, with all of the activities just too much for her to tolerate. After discussion, we thought a calmer environment might help. We decided to change where she sat: each day going forward we sat her in the doorway to her room rather than in the Day Room so that she could still observe the “action” in the hall, but she was not exposed to the over-stimulating noise of the day room. We observed her each week and observed there was some improvement, but then she began to yell again.

The team met and wrote down possible causes. N.D. had a companion privately hired by her family, and one team member suggested that the one-to-one companion might be too much stimulation for her to tolerate. We decided to speak to the family about this and to suggest they discontinue the private companion because her presence might be causing N.D. to be uncomfortable. They listened to our suggestion and the reasons for it and agreed with our plan. When the privately hired companion was no longer coming in to sit by N.D. we observed that N.D. did yell less than before and she did seem more comfortable.

After a period of time, however, her yelling resumed. One staff member suggested that maybe even sitting in her doorway was too much stimulation for her as she was someone who seemed to need a very quiet environment particularly as her dementia advanced. We tried sitting her in her room near the window where she could see the outdoors and the sky. At the same time we began playing her favorite music softly on her radio. This had a calming effect on her. We continued to discuss her comfort level each week over the course of several months. We were concerned that her yelling never completely stopped. We continued to brain-storm solutions based on the principle that people need an individualized right balance of stimulation to be comfortable. We chose to try a rotation of sitting areas for N.D., periodically moving her from her doorway to inside her room, giving her the opportunity to look out her window (and back again). Our Director of Therapeutic Recreation suggested personalizing an opera iPod music program which might be soothing for her, and N.D. found the music pleasing. The combination of moving N.D. from an engaging activity to a calming activity continued to help ND reduce yelling and experience greater comfort.

We explored the possibility that some of N.D.’s distress might be the result of untreated pain by having a behavior-based pain assessment tool (the PAINAD) completed by all three shifts. Based on the results of the assessment, pain medication was prescribed for N.D., and after trials involving different medications and different doses at different times of the day, our team felt that much progress was made in identifying and treating N.D.’s previously unarticulated pain. Now we had an effective system of medication monitoring to meet her pain needs.

Enhancing N.D.'s. comfort took many steps over several months. We changed her sitting environment and we even took the counterintuitive approach in suggesting to the family to discontinue her private companion. There is an assumption that one-to-one companions generally help calm a person with advanced dementia. We also addressed ND's unidentified and untreated pain, and introduced new music. There is always a reason for a resident's discomfort. N.D. is calmer now and her plan of care is to keep her in a quiet environment most of the day, while acknowledging her needs for stimulation from music and visits from staff. She still occasionally calls out, but we doubt this is caused by pain because we continue to thoroughly monitor her pain. We continue our rotation of activities for N.D., anticipating when she needs a change of pace within a balance of stimulation, peace and quiet.

The point of this story is to highlight how long it takes to identify sources of distress, and sources of comfort—and how important it is to have the team working together to test different approaches so as to reach effective solutions.

Finally, remember to include nursing assistants in care plan meetings in addition to the weekly on-unit interdisciplinary meetings for effective care delivery. Nursing assistants provide most of the hands-on care. They have invaluable insights and they must also be included to understand the purpose and reasoning behind the concerns and recommendations of other disciplines.

Once care plans are developed, they must be easily accessed by all staff involved in providing care (including 'float' staff who are only on the unit temporarily). One of our facilities developed a one-page summary of care plan details that they laminate and place on the inside closet door for each resident. This insures the information is readily available to all staff while protecting privacy.

The comfort care practices themselves (detailed below) are absolutely essential, but facilities are still accountable for addressing needs with comfort practices one person at a time: what is causing this person's distress and what will make *this* person comfortable. The process of figuring this out for each resident is the purpose of care planning.

Families as Partners

It should be evident in our stories that close communication with families has been key to finding true comfort for residents. These comfort practices comfort family and friends as well. One family member acknowledged, “It has been palliative for me too!”

Discovering what makes someone comfortable can be challenging, but the language of comfort is not mysterious. If someone’s habit of many years has been to stay up late and sleep late, this tells us what is likely to be most comfortable for him/her. If someone has always been passionate about the outdoors, if someone loves classical piano, if someone has been a lifelong Mets fan, we must take note of all these pleasures. It is essential to gather information about the lives and preferences of residents when they first move into long-term care, and families are often the best source for this. Attached is a sample questionnaire, used by the Beatitudes Campus on **page 45**.

As dementia progresses, we can still usually see or observe whether someone is comfortable-- it’s harder to understand what is causing discomfort. Our experience reinforces that families are grateful to have discussions with staff that focus on comfort, and families are invaluable partners in the problem-solving process. As hard as it is on someone with advanced dementia to be in a state of upset and distress, and as challenging as this can be for facility caregivers, it is even more extraordinarily painful for families to watch someone they care for in such distress. When we are able to comfort residents, we have a profound effect on their families as well.

If there are ongoing discussions between family members and staff, this can ease the dialogue about end-of-life questions as well, allowing for family and staff to develop a shared context for their conversations. Some families come in with clear directions around end-of-life decisions, while others have little or no clarity. Some families aren’t sure what the questions are until they are faced with a crisis. A deeper understanding of comfort helps family members better prepare for the implications of the decisions they may need to make.

When the project first started, all three homes sent letters to family members of residents living on the pilot units, telling them about the project and inviting their questions. As changes were made on the units, information about the project continued to be shared, and issues related to palliative care were frequently part of the discussion at care plan meetings with families.

Palliative Care in Action

Example 3



Sumi was born in Portland, Oregon in 1916. Soon after her parents moved the family back to Japan where Sumi grew up and received her education. She returned to the United States in 1942 and married her husband. Although Sumi was an American citizen, she and her husband were sent to an internment camp. When the internment was over, many people from the camp were sent to New York City, including Sumi and her husband.

After settling in Manhattan, Sumi stayed home initially to raise her two daughters until her husband had an accident and was temporarily unable to work. She then went on to work in the garment district making samples and eventually retired at the age of 65. Sumi and her husband enjoyed their retirement years traveling extensively and spending time with family until he died in 2010.

Sumi's daughters describe their mother as always a very active person —she walked every day in Central Park, went to the Y for water aerobics classes and kept busy doing jigsaw puzzles. In 2012 she moved in with her daughter and son-in-law when they noticed problems with her short-term memory and other cognitive changes. She was frequently up at night and wanting to walk around.

In May 2014 Sumi fell and sustained a second hip fracture; she was admitted to The New Jewish Home for post-acute rehabilitation. After much deliberation, Sumi's daughters decided to move her into a long-term

care dementia community there. She was back up on her feet walking, forgetting to use her walker, but very purposeful in wanting to move around the community. The team spoke extensively with the daughters about Sumi's desire to move and the risk for falls. Both daughters agreed that restricting her freedom in any way would hinder her quality of life.

Sumi settled into the nursing home with the help of her daughters guiding the staff on what gave her comfort: her jigsaw puzzles, sweets, exercise classes, going to the garden and walking around. She would get upset if the staff were not familiar – so dedicated, consistent staffing helped Sumi to relax. Sumi maintains her independence with regard to her personal care needs and communicates to the staff when she requires their assistance.

During the course of her stay Sumi has fallen with injury: a subdural hematoma and a fractured wrist. When she was determined to get up and move about, she could not be stopped, nor was it possible to see where she was at every moment. The daughters both weighed in on allowing her this freedom rather than restricting her. Today, she continues to enjoy activities that stimulate her – her puzzles, trips outside to the garden with her daughters and the chair exercise program. Staff walk with her and continue to focus on her quality of life. Her daughter was able to take her first vacation in years.

Risk

Risk can be a complicated concept, and we don't always think about risk as fully as necessary. For Sumi, her family and the staff understood she was at risk of falls but all acknowledged her risks were greater from being unable to move around with some freedom. When comfort and quality of life and care are the priorities, we are obligated to look at individual and family values which may go beyond narrow definitions of "safety." If we do not consider the individual and family, we risk causing distress, rather than providing comfort.

Slow Down, We're Moving Too Fast

People with dementia are easily frightened when the people providing care move too fast. The person with dementia has difficulty thinking, which means it is harder to follow even familiar routines, unless the pace is slowed. Often, 'resistance to care' is used to describe a person who simply doesn't understand what is being asked and thus responds defensively. For the same reason, it is important to approach the person with dementia from the front, where you are visible, then move slowly, and explain what you are doing. While this may seem obvious, the demands of residential settings are such that this important principle can be overlooked in the pressure to complete care tasks. The consequence of moving too fast is a need to spend more time with the resident who is fearful, resistant or distressed.. *"The hurrier I go, the behinder I get,"* wrote Lewis Carroll, in [Alice in Wonderland](#).

Consistent Assignment

For anyone receiving care in a residential setting, consistent assignment is an extremely important component of good care. Consistent assignment is the same thing as primary assignment, and it means that individual staff members care for the same residents each day. Consistent assignment is especially valuable when working with people with dementia. People with dementia can't articulate their own needs and staff must learn the preferences, needs and routines of residents, including what distresses them and what makes them comfortable. Knowing the resident's needs and preferences means staff can move more easily and confidently through the day while building meaningful relationships with residents over time, all of which has been shown to increase job satisfaction.

However, experience suggests that even with overall consistency in assignments, there can be more use of 'relief' staff than expected. Relief staff start at a great disadvantage, taking care of people they don't know well or at all, a challenge made even more difficult when the residents have dementia. While relief staff are essential, organizing their schedules so that they work regularly on as few units as possible gives them an advantage in knowing the residents. Limiting the number of different nursing units worked by specific relief staff is certainly desirable.

The *Advancing Excellence* website has a useful tool to track how many different staff cared for a specific resident during a given month. The results can be startling. Even with consistent assignment, the number of different people caring for someone can easily rise to 20 or more during the month. Twenty staff caring for one resident in one month makes it unlikely a care plan will be understood or followed. The goal for long stay residents should be no more than 12 caregivers in a month.

The need for relief staff suggests the need to easily share information about the care needs and preferences of residents. Even if relevant information about residents is collected (i.e., Mr. Smith likes to go to bed after having a glass of milk every night), if this information isn't readily available, both Mr. Smith and his temporary caregiver are likely to be unnecessarily frustrated (all the more so if Mr. Smith has dementia). Making relevant information easily accessible to temporary caregivers should be a priority.

Pain

Pain is common in older people and is associated with a number of chronic and acute conditions. The person with dementia is as likely to experience pain as any other older person. There is evidence that as many as 83% of nursing home residents experience pain that often goes unrecognized or inappropriately treated. Pain is common but it is not normal. Pain has a powerful effect on mood, sleep quality and functional ability, and overall quality of life.

How does the person with dementia express pain?

Sometimes they express pain in words but often pain is expressed by the look on their faces or behavior changes. As dementia progresses, confusion and lack of insight make it even more difficult to accurately describe pain. A resident living with dementia may call out, moan, or become very agitated, sometimes even

striking out at caregivers. Rejecting care due to pain is especially likely first thing in the morning. Too often in the past, we assumed this behavior was an inevitable consequence of dementia, and only anti-psychotic medications would alter the behavior. But anti-psychotic medications do not help pain. Even worse, anti-psychotics may mask pain with sedation, making it even harder for the resident to communicate his/her discomfort or pain. Treating pain can prevent or limit the negative behaviors because the person is no longer suffering.

One of the biggest challenges in caring for someone with dementia is knowing when they have pain, and whether specific interventions are having a positive effect in eliminating, reducing or preventing that pain. First, don't assume the resident cannot explain or rate their pain. Always ask him/her directly if there is pain or if they are sore, ache, or hurt (using words like 'hurt' or 'sore' in addition to 'pain' when speaking with residents—whether they have dementia or not—is often more effective). If the resident responds to a particular word for discomfort, it is important to document this in the chart, so that other staff can also communicate more effectively with the resident using this same term. Remember when inquiring about pain, to eliminate distractions around the resident to enhance their ability to focus on the communication.

It is very common for people with dementia to deny real pain because they may not understand the question or connect it with their discomfort. When the person can no longer verbally express pain but s/he seems to be in obvious distress, explore further causes. Reviewing the chart may reveal possible causes of pain based on the person's history, such as arthritis in the knees, an old shoulder injury, or possibly a fall in the previous few days. Using this information, try lightly placing a hand on the resident where it is suspected they may be uncomfortable. This may help direct the resident's attention to the body part in question and help him/her make the connection between the questions about discomfort and a particular body part. Always rule out other forms of discomfort, such as a soiled brief or an acute medical condition. If no other probable cause for the distress can be identified, **assume that pain is present**. When the person can no longer report their pain, use a valid and reliable pain behavioral assessment tool, such as the PAINAD. There are several such tools; PAINAD was the one used by all three of our homes.

One of the reasons our homes selected the PAINAD is that it is easy to understand, by both clinical and non-clinical staff, and family members. The PAINAD guides staff to identify the degree to which a resident is manifesting specific behaviors, such as noisy, labored breathing, moaning or groaning, facial grimaces, or clenched fists, all of which could be indicative of pain.

Staff may think they have to 'see' pain before administering the PAINAD. Experience teaches us that the PAINAD should be administered whenever any of the behaviors the tool describes are observed. Behavioral expressions are always signs of distress, and the PAINAD helps us focus in on the nature of the distress. Our job is to prevent or minimize distress that often comes with pain. The PAINAD form and instructions for use can be easily accessed through the Internet from several different sites, including www.geriatricpain.org.

Explore non-pharmacological interventions first

Sometimes a change in approach can solve the problem. A resident who grew increasingly upset each day when being helped with dressing in the morning was discovered to have an old shoulder injury. Her dressing routine was adjusted so she could avoid moving her shoulder, and her pain was minimized.

Distractions can also be helpful. Staff reported that when helping a resident dress, he grew calm when they rubbed a spot on his shoulder. A nurse reported that a dressing change that had been previously very difficult was over in minutes without incident because she offered a lollipop before starting the dressing change. Listening to personalized music may also help to distract someone from discomfort.

Whenever an approach works with a specific resident, document it in the care plan. Staff are encouraged to remain alert, assessing whether the intervention continues to be effective, and taking action to explore other options if it is not.

Pharmacologic Strategies

When non-pharmacologic interventions are not sufficient to prevent or relieve the resident's distress, a further step is for the medical provider to start a trial of a pain medication (often in conjunction with non-pharmacologic strategies). During the trial period, seek regular input from all staff (all shifts) to determine if the treatment plan is providing overall comfort and pain control and whether the resident's behaviors suggest some relief. Document results of such trials. If the initial trial does not produce improvement for the resident, consider higher doses and/or different pain medications (including opioids), as appropriate.

All three facilities in our project immediately shifted away from PRN orders for pain medication. Instead, regularly scheduled analgesics were prescribed, and one facility observed a significant drop in rejection of care and other signs of distress in a single month.

Both the Center to Advance Palliative Care (CAPC) and the Society for Post-Acute and Long-Term Care Medicine (AMDA) offer on-line educational programs for physicians to assist them in the identification and treatment of pain.

Care Planning

In routine care plan meetings, the interdisciplinary team should always consider the possibility of pain, especially if any of the resident's diagnoses involve the likelihood of pain (i.e., arthritis). Whenever staff identify rejection of care, physical or verbal aggressiveness, or "other" behavioral expressions for a particular resident, pain should be considered as a possible cause.



Implementing a Pain Program

The elements of an effective pain program for people with advanced dementia include: (1) a behavior-based pain assessment tool, such as the PAINAD, with guidelines for use, integrated into overall facility policies and procedures; (2) education for all levels of staff (including nursing, physicians, recreation, social work, housekeeping, dietary and families) and all shifts on the potential signs and symptoms of pain for people with dementia, and on the procedures for reporting, treating and monitoring interventions; and (3) information and education for family members on the identification and treatment of pain.

One of our facilities chose to introduce a more rigorous approach to assessing and managing pain in people with dementia. The facility created a workgroup on their pilot unit, and focused on four residents, all of whom had communicated distress in a variety of ways. It took some detective work until they were able to identify the source of the distress but only two residents required pharmacological interventions, while each of the other two needed non-pharmacological adjustments. Staff found this method helpful in introducing new concepts, and each new unit used the same approach. After several units completed this process, staff chose to present what they had learned by developing 'skits' illustrating what they learned to assess and manage pain. The photo above shows staff members reacting with delight to one of the skits. A helpful way to help staff master new practices involves providing opportunities for them to teach others.

Rest and Sleep/Wake Routines: The Importance of Resting When Tired

One of the major findings from this project was the importance of a balance between stimulation and rest for people with advanced dementia. Being confused and unable to make sense of the environment is exhausting for the person with dementia, and over-stimulation only makes it worse. As the disease progresses, sleep cycles may change as well, leaving people even more at risk for the effects of sleep/rest deprivation.

The Beatitudes Experience

Early on, staff at Beatitudes recognized they had a serious problem with sundowning. They discovered that sleep and rest routines were a big factor. As Tena Alonzo from Beatitudes describes it, “In the dementia unit, every day at the evening shift change, the chorus would start: a few people would call out and then everyone in the vicinity would join in. You could hear ‘help me, help me’ and ‘oh, shut up’ continuously. Perhaps it wouldn’t have been so bad if that’s where the challenging behavior stopped, but this was just the beginning of the evening! People who were easy to get along with the rest of the day would suddenly want to fight with anyone who crossed their path. Others would pace the floor looking for an exit to escape. Dinner was disastrous as no one could hear themselves think. Visiting families and friends were distressed and upset. After several hours dealing with agitated residents and family visitors who were sometimes inconsolable, the exhausted staff would finally get everyone in bed so the whole process could begin again the next day.” As the staff looked at the frequency and severity of residents experiencing sundowning, they asked several important questions. Is sundowning just a part of the disease? Why do some older adults with dementia act so differently in the afternoon? Isn’t there something we can do to help everyone be more comfortable? The answers to these questions didn’t come all at once, but over time they learned some valuable lessons about older adults with dementia.

The Beatitudes team began to observe everyone residing on the dementia unit between the hours of 2:30 PM and 9:00 PM. This observation, which occurred over several days, shed light on possible directions. The staff saw that many residents looked tired and frazzled and wondered if they would be more comfortable if they were to lie down and rest. Much of the time these rest periods were challenging and not necessarily convenient for the staff. The team decided if someone looked tired, no matter when that occurred, they would assist him or her to rest either in a comfortable chair or on the bed (some prefer a chair or the couch, some may prefer to stay on top of the bed, with a throw, while others preferred to change and get back into bed, but the decision is based on the resident’s comfort). After some discussion, the staff agreed that it didn’t matter if the rest period was during a meal or an activity. After a few months, everyone accepted the ‘rest when tired philosophy.’ As residents started to sleep when they were tired and wake when they were rested, the change was obvious. They were happier and didn’t seem to need as much psychotropic medication. The nurses didn’t give PRN medications for agitation any longer and felt comfortable asking the physicians to begin tapering the medications. They started with the anti-anxiety medications because almost every resident was receiving one, and then worked on tapering the anti-psychotics.

Lessons Learned

Finding the right balance between rest and stimulation for someone with advanced dementia makes a big difference in the person’s comfort, and in providing care. The activity involved in morning care and breakfast is likely to prompt a resident to need a rest period. Another time when rest is often welcome is after lunch.

Early in our process, a nursing assistant decided to test helping two residents back to bed after lunch. Both of these residents typically did a lot of crying out at that time of day. When the nursing assistant later reported her experiment to the nurse, the nurse exclaimed, “No wonder it was so quiet!”

We learned as well that waking someone from a sound sleep is never a good idea. Reducing caffeine later in the afternoon and evening (substituting decaffeinated beverages) can be helpful.

Finally, we confirmed the well documented relationship between lack of sleep and falls in older adults, especially in people with dementia. Staff were reluctant to help residents back to bed to rest during the day because they assumed residents would fall when they tried to get up after waking. However, we learned that attention to natural sleep patterns can actually help reduce the incidence of falls.

Flexibility in wake/sleep patterns, while difficult for families caring for persons at home with advanced dementia, is less an issue in residential settings with 24-hour staff. Residential care makes it possible to remove this potential source of distress for residents and staff alike.

Implementing a Sleep/Wake Program

One pilot unit initiated a one-month project to explore sleep/wake issues. In weekly meetings including all disciplines, they reviewed their current practices regarding rising times, bed times, and rest during the day, sharing information and observations. They looked at mealtimes, therapy schedules, and cleaning schedules that might affect resident sleep patterns, preferences or sleep interruptions. Then they identified four residents who by verbal or non-verbal expression seemed to express a preference for other-than-routine sleep patterns, and studied them in depth. They kept a 24-hour activity log (looking at how residents actually spent their time, including facial expressions, body language, and verbal communication) for about three days, enough time to establish patterns. They sought participation from families, and also reviewed MDS data on the functional status and preferences (Section F) of residents.

Some of the issues they encountered included residents taken out of bed early (whether they wanted to be up or not) because they were considered at high risk for falls, breakfast only available until 11am, and complaints from dietary staff when nursing assistants returned trays too late. Some family members complained when residents were left in bed too late in the morning. Also, they realized that the MDS doesn't include questions about preferred waking times, or sleep routines at home before the resident moved to the facility.

Once they gathered and shared this information, they held staff in-service education sessions with all three shifts. They chose to try adjustments to each resident's sleep/rest cycle, using shift huddles, care plan meetings, and the communication book. They reviewed and changed medications in some situations, including the timing of medication administration. They also looked at turning and positioning, toileting, and appointment and therapy schedules, and they worked to coordinate cleaning and picking up of garbage (because of the potential for noise/disturbance).

They created a calmer and more reassuring and therapeutic environment by reducing noise, limiting the use of the room intercom system between 8am and 9am when many residents are still sleeping, reducing clutter in the environment, and turning off lights in hallways and rooms in the evening. Staff also offered hand and back massages, aroma therapy, chamomile tea, warm milk, and crackers. Snacks are offered to residents who are awake during the night.

After focusing on the sleep/rest patterns and needs of these four residents, and spreading the approach to other residents on the unit, staff found that residents were more relaxed, with fewer signs of distress as expressed through their behaviors. There were a decreased number of falls, decreased hospitalizations, and the use of psychotropic medication was reduced.

Now, all residents may sleep and wake up on their own. Staff monitor residents to see who is still in bed, and to be alert to when someone is ready to get up. Inter-shift reports include information about residents' rest/sleep experiences, and the Charge nurse briefs nursing assistants who are not regularly assigned to the unit. Breakfast is saved for late-waking residents and warmed when they are ready to eat. Hot cereal, fruits and sandwiches are available if preferred as breakfast alternatives. Activities and appointments are structured to meet residents' needs, and barbers and hairdressers routinely go to the unit. Pre-set bathing schedules are not followed—staff adjust bathing schedules and methods to each resident's preference and comfort.

Finally, they have expanded Section F of the MDS to include questions about preferred waking times, sleeping preferences prior to admission, and how many times the resident typically awakens during the night. This information is incorporated in the Integrated Admission Assessment, which must be completed within 48 hours of admission. They also continue to talk with families about the reasons for the focus on sleep and rest, and what works best for their relative.

When the staff team finished this project, they had a small party which included chamomile tea, soft sandwiches, soft and relaxing music, aroma therapy and back and hand massages. They did this between 3pm and 4pm to include staff from both day and evening shifts.

A Word About Falls

We learned staff were initially concerned that helping people back to bed to rest during the day might increase the likelihood of falls, should the residents rise on their own when there was no staff person present in the room. In addition all three dementia units tended to gather as many residents as possible in the day rooms, and to insist that they stay seated (“sit down, sit down” was a frequent refrain).

However, just as Beatitudes discovered, fatigue and lack of movement or exercise are actually likely to be the *cause* of falls. Staff must of course be vigilant regarding falls prevention, and care planning needs to look carefully at the best ways to support residents who are high fall risk, but it is clear that keeping residents from needed rest, or requiring them to sit all day, will not solve but only make the problem worse.

A word about falls....keeping residents from needed rest, or requiring them to sit all day, will not solve but only make the problem worse.

The Care Environment

The environment can have an enormous influence on comfort, and distress. While this is true for anyone (think about what it is like for you when a neighbor is playing music you dislike at a high volume), it is especially true for people with dementia who can be so easily over-stimulated, and overwhelmed. People with dementia increasingly lose the ability to understand what is happening around them, and can be easily startled. This is why the use of overhead pagers should be avoided.

Noise

There is a tendency in residential care to worry about whether residents get enough stimulation. Ironically, overstimulation can be very problematic as well. At Beatitudes, after addressing the sleep and rest needs of residents, staff members observed their overall unit environment (or milieu as they prefer to call it). As they describe it, what was seen and heard was appalling. At the evening shift change, the commotion increased significantly. Staff were used to speaking all at once and rushing around trying to complete tasks before end of shift or gearing up to begin their work. This cacophony and disruption were compounded by a television in the common area and general noise on the unit. Watching the residents respond to the din was enlightening. Sometimes people covered their ears or tried to get away from it. Some just looked scared and bewildered. It became clear to the staff that they needed to stop talking so loudly and slow down. They moved the television that had been so prominently displayed in the common area despite the fact that the residents rarely looked at the television. The milieu became quiet, and everyone responded positively to the change in the environment. Shift changes have intentionally become invisible.

Not surprisingly, this calming down of the environment makes it much easier for residents to engage with each other, and with staff members and visitors. Creating this more serene atmosphere, along with giving residents the opportunity to rest throughout the day, has resulted in the elimination of sundowning. An added benefit is an observed increase in the number of visits by families in the evening.

Comfortable Places to Be



Beatitudes taught us the importance of small sitting spaces in different parts of the unit, giving residents the option of sitting quietly on their own or with one or two companions away from more crowded common areas. All of the homes in our project remodeled old closet space along hallways to make new sitting alcoves. For residents who like to walk up and down the hallways, these alcoves also provide an opportunity to

rest along the way. Two of the homes also made existing sitting areas in front of the nursing station more comfortable and welcoming for residents.

Uncomfortable Places

The opposite of comfort is discomfort. We learned that day rooms/dining areas used for meals and activities throughout the day are often significant sources of distress for residents. There is a tendency to crowd a large number of people into these rooms, to ‘keep an eye’ on them. The unfortunate result is that some residents spend the entire day in that room, which can be both overwhelming and physically uncomfortable. Sitting in wheelchairs for long periods is especially disagreeable, and even painful.

These day room spaces are also often noisy. As noted earlier, there are usually televisions in these areas, and they are often left on for much of the day (whether residents are watching or not). Sometimes staff add a lot of noise and commotion during mealtimes. Residents may call out because they are uncomfortable from sitting too long, or they are feeling overwhelmed by the atmosphere.

In the beginning, we observed that almost all the activities in these rooms during the day were for large groups. We know that large group activities rarely work well for people with advanced dementia. The residents communicate their discomfort with large group activities by sleeping through them or trying to leave. All our facilities have a nursing assistant assigned during the day to ‘watch’ residents, and they were expected to conduct large group activities (trivia games or ball-tossing). These games may work with three or four people, but rarely with more than four. It is clearly important to have nursing and activities staff (including social workers, housekeepers, and dietary staff) working together on one-on-one and small group activities throughout the day, regardless of location in the day room or in resident rooms. Just walking a resident down the hall, or bringing a snack and sitting together while s/he eats it can be enjoyed for its real connection with the staff person. Such brief spontaneous “activities” are far more valuable and meaningful for the resident than an hour or more of sleeping through an activity they don’t understand or can’t follow. All our homes are moving toward more individualized, one-on-one or small group activities.

Finally, we had to address the issues of staff assigned to day rooms who were heard repeating “please sit down,” regularly moving to a resident who was trying to stand to convince them to sit down again. Keeping residents seated is, in effect, a restraint, with the same undesirable outcomes. Forcing a resident to stay seated can cause discomfort and pain from sitting too long or unsteadiness when standing or walking. Now all our homes acknowledge a resident’s preference to walk even if leaving the day room to return to their rooms. Some but not all residents will need to be accompanied when walking out on their own.

Making the Most of Meals

For most of us, meal times are pleasurable experiences, whether we crave comfort foods, new cuisine or self-prepared creations. For the person with dementia, however, meal times can be frustrating, confusing and extremely stressful, with associated risks of reduced appetite, weight loss and even malnutrition. It is not unusual for nursing home residents to resist eating, which often creates additional stress between residents and their caregivers or family members who feel obliged to persuade them to eat.

People with dementia may have medical conditions, physical disabilities or medication issues which affect appetite and ability to eat. They may forget whether they have eaten, have difficulty with chewing or swallowing, or even have difficulty recognizing foods or knowing how to use cutlery. People with dementia may also become easily distracted while eating. They may be unable to communicate food preferences or they may prefer only a few foods, or certain types of food, especially sweets like ice cream, cookies, cake or chocolate candy.

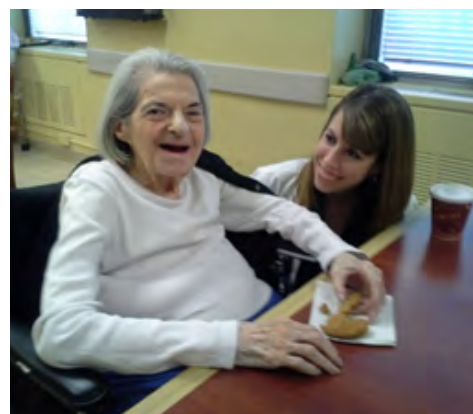
There is an unfortunate tendency to rely heavily on the use of supplements to address the nutritional needs of people with advanced dementia. If comfort is the goal, we can address both the nutritional and quality of life needs of residents. The strategies below address the prevention of weight loss, as well as the bringing of comfort and even pleasure. Facilities can learn to monitor reductions in weight loss and reduced use of supplements as measures of progress.

We are More Likely to Eat Food We Enjoy

Knowing what each person likes to eat is even more important than knowing what they don't like to eat. Even when people with dementia can't remember the name of a food, pleasurable associations may be retained with the sight and/or the taste of particular foods. If they like the food, they are much more likely to eat it. Most nursing home residents do not need special diets and restricting food options can increase the risk of weight loss. It is the position of the Academy of Nutrition and Dietetics that "...the quality of life and nutritional status of older residents in long-term care facilities may be enhanced by a liberalized diet." This almost always applies to residents with diabetes as well. The "Nutrition Recommendations and Interventions for Diabetes" position statement of The American Diabetes Association concludes with, "The imposition of dietary restrictions on elderly patients with diabetes in long-term care facilities is not warranted."

A Comfortable Dining Environment Makes a Big Difference

The dining area should be quiet and calm. Noise and other distractions can interfere with a resident's ability to focus. Soothing music may help, but it is important to observe residents in the dining area for reactions to different types of music. If the music selection or the music itself is causing anyone distress, change it to something else or turn it off. Television should be turned off during meal times. If a staff member or family member is able to eat with a resident, this may increase the likelihood that the resident will eat. When you share a meal with a resident, try to eat a similar food to encourage positive feelings of comfort and familiarity.



Residents should never be forced to eat. Do not take food away too quickly, however, because many residents will eat if given enough time. Plates should not be overcrowded, and sometimes it is helpful to serve only one item on a plate, one plate at a time. When using placemats or tablecloths, they should be a different color from the plates. This helps residents see the edges of the plate more clearly, making it easier for residents to feed themselves. Finally, finger foods increase the likelihood that residents will be able to feed themselves.

The Importance of Snacks

If a resident doesn't seem willing or able to eat much or anything at mealtimes, snacks like a piece of fruit, a cookie, pudding, or a peanut butter and jelly sandwich should be offered throughout the day. Real food is always preferable and more satisfying than supplements. Snacks have become a part of nursing home life, but snacks tend to be chosen for nutritional value only or they are offered at set times that may not fit resident preferences. Even if snacks are available at all times, the key element for residents with dementia is for staff to offer individually preferred snacks directly to individual residents approximately every hour around the clock while awake. The portions may be small (orange sections, a quarter of a sandwich, a cookie), but as Beatitudes demonstrated, this approach can be very effective in preventing weight loss.

Lessons Learned from a Snack Program

Staff began to make changes by discussing which foods residents liked and disliked. One facility's staff noted that residents didn't like hard cookies and they recommended a change to softer cookies, a change quickly adopted by all the other units in the home. Changes to the snack cart were tested first on pilot units to help kitchen staff adapt to the new approach. The most popular snack choices were peanut butter sandwiches (without the crust), fresh fruit, smoothies, cheese cubes, pound cake, soft cookies, Fig Newtons, corn chips, pudding, and applesauce. Even after more than two years, staff continue to observe changes over time. Staff were surprisingly willing to make these changes and even to make sandwiches when they were needed. The key is to offer snacks residents will actually eat.

The winning combination was offering the food directly to individual residents throughout the day and evening, whenever someone is awake. Because people with dementia slowly lose the ability to *initiate* or tell someone if they are hungry does not mean they won't welcome a specific offer of a cookie they are known to like.

Real food is always preferable and more satisfying than supplements.



Rethinking Activities: Meaningful Engagement for People with Advanced Dementia

Distress may result when people are feeling lonely, bored, or frustrated. When caring for people with advanced dementia, every interaction has the potential for meaning. Whether it is help with dressing, offering a snack, or a walk hand-in-hand down the hallway, there is connection and potential for comfort. All staff, regardless of discipline, have a crucial role in meaningful activities.

Activities must be customized to be meaningful. People with advanced dementia almost never engage in large group events. In the chapter on “Activities Programming” in Palliative Care for Advanced Alzheimer’s and Dementia: Guidelines and Standards for Evidence-Based Care, the authors relate the following story from staff about their ability to make meaningful connections with residents with advanced dementia,

When asked whether they could connect with an individual on a one-to-one basis, they unanimously and emphatically said, yes, they could. They also agreed that they could fairly easily make simultaneous connections with a 2:1 resident-to-staff ratio. When asked about resident-to-staff 3:1 situations, they hesitated before deciding it usually can be done, but can be challenging. However, when it came to 4:1 resident-to-staff ratio, they admitted that three was the limit and that they usually could not make meaningful connections with four residents at a time. (page 160)

Learn as much as possible about residents’ lives (occupation, family, hobbies), preferences and comforts before they arrive. Any staff can engage by helping someone get ready for bed, sharing some chocolate, or listening to favorite music. Daily flexibility means there are many options available and staff familiar with what will work with a given resident on a given day. Options always involve routine activities of daily living such as dressing and eating, as well as personalized activities, holding a baby doll, a walk with a staff member to an outside

garden, doing a simple puzzle, hand massages with essential oils, arranging paper flowers for the dining room, or cuddling with a visiting dog or cat. Any meaningful interaction will not be judged by its duration but its quality.

A wonderful opportunity for providing individualized engagement for people with even very advanced dementia, and used extensively by our three homes, is the personalized music (iPod) project developed by the non-profit organization Music and Memory, Inc., at www.musicandmemory.org. Music that is personally meaningful to residents has been found to evoke past memories, often helping the resident to feel calmer and more connected to other residents, staff and family and friends.

Anticipation of Need

Anticipating the needs of residents is a strategy that is extremely helpful in tying together the approaches discussed above, and should set the framework for care planning. As staff get to know individual residents, for example, they begin to know when someone is likely to need the bathroom, and can assist them before it becomes urgent. The same is true for waking and sleeping times, for rest periods, and for eating habits, etc. Things do change from day to day and over time, but they are also often pretty predictable. The objective here is not to come up with a set schedule, but to be guided by the resident in planning for their comfort.



Palliative Care Decision Points: Maximizing Comfort

Most people are aware that dementia results in a person's memory, speech and thinking slowly declining over time; however, what is sometimes less understood is that growing microscopic damage to cells in key areas of the brain are the cause of this decline. The most common type of dementia is Alzheimer's disease. Other types of dementia include: Vascular Dementia, Lewy Body Dementia, Frontotemporal Dementia, and more than 50 other rare types. While all are the result of brain damage, each type has its own set of symptoms that worsen over time.

Because decline is inevitable, there are significant decisions to be faced by people with dementia (while they are still able) or, eventually, by their family and friends, especially if there are no advance directives. These decisions typically arise with regard to aggressive medical treatment traditionally associated with curing disease, which are often not beneficial to someone with advanced dementia. The question becomes, with a disease for which there is no cure, will a specific intervention aimed at cure actually cause more pain or discomfort, with limited or no possibility of benefit? For family, friends and even caregivers, this question is

made even harder because it is often experienced by them as ‘giving up.’ While it is true that these moments often signal that the disease process is nearing its end, it is also true that there is never a more important time to pay attention to comfort.

Below are examples of the kinds of decisions that families may face. Of course if the resident has clear advance directives or expressed wishes, the decision should always follow those directives. If the directives are somewhat general, leaving room for interpretation, or if there are no directives, it is left to family members to make a judgment on behalf of the resident. What is most important is that families have information about the potential impact of their decision on the resident’s comfort, and that they understand that overall, dementia is eventually a terminal disease and continued decline is inevitable. In discussions with families, when there are no advance directives, or when they exist but there is room for interpretation, one question that can be helpful is, “If your parent could see themselves as they are now with dementia, what do you think they would want? In the context of having dementia that will worsen over time, would they choose to focus on aggressive medical interventions that may or may not prolong life and cause further distress or would they want to focus all efforts on care that promotes comfort and quality of life over quantity of days?” Most people when they are preparing advance directives are not thinking about the possibility of dementia (more likely they are thinking about cancer, heart failure, stroke, or similar situations), and asking this question helps families to focus more clearly on the circumstances their relative is actually facing.

Above all, decisions should be based on what is right for the person with advanced dementia. That means following advance directives, if there are any, and honoring verbal preferences if family members have heard them expressed by the resident in the past. If nothing is known about the resident’s preferences, families will need to use their best judgment, based on their knowledge of the resident and their understanding of the implications of the choices available to them.

Artificial Nutrition

People in the late stages of dementia often lose their appetite and lose weight, and they also often experience swallowing problems. This can be particularly stressful for family members and caregivers because rejection of food is such an upsetting sign of decline, because of fears that the person is dying, as well as because of concerns that starvation might be painful. At the onset of eating problems, acute medical problems (medication side effects, stroke, infection, etc.) should be considered and excluded. Easily reversible causes should be addressed, such as constipation or dental problems. However, most people with advanced dementia will have eating problems or will actively reject food in the final stages of their illness, and people should never be forced to eat.

As discussed earlier, creative ways of providing food for residents should also be thoroughly explored. It is common for people with advanced dementia to want smaller portions and less and less food, and to prefer food that is soft and sweet, as well as finger food which allows them to feed themselves. Frequent offerings of small amounts of food that has real appeal to the resident can delay the time when food is totally rejected, and just as important, can bring moments of pleasure. It should be explained to families that because of the progress of the dementia, body functions are naturally slowing down and no longer require additional calories or liquids.

Alternatively, artificial nutrition through gastric tube feeding does not prolong life nor does it prevent pneumonia, malnutrition or pressure ulcers, nor does tube feeding reduce risk of infections or improve one's comfort. Indeed it can be a source of discomfort such as bloating, aspiration, diarrhea, and other conditions.

Antibiotic Therapy

Infections and fever are very common for people with advanced dementia, and generally signal further decline in bodily functions. Pneumonia and urinary tract infections are the most common types of infections for people with advanced dementia. Often these infections are noted after acute changes in patient behavior, where residents become either more lethargic or aggressive than they usually are. The main treatment choice is whether to administer potentially curative antimicrobials, or institute solely palliative measures (eg, oxygen, acetaminophen).

Antibiotics are often prescribed without clear clinical evidence of infection, and they may cause significant harmful effects (including possible increased confusion, gastrointestinal distress or *C. difficile* infection, and have the potential for drug interactions, as well as possible discomfort associated with parenteral administration), along with the discomfort of the diagnostic and monitoring procedures associated with the use of antibiotics (such as chest x-rays, drawing of blood for white cell counts, urine specimens via catheterization, etc.). If the decision is to use antibiotics, providers should conduct a clinical assessment to be certain there is adequate evidence of infection to justify such treatment. There are also occasions when antibiotics may be used primarily for comfort purposes (e.g., a painful urinary tract infection). In either case, it may be possible and is preferable to give these medications orally, if appropriate, to avoid more invasive treatment.

Antipsychotic Medications

While antipsychotic medications are frequently prescribed for people with dementia who experience behavioral and psychologic symptoms, the U.S. Food & Drug Administration has warned that treatment with antipsychotic drugs are linked to serious side effects, including an increased risk of stroke and death. Antipsychotics do reduce psychotic experiences such as delusions or hallucinations, but do not address underlying causes of distress (such as pain), and may make the job of detecting or properly treating the causes even harder. As such, they should only be used, if at all, in cases of distressing psychotic experiences.

Cardiopulmonary Resuscitation (CPR)

CPR is a lifesaving technique useful in many emergencies when someone's breathing or heartbeat has stopped. However in persons with terminal or life-limiting illnesses, CPR is rarely helpful. Those who initially survive CPR are taken to an intensive care unit of a hospital where, research confirms, they rarely survive. The process of administering CPR requires pushing rhythmically and forcefully on the breastbone to restore the heart to its normal rhythm. Because most persons with dementia are old and frail, the ribs are prone to breaking in this process.

Screening Tests

When there are decisions to be made about whether to go forward with prevention services or screening tests, consideration needs to be given regarding the potential benefits and risks. Most screening tests identify asymptomatic cancers that would not present clinical signs or symptoms for at least 5 years. Patients with advanced dementia typically have life expectancies of less than 5 years and thus would not benefit.

Furthermore, when abnormalities are found, patients may be exposed to harm due to invasive tests and procedures. For example, if a mammogram discloses possible or probable cancer, is surgery and/or a rigorous course of chemotherapy something that is likely to be beneficial and what potential harms would be imposed? If not, the mammogram is unnecessary, and an unpleasant experience can be avoided for the resident. We don't tend to think of mammograms as more than mildly unpleasant, but for someone with advanced dementia, they can be quite painful and distressing. Many other tests can be extremely invasive, upsetting and sometimes painful, and the question always needs to be, is the stress and pain for the resident truly helpful in any way?

Hospitalizations

Most of the time the burdens of hospitalization for people with advanced dementia outweigh the benefits and should be avoided. Infection is the most common cause of hospitalization, but hospitalization is not necessary for optimal treatment, as immediate survival and mortality rates are similar whether treatment is provided in a long-term care facility or a hospital.

For other circumstances, such as surgical repair of a hip fracture, the question arises, is the resident likely to survive surgery? And even if they are, there is the danger that the anesthesia will trigger delirium. These questions must be carefully considered whenever surgery is contemplated.

Regardless of the reason for hospitalization, it is very hard on people with dementia. Their dementia places them more at risk, because they can't explain things to staff (e.g., that something hurts, that they are feeling sick to their stomach, that they are constipated, that they need to use the bathroom), nor are their individual habits and comforts known to staff. They are also more at risk for infections and bedsores. Because the environment and virtually everyone in it is unfamiliar, it can be frightening and overwhelming for the person; in addition, many hospital staff have had limited or no training in dementia care, so may be unfamiliar with the most effective approaches to care.

All of these factors also put the person with advanced dementia more at risk for delirium. Both the prevention and the treatment of delirium are tied to identifying and addressing its likely cause, which the person with dementia is rarely able to articulate. For example, untreated pain can be the cause of delirium, and yet the person with advanced dementia is rarely able to convey that they are in pain, except through their behavior which, unfortunately, may be ascribed to the delirium and therefore remain untreated. Anti-anxiety drugs, often provided to people with dementia in the hospital setting, may also contribute to delirium.

Medications

The effectiveness of any medication and potential for side-effects or interactions with other medications should always be closely monitored. As someone becomes frailer, the negative impact of some drugs may increase, and at some point in the advanced stages of dementia, questions can arise about the continued efficacy of various medications that residents may have been receiving for many years; for example, is there a point at which anti-dementia drugs are still of benefit to the resident? Diabetes or cholesterol-lowering medications may also need to be re-evaluated as a person reaches end-stage disease. Each situation must be discussed and carefully monitored if drugs are withdrawn, to assess the impact on the resident. It is also essential to educate family about these changes, and the reasons behind them.

Learning from this Project

As the project progressed, it became clear that many family members and even some staff did not fully realize the degree to which dementia is the result of physiological decline which ultimately results in death. This underscores why comfort is such an important element in the care of people with advancing dementia....while it is true that there is nothing that can be done to reverse the disease process, there is still a great deal that can be done to make a difference for residents, for families and for staff, when comfort and the prevention of suffering is the goal.

This means that in addition to ongoing education in dementia care principles and practices, staff need a basic understanding of the disease process for Alzheimer's and other dementias. This is quite important, because as we discovered, many staff either never had exposure to this information, or had it so long ago that they are unaware of some of the advances in knowledge and practice that have occurred over the last few years.

Further, family members and friends need ongoing information about both the disease process itself, as well as about how the person they care for is doing in that process. Ongoing discussions between families and staff can help families much better understand their options when the time comes that they are faced with the difficult choices they are likely to encounter. However, staff can't be helpful to families if their own understanding is limited, or if they are uncomfortable having these kinds of discussions. It is crucial that administration support staff, and physicians, in gaining expertise and skills in this area.

Finally, facilities need to make every effort to work with residents and their families to complete advance directives wherever possible, and to fully support and assist in the carrying out of these directives, including in all communications with hospitals when transfers occur.

Hospice and End-of-Life Care

Palliation helps people (and their families) who are living with dementia, often for many years. The gift of palliative care is its focus on finding what brings comfort for the person and those around him/her, including the prevention of suffering, for the usually long period of time before someone comes to the end of his/her life.

Hospice is a continuation of palliative care for people approaching the last six months of life. People with advanced dementia may receive hospice services when they meet specific Medicare eligibility guidelines. These guidelines require that the primary physician and the hospice physician, to the best of their clinical abilities, agree that the person has a life expectancy of six months or less. Although determining hospice eligibility can at times be complex, anyone can initiate a referral to hospice. Once a referral is made, the hospice provider will evaluate the resident to see if he or she qualifies for hospice care.

Specific hospice eligibility criteria for people with dementia include:

- Significant decline in ability to function independently (inability to be independent in at least 3 out of 6 ADLs, including walking, bathing, and dressing)
- Inability to speak more than a few intelligible words
- Incontinence of bowel and bladder.

In addition, one or more of the following has occurred in the past year:

- Aspiration pneumonia
- Kidney or other upper urinary tract infections
- Recurring fever after antibiotics
- Multiple pressure ulcers, stage 3 or 4
- Septicemia (blood infection)
- 10% weight loss in the past 6 months

“You matter because you are you, and you matter to the end of your life.”

- Dame Cicely Saunders, Nurse, Physician and founder of the hospice movement.

Physicians will also assess what additional life-limiting illnesses the person with dementia may be experiencing, as this may contribute to a shorter prognosis.

Although it can be particularly difficult to predict when the life of someone with dementia is nearing the end, there are signs which, when observed, are often an indication that the dying process has begun. These include:

- Loss of appetite and ability to swallow
- Decreased urinary output
- Person is less responsive, sleeps most of the time
- Pain may be evident
- Increasing weakness
- Loss of ability to close the eyes
- Breathing changes---breathing can fluctuate between slow and labored, quick and shallow
- Skin changes in coloration and temperature around feet and hands

The hospice team will skillfully assess the dying person for any indications of distress and use their expertise to manage pain and other symptoms to maximize comfort throughout the dying process.

For homes that do work with hospice programs, it is extremely important to include them in your education, planning and ongoing assessment efforts as you implement palliative care practices for people with advanced dementia. If families select hospice, your staff members, as well as families, have important information to share about what comforts someone (the way this person tends to express pain, favorite music, most comfortable way to ‘wash up,’ etc.). **Hospice providers are not intended to substitute for the facility’s care or staff, and care plans that are developed with hospice programs should reflect the individualized needs of a particular resident in terms of how the work is shared.**

For example, it may be desirable for a nursing assistant to continue to bathe a resident because the nursing assistant’s experience with the resident makes bathing more comfortable. Hospice programs can also be a very valuable source of ongoing education, support and consultation.

Finally, it is important to recognize that while families certainly have bereavement needs once their relative dies, so also do caregiving staff. The fact that someone has dementia does not lessen the attachment and compassion felt by staff. Finding ways to acknowledge their loss is not only a way of providing comfort for them, it is also a way to demonstrate that the home values the skill and compassion that caregivers bring to their work. One of our partner homes places a single flower in a vase at the nursing station, along with the

name of the resident who died. Making it possible for staff to attend funerals and memorial services is another way of supporting them, and of course there are other practices and rituals which can do this as well.

Quality Assurance Performance Improvement (QAPI)

Using QAPI tools and processes in the implementation of these practice improvements can be a big help. For example, in the section on meals, when interventions such as the snack cart were introduced, the facilities measured and monitored both weight loss and the use of supplements to assess the effectiveness of the intervention. All of the homes continue to monitor rejection of care on both an individual resident and a nursing unit (quantitative) basis, to help them identify and address sources of distress for residents. While quality assurance and performance improvement in the nursing home setting has tended in the past to focus on clinical issues, CMS now encourages facilities to use QAPI for quality of life concerns as well. The nature of comfort in the nursing home setting for persons with advanced dementia is one example of how quality of care and quality of life cannot be separated. QAPI can help us better understand the linkages as well as find ways of assessing and measuring our progress.

Most nursing homes have relatively little experience using MDS data on a unit-specific basis or in identifying measurements to assess how they are doing with people with advanced dementia. The MDS ‘behavior’ items discussed in the care planning section are a great tool for individual residents as well as nursing units. If a facility learned that 65% of the residents on a unit were ‘rejecting care,’ that would be a clear indication of a need for quality improvement. Measuring progress on specific units can be a real boon for staff. When you introduce a new practice and you have results to share with staff, the results reinforce the value of the new practice and instill pride in staff efforts. Think about how introducing a snack cart and dietary changes with measures of weight loss and supplement use helped staff in our facilities value their process and efforts.

Apart from using QAPI tools and processes to help in the initial implementation of these practices, some aspect of dementia care should always be included in a facility’s annual Quality Assurance Performance Improvement Plan. Typically, for example, when a new practice or change in policy is brought to the facility as a whole, it will be important to test whether it is (a) appropriate for someone with advanced dementia, and (b) *reaching* someone with advanced dementia. The introduction of a behavior-based pain assessment tool in our facilities is a good example of the importance of applying QAPI to advanced dementia.

Policies, Procedures, Protocols

Advanced dementia-capable palliative care requires a significant commitment to education of staff at all levels. Sustainability of these improved practices, however, is entirely dependent on the degree to which organizational policies, procedures and protocols are in place to support them. No matter how much training staff receive in using a behavior-based pain assessment tool its use will not be sustained unless it is incorporated into the facility's policies and procedures for pain. The twenty-four hour availability of food that residents like to eat will not be sustained unless facility protocols clearly state that this is the expectation. Consistent staffing will not be maintained if the systems used to make staff assignments are not aligned to achieve this. These are all important elements of practice, and they also need to be addressed periodically by quality assurance/performance improvement activities that assess whether they are being carried out as intended.

Over time, there are always changes in staff (at all levels), and when they receive orientation to the facility (regardless of their role), new staff often rely on policies and procedures to guide them as they begin their work. State survey agencies concern themselves with, among other things, whether facility practice matches facility policy.

It is all about expectations: what do we want, what are we trying to achieve?

Conclusion

One of the most profound outcomes of our work has been the degree to which it has reaffirmed the value of small daily interactions. By now we have all heard the person-directed care mantra, “person before task;” however, because the person with advanced dementia has trouble thinking and expressing themselves, the ‘person’ has too often been left out of the equation. To truly know and understand comfort is to bring the person back.

We are grateful and deeply indebted to all the residents who lived on the pilot units during this project, to the staff who cared for them, and to their family members and friends. They were our teachers, deepening and strengthening our understanding of all the ways that each and every moment is an opportunity for more comfort, more kindness, and greater dignity.



What Caregivers Should Know About Persons with Dementia

Record information about this person that allows caregivers to personalize his/her care. Do not answer questions that would violate privacy.

Name:	Preferred name:
Birthplace (city and state):	
Parents' names:	
Parents' occupation(s):	
Names of brothers:	
Names of sisters:	
Important information about brothers/sisters:	
Name of spouse/partner:	
Special memories of wedding day/honeymoon:	
Children's names:	
Grand-/great grandchildren's names:	
Places lived:	
Educational accomplishments:	
Occupation(s):	
Favorite job(s):	
Leisure activities:	
Spiritual affiliation/practices:	
Favorite spiritual songs:	
Favorite holiday:	
Favorite vacation activity/location:	
Favorite music:	
Favorite pet:	
Special rituals observed:	
Favorite food and drink:	
Favorite smells:	
Tobacco use—type:	frequency:
Wine or spirits use:	frequency:
Food dislikes:	
Coffee/tea use:	served with: frequency:
Special food preferences while ill:	
Preferred forms of comforting touch:	
Easily subject to temperature changes: cold/hot	
Preference for bathing:	time of day:
Clothing preference(s):	
Footwear preference(s):	
Beauty/barbershop usage:	frequency:
Manicure/pedicure usage:	frequency:
Shaving needs and razor type:	time of day for shaving:
Usual bed time and wake up time:	
Morning routines:	
Afternoon routines:	

[illegible]

References

Palliative Care: Comfort and Dementia

Arrighi H, Neumann P, Lieberburg I, Townsend R. Lethality of Alzheimer disease and its impact on nursing home placement. *Alzheimer Disease & Associated Disorders*. 2010;24(1):90-95.

Dougherty J, Gallagher M, Cabral D, Long C, McLean A. About me: knowing the person with advanced dementia. *Alzheimer's Care Quarterly*. 2007;8(1):12-16.

Edelman P, Fulton BR, Kuhn D, Gallagher M, Dougherty J, Long C. Assessing quality of life across the dementia continuum. *Alzheimer's Care Today*. 2007;8(4):332-343.

Gallagher M, Long CO. Advanced dementia care: demystifying behaviors, addressing pain, and maximizing comfort. *Journal of Hospice and Palliative Nursing*. 2011;13(2):70-78.

Martin G, Sabbagh M. *Palliative Care For Advanced Alzheimer's and Dementia*. New York, NY: Springer Publishing Company; 2010.

Mitchell S, Kiely D, Hamel M. Dying with advanced dementia in the nursing home. *Archives of Internal Medicine*. 2004;164(3):321- 326.

Power, GA. *Dementia Beyond Drugs*. Baltimore, MD: HPP/Health Professions Press; 2010.

Kitwood T. *Dementia Reconsidered: The Person Comes First*. Buckingham [England]: Open University Press; 1997.

Mead R. The sense of an ending: an Arizona nursing home offers new ways to care for people with dementia. *The New Yorker*. May 20, 2013.

Rader J. *Individualized Dementia Care: Creative, Compassionate Approaches*. New York: Springer Pub. Co.; 1995.

Schwab M, Rader J, Doan J. Relieving the anxiety and fear in dementia. *Journal of Gerontological Nursing*. 1985;11(5):8-9.

Zgola JM. *Care That Works: A Relationship Approach to Persons with Dementia*. Baltimore, MD: The Johns Hopkins University Press; 1999.

Pain

American Medical Directors Association. *Pain management in the long-term care setting: clinical practice guideline*. Columbia, MD: AMDA, 2009.

Jablonski A, Ersek M. Nursing home staff adherence to evidence-based pain management practices. *Journal of Gerontological Nursing*. 2009;35(7):28-34.

Horner J, Hanson L, Wood D, Silver A, Reynolds K. Using quality improvement to address pain management practices in nursing homes. *Journal of Pain and Symptom Management*. 2005;30(3):271-277.

Long C, Morgan B. *Pain Management: The Resource Guide for Home Health & Hospice Nurses*. Baltimore, MD: Hopkins Medical Products; 2008.

Nutrition

Academy of Nutrition & Dietetics. Position of the American Dietetic Association: liberalization of the diet prescription improves quality of life for older adults in long-term care. *Journal of the American Dietetic Association*. 2005;105(12):1955-65.

American Diabetes Association. Nutrition recommendations and interventions for diabetes: a position statement of the American Diabetes Association. *Diabetes Care*. 2007;30(1):S48-S65.

Ramesh BN, Rao TS, Prakasam A, Sambamurti K, Rao KS. Neuronutrition and Alzheimer's disease. *Journal of Alzheimer's Disease*. 2010;19(4):1123-39

Carrier N, West GE, Ouelett D. Cognitively impaired residents' risk of malnutrition is influenced by food service factors in long-term care. *Journal of Nutrition for the Elderly*. 2006;25(3-4):73-87.

Desai J, Winter A, Young KWH, Greenwood E. Changes in type of foodservice and dining room environment preferentially benefit institutionalized seniors with low body mass indexes. *Journal of American Dietetic Association*. 2007;107(5):808-814.

Dorner B, Friedrich EK, Posthauer ME. Practice paper of the American Dietetic Association: individualized nutrition approaches for older adults in health care communities. *Journal of American Dietetic Association*. 2010;110(10):1554-1563.

Dunne TE, Neargarder SW, Cipolloni PB, Cronin-Golomb A. (2004). Visual contrast enhances food and liquid intake in advanced Alzheimer's disease. *Clinical Nutrition*. 2004;23(4):533-8.

Leppert S. Bulk foodservice: a nutrition care strategy for high-risk dementia residents. *Journal of American Dietetic Association*. 2007;107(5): 814-815.

Nijs K, de Graaf C, van Staveren W, de Groot L. Malnutrition and mealtime ambiance in nursing homes. *Journal of the American Medical Directors Association*. 2009;10(4):226-229.

Consistent Assignment of Staff

Advancing Excellence, Retrieved from <https://www.nhqualitycampaign.org/goalDetail.aspx?g=ca>.

Falls

Dever Fitzgerald T, Hadjistavropoulos T, MacNab Y. Caregiver fear of falling and functional ability among seniors residing in long-term care facilities. *Gerontology*. 2009;55(4):460-467.

Bathing

Gallagher, M, Hall, G. Evidence-based practice guidelines – bathing persons with Alzheimer’s disease and related dementias: clinical implications. *Journal of Gerontological Nursing*. 2014;40(2), 14-20.

Rader J, Lavelle M, Hoeffler B, McKenzie D. Maintaining cleanliness: an individualized approach. *Journal of Gerontological Nursing*. 1996;22(3):32-38.

Meaningful Engagement

Cohen-Mansfield J, Parpura-Gill A, Golander H. Utilization of self-identity roles for designing interventions for persons with dementia. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*. 2006;61(4):P202-P212.

DeLauro R. Music and memory: elders with dementia find hope in a song. *Social Work Today*. 2013;13(1): 18.

Mockbee D. Advanced dementia care is vital to quality of life, part 2. *Long-Term Living*. April, 30, 2008.

Environment

Calkins MP, Chafetz PK. Structuring environments for patients with dementia. In: Weiner MF, ed. *The Dementias: Diagnosis and Management*, vol. 2. Washington, D.C.: American Psychiatric Press; 1996:299-300.

End-of-Life Care

Dougherty J, Long C. Seven steps to improving the hospice benefit in dementia. *Caring*. 2006; 25(5):21-26.

ELNEC Curriculum. Pain Assessment and management. 2012. City of Hope and American Association of Colleges of Nursing.

Engel S, Kiely D, Mitchell S. Satisfaction with end-of-life care for nursing home residents with advanced dementia. *Journal of the American Geriatrics Society*. 2006;54(10):1567-1572.

Johnson SH. Making room for dying: end of life care in nursing homes. *Hastings Center Report*. 2005; 35(6):S37-S41.

Kuhn D. Seeing a better way to die with and from dementia. *Generations*. 2013;37(3)70-73.

Volicer L. *End-of-life Care for People with Dementia in Residential Care Settings*. Chicago, IL: Alzheimer’s Association National Office; 2005 www.alz.org).

General: Palliative Care

Chair E, Meier D, Morris J, Goldhirsch S. *Geriatric Palliative Care: A Practical Guide for Clinicians*. New York, NY: Oxford University Press; 2014.

National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, Third Edition. NCPQPC, 2009
<http://www.nationalconsensusproject.org>).

Organizations and Websites

CaringKind - The Heart of Alzheimer's Caregiving. www.caringkindnyc.org
New York City's leading expert on Alzheimer's and dementia caregiving.

Center to Advance Palliative Care (CAPC). www.capc.org
A national organization dedicated to increasing the availability of quality palliative care services for people facing serious illness.

CMS: Hand in Hand, A Training Series for Nursing Homes. www.cms-handinhandtoolkitinfo/Index.aspx

End-of-Life Nursing Education Consortium (ELNEC). www.aacn.nche.edu/ELNEC. Administered by the American Association of Colleges of Nursing (AACN), Washington, DC and the City of Hope, Los Angeles, California. Geriatrics is one of their curriculum focus areas.

Iowa Geriatric Education Center. www.healthcare.uiowa.edu
Promotes training programs to improve the training of health programs in geriatrics, and develops and disseminates curricula for treating the health problems of elders.

Music & Memory. www.musicandmemory.org
A national non-profit organization that brings personalized music into the lives of the elderly through digital music technology. They train nursing home staff and other elder care providers as well as family caregivers how to create and provide personalized playlists using iPods and related digital audio systems.

National Hospice & Palliative Care Organization. www.nhpco.org
A nonprofit membership organization representing hospice and palliative care programs and professionals in the U.S. The organization is committed to improving end of life care and expanding access to hospice care with the goal of enhancing quality of life.

New York State Department of Health. www.health.ny.gov/disease/conditions/edge/
Electronic Dementia Guide for Excellence (EDGE) Project, a web-based resource program that offers guidance to identify and implement interventions that specifically address care and communication challenges faced in dementia care.

Pioneer Network. www.pioneernetwork.ne
The organization is a center for all stakeholders in the field of aging and long term care whose focus is on providing home and community support for elders.

The Society for Post-Acute and Long-Term Care Medicine (AMDA). www.amda.com
This organization was founded to support Medical Directors working in long-term care. It promotes excellence in patient care and provides education, advocacy, information and professional development to promote the delivery of quality post-acute and long-term care medicine.



- **24-hour Helpline** (646) 744-2900
- Care Planning/Social Work Services
- Education & Training
- Support Groups
- The Harry and Jeanette Weinberg Early Stage Center
- Wanderer's Safety Services
- Connect2Culture®

All services are free of charge
www.caringkindnyc.org

The mission of CaringKind* is to create, deliver, and promote comprehensive and compassionate care and support services for individuals and families affected by Alzheimer's disease and related dementias, and to eliminate Alzheimer's disease through the advancement of research. We achieve our mission by providing programs and services for individuals with dementia, their family and professional caregivers; increasing public awareness; collaborating with research centers; and informing public policy through advocacy.

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