

Finding Comfort:

Living with Advanced Dementia in Residential Care

A Consumer Guide

caringkind

The Heart of Alzheimer's Caregiving

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Disclaimer

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, to be applied based on individual patient needs and 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' content.

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CaringKind, The Heart of Alzheimer's Caregiving
360 Lexington, 3rd Fl., New York, NY 10017
Attn: Eleonora Tornatore-Mikesh

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Table of Contents

About Dementia	6
Distress and Challenging Behaviors	6
Palliative Care for People with Dementia	7
What Does Comfort Look Like for the Person with Dementia?	8
Palliative Care at Residential Care Facilities	8
Care Planning	11
Problem Solving	12
Comfort as Part of a Care Plan	12
Anticipate Needs	13
Antipsychotic Medications	14
Delirium	14
Pain	15
Sleep/Wake Routine	17
Rest During the Day	19
The Connection Between Sleep and “Sundowning”	20
Making the Most of Meals & Snacks	21
Artificial Nutrition	23
Rethinking Activities: Meaningful Engagement	25
The Environment	27
Memories, Including those that are Upsetting or Unpleasant	28
COVID-19	30
Choices about Treatment & Care	32
Treating Infections	33
CPR (Cardiopulmonary Resuscitation)	34
Mammograms, Colonoscopies, and Other Screening Tests	34
Going to the Hospital	35
Medications	36
Hospice and End-of-Life	36
PAINAD Form	38
What Caregivers Should Know	40
Resources	41

Acknowledgments

Several years ago CaringKind undertook a project focused on bringing a model palliative care program for people with advanced dementia to three New York City nursing homes. This groundbreaking program, Comfort Matters®, was developed by the Beatitudes Campus in Phoenix, Arizona. At the conclusion of that project we published guidelines for use by nursing homes, ***Palliative Care for People with Dementia: Why Comfort Matters in Long-Term Care.***

Our experience has taught us that for the person with even the most advanced dementia, comfort matters and is possible. This booklet was created to aid the family and friends of people living with dementia in residential care find their way to comfort. For these residents, we strongly believe that comfort is key to providing the best possible quality of life and care.

We are deeply grateful to all our colleagues at the Beatitudes Campus for the work they do every day to bring comfort to residents, with special thanks to Tena Alonzo, MA, Director of Comfort Matters® and Karen Mitchell, RN, BSN, Nurse Educator, Comfort Matters® for their help in the development of this guide. Thanks also to Maribeth Gallagher, DNP, PMHNP-BC, FAAN and Dementia Program Director, Hospice of the Valley, and to Lori Smetanka, Executive Director of The Consumer Voice, who provided valuable suggestions. Finally, we are greatly indebted to Helen Osborne, M.Ed., OTR/L, for her significant contribution as a plain language writer and editor.

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We are grateful to CaringKind's Board of Directors who embraced this project and continue to support its goals of bringing comfort to those with dementia. Indeed, CaringKind has adopted the principle of bringing comfort as a core principle.



Eleonora Tornatore-Mikesh
CaringKind President and CEO



Jed A. Levine
President Emeritus, and Director, External Relations

Finding Comfort: Living with Advanced Dementia in Residential Care

Cure sometimes, treat often, comfort always.
— 15TH Century Folk Saying

This booklet is for family members, friends and caregivers of a person who has dementia. The purpose is to provide information about the best ways to offer comfort and the best possible quality of life for someone whose dementia is progressing.

The approach to care described here is called “palliative.” The goal of this care is to increase comfort and pleasure and reduce pain and suffering. Palliative care can be very helpful to those who have advanced dementia. Many people think that palliative care is only for people who are about to die. But that is not so. Palliative care helps people who have many types of serious injuries or chronic illnesses. It can be helpful for many months, or even years. Studies show that palliative care can help people who have advanced dementia. It is not about giving up.



About Dementia

Dementia is a condition in the brain that affects how a person thinks and acts. It affects their ability to independently do daily tasks like getting dressed, eating, and going to the bathroom. Dementia can also take away a person's interest in activities they used to enjoy like playing games, taking walks, and watching sports.

It often takes about 8 to 10 years from the time someone shows symptoms of dementia until their death. Symptoms get worse over time. These are often described in terms of mild, moderate, and advanced stages of this disease. In the absence of a cure, the most important question becomes, how do we help someone live with dementia?

While someone's thinking becomes increasingly impaired, their capacity to feel emotions, to experience well-being (or its absence), to respond to kindness and cruelty, all remain. The goal of this booklet is to help point the way to well-being, for people with dementia, and for those who care for them.

Distress and Challenging Behaviors

If you are concerned because the actions of the person you care for indicate they are upset, the tools and strategies discussed below are intended to help. We can often tell when someone with dementia is comfortable and at ease. It can be harder to know when they have pain, feel upset, or are in other distress. Since they cannot say what is bothering them they might act on these feelings instead. For instance:

- They might spit out food when they have a toothache.
- They might yell or moan when bothered by loud noises in the room.
- They might push away a caregiver because they are in pain.

Challenging behaviors like these are almost always caused by a person's distress, not their dementia. It is much more likely that the person is simply unable to describe or explain what is upsetting them. It is important to find the cause of their distress and then manage it. Anti-psychotic, anti-anxiety and sedative medications do not take away pain or distress that is non-psychosis related. They do not comfort someone living with dementia who may be hungry, cold, too warm, tired, lonely, or frightened by noises or activity in the environment.

For these reasons a comfort, palliative approach has a lot to offer people with advanced dementia, and to their caregivers. Palliative care means focusing on what comforts someone and gives them pleasure and taking active steps to prevent or minimize unnecessary pain and suffering. **With even the most advanced dementia, a palliative approach can improve someone's quality of life.**

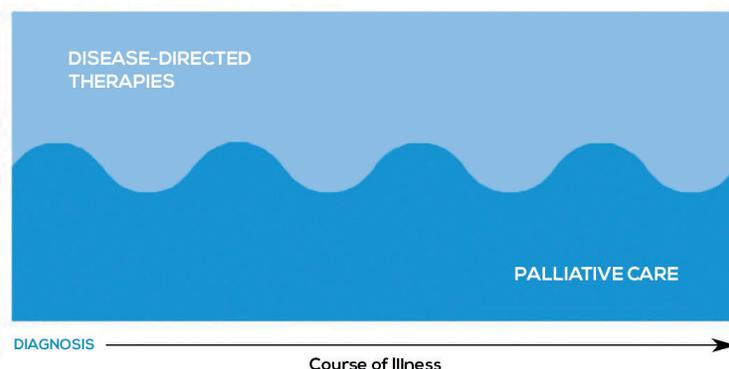
Palliative Care for People with Dementia

'Palliative care' describes an approach to treatment and patient care. Its goal is to increase a person's comfort and reduce their distress.

A person can get both palliative care and medical treatment at the same time. These help in different ways. Palliative care is a way to increase a person's comfort, reduce stress, and offer support to the resident and their caregivers. Treatment can include medication and medical procedures to help with specific disease symptoms. This might be a podiatrist to help with bunions, or a visit to the dentist to treat a toothache.

Here is a chart showing how palliative care and treatment for symptoms can work together from the time someone is diagnosed with dementia until their death. This combination has been well-tested.

Palliative Care is Appropriate at Any Point in a Serious Illness and Can be Provided Together with Disease-Directed Therapies



Source: Center to Advance Palliative Care



What Does Comfort Look Like for the Person with Dementia?

Familiar routines, freedom from pain, favorite foods, enough sleep, favorite music, a quiet place to sit away from a large group, and time with people who care about them, are all things which can contribute to someone being comfortable, or, if absent, uncomfortable and in distress.

Palliative Care at Residential Care Facilities

Not all residential facilities know about using palliative care with people who have advanced dementia. You can help change this. Here are some ways:

- Give them a copy of this booklet. You might highlight stories and examples that you find helpful. You can also share some of the studies, websites, and other resources listed on page 41 of this guide.
- Talk with staff about specific ways they might help. For instance, if you think the person you care about might need a different morning routine, then talk about this with the nursing assistant or head nurse. If you think they could be helped by taking a certain medication, then speak with the doctor. If you have a concern or recommendation but do not know who to discuss this with, ask the social worker for advice.

- Figure out best ways to increase the person's comfort and reduce their distress. Some ways are likely more helpful than others. What works for someone else might not be as good for the person you care for. What works today might not be as good tomorrow. Know that as your relative or friend's dementia progresses strategies might need to change.
- Ask staff to try different ways of helping and see what works. For instance, if your relative or friend seems to get upset when having meals in the dining room see if they do better when eating alone in their room. If the person you care about seems to have pain when they wake up, see if they are more comfortable when getting pain medication before the morning routine.
- An especially helpful way of exploring a change in practice is often by doing something on a trial basis. The important thing is for you and staff members to talk this through together, so you can all be on the alert for whether the change brings an increase in comfort, or whether another or an additional solution needs to be considered. Sometimes an intervention doesn't work, and sometimes it helps but more than one type of intervention may be needed
- Attend your relative or friend's care planning meeting. Learn more about care planning starting on page 11 of this guide.

Contact your local Long-Term Care ombudsman if you want advice or support about talking with staff at the residential care facility. You can find more information by going to the National Consumer Voice for Quality Long-Term Care website at www.theconsumervoice.org.



Anthony's Story: Palliative Care in a Residential Facility

Anthony has Alzheimer's disease. In the beginning, his wife Sharon cared for him at home. This got harder and harder for her as his disease got worse. Anthony spent time in different nursing homes, and in the psychiatric unit of a hospital.

Anthony then came to a new nursing home that provides a palliative approach to care for people with dementia. Anthony and the staff had trouble at first. They wanted him to go to bed at certain times, sleep through the night, and wake up for breakfast. But Anthony often resisted and pushed staff away.

When they explored this with Sharon, they learned that he had worked at night and it had been his pattern for many years to leave work at midnight, 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 happily this worked well. 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. 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, he was taking high doses of many different antipsychotic medications. Staff helped him slowly taper these off and within a few months he was no longer receiving any antipsychotic medications.

Sharon is delighted with these changes. "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."

Sharon's appreciation for this approach to care continues. "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 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."

There is a lot to learn from Anthony's story, including:

- Try to find out the source of distress that is causing a person's behavior. For Anthony, this was the sleep-wake routine. Once staff knew his preferred hour to go to bed and wake up, they changed the care plan so that Anthony could have a more familiar and comfortable routine.
- Allow staff enough time to find ways that work. Yes, this can take a while. But it is almost always better to spend time this way than trying to make a resident do something they do not want to do. For Anthony, letting him sleep later in the morning was better than his pushing staff away when they tried to get him up. Looked at from this perspective, working with Anthony's preferred routine was a much more successful alternative.
- Ask the nurse manager to let all staff know about ways to increase your relative's comfort and reduce their distress. This meant, for example, that all three shifts knew about Anthony's schedule and did not question why night staff did not get him out of bed before they left in the morning.

Care Planning

A care plan is an official document that makes clear how all staff will help each resident. It includes a thorough assessment of each resident's needs along with specific ways that staff will work with them. It includes details about nursing needs, personal care, therapy, meals, equipment, social services, and activities. These plans are also supposed to be individualized in a way that reflects the residents' preferences, such as when they rise, when they bathe, and how they spend their time.

Federal law requires that residential facilities have care plans for all residents who have Medicare or Medicaid. Staff must start assessing each resident on the day they are admitted and complete this care plan within 14 days. Staff must review and update this plan at least every 90 days. They should do so even more often when there are major changes in a resident's health. Family members are encouraged to attend care plan meetings, and residents as well if they are able.

Staff must use a tool called the Minimum Data Set (MDS) to assess residents at admission and use it as they create the care plan. They must review this plan at least 4 times each year. The MDS includes many topics. Here are some that relate to challenging behaviors:

- Does this resident resist care?
- Does this resident have verbal behavioral symptoms directed towards others?
- Does this resident have physical behavioral symptoms directed toward others?
- Does this resident have other behavioral symptoms not directed towards others?

If staff checks “yes” to any of these questions, they should find out why the resident is in distress and make a plan to reduce it. The answer should not be ‘It’s the dementia.’

These meetings are also a time to talk about other concerns, share resources, and discuss what to expect in the future.





Problem Solving

Family members and 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. Staff and family members together can focus specifically on what is happening for the resident, what the resident might be trying to communicate, and ideas to improve the situation. There is often no one solution, but a process of trial and error before the most helpful solution(s) are identified and put in place.

Comfort as Part of a Care Plan

Comfort is the opposite of distress and knowing what comforts someone can often be the clue to preventing or minimizing distress....and the behavioral expressions of distress. That is why preferred rising and sleep habits, preferred bathing routines, and food and dining preferences should be included in someone's care plan and incorporated into their daily routine.

Situations such as being constipated, loud noises in the environment, a new and unfamiliar caregiver, or a sore shoulder could cause the resident to lash out unexpectedly. They may resist caregiving efforts by pushing caregivers away or refusing to allow the caregivers to assist them. These behavioral expressions are all signs that the person is uncomfortable and experiencing distress. They need our help to prevent further suffering.

Sometimes it takes multiple tries to figure out how to offer comfort. Here are some ways that can help:

- Think about and share your relative or friend's lifelong habits.
- Help staff get to know about your relative's life. Some homes use questionnaires to gather this kind of information, such as the example you will find on page 40.
- Think about how they liked to spend their free time. Did they enjoy classical music? Did they like spending time outside? What about activities like taking a walk? Did they like to watch sports? If so, share this information with the staff and work together to find ways for them to keep doing activities they have always enjoyed.
- Work closely with the staff to problem-solve the cause of the distress the person you care about is experiencing and ways to comfort them instead. But know that it might take many tries before finding something that helps right now.
- Let staff know about the kinds of things that have comforted them in the past; for example, a back rub, a quiet room, soft music, dim lighting, etc.
- **Comforts should also be noted in someone's care plan.**

Anticipate Needs

Anticipating the needs of residents is a strategy that 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 purpose is not to come up with a set schedule even if that would be easier for family and staff but be guided by the resident in planning for their comfort.



Antipsychotic Medications

These medications are very strong and can cause serious side effects like a stroke or even death.

Residents should not be given antipsychotic medication just because they are yelling, hitting or doing other such actions. Instead, staff should work with each resident and their family to figure out the distress that is causing this action. A directive from the US government states: “When antipsychotic medications are used without an adequate rationale, or for the purpose of limiting or controlling behavior of an unidentified cause, there is little chance that they will be effective.”

When doctors recommend that a resident in residential care be given antipsychotic medication, they must inform the resident and their family or other legal representative. Before saying yes, ask why this medication is needed, how it could help, problems it may cause, and what other solutions have been tried. Know that you and your relative have a legal right to refuse this medication. If your relative is prescribed antipsychotic medication, then it should be given in the smallest possible dose and only for as long as needed.

Delirium

While delirium and dementia are two separate conditions, because they both focus on confusion it can be difficult for the untrained eye to distinguish between them. Many of the symptoms, such as inattention, memory impairment, sleep disturbance, and disorientation, are similar. However, the most obvious difference is that, while dementia is generally a chronic, slowly progressive condition that is not reversible, delirium develops more rapidly over hours or days, usually as the result of acute illness or changes in medication, or in the environment where someone lives (for example, if someone moves from home or nursing home to the hospital).

It is not uncommon for a person living with dementia to also experience delirium. When delirium is present it could signal the onset of a serious medical condition, such as an upper respiratory infection. Other possible causes of delirium include after-effects of surgery, dehydration, sleep deprivation, some medications, pain, poor nutrition, severe constipation and urinary tract (or other) infections.

If you perceive that someone is “just not themselves,” that could be a signal of delirium and it is time to talk to the nursing home staff and the medical provider. The risks for

not doing so can result in a worsening condition or even death. It is usually temporary but requires medical attention, so that the person can be assessed for delirium.

Pain

Look for the cause of distress. If not obvious, assume it is due to pain. A person with dementia is as likely to have pain as anyone else their age. But with advanced dementia, they might not be able to say so. Instead, they might show distress by grimacing (“making a face”), moaning, yelling, hitting, or getting very agitated. If you are aware of ways the person you care for expresses pain, share this information with staff.

Assume the person you care about is feeling pain even if you do not know the cause of their distress. Here are some ways to assess their pain:

- Ask them if they are in pain. If they do not respond to the word “pain,” then perhaps ask if they have an “ache,” “feel sore,” or something “hurts.” Note which word they respond to and encourage others to ask about pain in the same way.
- Try gentle touch if words do not help. If you think the person you care for has a headache perhaps lightly touch their head. Or touch their knee, shoulder, belly, or other part of their body that might be hurting.
- Explore other reasons for pain. Do they have a new health problem like constipation or a toothache? A chronic condition like arthritis? Or an old injury that might be painful now?
- Talk with staff about using a behavior-based pain scale such as PAINAD. This well-tested tool is designed to assess pain in people with advanced dementia who might not be able to say if they are in pain, or how bad it feels. You can find the PAINAD form and instructions on page 38 of this booklet, or online at <http://dementiapathways.ie/filecache/04a/ddd/98-painad.pdf>

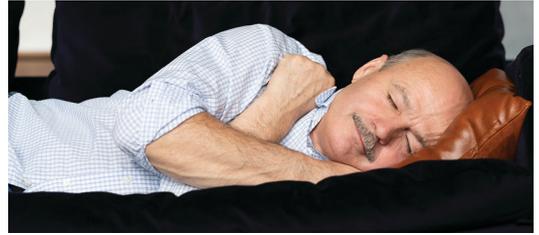


Ways To Ease Pain Without Medicine:

- Try to figure out the cause of distress. For instance, if the person you care about gets upset when staff are helping them get dressed, perhaps the problem is pain from an old shoulder injury. If so, try something different such as wearing a zip-up sweater that opens in the front rather than a pullover that goes over the head.
- Distract them when they are having something done that might be distressing. For instance, staff could offer a lollipop when applying a bandage to their wound. Another way to distract someone is by giving them a headset that is playing music they enjoy.
- Wrapping a person's achy shoulders in a toasty blanket heated in the dryer or placing warmed rice packs in one's arthritic hands may be quick and easy ways to offer comfort and show you care. Use caution to avoid burns when using any heated items.
- Remember that the person may have difficulty moving their body, so assist with repositioning to comfort or helping them to stand and take a few steps every couple of hours.
- Document what helps. Whether you or staff come up with these ideas, make sure they are included in the person's medical record. Knowing this, other staff who work at different times can use the same approach.

Ways to Ease Pain with Medicine:

- Ask the staff to start a trial of regular pain medication such as acetaminophen (Tylenol). During the trial period, regular input from all staff (all shifts) and family members should be sought to determine if the treatment plan is providing overall comfort and pain control and whether the resident's behaviors suggest some relief has occurred. The results of such trials should be documented.
- If the initial trial does not produce improvement for the resident, higher doses, and/or different pain medications (including opioids) should be considered, as appropriate.
- While PRN (as needed) orders for pain medication are common, it is usually preferable to prescribe pain medications to be given on a regular schedule. People with later stages of dementia are unable to understand, never mind request, relief from pain. In any case, sources of pain in the elderly are often the result of chronic conditions. The goal is to prevent, not just relieve, pain.



Sleep/Wake Routine

Problems with sleeping are common for people with dementia, and sleep fragmentation (interrupted sleep) can be just as harmful as sleep deprivation (not enough sleep). Lack of adequate sleep increases the risk for falls, and can result in an impaired immune system, aches, tremors, irritability, and increased memory loss. It may be obvious that someone has a sleeping problem, or it may be that a symptom of sleep deprivation (such as falls or irritability) should be explored to determine if lack of sleep is a contributing factor. Either way, getting started means collecting more information about the person's sleep habits.

- Ask how well your relative is sleeping. If there is concern that their sleep is not adequate, a 3-day time study which tracks the person's actual sleep experience over each 24-hour period can help. Staff should track when, where and for how long they are asleep, including if they are napping during the day, and if they exhibit signs of sundowning, when and for how long it occurs.
- Explore the cause of sleep problems. They might be due to pain, illness, or medication. Sleep problems can also be caused by noise, light, or even nearby smells. Other reasons can be too many naps, being active or not active enough, or even certain foods. It is common for dementia to create a disturbance in sleep wake periods.
- Always talk with staff about your relative or friend's former sleep habits. Anthony (see page 10) did better with a routine that he was accustomed to. Others may be used to saying prayers or listening to music before bed. It helps to offer familiar and comfortable routines.
- It is not desirable to use sedatives/hypnotics as an aide to sleep for people with dementia. Some of the common ones cause disturbing side effects, including increased confusion.
- As the dementia progresses, sleep cycles may change as well, leaving people increasingly at risk for the effects of sleep/rest deprivation.

Here are some questions to ask the staff:

- Are there any medical problems affecting their sleep? These might include a new illness, a chronic condition, or constipation or pain.
- Are medications part of the problem? Find out when they get medications and, if possible, ask that these be given at times that do not disturb sleep. If they take a nighttime medication, ask if it can be given as a liquid rather than pill so that they do not need to drink extra water before going to bed.
- Could pain be a factor? Look at their medical history to see if there is a reason for pain. This might be a new diagnosis of arthritis or an old sports injury. Then try ways to help ease this pain such as with a different pillow, mattress, or sleeping position. If those do not seem to help then perhaps try a long-acting pain medication that lasts all night.
- What about fluids? While everyone needs to drink enough fluids, it may be a good idea for your relative to drink more fluids early in the day and less later on. Unless there is a medical reason or the person requests it, it is best to not drink any liquids after dinner.
- Switch to decaffeinated coffee and avoid any forms of caffeine late in the day as it could affect sleep. This works if the person has a more 'normal' sleep schedule and might not fit with someone who sleeps during the day.
- Is incontinence a problem? If they wet the bed during the night, ask if an overnight brief that wicks away urine is a good idea.
- Is the resident getting enough sleep? As dementia gets worse, a person might need more time resting. Ask staff to let them rest whenever they seem tired, no matter the time of day.
- Are they awakened from sleep too early in the morning for morning care, or bloodwork?

- Does staff wake them up frequently during the night to adjust their position? Skin ulcers (wounds that can happen when someone is in the same position for too long) are common and serious problems. Common practice is often to reposition someone every two hours, which can significantly limit someone's ability to get enough sleep. One approach is to assess skin conditions for tolerating longer and longer periods of not being repositioned without causing untoward effects on the skin. This has to be done on an individual basis, based on the resident's preference and careful assessment and monitoring by staff to assure there are no negative outcomes.
- Are there other reasons the person you care about wakes up? It might be a noisy roommate, another resident's alarm, or staff talking in the hall.

Rest During the Day

Even during the day, people with advanced dementia are especially in need of a balance between activities and resting. People with dementia are likely to experience more fatigue as the disease progresses, because of the extra energy it increasingly takes just to think. This can make people prone to feeling more easily overwhelmed or overtired, which only makes it worse. It is beneficial to look at all the things a person does or needs to do during the day and find ways to pace them out comfortably for the person.

Changes in the sleep/wake cycle can occur as a natural part of dementia. If people are unable to sleep all night as in the past, they may need to supplement their sleep with naps during the day.

Finding the right balance between rest and activity for someone with advanced dementia makes a big difference in the person's comfort, and in providing care. People with moderate to advanced dementia have a difficult time focusing on selective things in their environment and can be overwhelmed by a bombardment of sights and sounds. This sense of feeling overwhelmed can make even simple tasks such as eating more difficult.

The activity involved in morning care and breakfast, for example, is likely to prompt a resident to need a quiet/rest period. Another time when quiet is often welcome

is after lunch. A nursing assistant told us about the time she decided to test helping two residents back to bed for a nap 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!” Mealtimes can be very noisy, with lots of commotion going on all around residents. This alone can be exhausting for someone with dementia, and in this case the crying out had clearly been a response to being overtired (and therefore overwhelmed). The naps made the difference for these two residents.

As dementia increases, many people spend more and more time sleeping. If someone is tired, they should be helped to rest regardless of the time of day. When their needs are met, they will naturally fall into a sleep pattern that works for them.

The Connection Between Sleep and Sundowning

Sundowning is a term used to describe the agitation, pacing, irritability and disorientation that many people with dementia experience during the late afternoon, evening or night. For those who work or live with older people who have dementia, this is one of the most challenging situations they encounter on a daily basis.

If your relative or friend is experiencing sundowning, the most likely cause is overstimulation. Being confused and unable to make sense out of the environment can be extremely tiring, and as the day wears on, increasingly overwhelming. Sleep and rest routines can have a big impact on sundowning. This would be a good time to assess with staff whether your relative is getting enough sleep, and also, whether they are able to balance activities and rest during the day. In addition, noise and disruptions in the environment can play a role in tiring your relative out: this could be a TV playing all day, or the commotion at change of shift, for example.





Making the Most of Meals and Snacks

For most of us, mealtimes are pleasurable experiences, whether we crave comfort foods, a night out at a favorite restaurant or that first cup of coffee in the morning. Throughout our lives, celebrations almost always center around food and memories of food are closely connected to our memories of those occasions. Each of us has favorite foods, and when we think of treating ourselves, or someone else, it is often food we think of first.

The person with dementia lives with a lifetime of these pleasurable moments, just as we all do. When comfort is the goal for someone living with dementia, food is not only a daily necessity, but a daily opportunity as well. These pleasures aren't necessarily complicated...how we like our coffee, a favorite cereal, favorite soups or wine or beer with supper.

- **Offer food that your relative enjoys.** They are more likely to eat foods they like. If they don't like the food, they may refuse to eat, spit the food out, or even choke.
- **Question whether a restricted diet is still needed.** Many people have diabetes or other conditions and have to eat a restricted diet with just certain foods. But when they also have advanced dementia, there may be less benefit to this diet. In a 2005 position paper of the American Dietetic Association, they stated: "Food is an essential component of quality of life; an unacceptable or unpalatable diet can lead to poor food and fluid intake, resulting in weight loss and undernutrition and a spiral of negative health effects."

- **Diabetic Diets.** The American Diabetes Association wrote in a 2008 report that, ‘the imposition of dietary restrictions on elderly patients with diabetes in long-term care facilities is not warranted.’ Younger people with diabetes need to be concerned about their A1C scores because these are predictors for the impact of diabetes 5-10 years into the future, but for someone with advanced dementia this is not an issue. For them, malnutrition is a much greater concern, in addition to the fact that food can be one of the few pleasures still available to them. For most people with advanced dementia, their diabetes is under control, and careful monitoring is no longer necessary (including finger sticks, which can be unpleasant). There are situations where someone’s diabetes is not controlled (and should be monitored), but these are rare.
- **When possible, real food is preferable to supplements.** Mealtime can be hard for someone with advanced dementia. They might lose interest in eating, refuse certain foods, or forget how to chew and swallow. In these situations there is an unfortunate tendency to rely heavily, if not exclusively, on the use of supplements. While supplements can be helpful, whole food is not only more pleasurable, but results in better health outcomes as well. Even if supplements are fortified, they don’t contain all the nutrients of a whole food source. Some residents do like supplements, others not so much. Even if residents have very limited interest in real foods, and they prefer primarily soft and sweet foods, if comfort is the goal, it is possible to address both the nutritional and quality of life needs of residents.
- **A quiet and calm dining area is preferable.** This way, the person you care for can focus on eating. It can be nice to have quiet background music, as long as it doesn’t disturb anyone. But it is best to turn off the television and minimize any loud, annoying or distracting noise. If the noise or commotion is overwhelming for your relative, work with staff to find another space for them to eat.
- **Food should be served at the pace that works best for the person you care for.** Use of a tablecloth or placemat can help them see edges of the dish. Having just 1 or 2 foods on the plate can be helpful. If they prefer, cut-up “finger foods” they can serve themselves can be effective. Your relative should not be forced to eat food they don’t want nor should they be forced to use a fork or spoon – this may make it more difficult for them to get the calories they need. And they should be given plenty of time, their plate shouldn’t be taken away too soon.
- **Changes in approach may be needed as the person’s dementia increases.**



The Importance of Snacks

If a resident doesn't seem willing or able to eat much or anything at mealtimes, snacks can be especially helpful. 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, a piece of fruit, pudding, or a peanut butter sandwich. Smoothies are another great snack.

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 when snacks are always available, the key element is for staff to directly offer snacks to individual residents frequently throughout the day. The portions may be small (orange sections, a quarter of a sandwich), but even so, this approach can be very effective in preventing weight loss while promoting overall personal comfort. When offering a snack, showing the item, and saying something like, "it's yummy...have a bite" or "doesn't this look good" may provide extra encouragement. **The key is to offer snacks residents will actually eat and enjoy.**

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. In fact, when the end of life is near, it is a natural process for the body to require less and less food and fluid.

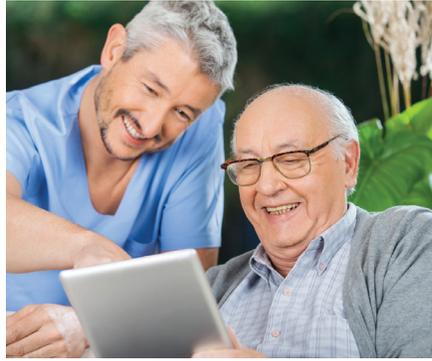
When Someone No Longer Wants to Eat

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.

However, because of the progress of the dementia, body functions are naturally slowing down and require fewer calories and liquids than before. You might worry that this is painful or that your relative might starve. Please know that as a person nears the end of life they need less food and fluid. Their brain releases a chemical called endorphins that helps lower any sense of pain.

Here are some ways to help:

- Find out if there is a special reason why your relative no longer wants to eat. This might be due to medication, illness, dental problems, or even constipation. If so, look for ways to address these problems.
- Be flexible in how and when to offer food. This might be smaller portions, soft or sweet foods, or finger foods to eat on their own. Offer snacks and drinks throughout the day rather than just at meal times.
- Do not force someone to eat. As a person's body starts to shut down they need fewer calories and liquids. It is not helpful to give artificial nutrition through a gastric feeding tube, as it is extremely uncomfortable and unpleasant and can cause problems like bloating and diarrhea. Artificial nutrition also will not prevent pneumonia or pressure ulcers and will not prolong a person's life or provide comfort.



Rethinking Activities: Meaningful Engagement

For all of us, how we spend our time is a reflection of what is important to us. Whether it is keeping up with a favorite team, walking the family dog, a phone call with a friend, or listening to music, these activities add variety, interest and purpose to our days. When we are able to spend time doing something we enjoy, we feel more like ourselves. It makes us feel good.

While someone with dementia may not be able to engage in some of the things they have enjoyed in the past, it is still possible for them to experience pleasure. They too can feel lonely, bored, or frustrated, and finding ways to help them feel engaged is one of the most important things we have to offer them. Whether it is help with dressing, offering a snack, or a walk hand-in-hand down the hallway, there is potential for connection and comfort. This means that family, friends and all staff, regardless of job title, have a crucial role in meaningful activities. Here are some ways that meaningful engagement can occur:

- Any staff member can engage with someone, in the way they interact when they are helping someone get ready for bed, or by sharing a piece of chocolate, or singing along with someone to their favorite music. Daily flexibility means that all staff need to pay attention to what will work best 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, or cuddling with a visiting dog or cat. **Any meaningful interaction will not be judged by its duration but its quality.**
- Few if any of us spend a lot of our time in large group activities, and for the person with dementia they can be simply overwhelming. For this reason, people

with advanced dementia often have difficulty interacting in a meaningful way with large group events. The important thing is to observe, if they are part of a group, whether they appear comfortable or engaged, or not. A phone call from a family member or friend, or a few minutes of hand massage from a member of staff, can be more meaningful than sleeping through or trying to leave a party or other large group event. Whatever the interaction, the purpose of that interaction should be to bring comfort and a sense of connection with someone who cares about them.

- For some people, spiritual practices bring comfort throughout their lives. Spending time out of doors, enjoying a cool breeze or feeling the warmth of the sun, can bring great pleasure. Holidays are often times when specific comforts can be identified – through music, foods, scents, celebrations. And remember, for the person with dementia, every day can be a holiday filled with these items if they bring particular pleasure.
- As we all have experienced, food presents many, many possibilities for pleasure. One home keeps wrapped chocolates on their medicine cart, and regularly offers lollipops to residents. Fresh watermelon in the summer, homemade smoothies, fresh-baked cookies, can all be occasions for enjoyment and a moment of connection.



Music & Memory

A wonderful opportunity for providing individualized engagement for people with even very advanced dementia is the personalized music project developed by the non-profit organization *Music & 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, family, friends, and staff. It can take a little detective work to discover what specific music someone enjoys — we all have music we prefer, and music we don't care for — but when we are able to help someone make that connection, the results can be transforming.

The Environment

Environment is a general term that refers to everything in a person's nearby space. This includes light, noise, and areas to be with others and areas to be alone.

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 easily be startled. Overhead pagers, loud talking in the hallways, noisy mealtimes, TVs always on, even the commotion from the coming and going of staff at shift change, any of these can be troubling or upsetting for someone. Efforts should be made to limit these disruptions, with quieter mealtimes, quieter shift changes, less TV, elimination of overhead pagers, softer tones in the hallway, and other similar measures.

It may also be appropriate to simply help the person move to another location if it is the environment that appears to be causing discomfort, by themselves or with one or two other people.



Memories, Including Those That Are Upsetting or Unpleasant

A person with advanced dementia might recall events from long ago. These memories are still a part of their life.

Memories can be of pleasant events. Hearing a familiar song, for example, can result in someone's suddenly remembering all the words and singing along. At one home, a woman in the advanced stages who had been a nurse was welcome to sit at the nursing station whenever she wanted, where they gave her paper and a pen. A familiar activity in a familiar place. A school principal kept taking the elevator to another floor, which had the same number as the floor where his old office had been.

But not all memories are of pleasant events. To someone with advanced dementia, these can sometimes feel as if they are happening again. If families are aware of past trauma, it is important they share that information with staff. Here are some examples along with ways to offer relief and comfort.

- **Veterans who served in combat.** Some veterans have a condition called PTSD (post-traumatic stress disorder). A sudden loud noise might cause them to have flashbacks or nightmares about something that happened many years ago. With advanced dementia, they cannot avoid or distract themselves from these feelings. This happened to a veteran who worried that he needed to do more to serve his country. Staff kept saying he had done so with honor. To reinforce this, they posted a certificate of appreciation in his bedroom he could look at every day.
- **Survivors of the Holocaust.** The Holocaust was an awful event in which millions of people in Europe were killed, starved, or abused in concentration camps. Some of those who survived might now have advanced dementia. They might still feel terror from years ago but have no way to deal with it. Be mindful of this if your relative lived through the Holocaust. If they get upset when asked to undress or refuse to take a shower, offer soothing alternatives instead. This might be a gentle sponge bath, hand-held shower, or having a family member be nearby. **Do not insist that your relative do something against their will.**
- **Survivors of abuse.** Past experience of abuse or neglect, while sadly not uncommon, can be hard to trace, in part because very often it was kept a secret at the time, and sometimes never spoken of at all. Nonetheless, people can still

suffer from its effects even at the very end of life. Someone who doesn't like to be touched, for example, may be giving a clear signal of distress that is based on an earlier, fearful experience. The important thing here is to recognize that this is a signal of distress, and to help the person find a way to be comfortable.

- **Other traumas.** People suffer for many reasons. They might have lived through fires, earthquakes, floods or other natural disasters. Or faced political, religious or ethnic persecution. Perhaps a storm outside or something on TV is causing them to remember this trauma. Think about your relative's life and if their distress now might be from trauma long ago. As always, offer ways to comfort them.

Sometimes there are specific triggers for these recurrences of past distress; sometimes, it is simply that the person is feeling generally more vulnerable, and it is this feeling which returns them to a time in their lives when they also felt very vulnerable.

Sadly, the recent situation with COVID-19 has been a time of terrible loss, and in many homes, the extremely stressful atmosphere may well have re-awakened old anxieties. Equally, of course, the pandemic will itself cause trauma for many, even if there is no troubled past.





COVID-19

The pandemic has been stressful for everyone. People with advanced dementia might be aware that things have changed, but not understand why. During this pandemic (or during other outbreaks of disease, such as the flu), nursing homes and assisted living residences are required by state and federal guidelines to follow different levels of restriction for visitation. Here are examples of how COVID-19 might affect your relative, along with ways to help:

- Feelings of isolation, fear and anxiety. These feelings can be present even if your relative does not have COVID-19.
- If your relative tests positive for COVID-19 they may or may not be physically sick. Whether they have symptoms or not, they might be moved to a different room and treated by a new team of caregivers. New caregivers need to know the most effective, specific ways to care for them and make them comfortable. This will help both the resident and the person providing care. Let them know what causes your relative distress and also ways to offer comfort. Be clear and specific when sharing this information.
- Phone calls and tablet or computer zoom visits can help, as well as 'window' visits, and should be made available as frequently as possible. For most people with advanced dementia, staff assistance will be needed, which inevitably affects how frequently they can occur. Unfortunately, phone calls and even virtual visual visits may not work for some people because of the degree of their dementia.

- During the pandemic, homes have offered the possibility of "compassionate visits," but interpretations of what this means varies widely, with some homes being much more restrictive than others in terms of the reasons why a visit might be allowed. In many cases, it was interpreted to mean, only when a resident was actively dying. Tragically, however, we know that the impact of isolation and disconnection from people we care for can itself cause decline and even death (for the resident, or for their elderly spouse still living in the community). Clearly, homes need to take the impact of isolation seriously into consideration when assessing the need for "compassionate visits," a concern which can affect virtually all people living in residential care. However, at the same time, the threat of spreading infection is real, and even just one visitor who has active infection can cause illness and death for many. Protocols for vaccination, testing and PPE are essential and need to be enforced for the good of all.
- Visitation rules have changed significantly over time, and the best way to address this variability is to speak with the leadership at the nursing home to learn what the rules are there and to ask how the family and staff might work together to maintain engagement and promote wellbeing for people with dementia and their families and friends.
- Find other ways to offer comfort. Think about what gives your relative pleasure. If they like music, create a playlist of their favorite songs on an iPad or other device. Many homes have a limited number of tablets, so it may also be helpful if family members are able to provide one for the resident's exclusive use. If they enjoy sweets or certain foods, see if you can send some of these treats to the home.
- Finally, COVID-19 is a reminder of how important it is to have advance directives in place. Advance directives make clear what to do if your relative gets very sick. Now is a good time to make sure that all needed paperwork is done. Decisions about hospitalizations and ventilators, for example, as difficult as they are, can be eased if there is clarity about treatment goals.



Choices About Treatment and Care

There are many types of dementia. Some people have more than one at the same time. The most common type of dementia is Alzheimer's disease. Others include: vascular dementia, Lewy Body Dementia, Frontotemporal Dementia, and more than 50 other rare types. While each has its own set of symptoms, all types of dementia cause changes in thinking, memory, behavior and functioning that get worse over time. The Mayo Clinic provides information regarding many different types of dementia, see www.mayoclinic.org/diseases-conditions/dementia.

No matter what type of dementia, it is almost certain that you will someday need to make choices about treatment and care. In the early stages of this disease the person you care about might be a part of making these choices. Later as the disease gets worse, you might need to make choices on their behalf.

An advance directive is an official form to make these choices clear. This form is important for everyone including those who have dementia, cancer, or other serious diseases.

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.

Here are some topics to think about and questions to ask:

- How could this treatment help? In other words, what are its benefits? What problems might it cause? The healthcare team might refer to these problems as risks.
- Is this treatment mostly for comfort? Or is it in hopes of a cure? Some treatments, like ventilators or feeding tubes, are unpleasant with little to no chance of helping. Talk with the healthcare team about whether this treatment might cause more harm than good.

- Are they nearing the end of life? Many people at this stage make choices based on comfort, not cure. At this point, even the best medical efforts cannot prevent death.
- What guidance would they give you about medical treatment? If they could see themselves now, what would they want? Would they choose to do everything possible in hopes of living longer in this condition even if it includes uncomfortable treatments? Or would they want care that focuses on maximizing comfort even if it means they might die sooner?
- 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.

Treating Infections

People with advanced dementia often get pneumonia and urinary tract or other types of infections. They might not be able to say when they have these problems. Often these infections are noted after acute changes in behavior, such as when residents become either more lethargic or aggressive than they usually are.

When someone has an infection, the first step is to review the goals of care to make sure that the treatments chosen honor and uphold the person's wishes (advance directives). When the goals of care are comfort-focused only, antibiotics are rarely prescribed. Instead, measures will include giving a pain reliever such as Tylenol, monitoring the person very closely for any signs of discomfort, and treating as needed. There are rare occasions when antibiotics may be used primarily for comfort purposes (such as with a painful urinary tract infection). Here is more to know about antibiotics:

- Antibiotic medication should only be given when there is a confirmed medical reason. It is important to first find out if the person indeed has an infection. The reason to do this is that antibiotic medication can cause increased confusion, stomach and digestive problems, or other side effects. Antibiotics can also cause problems with other medications.
- Ask the healthcare team how they will test for infection. This might be with a chest x-ray, blood work, or catheter to get a urine sample. Some of these tests can lead to other problems. Tests and procedures can be painful and scary for a person who may not understand what is happening. Before giving permission for a test, it is important to decide if the condition will be treated. For example, if the person does have a urinary infection, are fluids and cranberry supplements an option instead of an antibiotic? If it will not be treated, then spare the person with dementia any possible distress associated with testing and instead direct

attention to monitoring the person very closely for any signs of distress and enhance comfort as needed.

- When it is agreed that the person you care about should get antibiotic medication, request that it be given as a pill or liquid rather than by injection or through an IV tube going into their vein. Remember, needles can be scary and cause discomfort.
- It is important to note that these treatments may not prolong life and choosing not to treat can be the best course of action. Speaking with the physician about the person's wishes can help make these decisions easier.

CPR (Cardiopulmonary Resuscitation)

This is a way to try and restart a person's heart after it stops beating. To do CPR a health professional must push very hard on the person's chest. For frail older people, this can also cause a lot of problems:

- CPR often does not help a person live longer when they have a serious disease.
- Those who initially survive CPR are taken to an intensive care unit of a hospital where, research confirms, they rarely survive.
- CPR itself can cause problems. The healthcare team might need to push so hard they break the person's ribs. This is extremely painful.

Mammograms, Colonoscopies, and Other 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?



Going to the Hospital

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, which worsens confusion and may cause distressing hallucinations and delusions. 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 and moves at such an accelerated pace, 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 dementia. Thus, the pain (and the cause of the delirium) is therefore 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, including supplements, 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.

Conversations Between Family and Staff

It is important to keep talking with staff about how to help your relative or friend as their dementia gets worse. Talk about the care they are getting now and options for the future. It is critical that these conversations be ongoing, as circumstances change over time.

Hospice and End-of-Life Care

Palliation helps people (and their families) who are living with dementia or other illness, often for many years. Hospice is a continuation of palliative care, and usually starts when doctors certify that someone is expected to live about 6 months or less.

Medicare will pay for hospice care so long as certain guidelines and requirements are met. Here is more to know:

- Anyone, including family members, can start a referral to hospice. Your relative's primary care doctor and a hospice physician must complete paperwork stating the need for this service. They must also state that your relative is expected to live 6 months or less.
- 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 activities of daily living, such as walking, bathing, and dressing), inability to speak more than a few intelligible words, and incontinence of bowel and bladder.
- In addition, the person should have had at least one of the following medical problems: kidney or other upper urinary tract infections, recurring fever even after taking antibiotics; aspiration pneumonia, multiple pressure ulcers (bed sores)

that are stage 3 or 4, septicemia (blood infection), or weight loss of more than 10% in the last 6 months.

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

It can be hard to know when someone with advanced dementia is nearing the end of their life. Here are some signs to look for:

- Loss of appetite and ability to swallow
- Decreased urinary output (“peeing” less)
- 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

Hospice and residential care staff should work closely together. Residential staff should keep doing all they have learned about how best to care for your relative. This might be special ways of washing up, playing favorite music, or knowing when someone is in pain. Hospice can work with residential staff to decrease your relative’s pain and increase their comfort throughout the dying process. 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. Resident comfort should be the basis of the care plan shared between the residential setting and the hospice.

Finding Comfort

This booklet is intended to help you bring the best possible quality of life for the person you care for who has dementia. **For the person with even the most advanced dementia, comfort matters and is possible.** The more you are able to share with staff about what the person you care for enjoys and is comforted by, the better. In turn, when there are signals that your relative is not comfortable, the focus should be on working with staff to figure out what is causing the source of their distress and taking the necessary steps to prevent or minimize it in the future. This is how to bring “person centered care” to someone with dementia.



Pain Assessment in Advanced Dementia Scale (PAINAD)

Instructions: Observe the patient for five minutes before scoring his or her behaviors. Score the behaviors according to the following chart. Definitions of each item are provided on the following page. The patient can be observed under different conditions (e.g., at rest, during a pleasant activity, during caregiving, after the administration of pain medication).

Behavior	0	1	2	Score
Breathing Independent of vocalization	<ul style="list-style-type: none"> Normal 	<ul style="list-style-type: none"> Occasional labored breathing Short period of hyperventilation 	<ul style="list-style-type: none"> Noisy labored breathing Long period of hyperventilation Cheyne-Stokes respirations 	
Negative vocalization	<ul style="list-style-type: none"> None 	<ul style="list-style-type: none"> Occasional moan or groan Low-level speech with a negative or disapproving quality 	<ul style="list-style-type: none"> Repeated troubled calling out Loud moaning or groaning Crying 	
Facial expression	<ul style="list-style-type: none"> Smiling or inexpressive 	<ul style="list-style-type: none"> Sad Frightened Frown 	<ul style="list-style-type: none"> Facial grimacing 	
Body language	<ul style="list-style-type: none"> Relaxed 	<ul style="list-style-type: none"> Tense Distressed pacing Fidgeting 	<ul style="list-style-type: none"> Rigid Fists clenched Knees pulled up Pulling or pushing away Striking out 	
Consolability	<ul style="list-style-type: none"> No need to console 	<ul style="list-style-type: none"> Distracted or reassured by voice or touch 	<ul style="list-style-type: none"> Unable to console, distract, or reassure 	
TOTAL SCORE				

(Warden et al., 2003)

Scoring:

The total score ranges from 0-10 points. A possible interpretation of the scores is: 1-3=mild pain; 4-6=moderate pain; 7-10=severe pain. These ranges are based on a standard 0-10 scale of pain, but have not been substantiated in the literature for this tool.

Source:

Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc.* 2003;4(1):9-15.

Reprinted from *Journal of the American Medical Directors Association*, January-February 2003, Victoria Warden, Ann C. Hurley, Ladislav Volicer, Development and Psychometric Evaluation of the Pain Assessment in Advanced Dementia (PAINAD) Scale, pages 14 & 15.

PAINAD Item Definitions

(Warden et al., 2003)

Breathing

1. *Normal breathing* is characterized by effortless, quiet, rhythmic (smooth) respirations.
2. *Occasional labored breathing* is characterized by episodic bursts of harsh, difficult, or wearing respirations.
3. *Short period of hyperventilation* is characterized by intervals of rapid, deep breaths lasting a short period of time.
4. *Noisy labored breathing* is characterized by negative-sounding respirations on inspiration or expiration. They may be loud, gurgling, wheezing. They appear strenuous or wearing.
5. *Long period of hyperventilation* is characterized by an excessive rate and depth of respirations lasting a considerable time.
6. *Cheyne-Stokes respirations* are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

Negative Vocalization

1. *None* is characterized by speech or vocalization that has a neutral or pleasant quality.
2. *Occasional moan or groan* is characterized by mournful or murmuring sounds, wails, or laments. Groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
3. *Low level speech with a negative or disapproving quality* is characterized by muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining, sarcastic, or caustic tone.
4. *Repeated troubled calling out* is characterized by phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.
5. *Loud moaning or groaning* is characterized by mournful or murmuring sounds, wails, or laments in much louder than usual volume. Loud groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
6. *Crying* is characterized by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

Facial Expression

1. *Smiling or inexpressive*. Smiling is characterized by upturned corners of the mouth, brightening of the eyes, and a look of pleasure or contentment. Inexpressive refers to a neutral, at ease, relaxed, or blank look.
2. *Sad* is characterized by an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
3. *Frightened* is characterized by a look of fear, alarm, or heightened anxiety. Eyes appear wide open.
4. *Frown* is characterized by a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.
5. *Facial grimacing* is characterized by a distorted, distressed look. The brow is more wrinkled, as is the area around the mouth. Eyes may be squeezed shut.

Body Language

1. *Relaxed* is characterized by a calm, restful, mellow appearance. The person seems to be taking it easy.
2. *Tense* is characterized by a strained, apprehensive, or worried appearance. The jaw may be clenched. (Exclude any contractures.)
3. *Distressed pacing* is characterized by activity that seems unsettled. There may be a fearful, worried, or disturbed element present. The rate may be faster or slower.
4. *Fidgeting* is characterized by restless movement. Squirming about or wiggling in the chair may occur. The person might be hitching a chair across the room. Repetitive touching, tugging, or rubbing body parts can also be observed.
5. *Rigid* is characterized by stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding. (Exclude any contractures.)
6. *Fists clenched* is characterized by tightly closed hands. They may be opened and closed repeatedly or held tightly shut.
7. *Knees pulled up* is characterized by flexing the legs and drawing the knees up toward the chest. An overall troubled appearance. (Exclude any contractures.)
8. *Pulling or pushing away* is characterized by resistiveness upon approach or to care. The person is trying to escape by yanking or wrenching him- or herself free or shoving you away.
9. *Striking out* is characterized by hitting, kicking, grabbing, punching, biting, or other form of personal assault.

Consolability

1. *No need to console* is characterized by a sense of well-being. The person appears content.
2. *Distracted or reassured by voice or touch* is characterized by a disruption in the behavior when the person is spoken to or touched. The behavior stops during the period of interaction, with no indication that the person is at all distressed.
3. *Unable to console, distract, or reassure* is characterized by the inability to soothe the person or stop a behavior with words or actions. No amount of comforting, verbal or physical, will alleviate the behavior.

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: _____

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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. See their Toolkit: "Implementing Best Practices in Dementia Care."

Mayo Clinic. www.mayoclinic.org

MJHS Institute for Innovation in Palliative Care. www.mjhspalliativeinstitute.org

Music & Memory, Inc. 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 digital audio systems.

Pioneer Network. www.pioneernetwork.net
A national non-profit organization, recognized as the national leader of the person-directed care movement in long-term care.

The National Consumer Voice for Quality Long-Term Care. www.Theconsumervoice.org
The Consumer Voice is the leading national voice representing consumers in issues related to long-term care, helping to ensure that consumers are empowered to advocate for themselves. They are a primary source of information and tools for consumers, families, caregivers, advocates and ombudsmen to help ensure quality care for the individual.

The Society for Post-Acute and Long-Term Care Medicine (AMDA). www.paltc.org
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.

Notes:

caringkind

The Heart of Alzheimer's Caregiving

CaringKind offers programs and services for people living with dementia, their families, and professional care partners.

CaringKind Helpline
Individual and Family Counseling Sessions
Support Groups
Education Seminars and Training Programs
Early-Stage Services
Wanderer's Safety Program

To learn more,
please call our Helpline at 646-744-2900
or visit us at 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.

360 Lexington Avenue, 3rd Floor • New York, NY 10017

CaringKind Helpline: 646-744-2900 caringkindnyc.org

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CaringKind was formerly known as the Alzheimer's Association, NYC Chapter