

## Living with Dementia in Residential Care: Care Planning for Comfort

When someone who has dementia enters a nursing home or other residential setting, a comprehensive assessment is made of the person's care needs, along with a plan of care to address those needs. The purpose of the plan is to provide direction and continuity for staff regarding the specific care residents require, including nursing, personal care, therapies, meals, equipment, social service, 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 go to bed, what and when they eat, whether they eat with others or on their own, how and when they bathe, and how they spend their time.

In addition to providing guidance for care, nursing homes are required to submit this information to the federal government. This information is used in state inspections, monitoring quality, and setting nursing home payments.

For residents receiving Medicare or Medicaid, the actual assessment begins on the day of admission and the care plan must be completed within 14 days. Thereafter it is reviewed and updated at least every 90 days as needed, and possibly more if there are changes in the person's medical status. Both residents and family members are encouraged to attend care plan meetings.

### Care Plans and Dementia: Why Focus on Comfort?

While there is no cure for dementia, there is much that can be done to bring someone comfort while preventing or minimizing the discomfort, distress and suffering

that sometimes accompanies the effects of dementia. Throughout the course of the illness, the needs of the person with dementia obviously change. What makes the more advanced stages especially challenging is that the person has increasing difficulty in expressing what their needs are: are they hungry, are they in pain, do they need the bathroom, are they too hot or too cold, are they tired, lonely, or frightened by noises or activity in the environment? It becomes our job to determine what the person is trying to say and then to address these unmet needs by doing for the person what they can no longer do for his/herself.

When these needs aren't met, someone with dementia is likely to feel distressed, and their actions rather than words are most likely to communicate such distress. Unfortunately, these behavioral expressions (moaning, calling out, striking out, grimacing) are often not understood as distress, but rather are assumed to be the inevitable consequences of the dementia itself. However, dementia is rarely the actual cause.

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. We have learned that when we see such *behavior*, we should label it *distress*.

Why does this matter so much? When we think *behavior*, there is a tendency (however unconsciously) to assume the person has control



over something he/she 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. Relief from pain or discomfort cannot occur if the reason or triggers for distress are not known, understood or addressed. Discovering what makes someone comfortable can be challenging, but the language of comfort is not mysterious.

### What Does Comfort Have to do with Care Planning?

When people living with dementia are scared by things happening to them or around them, it can lead to them resisting caregiving efforts. Situations such as being constipated, loud noises in the environment, a new and unfamiliar caregiver, or even a sore shoulder could cause the patient to lash out unexpectedly. They may be experiencing not only distress and pain, but also feel the necessity to pull away. They may resist caregiving efforts by pushing caregivers away or refusing to allow

# RESOURCES

## Walk because you care.

Join CaringKind this fall for the  
2017 CaringKind Alzheimer's Walk!



### MANHATTAN

October 15 - 9 am  
Riverside Park

### QUEENS

September 17 - 9 am  
Flushing Meadows  
Corona Park

### BROOKLYN

September 24 - 9 am  
Coney Island  
Boardwalk

### STATEN ISLAND

October 1 - 9 am  
South Beach



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

This Publication is available for  
download here:

[www.caringkindnyc.org/  
palliativecare](http://www.caringkindnyc.org/palliativecare)

## Pain Assessment in Advanced Dementia

For more information about  
Pain Assessment in Advanced  
Dementia (PAINAD) go to:

[www.geriatricpain.org/  
assessment/pain-assessment-  
cognitively-impaired-older-  
adults](http://www.geriatricpain.org/assessment/pain-assessment-cognitively-impaired-older-adults)

CaringKind

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the caregiver to assist them. They may yell, or moan, or even push other residents who are close by. **These behaviors are all signs that the person is uncomfortable and experiencing distress. They need our help to prevent further suffering.**

Nursing homes use the MDS (Minimum Data Set) assessment form to assess care needs, as the basis for the care plan that is developed for each resident. As part of this assessment, staff are asked whether a resident (1) resists care; (2) has “verbal behavioral symptoms directed towards others;” (3) has “physical behavioral symptoms toward others;” or (4) has “other behavioral symptoms not directed toward others.” Staff bring these assessments to care plan meetings. **Whenever any of these items are checked off as part of the assessment, it is a signal that the resident is experiencing distress, which means a focus of the care planning process should be a plan to uncover what is causing the person’s distress. The answer should never be: “It’s the dementia.”**

Planning should start with determining what the resident is trying to communicate. If they are pushing staff away, what else is going on when this occurs? For example, is it during dressing, bathing, or meal times?

**While it can take awhile to figure out the best solution, sometimes through a lot of trial and error, you will find that the person with dementia is the best guide in letting us know when we are getting it right.** While someone may spit food out because they are not hungry, or because their dementia has progressed to the point where food is no longer of interest, it may also be true that they have pain in their teeth or gums, or that they simply don’t like the food they are being offered. **Whenever an effective approach is found, it should become part of the care plan.**

### What Brings Comfort?

Familiar routines, favorite food, enough sleep, favorite music, a relaxing environment, freedom from pain, a quiet place to sit away from a large group, and meaningful engagement are all things which can contribute to someone being comfortable, or, if absent, uncomfortable and in distress. When someone first moves into a home, it is as important to collect information about what specifically comforts someone as it is to collect information about care needs. The two are intertwined, and we will do a much better job of caring for someone if we understand their comforts as well. Further, **these comforts should be integrated into the care plan.** If someone enjoys frequent hugs from staff, or is bothered when a room gets too crowded, or is more relaxed when able to listen to music they like first thing in the morning, this information belongs in the care plan.

### Pain

Experience teaches us that pain is frequently the cause of someone’s distress, and can often result in rejection of care or other physical or verbal expressions which are usually described as a behavior. Observations of distress should trigger a search for the causes of discomfort, without waiting for a care plan meeting, and should start with ruling out other forms of discomfort, such as a soiled brief or an acute medical condition. If no probable cause for the distress can be identified, **assume that pain is present.** When someone can no longer report their pain, a valid and reliable pain behavioral assessment, such as the PAINAD, should be used. Behavior-based pain assessment tools should always be incorporated into a home’s overall pain policies and procedures, for use when needed. In routine care plan meetings, the team should always consider the possibility of pain, especially if any of the resident’s diagnoses involve the likelihood of pain (i.e., arthritis).

### Families as Partners

For the person with dementia, family participation in the care planning process is especially important because of the resident’s inability to speak for themselves. Ideally conversation between family and staff about care needs and preferences should start as soon as the person moves into the home (if not before), and should be ongoing as care needs change. Nursing assistants should be included in these conversations, including at care plan meetings, as they learn so much in their interactions with residents about their comforts and discomforts.