Stepping Up to the Plate

Is it possible for people with dementia to eat familiar and favorite foods safely? A growing number of clinicians say yes, offering suggestions for SLPs who want to avoid recommending the often-rejected modified diet.

Carol Polovoy (solr/searchResults.aspx?author=Carol+Polovoy)

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Tea and toast.

That’s what 77-year-old Mrs. L. had eaten for breakfast every day for the past 45 years. But ever since she had been deemed at risk for aspiration in the long-term care community where she lived, her breakfast choice was oatmeal or scrambled eggs—neither of which she would eat—and nectar-thickened tea that she rejected because it tasted funny.

Gone, too, was her favorite lunch of tomato soup and a grilled cheese on her mechanical soft diet. Dinner usually consisted of a variety of chopped-up mounds that didn’t look like food—and which she also didn’t eat.

Caregivers, alarmed that in two months Mrs. L. had lost seven of her 111 pounds and was beginning to show signs of dehydration, began to consider a feeding tube. They believed the risk of aspiration pneumonia was too high to allow Mrs. L., who has dementia, to eat the foods she liked.
Many speech-language pathologists who work in acute care, long-term care, inpatient and outpatient rehabilitation, and home care will recognize this difficult scenario. But some of the leading experts in swallowing contend that it doesn’t have to be this way. Research indicates, they say, that people with dementia can safely eat many of the foods they like—with appropriate supports.

“We are obsessed with aspiration,” said SLP Paula Leslie in a presentation at ASHA’s 2015 Health Care/Business Institute. Leslie, a University of Pittsburgh professor with a special interest in complex clinical decision making, ethics and end-of-life decisions in vulnerable populations, emphasized that “aspiration itself does not cause infection. It depends on what you aspirate, which is why oral hygiene is so crucial to address. We all aspirate micro-amounts of saliva daily and occasionally we’ve all experienced food or drink ‘going down the wrong way,’ but our immune systems cope. Clearly, if you get broccoli in your lungs, that’s not good!”

“The status quo
Caused by a number of progressive disorders, as well as infections, vascular issues and other conditions, dementia affects memory, thinking, behavior, the ability to perform activities of daily living—and nutrition.

In the early stages, a person may be easily distracted during meals, forget to buy food or forget to eat. As dementia progresses, and the person becomes more confused and unaware of surroundings, place and time, the person may forget how to use utensils, may not recognize signs of hunger or thirst, and be unaware of food temperature. People with dementia might forget to chew or swallow or even lose the sensorimotor ability to do so.

All of these symptoms increase the risk of aspiration—getting food or liquid in the lungs. But are the risks of aspiration worth the benefits of modifying the person’s diet?

Thickened liquids and modified diets—ranging from chopped to minced to pureed—have long been the standard of care for people at risk of aspiration. “We were taught to use thickened liquids as a way of preventing pneumonia and other complications from aspiration,” says SLP Jennifer Brush, owner of Brush Development Company. “And so clinicians may think that their patients are going to be safer if they give them thickened liquids.

“But there’s a whole list of other factors, such as poor oral hygiene, inability to feed oneself and non-
ambulatory status that contribute to the complications of aspiration.”

A 1998 study by Susan Langmore and her colleagues in the journal Dysphagia found that the best predictors of aspiration pneumonia (http://link.springer.com/article/10.1007/PL00009559) were dependence on others for feeding and oral care, the number of decayed teeth, having a feeding tube, having more than one medical diagnosis, the number of medications, and smoking.

“Dysphagia was concluded to be an important risk for aspiration pneumonia,” the study says, “but generally not sufficient to cause pneumonia unless other risk factors are present as well.”

SLP Mary L. Casper, a corporate rehabilitation consultant for HCR ManorCare, agrees. “We really don’t know if changing the consistency of food does anything for people with dysphagia,” she says. “We need research to address this question for all populations, but especially to inform decisions in end-of-life care.”

Even determining if someone is at risk for aspiration is complex when the person has dementia. “It’s important to carry out an assessment when a person is aroused, alert, aware, attentive and concentrating,” said SLP Luis F. Riquelme in a presentation at the 2015 Health Care/Business Institute. According to Riquelme, director of the Center for Swallowing and Speech-Language Pathology at New York Methodist Hospital and associate professor at New York Medical College, any number of factors—the time of day, the side effects of medications or the presence of infection, for example—may affect overall alertness and whether the assessment will present an accurate picture of the person’s ability to swallow safely.

Just the upsetting experience of going to a hospital for the instrumental assessment can affect results. “It’s an unfamiliar situation,” Leslie says. “The person with dementia is put in front of an X-ray machine and asked to swallow barium. The hospital smells funny, the barium tastes funny, the person is confused and may be too stressed or upset to cooperate. Under those circumstances, the evaluation report could be worthless.”

Other factors also make assessment complicated, Riquelme said. Procedures often are inconsistent in the protocol followed. In addition, the consistencies presented to the person being assessed are not very palatable. Communication between the person performing the test and the SLP who’s providing care may be incomplete if the information in the report doesn’t include the number of trials, the effectiveness of any compensatory strategies, the consistency of the liquid and the rate of penetration versus aspiration, for example.

Another harsh reality is that in some care facilities, financial considerations drive patient care decisions. If, for example, an aide is required to make sure four residents eat a meal in an hour, there simply may not be time to have each person supported individually with different diets and cues, Leslie said. “We need to bear in mind how we can support those care staff who are at the front lines in feeding and caring for our residents.”
Risk versus benefits

Many care communities continue to be over-cautious, pushing modified diets and thickened liquids because they are concerned about nutrition and believe these substances are safer. But an extensive review of the literature recently published in Dysphagia has identified some major gaps in the understanding of the impact of liquid consistency and food texture on swallowing physiology (http://link.springer.com/article/10.1007/s00455-014-9578-x), both in healthy and disordered populations.

The review, led by SLP Catriona M. Steele, concluded that thickened liquids appeared to reduce penetration and aspiration, but also appeared to increase the risk of post-swallow residue—which carries the risk of delayed aspiration. It also found no evidence that any particular method of modifying solid food had a statistically significant effect.

And even if a modified diet did make eating safer, it doesn’t help if the person won’t eat it. “Food is an essential component of quality of life, and an unacceptable or unpalatable diet can lead to poor food and fluid intake,” says Brush, whose company works to change dementia care in hospitals, assisted living communities, nursing homes and home care. “That leads to weight loss, it leads to undernutrition, it leads to a whole host of negative health effects.”

And “unacceptable” and “unpalatable” involve many factors, as Mrs. L.’s caregivers have discovered: The person’s culture, ethnicity, likes and dislikes, desire to socialize and other aspects of the person’s life affect what he or she will eat.

The bottom line? If the person doesn’t like the food presented—or if its consistency is changed to the point where the person doesn’t even recognize it as food—the person is unlikely to eat it.

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A new approach

Brush has been working with people with dementia for almost 25 years. As a new clinician in long-term care, she was frustrated by SLPs’ seeming inability to help people with dysphagia who had dementia. “It didn’t seem like we were doing enough for them,” she says. “They would come to the clinic for therapy, and they would be seen for a short time and they would be discharged because they couldn’t learn what they needed to learn to be successful in therapy. And I thought there had to be something more that we could do.”
Over the next two decades, Brush developed strategies to help people with dementia safely eat and drink the foods they prefer. Her approach has several facets: memory training to teach safe swallowing strategies, environmental adjustments that support safe eating, and coordination with all members of the care team.

But the approach begins, first and foremost, with the person with dementia, she says. Goals and treatment should be person-specific, not disease-specific. “I want to collaborate with the older adult to help them eat what they want, and to work with the other members of the care team, and then also modify the physical and social environment to maximize functioning.”

Enhancing memory. Brush uses spaced retrieval, a memory-training strategy, to teach new or previously known information to people with memory loss. It capitalizes on the use of procedural memory—the memory system that is less impaired in people with dementia—to help people store important information, such as to eat slowly. Motor learning research, including a 1992 Psychological Science article by Richard A. Schmidt and Robert A. Bjork, indicates that spaced retrieval is more effective than continuous practice methods for learning—and especially maintaining—information.


“The practices are spaced out over progressively longer intervals of time,” Brush explains. “So instead of using continuous practice methods, where you would instruct someone repeatedly over and over again, one trial after another, we space out the practices over gradually longer periods of time. By giving people success and spacing out the intervals, people with memory loss can relearn information they’ve forgotten, or learn new information and retain it for long periods of time.” (“A Look at Spaced Retrieval” below demonstrates how to use the method.)

Brush cautions, however, that not all dementias are the same. “Often health care professionals lump people with dementia into one big group, but the causes of cognitive decline are different,” she says. “Someone with Alzheimer’s may have difficulties eating because of a sensory problem, and someone with vascular dementia might have difficulties because of a motor problem. The more clinicians understand about dementia, the more they can do to improve the outcomes for the person.”

But care goes beyond just the diagnosis, she says. “I really support individualized care and self-directed living, versus the traditional diagnosis-focused treatment,” she says. “So just because someone has an Alzheimer’s dementia, or a vascular dementia, I don’t look at the diagnosis and decide how to treat the person. I really focus on a care plan that’s individualized.”

Changing the environment. Cues—a large card saying “Eat Slowly” at the person’s seat in the dining room, for example—are part of an overall strategy to make the environment as conducive to safe eating as possible. Brush references the dining practice standards developed by the Pioneer Network (http://www.pioneernetwork.net/), an organization that advocates for person-centered care.
for older adults in community-based settings.

The changes to the environment are based on the needs of older adults in general and people with dementia, Brush explains. They need more light, less glare, more contrast in a table setting to differentiate the food from the plate and the plate from the table, lower noise levels, and fewer distractions, for example. All of these modifications (explained more fully in “Small Changes, Big Differences” below) can help increase intake.

Equally important are the person’s preferences, Brush says. “Just because someone has dementia, it doesn’t mean that any of those habits that they’ve had through their whole life at mealtime change,” she says. “So the more that we can know about the person, the more we can support those preferences and habits at mealtimes. These things are not taken into consideration enough, especially in long-term care communities.”

It’s a fallacy that people with dementia can’t communicate their preferences, Brush says. “People with dementia make choices about their food every day. When they eat the foods that they enjoy and that they like, they’re making a choice, and when they leave food on their plate that they don’t like, they’re making a choice. Their behaviors communicate the choice to us.”

**Choices.** Reading is a preserved ability in many types of dementia, Brush explains, so you could give a person a choice at mealtimes by having two menu options written in print with a picture of each.

“They might not understand the verbal question—‘Would you like a ham sandwich or a cheese sandwich?’—but they can make a choice based on what they’re shown,” Brush says. “You’re honoring their right to make a decision, but you’re supporting them by giving them a visual cue to help. This simple cue and environmental modification promote their dignity and allow them to be more independent.”

**Breaking the mold**

As much as SLPs in a care community may want to carry out these strategies, they can’t do it alone. “Being able to work effectively as a member of a clinical team is really critical,” Brush says. “People with dementia have complex health needs, and they typically require more than one discipline to address issues regarding their health status. When you work as a team, you’re using the individual and collective skills and experience of all the team members to ultimately improve the quality and the safety of client care.”

SLPs who work in facilities that don’t encourage person-centered, interprofessional care can begin to introduce the approach. “If you start one person at a time being the change that you want to see, really modeling how you want people cared for, you can begin to educate others,” Brush says. “You can pick one project, one small project that you can do at your care community that will make a change. Maybe it’s changing the contrast in the dining room, or maybe it’s reducing noise, or maybe
it’s helping people express their choice at meals. When people see the positive change in the resident, then they’re more likely to kind of jump on the bandwagon and they’re more likely to listen to you and to try something new.”

Brush returns to Mrs. L.’s breakfast as an example. “It’s important to her to have her piece of toast and her tea every morning, and not that bowl of oatmeal or those eggs that she won’t eat. So you start by collaborating with the dietitian and the dining services staff—you say, ‘This is important to this resident; this resident will eat breakfast if we give her this. So I’d like you to honor this person’s choice, and give her a slice of toast and a cup of tea for breakfast. And let’s cut the toast into small pieces.’ Just because some in the nursing home are narrow-minded, doesn’t mean that the SLP has to be.”

The movement to focus care on the person’s specific needs and desires—and not just on the person’s deficits—is gaining momentum nationwide, says Mary Casper of HCR ManorCare. If the person wants to eat tea and toast, and modifications and cues can help that happen, there is no reason not to allow it.

“Figuring out modifications and cues and helping people with dementia to eat and swallow the foods they want to eat requires the skilled expertise of an SLP,” Casper says, and those services are reimbursable by Medicare. She sees patient-centered eating as critical to long-term care communities. Using the approach may lower patient risk and lead to the organization receiving higher ratings on state surveys and on patient satisfaction reports.

But more importantly, she says, “It’s the right thing to do.”

**Small Changes, Big Differences**

A few changes in the cognitive, visual and auditory aspects of a dining environment can help people with memory loss to eat safely and independently. These suggestions are adapted from “Environment and Communication Assessment Toolkit for Dementia Care” by Jennifer Brush, Margaret Calkins, Carrie Bruce and Jon Sanford.

**Visual cues help the person locate his or her place.**

- Add a photo or name label to the table setting.
- Add a fabric to the person’s chair seat or back.
- Allow the person to sit in the same, easy-to-find location.
- Arrange tables and chairs to allow for clear paths.
- Seat the person with others he or she recognizes.
- Seat people together who get along and who use similar eating strategies, such as alternating liquids and solids.
Contrast and lighting help the person see and distinguish among important items.

- Ensure lighting of at least 50 foot-candles at each table.
- Move tables situated directly under lighting that causes glare.
- Use contrasting colors for the tablecloth, placemats, dishes and, whenever possible, the food.

Personalized cue cards or pictures help the person complete appropriate tasks.

- Put cue cards or pictures in easily accessible places.
- Indicate the proper sequence of tasks with appropriate text and graphics.
- Seat struggling eaters away from high-traffic pathways.
- Serve courses one at a time so the person won't be overwhelmed by choices.

Lowered auditory stimuli reduce distractibility.

- Turn off music and television.
- Move ice machines and other noisy equipment away from eating areas.
- Eliminate all overhead paging.
- Limit staff conversations to meaningful exchanges whenever possible.

—Jennifer Brush

‘Eat Slowly’: A Look at Spaced Retrieval

Mr. B., who has Alzheimer’s dementia and lives in an assisted living community, eats much too quickly, putting him at risk for choking. If he is reminded to slow down, he eats safely, but there are not enough staff members for someone to sit with him at every meal and snack to remind him.

The SLP uses spaced retrieval to help Mr. B. remember. She asks him, “What should you do when you eat?” His correct response is “Eat slowly,” and he demonstrates eating slowly after every verbal response.

The SLP scheduled Mr. B.’s treatment sessions for the time that he usually eats an afternoon snack. She screened his reading to determine comprehension and appropriate type size needed, and created a 3-inch-by-5-inch tabletop note card with the words “Eat Slowly” in a 28-point Arial typeface.
As Mr. B. ate, the SLP used spaced retrieval, increasing the time between practices (5, 10, 20, 30, 60 seconds, then 2, 4, 8 and 16 minutes) and providing the visual cue in his line of sight at all times.

After a week of 30- to 45-minute sessions using the continuous visual cue “Eat Slowly” and additional practice during the snack, Mr. B. successfully recalled the information and demonstrated eating slowly at the first practice over three consecutive sessions—and demonstrated the act of eating slowly while eating independently outside of practice sessions.

The SLP updated the care plan to reflect the spaced retrieval goals, met with the care team to explain the change, and provided the continuous visual cue for the Mr. B.’s table in the dining room.

—Jennifer Brush

When Patient and Clinician Disagree
What should a clinician do when someone—or the person’s designated decision-maker—rejects a recommendation to modify diet? Is a diet waiver appropriate?

People who live in care communities and their family members have the right to make an informed choice—including the choice to disregard the SLP’s recommendations for diet modifications. Informed choice is a central tenet of person-centered care and represents a shift from traditional diagnosis-focused treatment.

A diet waiver is a written document, signed by the person or decision-maker, acknowledging the person understands and accepts the risks of not complying with a recommended diet. A signed waiver does not, however, automatically absolve a facility or clinician of liability. The key protection is to document that the clinician has discussed findings, recommendations, risks and potential consequences of refusing restrictions or modifications with the person, caregivers and medical team.

The SLP should collaborate with the person and medical team to help find the safest way for the person to eat (while still documenting any concerns) and provide treatment if the person is a candidate. If no treatment is warranted, the SLP may make recommendations about the safest course, document the risks, and provide training to caregivers and family, if appropriate. The SLP may then decide to discharge the patient, but provide additional consultation or follow-up if the patient’s situation changes.

Read more about culture change in nursing homes (http://on.asha.org/cchangenursingh) and the ethics of swallowing (http://on.asha.org/dysphagia-info).
Stepping Up to the Plate: Is it possible for people with dementia to… who want to avoid recommending the often-rejected modified diet.

—Gennith Johnson, MCD, CCC-SLP, is associate director of ASHA health care services. gjohnson@asha.org (mailto:gjohnson@asha.org)

Carol Polovoy is managing editor of The ASHA Leader. cpolovoy@asha.org (mailto:cpolovoy@asha.org)

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3 Comments

October 7, 2015
Gwen Griffin
Nothing New
There is really nothing new presented here. We all want to keep our patients on the "least restrictive diet". In home care, we have a little more freedom then in an institution. Waivers are against policy in many institutions. Waivers do not always hold up in court.

October 9, 2015
Megan Sutton
Spaced retrieval app
Great article! Spaced retrieval is an excellent way of helping people with memory impairments learn new strategies and information. There’s a very helpful app to help SLPs track the intervals and data. So nice to see examples of how it can be used in dysphagia management too. http://tactustherapy.com/app/srt/

October 9, 2015
Emily Bowman
Spaced retrieval and dysphagia
While the benefit of spaced retrieval for eating does work in the short term, the long term benefit does not. The dementia patient would need ongoing cues for lasting change. With dementia patients permanent change is often nonexistent.

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