

# When dementia becomes too much to handle, this tool offers guidance

A first-of-its-kind website offers caregivers a comprehensive approach to managing combativeness and other neuropsychiatric symptoms of dementia.

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Caring for older adults with dementia is stressful, especially when they become physically or verbally aggressive, engage in other inappropriate or repetitive behaviors, or refuse to let caregivers help them.

Over 95 percent of patients experience these and other neuropsychiatric symptoms of dementia, which tend to fluctuate over time and vary in intensity. They're often the reason people with dementia end up in assisted-living facilities or nursing homes, according to the Alzheimer's Association. At some point, families and friends trying to help at home simply can't manage.

“When people think about dementia, they usually think about forgetfulness and memory impairment,” said Mary Blazek, director of the Geriatric Psychiatry Clinic at the University of Michigan. “But it’s behavioral and psychological disturbances that are most disruptive to patients’ and caregivers’ lives.”

Now, help is available from a first-of-its-kind website created by prominent experts in the field. It offers free training in a comprehensive approach to managing neuropsychiatric symptoms of dementia — a method known as DICE, based on decades of scientific research as well as extensive clinical practice. DICE stands for Describe, Investigate, Create and Evaluate, the four pillars of the approach.

The website’s goal is to “give people tools to better manage often-distressing situations,” said Helen Kales, chair of the Department of Psychiatry and Behavioral Sciences at UC Davis Health in Sacramento and one of DICE’s creators. Users learn that neuropsychiatric symptoms are caused by changes in the brain that increase people’s vulnerability. Nine video modules and two simulations provide comprehensive information and problem-solving techniques. Although DICE training is free, people can pay for a written manual.

### **Moving beyond prescription drugs**

More than 16 million unpaid caregivers — primarily family members and friends — help people with dementia live at home. (An estimated 20 percent of patients live in institutional settings, according to data from the Centers for Disease Control and Prevention.) The most common form of dementia, Alzheimer’s disease, affects nearly 7 million Americans 65 and older.

DICE is also designed to help “avoid the knee-jerk prescribing of psychoactive medications” that have potentially serious side effects, Kales said. Several medical organizations recommend that non-pharmaceutical approaches to troublesome behaviors be tried before drug therapy, but, in practice, this doesn’t routinely happen.

Drugs prescribed for dementia include antipsychotic medications, such as risperidone, that carry black-box warnings noting a higher risk of early death in elderly patients; anticonvulsants, such as gabapentin, whose use has been on the rise despite safety concerns; benzodiazepines, such as Ativan,

which are associated with an increased risk of falls and, thus, fractures; and Celexa and other such antidepressants that have limited data supporting their effectiveness in easing dementia symptoms.

At DICE's core is an assumption that people with dementia engage in disturbing behaviors for often-unrecognized reasons that can be addressed once they are understood.

Take an example on the website featuring Jennifer, a 55-year-old caregiver for her mother, Betty, 85, whom she tries to bathe daily in the late afternoon. When Betty resists getting into the tub, Jennifer insists, "Let's go! I have things to do." Betty responds by smacking her and shouting, "Leave me alone. It hurts."

### **Look for underlying causes**

DICE asks caregivers to step back from the heat of the moment and examine issues from three perspectives: the person with dementia, the caregiver and the environment. All can contribute to distressing situations, and all need to be considered in fashioning a response.

Examining the problem by using a "who, what, when, how, why" prompt can reveal several potential issues:

- **The patient.** Betty has arthritis and may experience pain getting in and out of the tub. She may feel tired and overwhelmed in the late afternoon.
- **The caregiver.** Jennifer may become easily frustrated when she encounters resistance — adopting a scolding and commanding tone rather than breaking down what Betty needs to do in simple steps.
- **The environment.** The bathroom tends to be cold, with overly bright lights, tepid bathwater and no grab bars around the tub.

Some possible solutions discussed on the website: Offer Betty an over-the-counter pain reliever before her bath. Try baths in the morning, not the afternoon. Relax expectations that she'll have a daily bath and offer sponge baths several times a week. Install grab bars around the tub, and make sure the water temperature is comfortable. Use a nicely scented soap and play music to help Betty relax. Speak calmly, making simple statements.

These embody strategies shown to improve neuropsychiatric symptoms associated with dementia: recognizing and addressing underlying medical issues such as pain, infections or delirium; simplifying the tasks a person with dementia is expected to perform; and establishing daily routines that give structure to the day.

### **A new tool for family caregivers**

Other important steps: Engage the person in activities that are meaningful to them, including social interactions. Reduce clutter and the potential for overstimulation in the environment. Make sure the person is using hearing or vision aids, if needed. Get them outside and exposed to light.

If safety, psychosis or major depression are urgent concerns, then consider using psychoactive medications after consulting a physician.

Of course, this isn't a comprehensive list of recommendations. Nor is the method prescriptive. What works for one person with dementia may not work for another.

Using DICE requires creativity and frequent evaluation to assess whether strategies are working, Kales said. If not, it's time to try new interventions. Although the DICE tool kit is new to family caregivers, the program has been available to health-care professionals for a while. Notably, all of Wisconsin's dementia-care specialists have been trained in DICE (every county in that state has a specialist who helps families with dementia).

"It's a really pragmatic approach that's put together in a very thoughtful fashion," said Art Walaszek, a professor of psychiatry and medicine at the University of Wisconsin School of Medicine and Public Health who has been involved in that effort.

Other dementia training programs are available, some of which review behavioral and psychiatric symptoms in less depth, and they, too, are increasingly available online. Another valuable resource, [Best Programs for Caregiving](#), launched in March, lists evidence-based programs across the country and their availability. Enter a Zip code to find information that previously hasn't been assembled in one place. This site, too, is very much worth consulting.

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<https://www.washingtonpost.com/wellness/2024/05/26/dementia-caregivers-aggressive-repetitive-behavior/>