

The New York Times

One Day Your Mind May Fade. At Least You'll Have a Plan.

Paula Span

When Ann Vandervelde visited her primary care doctor in August, he had something new to show her.

Dr. Barak Gaster, an internist at the University of Washington School of Medicine, had spent three years working with specialists in geriatrics, neurology, palliative care and psychiatry to come up with a five-page document that he [calls a dementia-specific advance directive](#).

In simple language, it maps out the effects of mild, moderate and severe dementia, and asks patients to specify which medical interventions they would want — and not want — at each phase of the illness.

“Patients stumble into the advanced stage of dementia before anyone identifies it and talks to them about what’s happening,” Dr. Gaster told me. “At what point, if ever, would they not want medical interventions to keep them alive longer? A lot of people have strong opinions about this, but it’s hard to figure out how to let them express them as the disease progresses.”

One of those with strong opinions, it happens, was Ms. Vandervelde, 71, an abstract painter in Seattle. Her father had died of dementia years before, in a nursing home after her mother could no longer care for him at home. Ms. Vandervelde had also spent time with dementia patients as a hospice volunteer.

Further, caring for her mother in her final year, Ms. Vandervelde had seen how family conflicts could flare over medical decisions. “I was not going to leave that choice to my children if I could spare them that,” she said.

So when Dr. Gaster explained his directive, “it just made so much sense,” Ms. Vandervelde said. “While I could make these decisions, why not make them? I filled it out right there.”

Like a growing number of Americans over age 60, she already [had a standard advance directive](#), designating a decision-maker (her husband) to direct her medical care if she became incapacitated.

Not all experts are convinced another directive is needed. But as Dr. Gaster and his co-authors recently argued in the journal JAMA, the usual forms [don't provide much help with dementia](#).

“The standard advance directives tend to focus on things like a ‘permanent coma’ or a ‘persistent vegetative state,’” Dr. Gaster said. “Most of the time, they apply to a person with less than six months to live.”

Although it’s a terminal disease, dementia often intensifies slowly, over many years. The point at which dementia patients can no longer direct their own care isn’t predictable or obvious.

Moreover, patients’ goals and preferences might well change over time. In the early stage, life may remain enjoyable and rewarding despite memory problems or difficulties with daily tasks.

“They have potentially many years in which they wouldn’t want a directive that says ‘do not resuscitate,’” Dr. Gaster said. But if severe dementia leaves them bedridden, unresponsive and dependent, they might feel differently — yet no longer be able to say so.

Whereas a persistent vegetative state occurs rarely, Dr. Gaster tells his patients, dementia strikes far more commonly.

How commonly? That’s not a simple question to answer.

Researchers often cite the long-term Framingham study, which in 1997 estimated the lifetime risk at age 65 as [10.9 percent for men and 12 percent for women](#).

But the participants in that study were overwhelmingly white. Among the populations facing higher dementia rates are African-Americans, Dr. Murali Doraiswamy, a neuroscientist at Duke University, pointed out.

Last year, the journal *Demography* published a more representative model, estimating that for the cohort born in 1940, the lifetime risk at age 70 [was 30.8 percent for men and 37.4 percent for women](#).

Dr. Gaster tells patients that “somewhere between 20 and 30 percent of us will at some point develop dementia.” Over the past year, as patients turn 65 and qualify for Medicare — which covers a visit to discuss advance care planning — he has offered them his dementia-specific directive, intended to supplement their other directives.

For each stage of dementia, the patient can choose among four options. “Full efforts to prolong my life” and “comfort-oriented care only, focused on relieving suffering” represent two ends of the spectrum.

Patients can also opt for lifesaving treatments — except when their hearts stop or they can’t breathe on their own, precluding resuscitation or ventilators.

Or they can opt to receive care where they live but avoid hospitalization. “For someone who doesn’t understand what’s happening, going to an E.R. or being hospitalized can be really traumatic,” Dr. Gaster said. The experience can lead to delirium and other setbacks.

So far, 50 to 60 patients have filled out the form. A few have declined his offer to discuss dementia; others “nod and thank me and take it home and never mail it back.”

But most appreciate the overture, Dr. Gaster said, especially if family members have experienced dementia. “It’s something they think and worry about, and they welcome the idea because they do have clear wishes.” In that case, he adds the completed form to their medical records.

We could debate whether a separate dementia form, on top of the general advance directive everyone should have, makes sense. Already, nurses and doctors lament that paperwork [often winds up forgotten in a drawer](#), a safe deposit box or a lawyer’s office, unavailable in a crisis.

If patients haven’t updated the directive in years, their designated proxies may have moved or died. Proxies may never have learned their loved ones’ preferences in the first place. Will adding another directive clarify this process?

Other leaders in the campaign to persuade Americans to document their end-of-life wishes had questions, too.

Ellen Goodman, founder of [The Conversation Project](#) (whose dementia-related kit similarly presents choices at different stages), pointed out that the new form represents a patient-doctor agreement.

“We need to have families involved,” she said. “No checklist on earth is going to cover everything you encounter. Most important is the conversation with the decision-maker. That person has to understand what you value and what’s important to you.”

Dr. Rebecca Sudore, a geriatrician and palliative care specialist at the University of California, San Francisco, agreed. Her effort — [Prepare for Your Care](#), an online guide — encourages users to incorporate their reasons for various decisions. “At the bedside, the ‘why’ is very important,” she said.

Both The Conversation Project and Prepare for Your Care provide links to the advance directive/durable power-of-attorney forms legal in each state.

What's not in dispute: It's crucial to talk to family, friends and doctors about the quality of life we find acceptable and unacceptable, which interventions we agree to or don't — and then to document those decisions and circulate the document to designated decision-makers and everyone else who might be involved.

And yes, we should incorporate decisions about dementia into that process, whether in a separate form or not.

When Ann Vandervelde completed her dementia-specific directive, “I felt great relief,” she said. It gave her a sense of control, “and that's really important to me, to be in the driver's seat all the way to the end.”

Follow @NYTHealth on Twitter. | Sign up for the Science Times newsletter.

A version of this article appears in print on January 23, 2018, on Page D5 of the New York edition with the headline: One Day Your Mind May Fade. But You Can Plan Ahead. Order Reprints