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Our Irrational Fear of Forgetting

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IN our hypercognitive society, fear of forgetfulness has made deep inroads into the psyche. Misplacing car keys, once considered mere absent-mindedness, is now a clinical symptom. Technological ineptitude in the prime of adulthood is ascribed to memory failure.

The mere whiff of perceived memory loss can have terrible consequences in an insecure economy in which midlife workers are regularly (and illegally) laid off on account of their age. This epidemic of anxiety around memory loss is so strong that many older adults seek help for the kind of day-to-day forgetfulness that once was considered normal.

Greater public awareness of Alzheimer's, far from reducing the ignorance and stigma around the disease, has increased it. People over 55 dread getting Alzheimer's more than any other disease, according to a 2010 survey by the MetLife Foundation. The fact that only 1 in 8 Americans older than 65 has Alzheimer's fails to register.

Is the prospect of the disease so horrifying that it should prompt someone to consider suicide? A writer I know whose mother had Alzheimer's told me she is stockpiling pills. An academic told me he has found someone who will help him die "before I lose my mind."

Advocacy groups, manufacturers of so-called anti-aging products and the news media have, for varying reasons, tended to inflate the number of sufferers and the horrors of the condition. Doctors, too, have been complicit: some use "cognitive impairment" as an argument for ending dialysis or other life-sustaining treatments.

And some voices in our culture amplify these alarming sentiments. Tony Kushner links Alzheimer's to suicide in his new Off Broadway play, "The Intelligent Homosexual's Guide to Capitalism and Socialism With a Key to the Scriptures."

His 72-year-old hero, Gus Marcantonio, a retired union organizer, tells his assembled family that he has guessed he has Alzheimer's, and wants to sell the family house and kill himself over the weekend. Gus has no symptoms that the audience can see except once losing his place in a voluble, earnest and moving speech.

In the Korean director Lee Chang-dong's film "Poetry," which won the award for best screenplay at Cannes last year, the graceful and empathetic heroine, who is 66, is given a

diagnosis of Alzheimer's. She too has no symptoms other than once forgetting the word for "bus station." Yet in the film she jumps off a bridge.

The characters have other motives besides fear to end their lives — guilt, mainly. So why is Alzheimer's brought into these plots so conspicuously? Perhaps because no other motivation seems as plausible to an audience as a reason to kill oneself.

Despite the prevalence of Alzheimer's in our national conversation, diagnosing the disease is actually difficult. There is no test that can predict whether forgetting names or words like "bus station" is an indicator of the onset of a degenerative disease. Many older people lose the ability to remember proper nouns but then never progress to losing any other part of speech.

Most forgetfulness is not Alzheimer's, or dementia, or even necessarily a sign of cognitive impairment. And yet any prophecy about impaired cognition — whether it is fulfilled or not — harms people's sense of self. They begin to be treated like children, patronized with baby talk or avoided. At the assisted living facility where my mother lived until she died last year at age 96, the nursing director told me that some people think Alzheimer's is contagious. Victims of misdiagnosis — or, just as devastating, self-diagnosis — dread being shunned, rejected by their offspring, going into

debt, becoming a “burden,” losing selfhood.

It needn't be this way. People with cognitive impairments can live happily with their families for a long time. My mother was troubled by her loss of memories, but she discovered an upside to forgetting. She had forgotten old rancors as well as President George W. Bush's name. We sang together. She recited her favorite poems and surprised me with new material. We had rich and loving times. Suicide didn't cross her mind.

The mind is capacious. Much mental and emotional ability can survive mere memory loss, as do other qualities that make us human.

In fact, a revolution in care-giving might be slowly taking root, at least among those aware of alternative narratives of memory loss.

Thomas Kitwood, a British psychologist who was a pioneer in the field of dementia care, died in 1998, but his books, which emphasize personhood instead of debilitation, remain influential. “Making an Exit,” a memoir by Elinor Fuchs, a drama professor at Yale, explored the conversational patterns of her mother when she was in an advanced stage of Alzheimer's. Anne Basting, director of the Center on Age and Community at the University of Wisconsin, Milwaukee, who wrote a play from poems created by people with Alzheimer's,

has a slogan: “Forget Memory. Try Imagination.”

What a difference it would make if everyone began to share these attitudes. We could make cognition-related fear-mongering shameful and rare, make debates about end-of-life care less searing, improve treatment protocols, reaffirm our collective compact with older people, ease our relationships with people of any age who are cognitively impaired, and enable adults to look forward to getting older with hope instead of despair.

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