



TRANSCRIPT

Public Policies to Help Us Live Well with Dementia

My colleague, Steven Arnold, talked about how we've made and we will continue to make some path-breaking and even spectacular advances in developing better diagnostics and, especially, better therapeutics. Particularly the therapeutics that target the mechanisms of the diseases. And I can identify the patients who are most likely to respond to those therapeutics.

So, what does that mean? Well, we should expect that Alzheimer's disease is becoming a treatable disease—or, as pharma calls it, a “druggable” disease. But we shouldn't expect that every cause of disabling cognitive impairments will be treatable, certainly not curable. Not everyone is eligible for the drugs that have been developed, and the finding from research over the last 20 or 30 years has been heterogeneity. Namely, that the typical person with Alzheimer's has not just Alzheimer's pathology, but other pathologies.

So there's a real policymaking implication to that, which is that we're going to have to learn how to live with disabling cognitive impairments, or, in a word, how to learn to live with dementia, and disabling cognitive impairments. Treatments may slow, for some patients, the course of their disease—perhaps for some, completely arrest it—but we need to live with the fact that we will have to live with dementia.

So let's talk about that. How can we set up a society in America that allows us to live well with dementia? I think we can break this into two parts. First, how will persons living with dementia and their caregivers carry on with their lives—in particular, with benefits from the kinds of interventions and supports that Felicia Greenfield described?

Second, how will persons living with dementia die of it?

Let's first start with living with the disease. Felicia explained that we have the means to make these diseases livable. For both patients and for caregivers, we have what's known as long-term care services and supports. That's what she described. But those aren't

routinely available. In America, we have a federally funded social insurance program for health care. It's called Medicare.

In the Medicare statute, signed into law in 1965 by President Johnson, there is an explicit list of items of interventions that Medicare does not cover. They include hearing aids, plastic surgery, and “custodial care.” In 1965, that was the term used to describe the care that someone gave to another person who was disabled from an illness. Custodial care. Think about what that word suggests. It's as if the person is a building to be swept and mopped, etc., not a person who needs care. But that was the way we thought about it back then, was custodial care, and the statute explicitly prohibits it. So long-term care services and supports are not supported by Medicare. Medicare supports hospital-delivered services, and outpatient-delivered services. It supports the delivery of *medical* care.

For example, Dr. Arnold talked about some spectacular diagnostics and therapeutics that are coming out. Those may be covered by Medicare. There's been debate about that, but I expect that they will be. However, the kind of services that Felicia Greenfield talked about are *not* routinely provided. Indeed, at Penn Memory Center, access to people like Felicia and her colleagues is available, but it's made possible by a generous gift from a grateful patient's spouse. Without that donation, we couldn't provide the long-term care services and supports that are the standard of care after diagnosis.

Put another way, if we relied on Medicare billing to support our memory center, we would not be able to provide services and supports that are so essential. And again, I'm very encouraged about the prospects of treatments that will slow the progress of the disease, but that will only extend the period of time that people need long-term care services and supports. We're not going to drug our way out of the need to care, so we're going to have to face that as a society. Right now, access to social insurance for long-term care services and supports

is made possible on a state-by-state basis through *Medicaid*. Not Medicare, but *Medicaid*. Medicaid is a means-tested program, though, where you have to qualify for certain poverty thresholds in order to receive the supports. It also varies from state to state how much support is available. And frankly, because of legal matters that are excepted, essentially long-term care services and supports through Medicaid are rationed when the funds run out in a state in any given year.

I think a lot of what we're witnessing in supports for caregiving in America reflects that term that was in that Medicare statute: custodial care. At the same time that America committed to paying for medical care, it was unable to even conceptualize what it means to provide care for someone who is disabled. Indeed, the word "caregiver" wasn't even in use in the English-language lexicon at that time. It was not until the 1980s that we began to use the word "caregiver" to describe that person who essentially supports the mind of another person whose mind is being transformed by a disease.

The concept of caregiving is as old as the Bible and the Book of Ruth. Naomi is cared for by her daughter-in-law Ruth. And yet nowhere in the Book of Ruth does it call Ruth a caregiver. She's just a good daughter-in-law, doing what good daughters-in-law do when their mother-in-law has no one else to care for them.

I thought that the pandemic would make us realize how important humans are to care for other humans, because as we all know, when humans were put into lockdown and taken away from access to visitors in long-term care residential facilities, or visitors in hospitals, that we would realize that not all visitors are visitors. They're essential mind support for a damaged mind. Much like lecanemab is a support for the mind that was damaged by beta-amyloid plaques.

I thought that after the pandemic we would realize that we needed to support America's caregivers. But that hasn't happened. In the language that was drafted after the pandemic, in the Inflation Reduction Act, there was clear support to expand the wages paid to providers of long-term care services and supports. But that was rapidly lined out in the negotiations. It

was never part of the Inflation Reduction Act. And so we never made any progress in expanding long-term care services and supports. And this matters, because the hours spent caregiving are the argument for why this disease is such a problem. The triple-digit, billion-dollar cost of Alzheimer's in America, of dementia, is not the cost of providing medical care, it's taking the hours that a spouse, a daughter, and rarely, a son, spend caring—and putting a wage on it, and calculating wages spent by America's families caring for a disabled family member, disabled from dementia.

These wages are wages that are not available for other things a family needs, like paying for college tuition. These wages cause people to have to be out of the workforce, and therefore not paying into Social Security or advancing their jobs. So America is paying for long-term care services and supports, but it's the American family paying out of their strained pocket that's doing this.

What this will take is amending Medicare to expand its coverage for long-term care services and supports. This isn't a radical idea. In Japan, Germany, the Netherlands, long-term care services and supports are backed up by the government. Germany has had a system in place for over 25 years paid for by a payroll tax. It's solvent and it works. It keeps the German family from the fiscal threat that they would face when a family member is diagnosed with dementia. So we can do this, we just have to muster the political will.

We also have to recognize that for persons living with dementia, the theory of at-home-is-best has to be questioned. Increasingly, over the last decade or so, Medicaid has directed its funds towards what are known as home-based, community-based services and supports in the home. This means that they'll provide support for a family member to give care in the home. But sadly, as we know in this disease, there comes a time when "home" is no longer working. The person being at home is lonely, the person caring for them is overwhelmed, and a residential setting, with experts in how to care for people with damaged minds, is what's needed. But unfortunately, the trend in America is not to provide good-quality residential care. Indeed, the

nursing home has become a dreaded place, and also an industry used by venture capital in order to simply make money. Not to deliver care. So we really need to rethink what it means to have residential long-term care.

Finally, we need to think about in the beginning of the disease, the laws that we've set up to support someone to exercise their autonomy. Right now, you're either competent and capable, or you're not competent and not capable. That's the way that we've all envisioned things. For the vast majority of people living with these diseases, they have marginal capacity. They're able to make decisions, but they need someone else to support them. That's oftentimes the caregiver. But we don't recognize the role of the caregiver in the law to help people make decisions. There's a concept known as supportive decision making, developed in the world of disability rights, that allows an adult to be designated as the supporter for another adult, to help them make decisions. This isn't a guardianship. It doesn't strip the right from that individual, but it recognizes, for financial matters, for medical matters, that this other person should be there and be part of the decision making process. This could go a long way to support the lives of persons with mild cognitive impairment (MCI) or mild-stage dementia.

Finally, I'll close with a somewhat dark topic: It's all very well to know when to *start* the treatments that Dr. Arnold talked about, but when should we stop them? And after we stop those treatments, how should we care for someone? Hospice benefits are limited to people who have six or fewer months of life left to live. Prognostication of dementia is extremely difficult, to know how long someone has to live. Many a time, when I've referred one of my patients to hospice, the family will say to me, "Gosh, I wish we had access to this earlier. Why not?" and I unfortunately have to say to them that they're lucky to have gotten it when they've gotten it, given controversies of access. So we need to rethink what palliative care is for this disease—when the mind oftentimes is more damaged than the body. When palliative care is needed. I thank you for this opportunity to talk about some of the policy initiatives that are needed: expanding access to

long-term care services and supports, recognizing the role of supportive decision making, rethinking and revolutionizing residential long-term care. These are things that we can do. We know how to do them. We just have to muster the political will to do it.

Question: You talk about these very ambitious goals, and one of them is, how do we improve residential care? Where do we begin? How would you go about doing that?

Dr. Karlawish: Number one, we really need to rethink the financing that surrounds nursing homes. There are huge conflicts of interest in nursing home ownership, such that the owners of the nursing home also will own the businesses that supply the nursing home. In a sense, for many corporations, nursing homes have become just simply real estate ventures. That's what they're there for. So we really need to scrutinize the business models that surround nursing homes. More generally, also, the memory care units are often embedded in assisted living facilities. I have no fundamental problem with assisted living, except assisted living sort of operates on a state-by-state, ad hoc basis. There are some really good models out there for developing residential settings for individuals living with dementia. I think the Green House model is a good example of how architecture and staffing can be thoughtfully deployed to create a space that allows an individual's mind to be supported, but this just requires the recognition that the sort of hospital ward design that we have for residential long-term care just simply doesn't serve a mind that needs support. So those are all steps that we can do. Reforming the regulations, the financing structures, and embracing, frankly, the building of facilities that adhere to the kind of principles developed by programs like the Green House program.

Question: I'm not aware that a U.S. payroll tax to pay for LTS has ever been legislatively proposed. Is it realistic that it will be?

Dr. Karlawish: The last effort in the United States to create a system of long-term care services and supports was in the 1980s. The 1988 presidential election. Every single candidate lined up in support

of creating an essentially Medicare-style benefit for long-term care services and supports paid for out of the payroll tax. Because you have to have a tax that essentially covers everyone who is going to tap into a widely spread risk. Hence the payroll tax is a good model. Long-term care '88 never became statute, because there was one candidate who just wouldn't come down in favor of it, and that was George Herbert Walker Bush, who of course would go on to win the election.

Since then, the political climate has been one that has never advanced any significant legislation to address this. The CLASS Act was buried in the Affordable Care Act (Obamacare), when it was widely recognized from the moment it was written that it was actuarially unsound, and essentially died even after passage. So let me give you sort of a bleak statement. One half of the American political system, if you look at it by the parties, has come down plainly saying that raising taxes is anathema to what we're doing. So as long as you have a political party simply saying that any tax increase or attempt to increase revenue is a non-starter, you pretty much have a non-starter for addressing the problem through taxation, which is disappointing.

Jason Karlawish, MD

*Professor of Medicine, Medical Ethics and Health Policy,
and Neurology*

University of Pennsylvania

Penn Memory Center and P3MB, the Penn Program
on Precision Medicine for the Brain

www.jasonkarlawish.com

@jasonkarlawish