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At Risk for Huntington's Disease

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## In this electoral season, let's highlight our natural role as caregivers and support care professionals

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# At Risk for Huntington's Disease

*HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.*

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 GENE VERITAS

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## HD Links

[Huntington's Disease Society of America](#)  
[International Huntington Association](#)  
[Huntington's Disease Drug Works](#)

MONDAY, AUGUST 31, 2020

## In this electoral season, let's highlight our natural role as caregivers and support care professionals

In the Huntington's disease community and many others facing debilitating diseases, caregiving is essential.

The COVID-19 pandemic has made the need for volunteer caregiving perhaps more apparent than at any time in recent memory. In addition, [examples of "heroes"](#) have emerged among care workers such as healthcare professionals, first responders, and other occupations.

In this electoral season, no matter what your political persuasion, let's *highlight* people's natural role as caregivers and support the care specialists, many of whom work for very low pay.

### The bedrock

Caring for others forms the bedrock of human relationships. This frequently extends to assisting individuals with health challenges.

We come into the world cared for by parents and other adults. Teachers care for us and become key role models as we progress through the school system. If we attend college, professors, peers, counselors, and others provide comprehensive support.

Spouses and partners care for and support each other, and if one falls seriously ill, the other helps. The same often happens with siblings.

Just as our parents raised us, so do we often look after them in their old age. In the U.S., where extended families once took in parents and relatives, caring for the elderly has increasingly become the responsibility of assisted living facilities and nursing homes. Nevertheless, children often bear the responsibility of finding a safe, good-quality place.

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Many developing countries (such as Brazil, the country I study) lack assisted living, putting the responsibility squarely onto families.

However, as discussed below, in the U.S. the demand for caregiving is shifting much of the responsibility back into people's homes.

### **Lessons from the Huntington's community**

As a Huntington's advocate and family member, I have learned many lessons about caregiving and seeking professional assistance.

My "HD warrior" father Paul Serbin cared for my HD-stricken mother Carol throughout most of the 20-year course of the disease ([click here](#) to read more). She also had an in-home care worker assist her with such needs as bathing and styling her hair.

Spending the last months of her life in a nursing home, my mother died in 2006 at age 68.



*Paul Serbin pushing Carol Serbin in wheelchair (photo by Gene Veritas, aka Kenneth P. Serbin)*

And, as an HD gene carrier “ racing against the genetic clock,” I know that the inevitable onset of symptoms could lead me to depend completely on my wife Regina and others for care.

(Two nights ago – perhaps in anticipation of writing this article – I had a nightmare in which a prominent leader of the HD cause told me that I had chorea, the involuntary, dance-like movements typical of the disorder. The symptoms remained throughout the dream.)

I have also witnessed how a mother like Angela Leach tenderly looked after her son Terry, hit with HD in the toddler years. He died at 18.

### **Demand on the rise**

As I noted in a previous article, volunteer caregiving is a “prominent yet often unheralded human practice.”

I've also reported on how some HD-afflicted individuals face subpar institutional care, fueled by ignorance and approaching neglect.

The demand for both volunteer and professional caregiving will continue to increase as humans generally live longer, and as millions develop neurological disorders such as Alzheimer's disease and others.

### **One in five is a caregiver**

In May, the Family Caregiving division of the American Association of Retired People (AARP) and the National Alliance for Caregiving (NAC) issued the extensive report *Caregiving in the U.S. 2020*.

"Today, more than 1 in 5 Americans (21.3 percent) are caregivers, having provided care to an adult or child with special needs at some time in the past 12 months," the report states. "This totals an estimated 53.0 million adults in the United States, up from the estimated 43.5 million caregivers in 2015."

The report asserts that the number of recipients of care living with caregivers continues to rise.

Caregiving is also becoming more complex, because individual care recipients have an increasing number of health conditions, the report states. Caregivers also rely more on household minors for assistance.

According to the report, caregiver self-reported health is also declining, because of the added stresses of caregiving.

The report observes: "Caregivers who cannot care for themselves may become unavailable to care for others; likewise, caregivers have their own financial, health, and wellness needs, which begs the question, 'Who will care for the caregivers?'"

Financial stress is also common: "In fact, caregivers' savings are eroding, with 22 percent who used up personal short-term savings and 12 percent who used up long-term savings (for things like retirement or education)."

Unpaid caregivers serve as a "core piece" of the health and long-term services and supports formal care systems, "as well as the

main source for long-term care for adults living at home and in the community.”

### **Supporting caregiving**

With the AARP-NAC findings, and as we approach the November 3 election for president and other key offices, we once again should pause to reflect on a crucial question:

How can we meet the caregiving challenge – including paying professional caregivers more, providing respite for family members, and improving the regulation and overall quality of facilities?

The AARP-NAC report informs that 68 percent of caregivers surveyed support an income tax credit for caregiving. A similar percentage want back pay for caregivers for some of their hours worked. More than half favor establishing the right to partially paid leaves of absence from work for caregiving.

### **The party platforms**

For the upcoming election, the Republican Party did not develop a new platform, simply readopting the 2016 version. It does not mention “caregiving” or “caregivers.”

The 2020 Democratic Platform proposes Social Security reform to provide benefits to assist those who forego paid work because they are caregivers. The platform further proposes making it easier for unpaid caregivers to save for retirement.

In addition, the Democrats advocate expanding access to home and community-based long-term care services and supports; eliminating waiting lists for home and community-based care; and bolstering Medicaid’s capacity to fund such services. The Democrats support a tax credit for informal and family caregivers and increasing the Child and Dependent Care Tax Credit.

“Democrats will also pursue policies to improve nursing home staffing and quality standards, strengthen accreditation processes, and combat corporate abuses in nursing homes,” the platform states. The party also supports a “roadmap to citizenship” for undocumented caregivers.

### **Building a better society**

The benefits desired by the surveyed caregivers and the Democrats' policy statements bear serious consideration.







In my more than two decades as an HD advocate, I have heard many stories of families whose resources were depleted by caregiving costs, lost work opportunities, and the government requirement that practically all assets be spent before receiving public aid for nursing home care.

I believe that highlighting our common role as caregivers can benefit all of us.

As a nation, we must embrace caregiving and professional care work as a non-partisan issue. Perhaps in some way this could serve as an antidote to the deep political polarization that afflicts us.

At the very least, it can help point us in the direction of building a better society.

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Posted by [Gene Veritas](#) at [11:36 PM](#)      

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