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Jasmin Tahmaseb-McConatha

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Struggling with Caregiving: My days in Solitary Confinement

Caregiving is a modern American tragedy

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I recently went to see the film *Amour*. Director Michael Haneke's 2012 Oscar winning film is primarily a story about [caregiving](#). In the film Georges and Anne, both of whom are in their 80's, are living a cultivated life in Paris. Then Anne suddenly has a stroke, which begins her slow decline and ultimate end. During this decline, George becomes his wife's caregiver. In scene after scene, we are presented with the George and Anne's struggles. There are, as well, occasional moments of sad joy as Anne's good days come to an end. This well-crafted film is moving. It is also a film that depicts the plight of one caregiver whose struggles are similar to those of millions of men and women

from diverse cultures, backgrounds, and levels of [education](#). Indeed, millions of people struggle to help loved ones live out their last days with a degree of comfort and dignity. In the process they often have to sacrifice their own [happiness](#) and well-being. In this way the film also illustrates a rarely mentioned truth: that caregiving exacts a heavy toll on the life of the caregiver. In the case of *Amour* we learn little about Georges. We are not introduced to his passions, details of his past, the nature of his work, or to his own state of health. In following Georges's household routines, though, we see how the demands of caregiving have consumed everything this man was, is, and hopes to be. This story is a modern tragedy.

My mother cared for my father, who had [dementia](#) for last five years of his life. During those trying times, she often neglected her own health and well-being. What's more, she had neither the time nor the energy to engage in her interests and passions. If my mother's case is indicative, most caregivers lead lives of quiet desperation. All too often they are isolated people whose days are filled with concern and worry over the suffering of a loved one. When politicians coldly debate "cuts" to various health support services, such as Medicare and Medicaid, many of them do not realize or care that they are adding to the [stressful](#) burdens of millions of Americans who sacrifice their lives to help a spouse, or parent, or other loved one who needs a helping hand.

Elders in the 21st century are living longer and healthier lives. Most live independent and active lives well into their 80's. Even so, most of us can expect to spend some part of our later years in need of help and support, especially if we develop a [chronic illness](#). Indeed, the increase in life expectancy has resulted in an expanding population of women and men who spend years coping with such chronic health concerns such as heart disease, diabetes, cancer, and various forms of dementia like Alzheimer's disease. It is estimated that approximately one quarter of the U.S. population has at least one chronic condition, which means that in the United States between 30 and 38 million adults provide regular ongoing care for a family member or loved one. Approximately 75% of these caregivers are women, most of them over the age of 65.

The stressors and burdens of caregiving, in turn, have a negative impact on the health and well-being of care providers. When the U.S. Congress approved Medicare in 1965 it guaranteed access to health insurance for Americans with disabilities and those over the age of 65. Even so, the number of elders living below the poverty line in the U.S. is growing. For them

Medicaid is often the only answer. I have seen many older men and especially older women lose their savings, their homes, all in an attempt to live out the last years of their life with a guarantee of health care. The poverty rates in the U.S. are growing, up to 9/5 % for those between 65 and 74. The number is even higher for those over 75 and for minority and immigrant elders.

Indeed, caring for a loved one with a chronic condition all too often leads to poverty in America. Each time one of the millions of caretakers takes a break to listen to the news and hears the on-going debate about cuts to programs like Medicare and Medicaid they feel a little less safe, a little more stressed, a little more isolated. Can we really not care for those who have spent their lives working and caring for others? Are there lessons we can learn from other industrialized countries?

The United States was not the first Western country to introduce benefits for older adults. In fact, most countries in Western Europe provide significantly more comprehensive programs for elders. Germany, for example, has long provided a comprehensive social service program for its senior citizens. Long-term care insurance (Pflegeversicherung), for example, offers coverage for chronic diseases. This coverage includes substantial governmental subsidies for care in a [retirement](#) community or at home. The German system is based on a history of paternalism [dating](#) back to the 1880's. In the late 19th century, Germany was the first country to introduce a system of universal health insurance and old age pensions. While elders in Germany cope with many of the same concerns that elders everywhere cope with, they do not have the added stress of worrying about losing their home because of poor health. Studies have found that when the older adults in the US consider the possible reduction of social security and other benefits, the prospect provokes widespread [fear](#) of "old age".

Most Americans do not wish to leave their elders without resources. Surveys in the United States indicate that only a small percentage of people are in favor of reducing benefits for older men and women. In fact, most people stated that rather than cut services such as Medicaid, they would favor an expansion of benefits for long-term care. For caregivers, whose problems are often ignored, the emotional, physical and financial responsibilities associated with caring for a loved one can be devastating. As witnessed in the film *Amour*, caregiving leads to feelings of helplessness, isolation, [anxiety](#), and [depression](#). In the minority and immigrant population, these feelings are compounded. Like my mother and the dozens of other caretakers from around the world that I have interviewed over the past five years, immigrant and

minority caretakers often face additional stressors that result from [discrimination](#), language inadequacy, and a lack of social and financial resources.

Most of us care for our loved one's willingly. Providing comfort to those in need can be rewarding. But the often-invisible caregiver is still a human being. He or she has a life to live, a family to tend to, passions to develop, interests to follow, and thoughts about the future. Don't we need to advocate for their rights so that they can take advantage of informal and formal supports that will improve their lives. We will all one day have to care for someone we love who is dying and need the help and support of a caregiver?