Long-Term Care Planning: Tina and Ron's Personal Story

Most Americans are not aware of the financial costs of long-term care and do not fully understand the time commitment and emotional cost of being a family caregiver. Yet every day, more than 40 million Americans take care of their loved ones so they can live independently at home. Tina and Ron's story illustrates why discussing and planning for long-term care before a health crisis impacts the family are important for every household.

TINA AND RON

Tina and Ron are both 78 years old and retired. They have a total of $300,000 in retirement savings with no private long-term care insurance. They own their home and do not have a mortgage.

When Tina is diagnosed with dementia, she and Ron start to discuss how they will manage financially when Tina is no longer able to remain at home on her own. Ron would like to take care of her, but he has heart disease and diabetes and will need help. Fortunately, they have a daughter, Anita, who lives 30 minutes away with her husband Jeff. They also have a granddaughter, Leah, who lives 15 minutes away.

Once Tina is unable to perform daily activities such as bathing, dressing, cooking, and getting from her bed to a chair alone, she will need a caregiver. However, Medicare does not cover the cost of a caregiver to help with these non-medical services. She will need to rely on either Ron, her daughter Anita, Anita's husband Jeff, their granddaughter Leah or another caregiver, paid or unpaid, to help her.

Tina may need daily assistance for an extended period. Those who have been diagnosed with Alzheimer's may live up to 20 years with the disease, and the point in which they need assistance varies significantly.

Paid care is costly and can be difficult to find. The cost of care varies depending on the setting and length of time that care is necessary. For those who wish to remain in their own home, paid care can cost more than $45,000 per year. For care in a nursing home, the cost can be more than $85,000 per year.

Without insurance, Tina and Ron will have to use their retirement savings. Once their savings are exhausted, they have options: take out a reverse mortgage on their home to continue to pay for care or spend down their resources to qualify for Medicaid, the safety-net for low-income individuals. Under Medicaid, Tina would be eligible for nursing home care, but there is a two-year wait list for home and community-based services. The family decides to rely largely on care from family members and to take out a reverse mortgage on their home to cover the cost of part-time paid in-home care.

ANITA AND JEFF DAUGHTER AND HUSBAND

Anita is the only child of Tina and Ron. She is 56 years old and her husband Jeff is 54. Anita works in marketing for a large company and Jeff works as a paralegal at a small law firm. Their daughter Leah is 23 years old. Combined, Anita and Ron earned $130,000 annually and have about $450,000 in their retirement accounts and $2,000 in savings. They are helping Leah pay her $40,000 school loan payments until she finds a full-time job in her field. They own their own home and are working to pay off the mortgage.

As an only child, Anita realizes that the primary responsibility for caring for Tina will fall on her since her father is unable to provide full-time care for her mother and sometimes needs help himself. After a family conversation about long-term care, they decide that Anita will come in the mornings and evenings to help her parents, and a part-time caregiver will be hired during the day.

Jeff and their daughter agree to assist as needed. Once Anita's parents' finances are exhausted, she and her husband are prepared to use their own savings to provide care for Anita's parents, but they worry about their own looming retirement needs.

Recommendations from BPC's Report:
A Policy Roadmap for Individuals with Complex Care Needs

BPC's recommendations address the needs of all three generations involved in providing care to Tina, who is eligible for Medicare, but not currently able to receive the type of care she and her family needs.

Recommendation	Description
Changes to Medicare and Medicaid to Support Tina and Ron	
Allow Medicare Advantage (MA) Plans to Target Non-Medicare-Covered Supports and a Respite Benefit to Enrolled Individuals with Complex Care Needs	Current Medicare rules require "uniform benefits" that prohibit targeting of benefits to individuals with complex care needs. Flexibility to account for the unique circumstances of individuals and to target social supports to individuals with complex needs should make benefits more affordable and allow MA plans to offer a respite care benefit for enrolled individuals.
Clarify that Accountable Care Organizations (ACOs) May Provide Non-Medicare-Covered Supports	ACOs may furnish non-Medicare-covered supports, at no cost to the individual. However, Medicare program integrity rules create uncertainty amongst ACO providers as to whether the providers can furnish the supports for free. Clarifying the rules could increase the likelihood that ACOs will provide such social supports.
Use Quality Measurement to Incentivize the Provision of Non-Medicare-Covered Supports	Use the payment incentives linked to quality measures to incentivize MA plans and ACOs to integrate social supports into care models. Provide individuals who have complex care needs with information onorganizations providing the services they seek.
Allow MA Plans and Medigap Plans to Offer a Limited Long-Term Services and Supports (LTSS) Benefit	Allow purchase of a limited LTSS benefit with modest premiums paid by the enrollee, to help cover the costs of some LTSS and social support expenses.
Increase the availability of Medicaid Home and Community Based Services (HCBS)	Streamline and simplify current Medicaid Program to incentivize states to provide more HCBS.
Changes to Long-Term Care Insurance to Assist Anita and Jeff	
Establish lower-cost, limited benefit private long-term care insurance (LTCI) policies called "Retirement LTCI"	"Retirement LTCI" policies would offer three basic plan designs with choice among basic features, such as daily coverage amounts, length of benefit period, and the size of the cash deductible, simplifying decision-making. These plans would be designed to meet the needs of individuals that would need LTSS for two years or less.
Allow working age plan participants, age 45 and older, to use retirement savings to purchase "Retirement LTCI" without withdrawal penalties	Employees aged 45 and older in defined-contribution retirement plans, such as 401(k) and 403(b) plans, and IRA plan holders aged 45 and older, would be allowed to take distributions from the plan solely for the purchase of "Retirement LTCI" for themselves and/or a spouse. Distributions would be subject to income tax but exempt from the 10 percent early withdrawal penalty.
Provide incentives for employers to offer LTCI workplace retirement plans on an op-out basis	Reduce impediments for employers to auto-enroll employees in a LTCI program (with employee opt out).