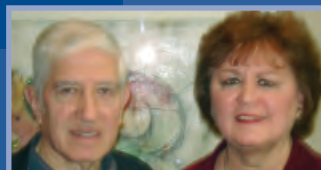
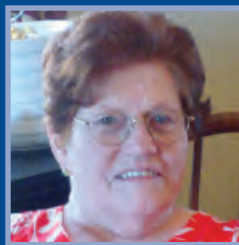


LIVING CLOSE TO THE EDGE

Financial Challenges and Tradeoffs for People on Medicare

JUNE 2011



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We gratefully acknowledge the assistance of Jennifer Huang of the Kaiser Family Foundation in preparing this report.

INTRODUCTION

This report presents profiles of 16 Medicare beneficiaries and the ways they manage their household budgets, often with limited financial resources. The profiles are based on face-to-face interviews conducted with both married couples and single individuals (or in some cases, their caregivers), with varying incomes and financial resources, in three metropolitan areas in early 2011 – Washington, DC; Detroit, Michigan; and Los Angeles, California. The profiles present detailed information on beneficiaries' incomes, retirement savings, and expenses, including their routine costs for health care and insurance premiums, housing, transportation, food, gas, and utilities. The interviews took place primarily in English (one in Spanish) from February to April 2011.

The information in this report is not intended to be representative of the experiences of the entire Medicare beneficiary population, but rather to provide a snapshot of the financial situation of several individuals and to complement other larger-scale, quantitative analyses of household spending among people on Medicare and the financial burden of health care spending.¹

Participants represented a range of incomes, from roughly 100 percent to 600 percent of the federal poverty level (FPL), which corresponds to annual income of \$10,890 to \$65,340 for an individual and \$14,710 to \$88,260 for a couple in 2011. At these income levels, most participants do not qualify for any extra help from the government for their health care costs or other living expenses. These are profiles of people on Medicare who are, in their own words, just getting by, and worried about making ends meet for the remainder of their lives.

SUMMARY OF FINDINGS

These profiles reveal the difficult choices and tradeoffs made by many Medicare beneficiaries in trying to make ends meet – paying for regular monthly expenses as well as for the unexpected – on a fixed income and with modest savings:

- ❖ Half of the individuals and couples profiled in this report have incomes below twice the federal poverty level – under \$22,000 for an individual – the same share as in the total Medicare population. Yet even those with higher incomes often struggle to make ends meet, in some cases depleting their life savings or running up credit card debt to cover unanticipated but major expenses that exceed their monthly budget, such as car or home repairs, funeral expenses, or dental work.

¹ See, for example, Kaiser Family Foundation, “How Much ‘Skin in the Game’ Is Enough? The Financial Burden of Health Spending for People on Medicare,” June 2011, <http://www.kff.org/medicare/upload/8170.pdf>; and “Health Care on a Budget: The Financial Burden of Health Spending by Medicare Households,” June 2011, <http://www.kff.org/medicare/upload/8171.pdf>

- ❖ The loss of employment often represents a major financial shock to retirees, and many participants say they are continuing to work at least part time, or would work if they could find employment, to avoid living so close to the edge.
- ❖ Some have retirement savings, but are dipping into their nest eggs sooner and draining them faster than they had expected in order to cover their expenses.
- ❖ Many report that they have run up credit card debt to pay their bills, including regular monthly expenses and health care costs.
- ❖ Some reluctantly rely on their adult children for financial help, while others tap into their savings or spend the little extra money they have, when they can, to help their children and grandchildren.
- ❖ Participants seem to appreciate their Medicare coverage, but rising premiums for Medicare and supplemental coverage are a concern.
- ❖ Many say they are worried about how they will be able to afford services not covered by Medicare, especially dental care and long-term services and supports.

At a time when policymakers are considering changes to Medicare that would shift costs onto beneficiaries, this report underscores the financial realities that face this population.

Details about the methodology for the study are included in Appendix A. The budget worksheet completed by participants in advance of the interviews is included in Appendix B. Detailed information about Medicare benefits and cost-sharing requirements for 2011 is included in Appendix C.

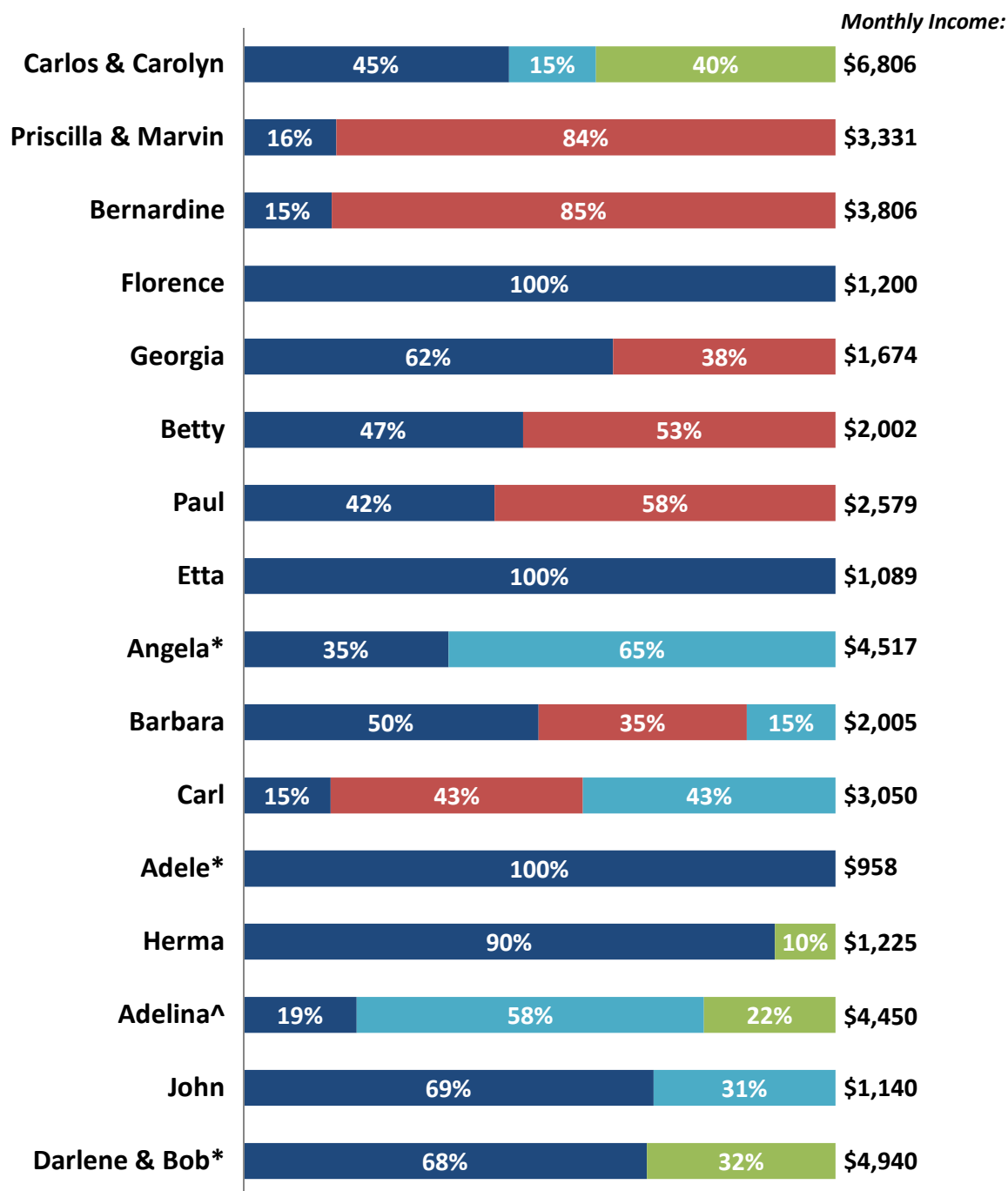
Medicare Beneficiary Family Profiles

Participants (age) - Family type	Estimated Annual Income (Percent of Federal Poverty Level-FPL)*	Amount in Savings/ 401(k)	Location and type of residence	Race/ethnicity	Insurance coverage in addition to Medicare	Work status/history
Carlos & Carolyn (71 and 66) - Married couple	\$81,672 (555% FPL)	\$4,000 in savings	Washington, DC; live in own home	Hispanic	Retiree coverage	Carolyn is retired; Carlos is semi-retired and self-employed
Priscilla & Marvin (66 and 68) - Married couple	\$39,972 (272% FPL)	\$2,500 in savings	Washington, DC; live in own home	Black	Retiree coverage	Both are retired
Bernardine (82); caregiver is her cousin Marshall - Widowed	\$45,667 (419% FPL)	None	Washington, DC; lives in group home	Black	None	Retired
Florence (89); caregiver is her son Joel - Widowed	\$14,400 (132% FPL)	\$30,000 in savings; \$200,000 in investment accounts	Washington, DC; lives in assisted living facility	White	Medigap	Retired
Georgia (80); caregiver is her daughter Rita - Widowed	\$20,088 (184% FPL)	\$2,000 in savings	Detroit, MI; rents in senior apartment facility	Black	Retiree coverage	No formal work history
Betty (78); caregiver is her daughter Marie - Widowed	\$24,024 (221% FPL)	None	Detroit, MI; lives in nursing home	White	Retiree coverage; TRICARE	Retired
Paul (80); caregiver is his daughter Connie - Divorced	\$30,948 (284% FPL)	None	Detroit, MI; lives in nursing home	White	Medicaid; retiree coverage	Retired
Etta (86); caregiver is her son John - Widowed	\$13,068 (120% FPL)	None	Detroit, MI; lives in assisted living facility	White	Medicare Savings Program; Medigap	No formal work history
Angela (42) - Married with 4 children	\$54,203 (181% FPL)	\$8,500 in savings	Detroit, MI; lives in own home	White	None	Stopped working due to disability
Barbara (69) - Single, never married	\$20,460 (188% FPL)	\$1,600 in savings	Los Angeles, CA; rents an apartment	White	Medicare Advantage w/ Part D coverage	Retired; works part-time jobs
Carl (73) - Married	\$36,600 (249% FPL)	None	Los Angeles, CA; lives in own home	White	Retiree coverage	Retired
Adele (88); caregiver is her daughter Barbara - Widowed	\$11,496 (106% FPL)	None	Los Angeles, CA; rents in senior apartment facility	White	Medicare Advantage w/ Part D coverage	Retired
Herma (66) - Divorced	\$13,200 (121% FPL)	\$20,000 in CDs	Los Angeles, CA; rents an apartment	White	Medicare Advantage w/ Part D coverage	Retired
Adelina (85); caregiver is her daughter Wanda - Widowed	\$53,400 (129% FPL)	\$319 in savings; \$58,000 in 401(k)	Los Angeles, CA; lives in daughter's home	Hispanic	Medicaid	No formal work history
John (70) - Single, never married	\$13,680 (126% FPL)	None	Los Angeles, CA; rents an apartment	White	Medicare Advantage w/ Part D coverage	Retired; works part-time jobs
Darlene & Bob (69 and 70) - Married couple	\$59,280 (403% FPL)	\$7,000 in savings; \$30,000 in 401(k)	Los Angeles, CA; live in own home	White	Medigap; stand-alone Part D plan	Darlene stopped working due to disability; Bob lost his job in late 2010

NOTE: *In 2011, the federal poverty level is \$10,890 for an individual and \$14,710 for a married couple. Annual income is estimated from monthly income reported by families.

MEDICARE BENEFICIARY FAMILY SOURCES OF MONTHLY INCOME

■ Social Security* ■ Pension/retirement account ■ Wages ■ Other**



NOTES: In 2011, 100 percent of the federal poverty level corresponds to monthly income of \$907.50 for an individual and \$1,226 for a couple. *Social Security income includes Supplemental Security Income (SSI) and Disability Insurance payments, where applicable. **Other income includes bonuses, child support, unemployment compensation, and gifts. ^Includes total household income from wages, child support payments, and SSI.

MAJOR THEMES

Income and Spending: Making ends meet is often a struggle

Incomes often fail to cover monthly expenses and aren't keeping pace with rising costs

Social Security is the main source of income for the majority of participants, and half live on incomes below 200 percent of poverty. Almost half report that their monthly spending exceeds their monthly income regularly. Others break even and have little or nothing left after paying their monthly bills. Many report that their incomes are not keeping pace with the cost of living and rising health care costs. As a result, many say their retirement years are not shaping up to be what they had envisioned when they were younger.

Everything keeps getting more expensive. We can't do the things we used to do... I used to laugh about senior discounts... Now I'm watching all my change in my change jar. Carl, age 73

Everything is increasing and our income is decreasing. Our income decreased due to the increase in the medical insurance and retired federal employees didn't get a cost of living raise this year and Social Security didn't give us a cost of living increase either... It's just hard to make it.Priscilla, age 66

Money-wise it's not too good, it's not too bad. I'm barely getting by...Barbara, age 69

I remember my father said, 'Honey, when you get older, life's going to be good.' Well, there's a lot of thorns, there's a whole lot of thorns, and I just keep stepping on them. Herma, age 66

Participants use a variety of strategies to manage limited budgets

Some participants pay only portions of their bills because they are unable to pay the total amount due, while others prioritize their bills, paying only those that they feel are the most critical each month. Negotiating payment plans with utility, phone, and credit card companies is another common tactic.

I'll sit down and I'll put all my bills out there...then I'll see how much they come to and then I'll see what's left. And then a lot of months...I don't grocery shop.Priscilla, age 66

Sometimes you pay some things but you don't pay others, you go back and forth. Wanda, caregiver for her mother Adelina, age 85

Once a month I get Social Security; I've got two pensions but they're small...So a lot of this I can't pay when it's due. I have to always make payment arrangements, even for my phone bill.Barbara, age 69

Many are cutting back on basic expenses and eliminating non-essential spending

Many participants report trying to scale back on their food expenses by using up whatever they find in their pantries before restocking, delaying trips to the grocery store, and restricting their purchases or buying less expensive foods. Some drive less and consolidate errands to save on fuel costs, while others put off needed home repairs. Participants also report cutting back on gifts for family, dining out less (if at all), and limiting or eliminating travel.

I eat a lot of TV dinners, and Slim Fast, because that's cheap. Herma, age 66

I don't like feeding [my children] canned stuff as much. They go through broccoli like crazy so...when it went up to \$2 a head or \$2 a pound I was choking. 'Okay, we can't do this right now.'Angela, age 42

The floor came loose and so now that's a major repair that has to be done... It's too much money to fix that. Wanda, caregiver for her mother Adelina, age 85

I don't travel. I used to travel a lot. I certainly don't eat out as much as I used to. Anything that costs money I don't do as much. Don't go to movies as much. That's kind of limiting, but you got to be comfortable living within that..... John, age 70

The support of family members is critical to many participants

Many participants are dependent on one or more of their adult children to manage their financial and health care arrangements, and in some cases, to provide them with financial assistance – ranging from help with groceries to paying for nursing home care or large medical bills. Providing such support is a concern for some of the children, as they divert resources from their own families to help their parents.

If it were only her own resources and...what's left over from my parents' resources, she would be going on Medicaid in a nursing home. Joel, caregiver for his mother Florence, age 89

[Her finances are] pretty stable unless she gets sick. That's when these overwhelming doctor bills come in. Then sometimes there's not enough so we just write a check out of my account. Rita, caregiver for her mother Georgia, age 80

Luckily my siblings [and I]...are able to pool, but it comes to a point where...you want your parents cared for but, my gosh, where do we draw the line here? Connie, caregiver for her father Paul, age 81

Health Care and Insurance: Coverage is essential, but costly

Medicare and Medicaid are critical to financial security

Were it not for Medicare and Medicaid coverage, many participants, especially those with significant health care needs and those needing long-term care, would not have sufficient funds to pay for this care out of their own pockets. Supplemental coverage also plays an important role in reducing costs.

I'm very glad I'm insured and I'm being taken care of. John, age 70

If I get a bill from Medicare and it'll say, 'Medicare will pay this amount; you may be billed \$64', I consider that a pretty good bargain. Marshall, caregiver for his cousin Bernardine, age 82

If I had to take her to the doctor on my own, I couldn't afford that. I just couldn't do it. Wanda, caregiver for her mother Adelina, age 85

Despite having coverage, some are not seeking medical care due to cost concerns

Some participants report that they are delaying or foregoing needed medical care because they can't afford it or worry about the additional expense – in some cases, dental care not covered by insurance; in others, preventive tests, eyeglasses, physical therapy, medical supplies, or brand-name medications.

I deny myself because I just don't have the money... I'll go to therapy and use their heat pads, but after that I've got to get my own. We're looking at a lot of money. Barbara, age 69

I should be having an MRI. I should have had it already six months ago and I've put that off. I don't know how much they cover. Darlene, age 69

Her eyesight [is] the one thing I couldn't do... the dentist, we can't do that either. It makes you feel bad because you wish that you could give her everything. Wanda, caregiver for her mother Adelina, age 85

Many participants struggle with costs for medical and dental services

While most participants don't report major difficulty paying their share of medical expenses, some face high costs associated with supplemental coverage premiums, prescription drugs, or hospitalizations. Several participants report that dental services beyond preventive care are unaffordable.

When you pay \$600 per month for medical insurance and you still pay almost \$4,000 something for medical bills, that upsets me. Priscilla, age 66

There's always all these co-pays. I just don't understand what they think – you know, you have insurance but you still have all these co-pays... Connie, caregiver for her father Paul, age 80

The various kinds of insurance that we're paying are astronomical if you put them all together – medical insurance, long-term care insurance, car insurance, life insurance. Carlos, age 71

Some participants have unpaid medical bills

Some participants have medical debts from hospital stays or expensive procedures. Others have accumulated debt as a result of cost sharing for covered services or paying the full cost of uncovered services and supplies, such as physical therapy, dental and vision care, or over-the-counter medications. A couple of participants report having their unpaid medical bills turned over to collection agencies when they could no longer keep up payments.

The bills just keep racking up... Somebody's in a nursing home, they're juggling to pay for health insurance, we're giving you just about everything he has to pay for the nursing home, but yet he goes into the hospital and now all these bills start coming in. Connie, caregiver for her father Paul, age 80

I keep going further in debt because I can't afford to pay for everything, but when I have the cash I pay cash. Carl, age 73

I paid as much as I could and I finally called them and said, 'I can't do this.' And they said, 'Well, we'll have to throw it in collection,' and I said, "Then throw me in collection. Herma, age 66

Future Outlook: Debt, minimal savings, and worry are the norm

Many participants carry substantial credit card debt

The majority of participants use credit cards on a regular basis, often to pay for basic needs such as food and gas. In most cases, participants are paying only the minimum amount due each month, and are unable to make a significant dent in what they owe.

[I'm] trying to make ends meet... I use the American Express simply because I have to. Priscilla, age 66

I'm worried that if cash flow or income is not high, I won't be able to pay. I'll be paying the minimum and then it takes forever. That bothers me. Carlos, age 71

[We] ended up with a God awful couple hundred dollar bill [from the gas company]... 'We were just getting ready to shut you off.' [We] put it on the credit card to pay it. Angela, age 42

This debt is a cloud over me right now and I feel I'll never get out of it. Barbara, age 69

They tell you that you should pay more than the minimum, but where am I going to get the money? Carl, age 73

Most participants have little or no savings to help cover routine or unexpected costs

Many of those who now have no money in savings or retirement accounts say they already depleted the savings they had accumulated before retiring. Those who have savings say they find themselves dipping in on a regular basis to cover the cost of basic needs and unexpected expenses, and are unsure about how long their savings will last and whether it will be enough to cover their needs in the future.

Every time I seem to get three or four hundred dollars I'm in there taking it out because I need it for something. I can't seem to build it up at all. Priscilla, age 66

We were able to save but that money's almost gone. We had to dip into it for every bill. Carl, age 73

Some months you can put what you want to put in...and other months you're like, well, these unexpected things, groceries, our heating bill... so now we have to put the money towards that instead of putting as much as we wanted to put into a savings account. Angela, age 42

[He] had a nice nest egg, but it quickly just went away. Connie, caregiver for her father Paul, age 80

I don't want to deplete [our savings] because I don't know how bad things will be in the future. Darlene, age 69

Participants do not have the resources to pay for long-term care

Most participants could not afford to pay out of their own pockets for long-term care if they needed it, while those caregivers with loved ones who had long-term care insurance say it ran out quickly. Some participants say that in their experience, higher-quality nursing home care is very expensive. Others say they have no idea what long-term care would cost but perceive that it would be unaffordable. Most participants say they would prefer to remain in their homes, rather than ever move to a nursing home.

The cost of a decent nursing home in my experience is \$6,000 a month. So there's no way I could even consider trying to subsidize [that]. Marshall, caregiver for his cousin Bernardine, age 82

Some of them are very costly, these homes, very costly.... I worry about that. Barbara, age 69

I don't even want to think about it. I want to be independent. I want to be like my mother. She died in bed. Just let me be like Mom, close my eyes and don't wake up. Herma, age 66

To put her in a nursing home that I would really, truly, 100 percent like, I don't think I could afford to do that. It's just not possible. Marie, caregiver for her mother Betty, age 78

Participants, even those receiving financial support, wish for financial independence

Some participants who receive assistance from family members are unhappy about not being able to get by on their own resources. Others who have been managing without help say they never want to be in a position where they need to rely on their children or others for financial support.

[The hardest part is] knowing I can't do it. Being really independent and having to depend on other people, that's the worst. Herma, age 66

[Our kids are] not really capable at this point. They're just starting their careers, their lives, their families, I don't know if I'd even want to try to ask them. Bob, age 70

I like to be independent. I don't want to lean on anyone. Barbara, age 69

Everybody is living tight. My daughter is on Social Security, my son is on Social Security.... I've got to learn to live on what I get. Adele, age 88

Their future financial and health status and the uncertainties associated with aging are of considerable concern to participants

Several participants are upset to find that they (or their loved ones) worked hard all their lives and yet still struggle to pay for health care when they need it most, on top of other basic expenses. Some participants are worried about the cost of medical care that they might need in the future. Many are generally anxious about what the future may bring, hoping just to maintain the status quo.

If I work a little bit it's fine, but if something happened, God forbid, I couldn't work, I couldn't do a management job, or something, what do I do then? John, age 70

I know my children can survive without me, but not [my mother]. I'm really worried about her. I am very afraid. When I start thinking about those things, I just distract myself and try not to dwell on it. Wanda, caregiver for her mother Adelina, age 85

Not having enough money if she should get really sick. And then, putting her away in a nursing home. That frightens her. Rita, caregiver for her mother Georgia, age 80

We don't have any children and I don't have any brothers or sisters.... If something happens, I have Carlos. If Carlos isn't around, I don't know what I would do. Carolyn, age 66

I'm trying to find some kind of place where I can feel good and try to keep that fear of not having money and not being able to take care of ourselves, trying to push that away. Darlene, age 69

Let's say one day I can't walk up the stairs. What's going to happen to me?... Who's going to take care of me?... I want to just try to be healthy. Barbara, age 69

PROFILES

Washington, DC

- Carlos and Carolyn
"The various kinds of insurance that we're paying for are astronomical"
- Priscilla and Marvin
"Trying to cut back, cut back, cut back"
- Bernardine; caregiver is her cousin Marshall
"The biggest challenge has been finding quality help"
- Florence; caregiver is her son Joel
"This is what they had saved for all these years"

Detroit, Michigan

- Georgia; caregiver is her daughter Rita
"It's pretty stable unless she gets sick"
- Betty; caregiver is her daughter Marie
"She's gone through all of her savings"
- Paul; caregiver is his daughter Connie
"He should not have to worry about anything"
- Etta; caregiver is her son John
"It's very tight"
- Angela
"We're praying that we don't have an emergency"

Los Angeles, California

- Barbara
"Debt is a cloud over me right now"
- Carl
"We were able to save but that money's almost gone"
- Adele; caregiver is her daughter-in-law Barbara
"She is surviving"
- Herma
"I'm living very close to the edge and it bothers me"
- Adelina; caregiver is her daughter Wanda
"If I had to take her to the doctor on my own, I wouldn't be able to afford that"
- John
"I'm very glad I'm insured"
- Darlene and Bob
"We just have kind of been scrimping along here"

“The various kinds of Insurance that we’re paying for are astronomical”

Family profile

Carlos and Carolyn, ages 71 and 66; married

Most recent annual income

\$81,672 (555% of the federal poverty level)

Sources of financial support

Social Security, self-employment income and bonuses, savings

Work status/history

Carlos works as a consultant on a contract basis;

Carolyn is retired

Insurance in addition to Medicare

Retiree coverage through Carolyn’s former employer



Typical Monthly Income = \$6,806
Typical Monthly Expenses = \$6,649

■ **Health care & premiums \$1,556 (23%)**

In addition to the monthly Medicare Part B premium, the couple pays a \$700 monthly premium for a supplemental retiree health plan; also pays for a long-term care policy

■ **Food \$470 (7%)**

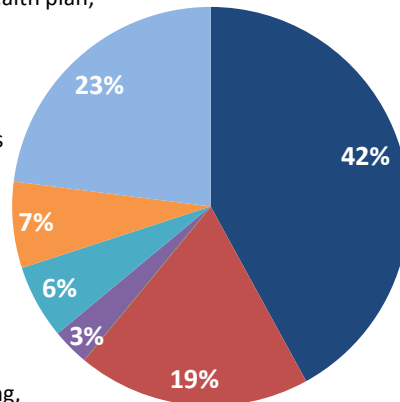
The couple eats out less than they used to but still face costly grocery bills

■ **Transportation \$381 (6%)**

The couple owns two vehicles; spending is for gas, insurance, and maintenance

■ **Other \$173 (3%)**

Other expenses include occasional purchases such as clothing, dry cleaning, going to the movies



■ **Housing & utilities \$2,824 (42%)**

Their monthly mortgage payment of \$2,137 is roughly one-third of their monthly income but will be paid off entirely in three years

■ **Debt/loan payments \$1,245 (19%)**

Monthly payments towards paying off \$20,000 in credit card debit; fluctuates month to month; includes \$200 in interest payments each month

■ **Savings \$0 (0%)**

The couple is unable to save on a regular monthly basis; occasional work bonuses go to paying down debt

Income and Spending Overview

Since retiring from full-time employment at age 65, Carlos has relied on consulting projects to supplement the couple’s monthly Social Security payments: *“We depend on the consulting work that I do and we depend very heavily on the Social Security that we both get.”* However, due to cash flow issues, the company that he is currently doing work for is only able to pay him on a deferred basis. He is currently owed for six months of work, which makes budgeting for monthly expenses challenging for the couple. *“When money starts coming in, they’ll pay for X number of months that they haven’t paid me. That’s a little stressful.”*

The couple’s mortgage, over \$2,100 per month, consumes a significant portion of their monthly income. Their next biggest spending category is for insurance premiums (Medicare Part B, supplemental coverage, long-term care, and life insurance) and health care, expenses which are a significant concern to them: *“There’s some expenses that I believe are affecting us very significantly. That starts with the letter ‘I’ – Insurance.”* In addition to regular spending on necessities, they have had to draw down their savings from \$20,000 to roughly \$5,000 due to some major unexpected expenses last year, including dental work and household repairs. According to Carolyn, *“I*

worry because I know that savings that he was lucky enough to put away when he was making better money for that brief time is dwindling.”

The couple accumulated more than \$45,000 in credit card debt over the course of several years, but they have been able to reduce their outstanding debt to roughly \$20,000 by paying more than the minimum amount due each month. Carlos and Carolyn rely heavily on coupons and search out sale items, opting for less expensive grocery items, dining out at fast food restaurants, if at all, and putting off needed home repairs. According to Carolyn, *“I worry about going to the grocery store. I’ll say, ‘What kind of a check can I write?’ And he’ll say to me, ‘You better not write anything more than fifty, sixty dollars.’”*

Health Care Needs, Spending, and Insurance Coverage

Carolyn has been diagnosed with diabetes, Carlos is a borderline diabetic; they both have high blood pressure and high cholesterol. Carolyn also has neuropathy in one toe as a result of her diabetes, for which she needs to see a podiatrist every three months. They are able to maintain reasonably good health with prescription medications, insulin, yearly blood-work, and semi-regular doctor visits.

When Carolyn turned 65 and became eligible for Medicare, this opened the door to getting care she had been putting off: *“I did get a physical last year because I got Medicare. I hadn’t had one for a year and a half or two years. I just put it off.”* Still, a major concern of the couple is the amount they pay for insurance coverage in addition to Medicare. The couple has a supplemental policy through Carolyn’s former employer, for which they pay the entire annual premium, which amounts to \$700 per month. This year they switched from a more generous plan to a less generous plan in order to avoid a \$240 monthly premium increase: *“We can’t afford another \$240 a month.”* As a result of moving to a less generous plan, they anticipate that their doctor visit co-payments will increase from \$10 to \$15 or \$30 to \$35. The cost of one of Carolyn’s medications increased from \$30 to \$75 for a two-week supply. She also anticipates an increase in the cost of her diabetic supplies: *“We’re going to be hit on the medicine.”*

Another large concern for the couple is the cost of dental care. According to Carlos, *“The worst insurance, in my view, is dental insurance. All of a sudden, a year and a half ago, she broke a tooth. It’s going to cost \$7,000 to fix. And there’s no insurance to cover it, so that’s a big expense.”* They have been paying the dental bill down incrementally at 18 percent interest, sometimes with the help of credit cards, but still owe \$5,000. Yet despite major concerns about the amount they are paying for insurance, their financial situation has not led them to go without medical care they feel they need.

Thoughts about the Future

Carlos and Carolyn are focused on paying down their outstanding credit card debt and their mortgage. However, the uncertain and fluctuating nature of Carlos’s consulting income is cause for concern about their continued ability to pay down the debt: *“I’m worried that if cash flow or income is not high, I won’t be able to pay. I’ll be paying the minimum and then it takes forever. That bothers me.”* says Carlos.

As far as their health care needs are concerned, the couple worries about having to switch doctors in the future because they know of several doctors in their area who no longer accept Medicare. In Carolyn’s view, *“if you’ve been very satisfied with one doctor, such as my case for 20 years, going to another doctor could be something that’s not that helpful.”* The couple purchased a long-term care insurance policy a few years ago, for \$259 per month, an expense that Carolyn justifies: *“We don’t have any children and I don’t have any brothers or sisters....If something happens, I have Carlos. If Carlos isn’t around, I don’t know what I would do.”* They also view their house as a form of insurance against expensive medical or long-term care needs in the future; according to Carlos, *“[In] the worst of the cases...we would sell our house....That’s my backup system.”*

“Trying to cut back, cut back, cut back”

Family profile

Priscilla and Marvin, ages 66 and 68; married

Most recent annual income

\$39,972 (272% of the federal poverty level)

Sources of financial support

Social Security, pension, 401(k), savings

Work status/history

Both are retired

Insurance in addition to Medicare

Retiree coverage through Priscilla’s former employer



Typical Monthly Income = \$3,331
Typical Monthly Expenses = \$4,378

■ Health care & premiums \$1,034 (24%)

In addition to Medicare Part B premiums (\$96 each), the couple pays a \$431 premium for a supplemental retiree health benefits plan each month

■ Food \$506 (12%)

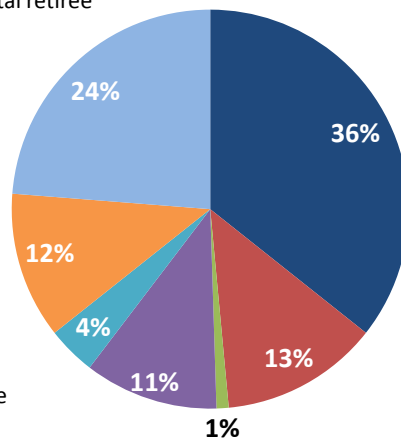
With an adult son living at home, the monthly budget for groceries covers three adults

■ Transportation \$175 (4%)

The couple own their car; spending is for gas, insurance, and maintenance

■ Other \$483 (11%)

In addition to spending on occasional gifts for their grandchildren, the couple tithe \$300 each month to their church



■ Housing & utilities \$1,570 (36%)

Nearly two-thirds (\$915) goes to the monthly mortgage payment; also includes electricity (\$300) and telephone/cable (\$167)

■ Debt/loan payments \$550 (13%)

Monthly payments towards paying off \$2,900 credit card debit

■ Savings \$60 (1%)

They try to add to their savings account each month; currently have about \$2,500 total in savings

Income and Spending Overview

Priscilla and Marvin’s retirement income consists of his pension, their combined Social Security, and a small monthly payment she receives from a 401(k) plan. This income supports the couple along with one of their adult sons, who is currently unemployed and living at home. Priscilla is concerned that *“Everything is increasing and our income is decreasing.”* She notes that Marvin’s monthly pension amount decreased \$71 this past year due to an increase in their health insurance premium, and they received no cost-of-living increase in either the pension or their Social Security payments. Meanwhile, the couple has minimal savings – *“teenie weenie”* in Priscilla’s words – roughly \$2,500, which Priscilla has accumulated gradually in increments of \$60 each month. But Priscilla is concerned that ongoing expenses make it increasingly difficult to put that money aside: *“Every time I seem to get three or four hundred dollars I’m in there taking it out because I need it for something. I can’t seem to build it up at all.”* They also rely on the benevolence of friends to occasionally help them get by, for example: *“My girlfriend got an insurance policy and she just sent me a check out of the clear blue sky, you know – sent me some money....Another friend of mine sold a piece of property and she gave me \$200.”*

“Simply getting by” and *“Just being able to pay the bills that come in”* are their main financial concerns. According to Priscilla, when the bills come in, she lays out each and prioritizes which ones need to be paid that month, and

tries to negotiate or arrange payment plans for the bills that cannot be paid in full. *"You have to cut back on the electric or the telephone or something else like that. It's like I really just shuffle the bills."* She continues, *"Usually I just take what's at the top that's most urgent, and then the rest I call and say, 'Can I pay this later...? Can I send part of this now?' Whatever way I can do it."* The couple currently owes \$1,000 on their utility bills.

Priscilla says that paying for utilities and food are among their biggest challenges: *"Every time you go to the grocery store, everything is more and more and more.... Some months I don't grocery shop,"* a decision she makes after examining the monthly bills. She volunteers at her church's food pantry, where she gets surplus food donations to supplement what she has to purchase. *"We never know what we're going to get... but you know – that helps tremendously and that fills in a lot,"* she says.

Paying down their credit card debt is another challenge. The couple currently owes almost \$3,000 on three credit cards. Priscilla says she often charges gas, food, and other essential items. Although she says, *"I really don't believe in credit cards...I use the American Express simply because I have to.... [I'm] trying to make ends meet."*

Health Care Needs, Spending, and Insurance Coverage

Between them, the couple struggles with a number of serious medical issues. Marvin has suffered four major strokes in the past three years, which has impaired his ability to walk and talk and, as a result, required physical, speech and occupational therapy, in addition to a nursing home stay. In addition, he has been diagnosed with early-stage Alzheimer's, has had a number of hospital stays for uncontrollable vomiting over the past two years, has regular monthly visits with several different specialists for a total of five or six visits each month, and takes nearly 20 prescription medications each day in addition to insulin. The burden of Marvin's caretaking needs while living at home have fallen largely on Priscilla who struggles with her own medical concerns. She is recovering from endometrial cancer, and although she finished a successful round of chemotherapy in the fall 2009, she requires CT scans and blood work every three months. In addition, her gout, diabetes, arthritis, and muscle spasms in her stomach all require regular visits to a variety of doctors.

Relative to the amount they spend on utilities, mortgage, and food, health care costs are less of a financial burden for the couple, but Priscilla attributes this to their generous insurance coverage – both Medicare and retiree health benefits – for which they pay a high monthly premium. As Priscilla explains, *"Insurance picks up the co-payments; that's the blessing of paying the high insurance [premiums]."* Despite the financial protection afforded by her insurance, she is troubled by the premium amount: *"I want to find out a way to get out of that, paying all that money at the top of the month, I hate it; but it covers everything."* She also thinks their premium is unfair because she does not think they should have to pay as much as a family when they are only a couple.

The couple does pay a significant amount out of pocket for their prescription medications – over \$4,500 in 2010 – which troubles Priscilla: *"When you pay \$600/month for medical insurance and you still pay almost \$4,000 something for medical bills. That upsets me. That upsets me."*

Thoughts about the Future

Priscilla enjoys the freedom of being retired, but says that neither she nor her husband anticipated the rising cost of living nor did they focus on putting aside additional money for their older years when they were working, under the assumption that their retirement income would be sufficient. *"I worked 28 hours per week, I didn't work full time, being a mother was most important to me; you didn't zero in that things would continue to grow and be more expensive and living on a fixed income,"* she says. As for the future, Priscilla does not want to spend any time in a nursing home, nor does she know how they would pay for it, short of losing their home, since they can't afford a long-term care insurance policy and have little savings to fall back on. *"I guess the main thing is, hopefully, that we'll be dead before [we] have no more money in the retirement or no more Social Security.... Hopefully that income will always be with us until we depart."*

POSTSCRIPT: *Subsequent to our interview with the couple, Marvin was hospitalized and required emergency surgery to remove his gallbladder. He died soon thereafter.*

“The biggest challenge has been finding quality help”

Family profile

Bernardine, age 82; widowed; caregiver is her cousin Marshall

Most recent annual income

\$45,667 (419% of the federal poverty level)

Sources of financial support

Social Security, pensions

Work status/history

Retired

Insurance in addition to Medicare

None



Typical Monthly Income = \$3,805
Typical Monthly Expenses = \$3,875

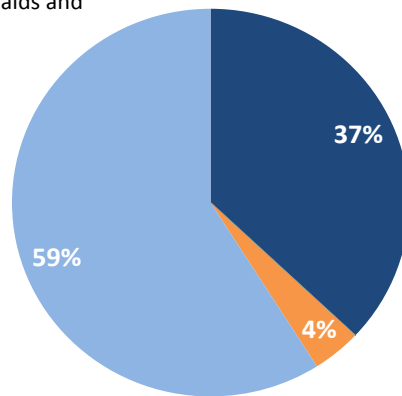
■ **Health care & premiums \$2,275 (59%)**

In addition to the \$96 monthly Medicare Part B premium, roughly \$2,000 is for health aids and personal care assistance

■ **Food \$150 (4%)**

■ **Transportation \$0 (0%)**

■ **Other \$0 (0%)**



■ **Housing & utilities \$1,450 (37%)**

Primarily the monthly rent for the downstairs apartment where she lives; also includes utilities

■ **Debt/loan payments \$0 (0%)**

■ **Savings \$0 (0%)**

Income and Spending Overview

Since 2007, Marshall, age 55 and married, has been taking care of his cousin, Bernardine, age 82, and widowed. She and her mother (Marshall’s aunt) arrived in Washington, DC from New Orleans after surviving Hurricane Katrina. Bernardine’s mother passed away in 2010, and Marshall has continued to care for Bernardine. While the burden of providing and arranging caregiving for his elderly cousin rests largely on Marshall, he does not complain – in fact, he says that having her in his home rather than a nursing home *“has been a really, really good thing.”*

Marshall has power of attorney over Bernardine’s finances. Her income – consisting of Social Security and two pensions (her deceased husband’s Navy pension and her own teacher’s pension) typically covers all of her expenses: rent, utilities, food, Medicare premiums, and medical expenses (primarily home health care). Marshall says that sometimes there is a little money left over, and sometimes, when there are unexpected expenses, such as hospital bills, doctor visits, or extra hours of personal care assistance, Marshall pays out of his own income. Marshall’s wife has a steady job and stable income, but he is a musician with a fluctuating income, which makes picking up these extra costs somewhat difficult for him at times. But Marshall says that Bernardine’s income is usually sufficient to cover her expenses. Besides, he says, *“I’m not in the group of folks who are kind of like wringing their hands all the time.”*

Health Care Needs, Spending, and Insurance Coverage

Bernardine suffers from severe dementia, dehydration, and occasional constipation. She needs considerable help with all of her daily needs, including getting in and out of bed, eating, bathing, and using the bathroom. Marshall has relied on help from home health aides, but recently, he decided to move Bernardine into a group home where her needs could be met on a 24-hour basis and her medical issues could be better addressed. Because the amount of money coming in did not cover the cost of 24-hour help at home, the day-to-day tasks of caregiving were growing more difficult for Marshall to manage: *“Either I’d get her up in the morning or I’d put her to bed or I’d do something in the middle. And I have to work too.... So it became kind of difficult.”* Although a more suitable arrangement for him personally, Marshall worries a great deal about Bernardine’s quality of life in the group home. Although she receives a level of assistance there that he was unable to provide, *“it’s not family.”* But he derives some comfort knowing that she now resides only ten minutes away.

Despite needing assistance with activities of daily living, Marshall reports that Bernardine is otherwise in relatively good health. However, she does need dental and vision services that she has not received: *“She needs glasses, but she can’t take an eye test because she can’t follow the instructions. I have no idea how well she sees.”* In addition, he says, *“She needs a dentist pretty badly”* and she could probably benefit from new dentures, but she doesn’t have dental insurance, so he anticipates the cost of the services she needs would be *“significant.”* Marshall says he is extremely satisfied with Bernardine’s Medicare coverage: *“If I get a bill from Medicare and it’ll say, ‘Medicare will pay this amount; you may be billed \$64’, I consider that a pretty good bargain.”* She has no other source of coverage to supplement Medicare; as Marshall explains it, *“By the time I got hold of her, it was too late to do that.”* He does not perceive her medical expenses to be a burden, neither consuming a great deal more than the income she has coming in nor taking too much out of his own pocket when there are unexpected costs. As Marshall explains, *“She doesn’t take any medication, doesn’t have any chronic problems except for the one that I mentioned. So the idea of paying insurance to plan for the unexpected, I kind of figured I was ahead of the game if I just pay the extra [amounts]....”*

Marshall’s biggest concern related to providing care to his cousin has been finding quality home health care providers: *“I wish there was someone there all the time with her that cared about her like her family would.”* In his experience with home health aides over the past few years, he has found quality care to be more expensive. *“There are people that just care about what they’re doing and these people, they cost more.”* In reflecting on the home health aides he has hired while Bernardine lived with him, *“there have been some that have been wonderful,”* but with others there have been problems with language barriers or *“they’re lazy to the extreme.”* The ideal situation would be *“having someone that will dance with her and talk to her, show her pictures and try to stimulate her, that’s really what I’d want.”*

Thoughts about the Future

In light of the fact that Bernardine doesn’t have coverage to supplement what Medicare pays, Marshall is concerned about her financial situation in the event that her health deteriorates to the point where she needs major medical care or long-term care: *“I know that if there’s a catastrophic problem...If she had to go to the hospital and there was a big problem...I know Medicare is not going to pay enough of it to make it manageable.”* He does not like to think of the scenario where she required more costly long-term care than what she is getting in the group home. Furthermore, he fears that he would have to choose a less-than-adequate nursing home for her as a result of limited funds: *“I don’t want to knock nursing homes, but I haven’t found one that I would want to live in.... The cost of a decent nursing home in my experience is \$6,000 a month. So there’s no way I could even consider trying to subsidize that.”* Ultimately, Marshall says that if he could afford the best possible care, he would choose to move her back into his home rather than living in the group home: *“I’d have her home and on her birthday, I’d have her out in our backyard with a nice cake that my wife made and the neighbors over the fence singing, ‘Happy Birthday.’”*

“This is what they had saved for all these years”

Family profile

Florence, age 89; widowed; caregiver is her son Joel

Most recent annual income

\$14,400 (132% of the federal poverty level)

Sources of financial support

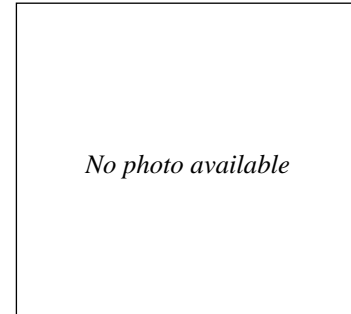
Social Security, savings and investment income, financial support from her children

Work status/history

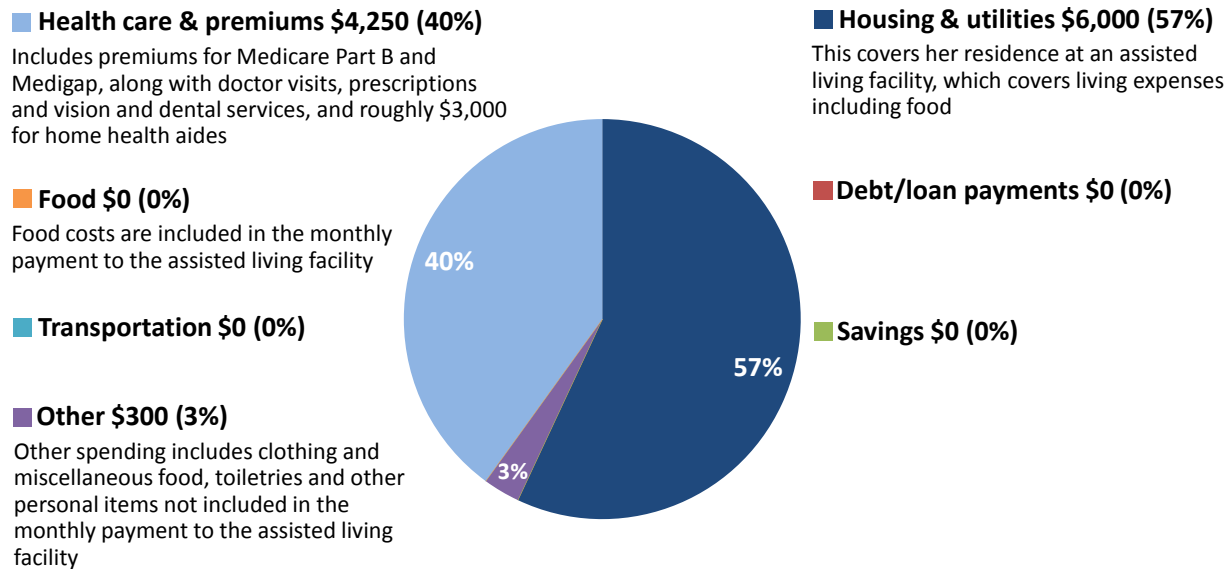
Retired

Insurance in addition to Medicare

Medigap



Typical Monthly Income = \$1,200*
Typical Monthly Expenses = \$10,550



**Excludes savings that are drawn upon each month to pay for monthly expenses; includes Social Security income only.*

Income and Spending Overview

Joel and his brother manage the finances for the care of their mother, Florence, age 89, who is widowed and resides in an assisted living facility in Florida. Florence’s income is composed of a monthly Social Security payment, supplemented by a significant amount of resources in savings and investment accounts. The savings derived primarily from the sale of the apartment where Florence and her husband were living prior to moving into the assisted living facility several years ago, money which was invested and is now being managed on her behalf by her two sons.

The amount in her savings account is being spent at a quick pace in covering the cost to live in the facility, which amounts to \$6,000 each month for rent and meals, plus additional amounts for round-the-clock home health assistance and other medical bills. Florence was diagnosed with a degenerative neurological condition about four years ago, and according to Joel most people with this condition do not survive for more than a few years. “[My parents] had a reasonably sized nest egg, and...had fate been kinder to my mother...expenses would’ve been almost half of what they’ve been for the past three years, and their nest egg wouldn’t be running out now as quickly.” Joel

indicates that the money he and his brother thought would be sufficient to cover their mother's expenses for the remainder of her life might in fact run out before her need for the money is gone: *"Two years ago, when my father died, she was semi-comatose.... Our assumptions were based on a couple more years, and those assumptions are all wrong."* Joel estimates that the remaining amount of savings is sufficient to cover another roughly two years at their current rate of spending. But he adds, *"Not all of it is accessible immediately, so there's some question marks about how things are gonna work out..."*

Joel explains that one major trade-off that has arisen in his mother's situation was her decision to remain at an assisted living facility that was far away from her children when her husband died, rather than relocate to be closer to one of them, because she wanted to remain where she was most comfortable: *"A real important factor for my mother has [always] been her physical surroundings...she likes the aesthetic, she likes the apartment,"* explains Joel. In addition to the difficulty associated with managing her care and finances from several states away, Joel believes that the health care system is not as adequate in Florida as he thinks it is in other states: *"The home health care agencies [in Florida] don't have any physical therapists with experience in [my mother's] condition... The availability of expertise changes from geographic area to geographic area significantly,"* he says.

Health Care Needs, Spending, and Insurance Coverage

Florence has been diagnosed with a Parkinson's-like condition called PSP - progressive supranuclear palsy - which affects her eyesight and her balance and requires 24-hour care, regular doctor visits, and at least five different prescription drugs. The cost of providing Florence with daily home health aides runs about \$3,000 per month.

In addition to Medicare, Florence and her husband signed up for a Medigap policy when they turned 65. There is no other source of supplemental coverage, including no coverage for prescription drugs through Part D. Joel says he investigated his mother's Part D options when the drug plans became available: *"I tried to figure out what made sense, and there's this amalgam of this public - something public and all these private plans... They're all slightly different."* But in the end, he did not enroll her in a Part D plan: *"I just threw my hands in the air, and said, 'I'm going to buy drugs from Canada.'" As a result, Joel and his brother take the time to find which prescriptions they can buy more cheaply in Canada and which ones to buy in the United States. The average monthly cost is about \$300, which they pay out of Florence's resources.*

From Joel's perspective, the most difficult part of managing Florence's finances and her medical care has proved to be overseeing the care she receives from several different doctors and making sure she gets the prescriptions she needs. Joel describes some tension among his siblings about the level of care their mother is receiving: *"[My brother and I] are less inclined not send her to be poked and prodded because the diagnosis...isn't going to change.... [But my sister] has encouraged lots of visits to the specialists, and we've, rather than court conflict, we've agreed."* They have hired a geriatric case manager to assist them, which is an additional expense on top of the cost of the assisted living facility: *"Geriatric care management is not covered by Medicare. So...the family pays out of pocket."*

Thoughts about the Future

Joel does not describe his mother's current financial situation or paying for her medical needs as burdensome for her or for the family, and reports that she has not had to delay or forego any needed medical care because of cost: *"Finances haven't been a barrier."* While he does acknowledge that a great deal of money is being spent on the assisted living facility and the medical care she receives, he states, *"Given the resources involved, the utility of the dollar spent on the doctors is not regretted."* Joel hopes that his mother's medical condition does not deteriorate to the point where she needs to transfer to a nursing home. Yet he also recognizes that his mother may outlive the financial resources that currently provide her with the means to afford the high-cost residential setting and medical care she receives, but says that things will continue on their current course *"until her money's spent down and Medicaid kicks in. And that could still happen, depending on how long she defies the odds."*

“It’s pretty stable unless she gets sick”

Family profile

Georgia, age 80; widowed; caregiver is her daughter Rita

Most recent annual income

\$20,088 (184% of the federal poverty level)

Sources of financial support

Social Security, pension, savings, financial support from her children

Work status/history

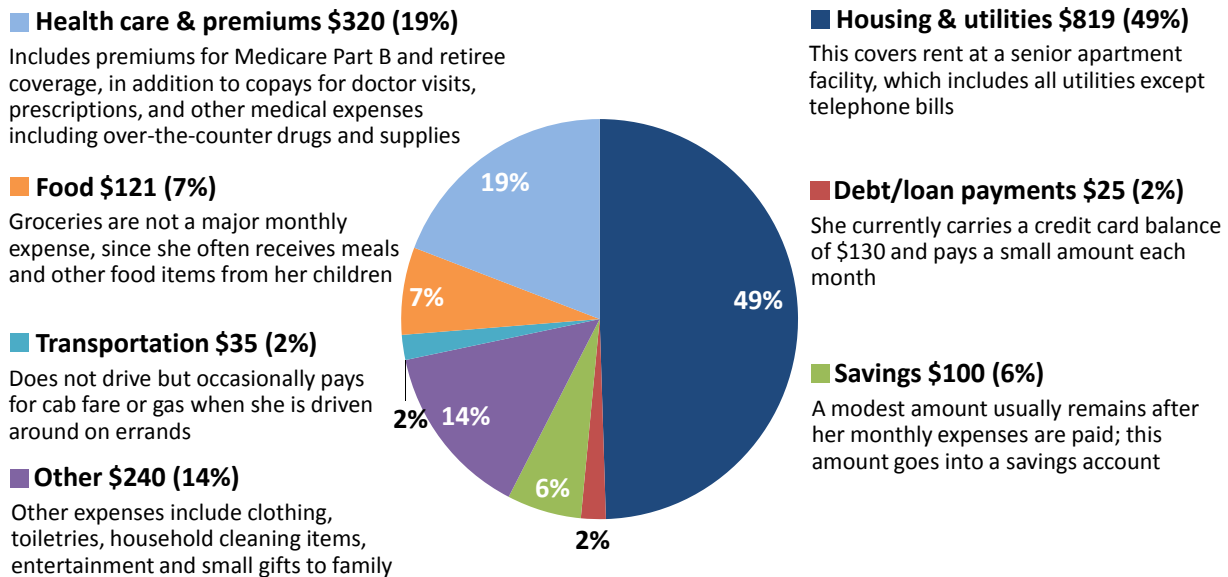
No formal work history

Insurance in addition to Medicare

Retiree coverage through her deceased husband’s former employer, including Part D coverage



Typical Monthly Income = \$1,674
Typical Monthly Expenses = \$1,660



Income and Spending Overview

Rita and her siblings share caregiving responsibility for Georgia, their 80-year-old mother who is widowed and lives in a senior apartment facility. This includes overseeing her finances and health care needs. As Rita explains, “Mom is it; Dad is gone and I want to do whatever—and I did make a promise to my dad that I would take care of my mother if anything happened to him. We all promised that.” Georgia’s income consists of a monthly Social Security payment and a small pension from her deceased husband’s former employer. Typically, her income is roughly equal to her expenses, and any amount remaining at the end of the month goes into a savings account: “She likes to save whenever she can,” says Rita of her mother. Rita and her siblings do the grocery shopping for their mother and regularly add to her food supply with items from their own pantries or cooking they do for her: “One Sunday I took her chicken breast over there.... What else did I take there? Bread, rice, tomato sauce, coffee.” Utilities are included in Georgia’s monthly rent, and she no longer drives so incurs no costs for car payments or insurance. There are times when Rita and her siblings have to dip into their own resources to pay their mother’s medical bills or to treat her to small pleasures. As Rita sums up her mother’s current financial situation, “She’s getting by. She

has enough to meet her daily needs, but like the extra things that she likes, me and my sister and sometimes my brother will go and get her and say, 'Come on, let's go to dinner,' or 'Wouldn't you like to do this?'"

While Rita does not complain about her caregiving responsibilities and says she knows *"it could be a lot worse,"* she also acknowledges that sometimes it requires minor sacrifices and trade-offs on her part. The money that she spends supplementing her mother's income, whether it be by paying for a medical bill when her mother's income is insufficient or groceries on occasion, is money that she can't spend in other ways, which causes her to ponder *"How much I'm able to give without saying okay, you're not going to be able to do this or do that either because I also help with my grandchildren and there are like 20 of them..."* In addition, caregiving has affected her and her husband's long-range plans for their retirement years. They purchased a home in Alabama and intended to move when they both retired, but now that Rita is retired she says she is unwilling to leave her mother, and in fact, *"I'm happy in the fact that I'm able to do more for my mother."* She adds that both she and her husband have their own medical concerns and relationships with doctors in Michigan that neither of them want to disrupt by moving.

Health Care Needs, Spending, and Insurance Coverage

Georgia has dementia, high blood pressure, high cholesterol, chronic obstructive pulmonary disease, asthma, and frequent back pain. She takes about five prescription medications to manage her medical conditions and visits a few different specialists month. In addition to Medicare, Georgia has a retiree policy through her husband's former employer, which includes Part D drug coverage. Rita believes Georgia's Medicare and supplemental coverage is *"reasonable, especially as many times as she goes to the doctor."*

Rita says that Georgia's monthly health expenses are generally payable out of her own resources, except in extraordinary circumstances: *"It's pretty stable unless she gets sick. That's when these overwhelming doctor bills come in. Then sometimes there's not enough so we just write a check out of my account."* One example of this was when Georgia was hospitalized for nine months in 2009, after developing a MRSA staph infection. To avoid placing their mother in a nursing home when she was released from the hospital, Rita and her sister learned how to care for their mother at home, but she still needed physical and occupational therapy. *"The doctor bills [kept] coming...My sister was paying the minimum that she could pay on them but there were a lot of doctor bills."*

Although Georgia's health has stabilized, Rita still has to juggle the bills on occasion: *"Usually what I'll do is I'll pay maybe two or three doctor bills this month and sometimes let it roll over to the following month."* But she doesn't describe this as a major problem: *"Most of her doctors know me personally now and you know, I'm going to pay the bill, it might be a little late, but I'm going to pay the bill."* Rita works hard to stay on top of her mother's health care bills, but notes, *"You finally get rid of one issue and then comes something else."* She also struggles to communicate to her mother the costs associated with her medical care: *"The biggest thing is getting her to understand how much the doctor charges...and that it has to be paid. She thinks they overcharge or 'I shouldn't have to pay for this...'"* Rita notes that Georgia needs new dentures but is reluctant to pay the cost. *"She just said, 'I've got to get me some new teeth. I need some new teeth.' I'm like, 'Okay, Mom,' but then when you call and you get a rough estimate she says, 'Oh no, I'm not going to pay that kind of money for no new teeth.'"* Rita suggests a local dental school where she could try to work out a payment plan on her mother's behalf.

Thoughts about the Future

While Rita and her siblings are doing as much as they can to maintain Georgia's quality of life, they do have concerns for the future; for example, *"Not having enough money if she should get really sick. And then, putting her away in a nursing home. That frightens her,"* says Rita. Rita says they would not put their mother in a nursing home unless she is no longer of sound mind or needs round-the-clock care: *"I wonder if my mother's mind ever gets that bad...what will we do and how will we be able to get through that... I don't think any of us would want to be required to be with her 24/7 because it was difficult enough being with her when she was sick."* Even if Georgia were to move to a nursing home, Rita thinks they would still be supplementing her finances: *"There would be no extras unless we contributed."* Rita also worries about the possibility of future cuts to Medicare: *"It might mean that some of the services that she gets may not be there, or some of the doctors she sees she might not be able to see,"* she says.

"She's gone through all of her savings"

Family profile

Betty, age 78; widowed; caregiver is her daughter Marie

Most recent annual income

\$24,024 (221% of the federal poverty level)

Sources of financial support

Social Security, pension, financial support from her daughter

Work status/history

Retired

Insurance in addition to Medicare

Retiree coverage through her deceased husband's former employer; TRICARE for drug coverage; will soon qualify for Medicaid



Typical Monthly Income = \$2,002
Typical Monthly Expenses = \$2,812

■ Health care & premiums \$826 (29%)

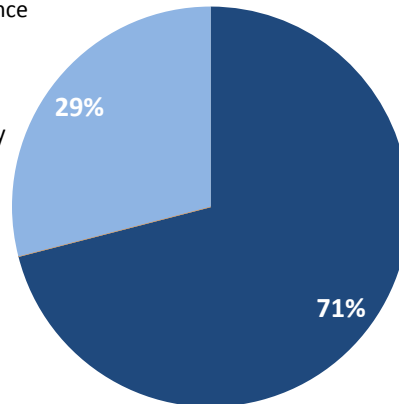
Includes premiums for Medicare Part B and a retiree insurance policy, in addition to prescription drug copays and personal care assistance

■ Food \$0 (0%)

Food costs are included in the monthly payment to the assisted living facility

■ Transportation \$0 (0%)

■ Other \$0 (0%)



■ Housing & utilities \$1,986 (71%)

This covers her residence at an assisted living facility, which includes all expenses including food

■ Debt/loan payments \$0 (0%)

■ Savings \$0 (0%)

Income and Spending Overview

Marie is the caregiver of her mother, Betty, age 78, who was diagnosed with Alzheimer's disease in 2005 while living in Utah. Marie placed her in a nursing home there, but after a year, Marie says, "I knew she wasn't really ready to stay in a nursing home at that time. She was just mostly confused..." After that, Marie brought her mother back to Michigan: "There was quite an argument between the whole family and I about where she would go.... I said, 'Nobody's here that's going to take care of her, and check on her, and make sure that things are going well.'" Marie placed her mother in an assisted living facility nearby, where she could visit her regularly and better oversee her care.

Betty's income consists of Social Security and a pension, all of which is spent on her living expenses and medical costs. Marie says that her mother had money in savings and investment accounts when she lived in Utah, but these funds were quickly depleted during the year she lived in the nursing home. According to Marie, "She did have a long-term care insurance policy, which lasted for a year, so that helped a lot with the finances."

As Marie's disease has progressed, she has required an increasing level of medical care and personal care assistance, the cost of which has exceeded her income for nearly two years. As a result, Marie has dipped into her

own retirement savings to make up the difference of around \$1,000 each month – nearly \$20,000 in total: *“It was coming out of my retirement, but what can you do?... I don’t like doing it, but I will do it because it’s my mother.”*

Health Care Needs, Spending, and Insurance Coverage

Recently Betty’s disease has begun to advance quite rapidly, and after a series of falls, a hospitalization, and several days in a rehabilitation facility late last year, Betty was moved into a skilled nursing facility in early 2011. Soon she will transition to a nursing home, where Marie expects that she will remain because she can no longer function independently: *“She can’t walk, and she has no bathroom habits anymore. She can’t dress herself and she can’t bathe herself. She basically needs help with everything.”* Although Marie knows this is where Betty’s personal care needs can best be addressed, she still feels guilty that she can’t do more for her mother: *“I’m not qualified to take care of her.... I want to be there for my mother, but I don’t want to be tied down 24 hours a day... At times I have these guilty feelings about it and it makes me want to cry....”*

In addition to Alzheimer’s, Betty suffers from high blood pressure, renal insufficiency, and heart problems, for which she takes several medications. Betty has drug coverage through TRICARE (from her deceased husband) and a retiree policy that supplements Medicare. Betty also receives a dental cleaning every three months but lacks dental insurance, so these expenses come out of her own pocket. Marie says that her mother has not gone without care she needed because of cost: *“I wouldn’t allow that. I would make sure it was taken care of... I have to. It’s my mother.”* Yet she is troubled by the fact that she has had to pay out of her own pocket for personal assistance her mother needed in the assisted living facility: *“The only thing that [Medicare] could help us with was a little bit of physical therapy, they couldn’t help with someone coming in, and sitting with [her], and helping her with getting dressed, or anything.”* This troubles Marie, because she thinks that if Medicare covered this type of assistance, her mother could remain at the assisted living facility and would not need to go to a nursing home: *“I think [Medicare] should cover more to help [people with] Alzheimer’s.... It would cost them so much less than being in a hospital or a nursing home. I don’t get it.”*

With limited financial resources at Betty’s disposal, Marie reports that her mother will soon be eligible for Medicaid coverage, which will take most of her income but will cover the cost of her nursing home care. Marie says that Medicaid will provide much-needed assistance: *“She certainly can’t afford to go to pay for a nursing home. She’s gone through all of her savings.”* Knowing that Betty will qualify for Medicaid, Marie needed to find a nursing home that she thought was acceptable and one that would accept her mother once Medicaid starts paying the bill: *“I did look at a lot of places. It is really a challenge to get a place for a loved one that you feel is decent. They might be decent, but they won’t accept you...because they will only accept so many Medicaid people.”* While Marie knows that her mother is in good hands where she is – *“She’s comfortable there. She’s certainly not going without anything”* – she also wishes the atmosphere in the home *“was a little bit more cheery.”* But she has no illusions about her or her mother’s financial situation: *“To put her in a nursing home that I would really, truly, 100% like, I don’t think I could afford to do that. It’s just not possible.”*

Thoughts about the Future

Marie has several concerns about her mother’s future. On the one hand, she worries about Betty’s failing health and what the future holds for her: *“From what the doctors are telling me...they think [the Alzheimer’s disease is] going to progress pretty fast now.... She’s already starting to just sit there and not do anything.”* She is also uncertain of what exactly Medicaid will cover. For example, Marie reports that Betty is likely to need a new wheelchair and the potential cost is a source of concern: *“I suppose if the doctor wrote for it, it would be covered. I don’t know for sure.”* She is also concerned about the possibility of cuts or changes to Medicare and Medicaid: *“What if the government changes what they cover?... Am I going to have to bring my mother home and care for her? I’m not going to be able to care for her right...I can’t imagine taking care of my mother’s personal needs. I just can’t imagine that.”* Finally, there is the issue of Marie’s own financial security when she retires, having depleted roughly \$20,000 of her own savings to take care of her mother’s needs, which she fears *“will probably end up being a hardship on me.”*

“He should not have to worry about anything”

Family profile

Paul, age 80; divorced; caregiver is his daughter Connie

Most recent annual income

\$30,948 (284% of the federal poverty level)

Sources of financial support

Social Security, pension, financial support from his children

Work status/history

Retired

Insurance in addition to Medicare

Medicaid and retiree coverage



Typical Monthly Income = \$2,579
Typical Monthly Expenses = \$2,775

Health care & premiums \$200 (7%)

Medicare premiums are covered by Medicaid, but he incurs some modest expenses for health care and dental services

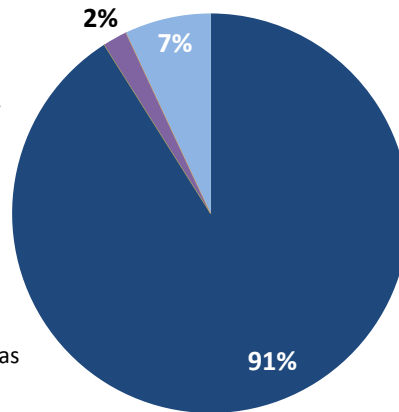
Food \$0 (0%)

Food costs are included in the monthly payment to the nursing home

Transportation \$0 (0%)

Other \$56 (2%)

This amount includes incidentals such as haircuts and other personal items



Housing & utilities \$2,519 (91%)

This covers his residence at a nursing home, which includes all expenses including food

Debt/loan payments \$0 (0%)

Savings \$0 (0%)

Income and Spending Overview

Connie has power of attorney and is the primary caregiver among the five siblings in her family for her father Paul, who is age 80 and has lived in a nursing home since 2003. Paul's monthly income from a pension and Social Security is just over \$2,500, but Medicaid claims all but a small personal allowance to cover the cost of the nursing home, which exceeds \$4,500 per month. Connie explains that the \$2,000 difference is subsidized directly by the state of Michigan. The cost of the nursing home is Paul's largest expense and was initially paid for by a long-term care policy that covered \$70,000, or approximately one year in the nursing home. After that, the cost was paid for out of Paul's savings and retirement accounts for a few years. Connie says her father "had a nice nest egg, but it quickly just went away." Paul qualified for Medicaid after his savings ran out and all his assets were spent down – Connie says this happened four years ago. According to Connie, the long-term care policy "helped out, but really it just prolonged things.... Even if he didn't have it, his money would have been gone."

With Paul's nursing home expenses consuming the majority of his income, Connie and her siblings provide financial support to cover their father's other expenses, including some medical and dental bills and miscellaneous items such as haircuts, clothing, and other personal needs. While Connie says they all work full time, they also have families of their own to support and none are well-positioned to bear the financial burden on their own – yet "we all put our money together and we pay." Connie notes regretfully that the family has stopped taking Paul out of

the nursing home on occasion to restaurants (*"Food was my dad's passion,"* she says), due to the high cost of transporting him in his wheelchair: *"I do wish we could get him out more, but the transportation is expensive and we can't do it."* But she says that all of the siblings who live within driving distance of the nursing home make regular visits to see their father; for some this amounts to a two-hour drive, but Connie says *"We don't complain and we just do what we have to do."* But she does seem troubled that she and her siblings have to contribute financially to ensure their father has the things he needs, and that his resources alone were not sufficient: *"It's kind of crazy because if you work all your life and you have this great income – well, we say great, but you have an income at least – a pension and Social Security – but it's never enough to pay for a place to be cared for."*

Health Care Needs, Spending, and Insurance Coverage

In addition to Alzheimer's disease, Paul has diabetes, obesity, and high blood pressure. He has been confined to a wheelchair since undergoing knee replacement surgery many years ago and having his kneecaps removed last year due to infection. According to Connie, Paul's doctor said, *"He hasn't walked in two years, let's take them out."*

Although Paul has Medicare, Medicaid, and a retiree supplemental policy, yet Connie is troubled by the number of medical bills he receives: *"He should not have to worry about anything. He should not see these bills. If you have insurance it should take care of it. He worked all his life and he's still having to pay."* Connie is especially confused about the bills her father has been receiving since he qualified for Medicaid: *"It's just about the last couple years that all of a sudden I've been getting all these bills that I just don't know why. All of a sudden now things aren't being covered that were before."* Although she and her siblings have tried to stay on top of the bills – *"We have juggled and paid"* – they are reaching the point where they aren't sure whether they should continue to pay them, *"not because my siblings can't afford it, it's because you have to put your foot down."* She says that most of the bills are *"small, but they add up"* and estimates his current medical debt to be roughly \$2,000, which includes \$700 for new dentures: *"There's always all these co-pays. I just don't understand what they think – you know, you have insurance but you still have all these co-pays..."* She goes on to speculate, *"...that's why people aren't going to the doctors.... Even if they have insurance, they can't afford the co-pays."* Still, Connie notes that her father has not gone without care he has needed due to concerns about or lack of money, and if money became an issue, *"we would get second jobs, we would do whatever."*

Connie says that another area of concern for her father is finding providers that will visit patients in a nursing home: *"No dentists want to come to the nursing home, and it's not covered under Medicare... He has to be transported and it's costly,"* she says. This became an issue recently when Paul's dentures were lost somewhere in between the nursing home and a hospital, and the family struggled to find a provider who would come in to fit a new pair for their father.

Thoughts about the Future

Connie worries that if their current pattern of spending on their father's medical bills continues into the future, her siblings might become reluctant to keep paying the bills: *"It comes to a point where, you know, you want your parents cared for but my gosh, where do we draw the line here?"* She knows she could not handle these extra costs on her own, which is a concern because she does not foresee her father's circumstances changing anytime soon: *"I can see my dad still in the nursing home in another ten years..."* She is also concerned that if they don't pay the bills, Paul's medical providers are *"going to not want to treat him or take him."* She knows she could not provide her father with the care he needs if he was not able to stay in the nursing home: *"If I could have my father in my home and take care of him I would.... He needs skilled care that...we cannot provide.... We could never take him home."*

Connie's hope for her father is that *"So long as he has his pension and his Social Security, hopefully he can be cared for somehow in the place that he's at and he'll never have to leave..."* She wishes that Congress would *"find a solution"* to care for the elderly, one that places less of a burden on families themselves: *"You don't want to think that when you get older that your kids are going to have to make sacrifices to take care of you. You don't want that burden.... Family shouldn't have to worry about the elderly."*

"It's very tight"

Family profile

Etta, age 86; widowed; caregiver is her son John

Most recent annual income

\$13,068 (120% of the federal poverty level)

Sources of financial support

Social Security, financial support from her son

Work status/history

No formal work history

Insurance in addition to Medicare

Medicare Savings Program; Medigap



Typical Monthly Income = \$1,089
Typical Monthly Expenses = \$1,090

■ Health care & premiums \$150 (14%)

Medicare Part B and Part D premiums are covered by the Medicare Savings Program; she incurs modest expenses for doctor visits and drug copays; also pays \$52/month for a Medigap policy

■ Food \$150 (14%)

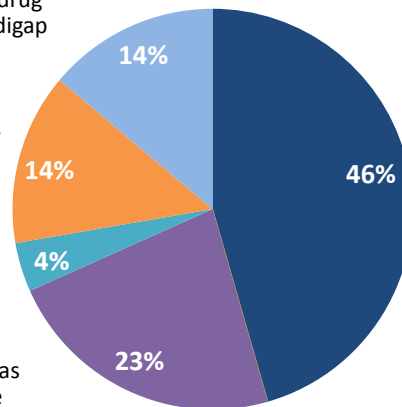
Food costs are included in the monthly payment to the assisted living facility

■ Transportation \$40 (4%)

She occasionally travels by cab to and from the facility

■ Other \$250 (23%)

This amount includes incidentals such as snacks, toiletries, and expenses for the care of her cat



■ Housing & utilities \$500 (46%)

Receives a housing subsidy from HUD; pays \$385 in rent for assisted living facility (includes meals), plus utilities and renters insurance

■ Debt/loan payments \$0 (0%)

■ Savings \$0 (0%)

Income and Spending Overview

John provides modest financial assistance to his mother, Etta, who is age 86, widowed, and living in an assisted-living apartment facility. Her only source of income is a monthly Social Security payment of \$1,089, which puts her at 120 percent of the federal poverty level. According to John, Etta previously had "savings to draw from" in the form of a trust left by her deceased husband, "but she pretty much went through it." John describes her current financial situation as "very tight. It's tough...Just not having any retirement income other than Social Security." She receives a housing subsidy for her monthly rent, without which John says, "She wouldn't be able to make it" on her own. Since Etta's monthly expenses typically exceed her monthly income, if only by a small amount, John says, "I help her every month" – assistance which he says can range anywhere from \$80 to \$125 each month. He is an accountant working on contract and teaching on the side, which means his own income is relatively "unstable."

Etta pays \$385 every month to the assisted living complex, which includes a meal plan. Without the housing subsidy, John says she would be paying considerably more to live there: "They told her that the market value of [her] apartment and the meal plan if it was not subsidized is eleven hundred dollars." Her meal plan only covers five meals a week, so she incurs additional expenses for food and other personal care items. John says that his mother had been spending money regularly for gas and car maintenance up until last year, but she recently got into a car accident in which she was not harmed but her car was damaged beyond repair. According to John, his

mother *“just decided that she needed the insurance money to live on and she didn’t really want to spend it on a replacement car.”* But without her own car, she is more reliant on other people or public transportation to get around. *“The car is an obvious [trade-off] where she would like to not have to rely on others,”* John says.

John reports that Etta’s financial situation has been relatively stable recently. But he also notes that *“She carries some credit card balances that concerns her.... Probably around a couple grand.”* He says she uses the credit card mainly for *“what’s unexpected”*, including more than \$1,000 in veterinarian bills last year for her cat: *“She spends more on her cat than she does on her health care out of pocket.”* He notes that while his mother wasn’t directly affected by the recession, she was affected *“indirectly, because it affected...what I was able to give her every month.”* John also reports that Etta limits her miscellaneous purchases because her budget is so tight: *“I gave her extra money to go out and buy a coat, probably like fifty, sixty dollars,”* he says.

Health Care Needs, Spending, and Insurance Coverage

John reports that Etta’s two major health concerns are heart disease and rheumatoid arthritis, which result in about three doctor visits each month. Her medical expenses are relatively low; her prescription and over-the-counter medications and the occasional doctor visit add up to roughly \$100 each month. She had heart valve replacement surgery a few years ago, and needed physical therapy afterward to restore her fine motor skills, which he says are *“still...not very good.”*

Because of her low income, Etta qualifies for the Medicare Savings Programs, which pays the premium for Etta’s Medicare Part B and Part D drug coverage. Out of her own pocket, she pays \$52 a month for a Medigap supplemental plan, which she has had for several years: *“She knew it was something she needed.”* Overall, John has a positive opinion of his mother’s medical coverage: *“I think it’s working well because...she has months where she might have two, three, four, doctor visits, so you think about the Medicare co-pays and if she didn’t have the Medigap insurance, between the ophthalmologist, rheumatologist, the cardiologist,...the co-pays would be quite high.”*

John describes his mother’s medical needs as not very significant, and her financial situation is not so dire that she has had to deny herself any needed health care, with one exception: *“I think she had to cut back on physical therapy...because of the money, but also it was partly because she didn’t feel it as doing that much good and she always complained about it...just the inconvenience of having to go.”*

Thoughts about the Future

John is concerned that his mother will need dental care in the near future, which would be an expense that would likely have to go on a credit card: *“She doesn’t have dental insurance, so there is a possibility that she could have some dental expenses...[It worries me] a little bit. It’s a big expense.”* Furthermore, John is somewhat concerned about future changes to Medicare that would affect his mother’s out-of-pocket costs. But given that his mother is in relatively good health, with no acute problems – *“She’s on the ball”* – John has not given much thought to his mother’s future situation or the possibility that someday she might need more costly nursing home care: *“I’m not really a worry type of person. If I was, maybe I would think, ‘Oh, geez.’”*

“We’re praying that we don’t have an emergency”

Family profile

Angela, age 42; married with four children

Most recent annual income

\$54,203 (181% of the federal poverty level)

Sources of financial support

Social Security disability insurance, wages from husband’s job

Work status/history

No longer able to work due to disability

Insurance in addition to Medicare

None



Typical Monthly Income = \$4,516
Typical Monthly Expenses = \$3,620

■ Health care & premiums \$400 (11%)

Includes her Medicare Part B premium, and monthly premiums for her husband’s major medical policy and her children’s health coverage, plus

■ Food \$445 (12%)

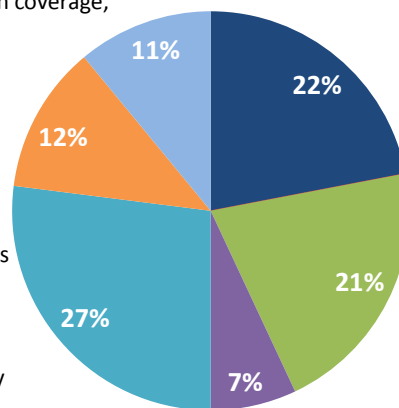
With only occasional nights of dining out, groceries are the major food expense for the family of six

■ Transportation \$975 (27%)

The family has three car payments, plus gasoline, insurance, and maintenance

■ Other \$250 (7%)

Life insurance is \$200; the family rarely buys new clothes but does need new shoes for the children regularly



■ Housing & utilities \$800 (22%)

Having paid off their mortgage, this covers utility bills and home repair and maintenance

■ Debt/loan payments \$0 (0%)

■ Savings \$750 (21%)

Now that they no longer have a mortgage payment, they can put this money aside in savings

Income and Spending Overview

Angela is 42 years old and married. Together with her husband, Paul, the couple is raising four young children. Even though she has not yet reached age 65, Angela is covered by Medicare because she incurred a work-related injury several years ago that has prevented her from returning to work. She received worker’s compensation for a while, then qualified for disability payments, and after a two-year waiting period, qualified for Medicare coverage in 2004. The family lives on income from Paul’s employment as an auto mechanic and her monthly disability payment. According to Angela, the money “coming in is steady. It’s pretty much the same every month. Going out varies...” While she describes their budget as “stretching some months more than others,” she also notes that “we keep an upbeat attitude... we are blessed for what we have and the ability to be together as a family.”

Major household expenses include utilities and transportation. “Winter is really hard because of our heating bills... this house is not well insulated,” Angela says. They pay nearly \$1,000 for auto expenses, including gas, insurance, and repairs. One bright spot financially is that the couple owns their home outright, having recently paid off their mortgage after 17 years, which allows them to put some money into savings accounts each month: “Some months you can put what you want to put in.... other months we have to put the money towards...these unexpected

things.” They are saving in order to purchase a larger home in a nicer neighborhood. With regard to other debts, Angela says, *“We use credit cards a lot but we try to pay them off every month.... We do not hold debt.”*

Even without the mortgage payment, they live frugally: *“We have limited ourselves. We don’t go for new and exciting things. We’re pretty basic.”* They buy used or heavily-discounted clothing for themselves and the children, and don’t buy as much fresh fruit or vegetables or seafood as they would like: *“The blueberries in the summer, we’ll go through four or five pints after lunch or after dinner and...I’m going ching-ching-ching-ching in my head, but you’ve got to eat.”* And there are some large purchases that they are putting off, such as a new stove: *“It just is starting to fall apart...it doesn’t heat right [but] I’m like, it still works.”* Saving for a new home is their overriding goal, and Angela says she is *“praying that we don’t have an emergency that has to take that [savings] away.”*

Health Care Needs, Spending, and Insurance Coverage

Angela’s disability is related to a knee injury she sustained on the job in the late 1990s. As Angela describes her present medical condition, *“Everything’s off. I can’t even put my leg straight down so my hips are all off...so it’s a constant battle between which one’s hurting more on which day.”* She has seen several doctors and had two surgeries to fix her knee, but continues to suffer from chronic leg and hip pain and fatigue, as well as back pain that has been aggravated by this situation. She cannot walk without a cane.

Up until late last year, she was covered by an employer-sponsored insurance policy that supplemented her Medicare coverage, the cost of which was paid in full by her former employer. That policy was terminated, which also affected her family’s insurance since they were all covered under that plan. Between the months of December and February of this year, as Angela searched for replacement coverage, Angela and Paul decided not to seek medical care, even when they thought it was needed. Although Angela filled enough of her own pain medications before her private insurance was cut off, she and her husband have both put off seeing the dentist, and she went without her regular chiropractor appointments. She also reports that three of her children developed ear infections over the winter and it appears that two may have suffered hearing loss as a result of not being treated in a timely manner: *“Yeah, we held off. That probably wasn’t the best mom thing to do...”*

Early this year, Angela obtained coverage for her children through a state health insurance program for uninsured children in working families: *“That’s a huge relief knowing that they can at least be seen and taken care of,”* she says. For her husband Paul, they purchased only major medical coverage: *“My husband’s employer – their coverage is astronomical and he’s pretty healthy overall.”* This has added a total of \$220 in premiums to their expenses each month - \$200 for Paul, \$20 for the children. But Angela says she has been unable to find an affordable supplemental plan for herself, which she says is *“stressful and challenging”* since without supplemental coverage she is unsure of what coverage she has and exactly how much of her medical bills Medicare will cover. She says she lacks prescription coverage right now and needs to look into getting a Part D plan so that she can continue filling her prescriptions – otherwise she will be *“checking into the stores to see what the generic versions”* cost and cutting back on the number of days she takes her pain medications: *“I hope I have a higher tolerance for pain.”*

Thoughts about the Future

Angela says one of her major financial challenges is *“wanting to move to a bigger house and trying to figure out how we can afford it when we look at what our bills are now.”* But she reminds herself of her husband’s positive attitude: *“Things will eventually work out and get paid for.”* She also lives in constant fear that her husband will get seriously ill or hurt at his job: *“If my husband gets anything wrong with him, we’re just in more disaster mode because he’s the breadwinner. He only has major medical insurance, so for him to go to the doctor’s it’s going to be out-of-pocket for everything.”* She also worries about what will happen as they age, especially about how her knee and back problems will affect her in the future. Right now, she says, *“I push myself to try to stay active for the kids.”* Her overriding health goal is to *“maintain the status quo. That’s my hope. My dream is to find somebody that’s willing to find out what is really going on and fix the knee...”* Angela would like to be healthy enough to return to work someday, but she worries that she will not be able to find supplemental insurance beyond her Medicare coverage that will allow her the freedom to see the doctors she needs in order to get a proper diagnosis and treatment: *“I’m not sure now that I don’t have a secondary [policy] how much they actually cover.... I don’t know what my co-pays [will be] and what Medicare is going to cover.”*

“Debt is a cloud over me right now”

Family profile

Barbara, age 69; single, never married

Most recent annual income

\$24,060 (221% of the federal poverty level)

Sources of financial support

Social Security, pensions, wages from part-time jobs

Work status/history

Retired, but works temporary part-time jobs

Insurance in addition to Medicare

Medicare Advantage



Typical Monthly Income = \$2,005
Typical Monthly Expenses = \$2,143

Health care & premiums \$258 (12%)

Includes her Medicare Part B premium, and out-of-pocket costs for prescriptions, over-the-counter medications, and vitamins

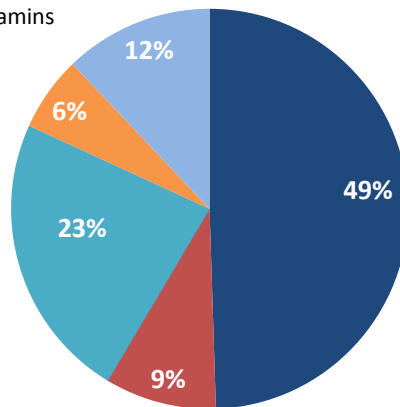
Food \$125 (6%)

Mainly spending on groceries and occasionally eating out

Transportation \$500 (23%)

Her monthly car payment is \$300; also includes gas and insurance

Other \$0 (0%)



Housing & utilities \$1,060 (49%)

Her monthly rent is \$900; she also pays additional modest amounts for utilities

Debt/loan payments \$200 (9%)

She is paying down \$10,000 in credit card debt with minimum payments each month

Savings \$0 (0%)

Income and Spending Overview

Barbara is 69 years of age, has never married, and lives in an apartment on her own. She is financially self-sufficient, with no family or friends to rely on. Barbara describes her current financial situation as “not too good but not too bad.” Her income is derived from monthly Social Security payments, two small pensions, and occasional part-time and temporary jobs. Barbara describes these “little piddly jobs” as the “supplemental income” she needs to help make ends meet, since her Social Security and pension income don’t fully cover her monthly expenses: “It’s iffish but I’m making it. I have to make it. I do whatever I can.” She officially retired at age 62, but was not ready to stop working entirely, and says she enjoys the part-time work: “I like to work as much as I can, ‘til I’m 90 if I can.... I have to work. That’s me.... I need to feel like I have to go somewhere and make some money.” She has a small amount of savings, which was left to her by her brother when he passed away last year. She intended to use this money as “emergency funds” but she says she has had “no choice” but to take some money out of this account recently to pay some expenses: “I feel guilty now. I’m starting to pull from that money. I don’t want to.... I have to repay it...”

Barbara’s biggest expenses are for rent and her monthly car payment and other transportation costs. She says she can rarely pay her bills at once or on time, but has made payment arrangements for a few of her monthly bills, including for electricity and telephone. She tries to be frugal when grocery shopping, buying only what she needs

and watching her spending: *"I buy an avocado once a week; they're \$1.50 right now.... Sometimes I deny myself an avocado. I love avocados."* She rarely goes out to eat, and only out to the movies when she can get free passes.

Barbara's major financial challenge is her struggle to pay off roughly \$10,000 in credit card debt that she accumulated over the years, mainly from charges to department stores while she was working. The burden of debt weighs heavily on her: *"Don't ever get yourself in this debt...because [it] is a cloud over me right now and I feel I'll never get out of it."* She has considered declaring bankruptcy, but doesn't think she can afford a lawyer to handle the process and also worries what it would do to her credit in case she needed to borrow money for a new car. Barbara says she is dealing with *"four different collection agencies...calling me right and left,"* and she says she pays what little she can each month: *"I'm making slowly very little progress but I'm paying the small bills first and then we work on the big bills."* She tries to maintain a positive can-do attitude: *"There's only one way to go – forward – because if you go backwards, you end in depression and everything goes bad. So you have to think positive, which I'm trying to do."* Barbara is looking forward to later this year when she will have paid off her car loan and can apply that money to paying down her credit card debt.

Health Care Needs, Spending, and Insurance Coverage

Barbara says she is in relatively good health: *"I'm in semi-good health compared to some people my age. Some people can't even walk."* She has high blood pressure, osteoporosis, an eye pressure problem, and high cholesterol, but these conditions all seem to be under control with the help of prescription medications for which she pays modest amounts. To save money, Barbara says she uses generics rather than brand-name drugs when possible, and asks for free samples from her doctors. In addition, she recently sustained a hairline fracture in her elbow from a fall, and is receiving physical therapy to regain the range of motion in her arm.

Barbara is enrolled in a Medicare Advantage plan, which also covers prescription drugs. She pays no monthly premium for this plan on top of the Medicare Part B premium. She says she is satisfied with her coverage and does not hesitate to seek medical care when she needs it: *"If I'm sick, I want to go [to the doctor] and get it over with."* Barbara's satisfaction relates to the fact that she pays nothing when she goes to the doctor; compared to the coverage she had when she was working full-time, she says, *"This is better because it's zero co-pay.... You walk in, zero for your office visits, zero for your private doctor, zero, zero, zero."*

Being enrolled in a managed care plan, however, has meant that Barbara has had to change some of her doctors in order to see doctors who take her plan. She also has a few unpaid medical bills from recent services that were not covered, including a preventive shingles shot and dental services. As with her other bills, Barbara tries to arrange payment plans when she owes medical bills. She does report occasionally holds off on purchasing medical supplies that are not covered by her Medicare Advantage plan: *"I deny myself because I just don't have the money...Right now I might need a knee wrap, supplies...I'll go to therapy and use their heat pads, but after that I've got to get my own. We're looking at a lot of money."*

Thoughts about the Future

Barbara expresses some major worries about uncertainties in the future. Although she says, *"I like to be independent. I don't want to lean on anyone"* her reality is that she does not have anyone else to depend on: *"I have to do things on my own."* Her financial situation is a constant source of worry: *"I'm trying to take each day as it comes, but yes, there could be unexpected things again. I don't know, but I can't pay for it. I just have to make payment arrangements like I've been doing with these big creditors that call me every day."* She is afraid of losing both her financial independence and her ability to live on her own and take care of her own needs: *"Let's say they said the pension isn't going to be coming through anymore.... I'd be lost. I'd be in the street. I can't live without this money coming in..."* About her health, she says, *"Let's say one day I can't walk up the stairs. What's going to happen to me?... Who's going to take care of me?... I want to just try to be healthy."* She does not know what her prospects would be if she needed long-term care in a nursing home: *"Some of them are very costly these homes, very costly. I don't know how they work that. I worry about that."*

“We were able to save but that money’s almost gone”

Family profile

Carl, age 73; married

Most recent annual income

\$36,600 (249% of the federal poverty level)

Sources of financial support

Social Security, pension, wages from wife’s employment

Work status/history

Carl is retired; his wife is working full-time

Insurance in addition to Medicare

Retiree coverage through Carl’s former employer



Typical Monthly Income = \$3,059
Typical Monthly Expenses = \$2,905

Health care & premiums \$500 (17%)

Includes his Medicare Part B and supplemental insurance premiums (medical, dental, vision), and out-of-pocket costs for doctor visits, prescriptions and over-the-counter medications, and medical supplies

Food \$230 (9%)

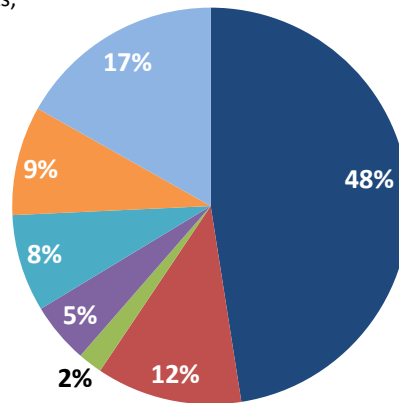
Covers mainly groceries but also eating out once or twice a month

Transportation \$200 (8%)

The car is fully paid off; monthly costs are for gas and insurance

Other \$150 (5%)

Other expenses include life insurance premiums and weekly lottery tickets



Housing & utilities \$1,400 (48%)

The mortgage is \$910; also includes monthly utilities and cable

Debt/loan payments \$350 (12%)

The couple has \$20,000 in credit card debt and pay as much as they can each month

Savings \$75 (2%)

The couple makes an effort to put some money aside each month in savings

Income and Spending Overview

Carl is 73 years old and his wife Paula is 65. They have two grown children. Carl retired in 2000 but his wife continues to work full-time. Their income comes from his Social Security payments and pension, along with her salary. Carl describes their current financial situation as “generally okay”, but then remarks, “It’s been going really, really downhill.” While their combined income typically covers their basic needs each month, Carl says, “Sometimes at night I lay there in bed and I think to myself, how did we make it through that month?” According to Carl, their “savings is very low now”, and he has spent all the money that he had accumulated in his retirement account: “We were able to save money, but the money is almost gone now.” Occasionally their spending exceeds their income, and when this happens, they “go further in debt on credit cards.” Currently, their credit card debt is around \$20,000: “They tell you that you should pay more than the minimum, but where am I going to get the money?” he wonders. A frequent lottery player, Carl says, “I want to win the big one to pay it off. I hate owing money to anybody.” The couple recently received a \$1,000 bill for homeowners insurance; had it not been for Carl’s \$1,400 in lottery winnings that same week, the expense would have been charged to a credit card.

Housing and utilities are the couple’s biggest monthly expense, consuming nearly half of their income. For a brief period of time, Carl and his wife were also supporting his daughter and grandson when they needed a place to live: “For a while I was paying all her expenses, too. Then, boy I tell you, the money really goes.” Carl is concerned about

the steadily increasing cost of living and how living on a smaller income has affected them: *“Everything keeps getting more expensive. We can’t do the things we used to do when I was working.... Now I’m watching all the change in my change jar.”* Carl has asked about discounts for utility customers with low incomes, but he was told his income was just above the limit to qualify. The couple tries to keep transportation costs down by driving only one car. He also consolidates his errands so that he can drive less often and use less gas, and offered to drive his wife to work. And they have cut back on many of the extras they used to enjoy – they go out to dinner and the movies far less often and rarely travel.

Although Carl says they are not spending as much as they used to when he was working, he still feels burdened by their current spending level: *“It seems like all the mail I get now are just bills.”* Retirement has not been as comfortable as Carl expected it to be: *“My expectations were to have enough money to do what I wanted to do. I’m not talking about extravagant things. I’m just talking, if I wanted to go to a movie, I can. Now I buy discount tickets.... When you don’t have any income for a while, boy it goes fast. It’s ridiculous how fast money goes.”*

Health Care Needs, Spending, and Insurance Coverage

Carl has had diabetes for over twenty years; in addition, he has high blood pressure and psoriasis, recently underwent cataract surgery, and was diagnosed with early-stage Parkinson’s disease last year. His out-of-pocket medical costs for prescriptions and doctor visits are around \$100 each month. Carl says, *“I keep going further in debt because I can’t afford to pay for everything...but when I have the cash I pay cash.”* The most recent significant medical expense that Carl can recall is a \$500 copayment for a three-day hospital stay last year, when doctors suspected he might have a brain tumor; as it turns out, he did not, and was released. The expense was paid by credit card.

Although Carl does not describe his out-of-pocket medical expenses as a burden, nor does he report going without care he needed because of cost, Carl does complain about the cost of insurance premiums for supplemental coverage through his union. In addition to the Medicare Part B premium, Carl pays premiums for medical and dental insurance, which are deducted from his pension check each month, and he says that his union *“keep[s] taking all my money away from me for more medical and dental.”*

Despite his concerns about the cost of insurance, Carl is quite content with his supplemental insurance plan, a large staff-model HMO: *“Everything is covered.”* According to Carl, *“I’ve never had a problem so I can’t really criticize them, because nothing major has ever happened that makes me upset that I can think of.”*

Thoughts about the Future

As Carl looks ahead into the future, one of his major concerns is going further into debt to keep pace with the rising cost of living, including medical expenses. Carl is very concerned about the plight of all seniors, not just himself and his wife: *“I feel that the government should take better care of the sick and the elderly.”* As one example of this, Carl mentions his Social Security income: *“My biggest gripe is I paid in, I worked all my life since I was 16, and the \$1300 per month they give me, how do they figure people can live on \$12-\$15k per year?”*

Despite Carl’s feelings of financial insecurity, he does not worry about the possibility of needing or paying for long-term care in a nursing home: *“I would never go into a nursing home... And my family knows it. I’d rather die at home.”* His unwillingness to go to a nursing home is not just related to the expense – *“I wouldn’t be able to pay”* – but because of the poor-quality care he said his parents received in a nursing home: *“I saw what they did to my mother and my father... I was paying out of my own pocket for my mother...and they treated her like crap.”* Carl continues, *“My wife and my children...are never going to put me in a nursing home. I’d rather die first.”*

"She is surviving"

Family profile

Adele, age 88; widowed; caregiver is her daughter-in-law Barbara

Most recent annual income

\$11,496 (106% of the federal poverty level)

Sources of financial support

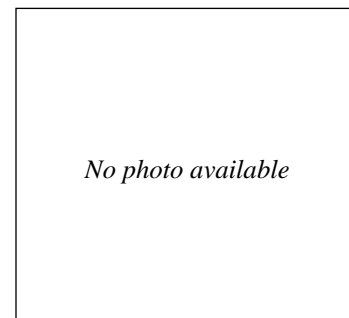
Social Security, Supplemental Security Income

Work status/history

Retired

Insurance in addition to Medicare

Medicare Advantage (includes drug coverage)



Typical Monthly Income = \$958
Typical Monthly Expenses = \$861

Health care & premiums \$237 (28%)

Includes her Medicare Part B premium, and out-of-pocket costs for prescriptions and vitamins

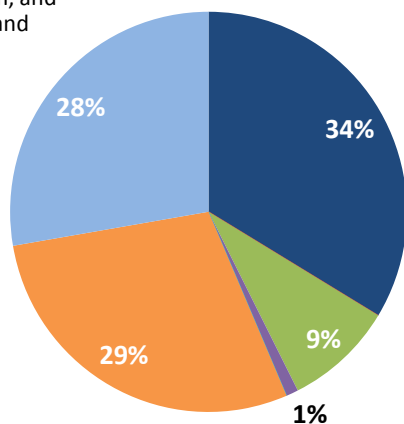
Food \$250 (29%)

Groceries are her second biggest monthly expense

Transportation \$0 (0%)

Other \$10 (1%)

She needs to replace the batteries for her hearing aid on a regular basis



Housing & utilities \$289 (34%)

She qualifies for housing and energy subsidies; rent is \$203 and the remainder is for utilities

Debt/loan payments \$0 (0%)

Savings \$75 (9%)

She is typically able to put aside a modest amount of her income

Income and Spending Overview

Barbara, age 70, is the primary caregiver for her mother-in-law, Adele, who is age 88 and lives on her own in a senior apartment facility. Adele qualified for disability when she started losing her vision more than 40 years ago; she is now legally blind as well as severely hearing impaired. While Barbara is Adele's caregiver in the sense that she has handled her finances due to Adele's vision impairment, Adele is in many other ways functionally independent despite her difficulty seeing. Barbara describes her mother-in-law as "a fighter and an optimist."

Regarding her financial situation, Adele says, "I would say it's tight, but most of the time I manage. I think I manage well." Her modest income consists of monthly Social Security and Supplemental Security Income (SSI) payments. She has no savings or retirement accounts to draw from for her monthly expenses. Due to her low income, Adele receives subsidies for her rent and utilities. Although Barbara provides her mother-in-law with caregiving support, Adele says she is largely on her own financially and tries not to lean on her two grown children – who are also elderly – or other family members for help: "Everybody is living tight. My daughter is on Social Security, my son is on Social Security.... I've got to learn to live on what I get."

Adele's monthly spending is divided nearly evenly between housing, food, and health care. Without her housing subsidy, it would be difficult for Adele to, as Barbara puts it, "make it through" on her current income. Adele says, "I am living in a senior citizen building. My rent is \$203. Where can you get that? The rent normally is \$1,280 a

month.” As a vegetarian, Adele incurs higher costs for fresh vegetables and fruit, but attributes her diet to lowering her cholesterol and blood pressure. But she is concerned that *“every time I go shopping, grocery prices are getting higher.”* While Adele’s resources are limited and her spending constrained as a result, she is not going without necessities. According to Barbara, *“Her needs are very basic. She lives very simply. She lives within her means.”* Adele herself says, *“If I pay my rent and have food, I’m happy.”*

Health Care Needs, Spending, and Insurance Coverage

Adele describes herself as *“in good health”*, yet she ticks off several health concerns, including neuropathy, hypertension, high blood pressure, and acid reflux, for which she takes seven prescription medications. One of Adele’s major expenses is for vitamins and herbs; she reports spending \$100 each month. According to Adele, *“I’ve got 15 different vitamins. That’s why I look so young.”* Furthermore, her hearing and vision impairments contribute to loss of balance and she falls occasionally. Regarding the pain in Adele’s legs, Barbara says: *“If she walks too much, she suffers for several days afterwards.”* As Adele describes it, *“Let’s put it this way, I have pain 24 hours a day. If I’m sitting, it’s calm, it’s achy. When I walk, then it’s painful. So my walking is limited.”* But Adele does not like to dwell on her health problems: *“I don’t like talking about that.”* Nor does she like taking a certain pain medication that was causing memory loss: *“I’d rather suffer with the pain than walk around not remembering things.”*

Because Adele’s income is low enough to qualify for SSI, she also qualifies for Medicaid in addition to Medicare. As a result of support she receives from both programs, her out-of-pocket medical expenses for drugs, doctor visits, and other needs she may have are relatively minimal. She is also enrolled in a large staff-model HMO, the same company she has had insurance coverage from for decades. Of her health coverage, Adele says, *“I am 100 percent happy with them.... They have treated me good. I’m still here.... If I’m ill, if I need help, they’re there. I never have to wait for anything. No complaints.”* She reports not having to put off or go without medical care because of cost.

Adele also benefits from being part of a program in which her senior apartment building offers extensive in-home support services for residents. As Barbara explains, *“They have registered nurses and then they have qualified caretakers. They help bathe her. If she is sick, they’re up there like that, they’ll take her blood pressure – if she needs to go to the hospital, they call the paramedics. There is always somebody there for her if she needs help.”* Adele is grateful for her situation, saying *“I want for nothing.... Not only do I get Medicare, Medi-Cal, my Social Security, I have the best care I can get at [my health plan].”*

Thoughts about the Future

At the time of the interview, Adele was extremely concerned about the impact that an impending government shutdown would have on her financial situation: *“Will we be getting our Social Security checks? [If not] I can’t pay my rent, I can’t pay my debts. It’s a little scary.”* Barbara explains, *“She is afraid that she is not going to get her Social Security and if she doesn’t get that, she doesn’t have anything – she has nothing to live on.”*

When asked about the possibility of ever needing to enter a nursing home for long-term care, Adele says that she has talked to her daughter about it: *“My daughter told me last night that I would never go into a home, that I would live with her...it’s comforting to know because I don’t want to go in a home.”* Yet Barbara explains that Adele’s daughter is disabled herself, so Adele would not be able to rely on her for long-term care. Adele hopes that in the future she *“won’t need anything but what I have.”* And Barbara concludes, *“I think that she is taken care of. She has nothing extra but she has everything she needs to live.”*

"I'm living very close to the edge and it bothers me"

Family profile

Herma, age 66; divorced

Most recent annual income

\$13,200 (121% of the federal poverty level)

Sources of financial support

Social Security, financial support from her sister and daughter

Work status/history

Retired

Insurance in addition to Medicare

Medicare Advantage (includes drug coverage)



Typical Monthly Income = \$1,225
Typical Monthly Expenses = \$1,224

Health care & premiums \$109 (9%)

Includes her Medicare Part B premium, and out-of-pocket costs for prescriptions and over-the-counter medications

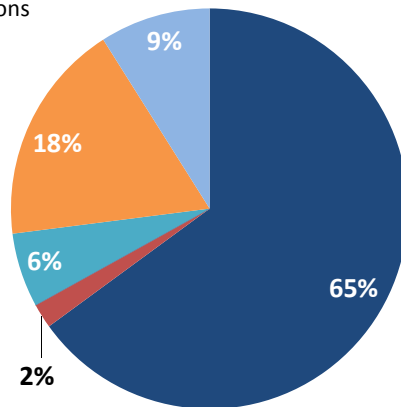
Food \$220 (18%)

Groceries mainly consist of ready-to-eat meals, diet shakes, and milk

Transportation \$75 (6%)

Primarily for gasoline, but also insurance and occasional minor car repairs

Other \$0 (0%)



Housing & utilities \$790 (65%)

Along with \$690 per month in rent, she pays additional modest amounts for utilities

Debt/loan payments \$30 (2%)

She is paying down a \$460 credit card balance with minimum payments each month

Savings \$0 (0%)

Income and Spending Overview

Herma is 66 years old, lives in an apartment on her own, and is no longer working. She is divorced, but has a sister and a grown daughter who live nearby. Although she had a stroke in 1979 which left her unable to use her left arm, she continued to work until 2004 when her company downsized and she lost her job: "I didn't retire, I'm [just] not working anymore." Herma says that if she could get another job, she would take it "in a heartbeat" – and not just because of her financial condition but because, as she says, "I'm bored. I'm too young. Hopefully I've got another 20, 30 years of [being] healthy." Her regular monthly income consists of a Social Security payment, and although she estimates that she has roughly \$20,000 in savings and CDs, she has also come to rely on regular financial support from her family in order not to deplete her savings entirely.

In a typical month, her income is not quite sufficient to cover her expenses, and as a result, she says, "This is where MasterCard comes in." According to Herma, "I keep drawing out of my savings, and my MasterCard just - you know, I can never get my MasterCard down.... I'm just lucky if I can maintain the status quo." She now has just under \$500 in credit card debt and pays a little more than the minimum amount each month.

Herma's major monthly expenses are for housing, including rent and utilities, followed by food. Herma says, "I basically eat TV dinners because it's just me. TV dinners and milk.... and Slim Fast because that's cheap." She owns an older car, which recently needed some costly repairs. She pays for insurance and gas, while her daughter pays

the registration. However, she says she tries not to drive much because of the high cost of gasoline, which she puts on her credit card: *"I really keep it down because I can't afford it...I'm really frugal,"* she says.

Herma admits that when it comes to necessities, she sometimes makes sacrifices or tradeoffs because she doesn't have enough money: *"I call it scrimping... there's times where I really need [or] I would like to buy something so I'll buy a smaller amount or I'll just have to pass on it."* Herma says that overall, *"I am very strapped.... I'm living very close to the edge. It bothers me."* She is clearly troubled by her current financial situation. She says she thought it would be different when she reached this point in her life: *"I thought that when I got older, this was the dream, you know. I remember my father said, 'Honey, when you get older, life's going to be good.' Well, there's a lot of thorns; there's a whole lot of thorns, and I just keep stepping on them. I can't get above it."*

Health Care Needs, Spending, and Insurance Coverage

Herma is in relatively good health. Although her stroke left her unable to use her left arm, she reports having few chronic conditions, and only takes two prescription drugs to treat high cholesterol and osteoporosis. Because Herma's health is relatively stable, her monthly medical expenses are minimal, and she says she has not gone without any medical care she needed recently because she couldn't afford it. According to Herma, *"Right now I'm just glad to be healthy and I do the best I can to stay that way so I don't have to worry about health care, because when I did have my challenges – and this was back in 1979 – [the total cost was] \$90,000...so I can only imagine if I got sick today what it would cost."*

Herma was uninsured for several years, from the time she stopped working in 2004 until she qualified for Medicare upon turning 65 last year. About four years ago, during the time when she lacked health insurance prior to qualifying for Medicare, she fell and hurt her head, resulting in an expensive emergency room visit and a \$3,000 bill: *"I gave the financial person my MasterCard for \$250 and then I made a few payments, but there was no way that I could continue to pay."* She reports that at least half of the bill was left unpaid: *"I finally called them and said, 'I can't do this.'" And they said, 'Well, we'll have to throw it in collection,' and I said, 'Then throw me in collection.'... I can't do a thing about it."*

Now that she has Medicare, her view of her coverage situation is favorable: *"It's better than I had before when I had nothing, so it's a bonus."* She is enrolled in a Medicare Advantage plan which also covers prescription drugs: *"They assigned me a doctor I really like and it's cheap."* She's grateful that she has Medicare to *"help me out in my later years"* yet she is also concerned that the Medicare Part B premium alone is a significant portion of her income: *"I'm paying \$96 and I'm only getting \$1,100, I mean, that's a tenth of my income."*

Thoughts about the Future

Herma is upset about the fact that she is not financially independent now and the future looks the same: *"[The hardest part is] knowing I can't do it, being really independent, and having to depend on other people, that's the worst."* When asked about the possibility of needing long-term care or living in a nursing home, Herma says, *"I don't even want to think about it. I want to be independent. I want to be like my mother. She died in bed. Just let me be like Mom, close my eyes and don't wake up."* Knowing that she wouldn't have the resources to afford to pay for long-term care, she says, *"I'm hoping my daughter will be there for me. And I know she would.... My daughter always said, 'No, Mom, you're never going to go there. You'll be with me.'"*

*“If I had to take her to the doctor on my own,
I wouldn’t be able to afford that”*

Family profile

Adelina, age 85; widowed; caregiver is her daughter Wanda

Most recent annual income

\$10,200 (Adelina; 94% of the federal poverty level for an individual); \$53,400 (total; 129% of the federal poverty level for a nine-person household)

Sources of financial support

Supplemental Security Income (Adelina); wages from employment; child support (household)

Work status/history

Adelina has no formal work history

Insurance in addition to Medicare

Medicaid



Typical Monthly Income = \$4,450*
Typical Monthly Expenses = \$4,579

Health care & premiums \$210 (5%)

Includes a small amount for Adelina’s prescriptions, along with Wanda’s premiums for her employer-sponsored coverage

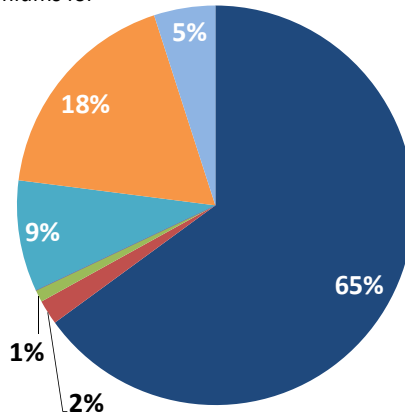
Food \$845 (18%)

Covers the cost of groceries for nine members of the household, including five adults, two teenage boys and three young children

Transportation \$418 (9%)

Wanda has a monthly lease payment for her car, in addition to gas and insurance

Other \$0 (0%)



Housing & utilities \$2,956 (65%)

Two mortgage payments consume nearly two-thirds of the household income

Debt/loan payments \$100 (2%)

Includes monthly payments on two credit card bills

Savings \$50 (1%)

Wanda typically sets aside a small amount from her monthly paycheck

*Includes Adelina’s monthly SSI payment of \$850, wages from employment, and child support payments.

Income and Spending Overview

Wanda, age 50, currently supports a nine-person household – her mother, Adelina, age 85; three sons, including one adult and two teenagers; one daughter-in-law; and three young grandchildren – on total resources of \$53,400, which amounts to 129 percent of the federal poverty level for nine people living together. Wanda’s household budget is derived from a variety sources: her income from full-time employment, child support payments from her children’s father, part of her adult son’s wages, and Adelina’s Supplemental Security Income (SSI) payments. Wanda describes her caregiving role for her mother this way: *“I’m the one that manages her money and her situation.”* And Adelina says, *“I have no income and so I depend on my daughter.”* But since Adelina’s monthly SSI payments help to support the family, Wanda concludes, *“You could say that she’s the one that’s supporting me.”*

Wanda puts 10 percent of her income each month into a savings account, *“but I always pull money out.”* She is also accumulating money in a retirement account, but last year, she dipped into her 401(k) to pay for airfare for

her and her mother to visit her dying father (Adelina's husband) in Nicaragua and for his funeral expenses: *"I had to choose between paying my home or seeing my father.... So I didn't pay for my home and...we got behind on the mortgage payments."* At roughly the same time she began relying more on credit cards and now owes nearly \$2,500. Wanda's approach to paying bills reflects the family's financial instability: *"Sometimes you pay some things and then you don't pay others, and then you get behind when you are going back and forth. So you pay here, you don't pay there, and the next month you pay here and you don't pay over there."*

Given the number of people supported by Wanda's resources, Household expenses typically exceed what comes in each month. Wanda has two mortgage payments, accounting for nearly two-thirds of household spending. Food expenses are another large share of the budget. Wanda notes with concern several repairs needed around the house that she cannot afford to address, some major, some minor - *"There are things that break down and there is not money to fix them"* - including a concrete floor with cracks, and a broken sprinkler system, door frame, and dishwasher: *"I wash by hand now,"* Wanda says. In addition to postponing household repairs, the family has also scaled back spending on travel and eating out: *"Those are things that we have pretty much cut out."*

In describing her financial situation, Wanda says, *"It's been very difficult.... What I've learned is to live on less."* When asked how she supports a large family on limited resources, she responds: *"'How do you get by?' I ask myself the same question many times."* She explains how she stretches her grocery dollar: *"Sometimes I don't buy lunch. I go and get food from the sample carts at Costco.... I buy those cup of noodle soups or I buy a lot of beans, we cook a lot of beans and rice and that lasts a whole week. I buy whatever's on sale... and I use coupons, and if I see that something is inexpensive, then I buy it. I try not to overspend so that everybody can eat."*

Health Care Needs, Spending, and Insurance Coverage

As a legal resident alien, Adelina qualifies for Supplemental Security Income payments, as well as Medicaid and Medicare coverage. Wanda is very satisfied with both programs and grateful to have free coverage for her mother. Wanda says they pay nothing for Wanda's prescriptions or doctor visits: *"No, thank God, no."* Wanda says, *"If I had to take her to the doctor on my own, I couldn't afford that. I just couldn't do it."*

Adelina has relatively few health problems. She takes medication for high blood pressure and was diagnosed with Alzheimer's disease last year. She also has problems with balance and uses a cane or a wheelchair to get around. While the majority of Wanda's medical needs are covered by either Medicare or Medicaid, Wanda reports that her mother is currently going without a new pair of glasses and dental care because of cost: *"For her eyesight, that's the one thing I couldn't do and the dentist, we can't do that either.... It makes you feel bad because you wish that you could give her everything [so] that she could have better care."* Wanda says she is also unable to afford other items that would make her mother's life at home easier: *"I would like to have a special bathroom. Showering is difficult, so she doesn't like to bathe."* She also mentions wanting to spend more to ensure that her mother has a healthy diet: *"The doctor told me to watch her diet more, that she has to eat healthier, more vegetables... It gets a little bit more difficult to buy the things that are healthier, they're usually more expensive."*

Thoughts about the Future

Wanda worries about the possibility that her mother might someday need care that she is not able to provide. When asked about the possibility of nursing home care for Adelina, Wanda says, *"She wouldn't want that. She's happy with me and I wouldn't want her in one of those places."* Adelina herself says, *"I want to be with [my daughter]. I'm more at ease if I'm with her. I'm comfortable and at peace at home."*

With regard to her mother and the family's general financial situation, Wanda says, *"I don't think that she is aware of many things and I try not to worry her with things like that."* A bigger concern for Wanda would be if she lost her job, thereby cutting off the family's main source of income. But she is primarily concerned about the effect this would have on her mother, not herself or her children: *"I know my children can survive without me, but not [my mother]. I'm really worried about her. I am very afraid. When I start thinking about those things, I just distract myself and try not to dwell on it."* Wanda concludes, *"As long as we're healthy and we have work, that's what keeps me going.... I feel satisfied that I've been able to take care of my mother and my children as well."*

"I'm very glad I'm insured"

Family profile

John, age 70; single, never married

Most recent annual income

\$13,680 (126% of the federal poverty level)

Sources of financial support

Social Security, wages from part-time jobs

Work status/history

Several jobs in various industries

Insurance in addition to Medicare

Medicare Advantage (includes drug coverage)



Typical Monthly Income = \$1,140
Typical Monthly Expenses = \$1,141

Health care & premiums \$50 (4%)

Though his low-income qualifies him for premium-free Medicare Part B and Part D, he has monthly copays for prescription drugs

Food \$161 (14%)

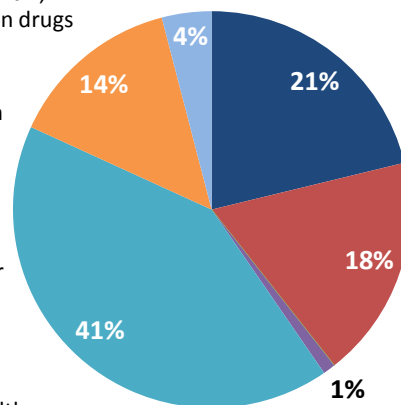
He pays modest amounts each month for groceries and eating out

Transportation \$470 (41%)

Needed to buy a new car after a recent car accident; faces monthly car payment, gas and insurance

Other \$15 (1%)

He pays to use the pool at a local health club



Housing & utilities \$245 (21%)

While living rent-free because he manages the apartment complex, there are costs for utilities and telephone

Debt/loan payments \$200 (18%)

He makes monthly payments on credit card debt and the down payment for his new car

Savings \$0 (0%)

Income and Spending Overview

John is 70 years old, has never been married, and lives in an apartment building on his own. John sums up his current financial situation as "month to month", which is dramatically different from his expectations earlier in his life, when he says "I thought I'd be a multimillionaire" in his retirement years. He worked in real estate for much of his career, engaging in "multimillion-dollar deals" and building "an empire." John reports that the recession in the mid-1980s wiped out his savings and reduced his income considerably: "It killed me." Although he continued to work regularly afterward, he never regained his previous financial well-being. Now he reports having no savings, "but I have a steady monthly income", which consists of a Social Security payment and a modest amount from part-time work. He also does occasional work as an extra in films and TV, which sometimes adds as much as several hundred dollars to his monthly income, but usually far less than that and sometimes nothing. As a result, John sometimes relies on credit cards for routine purchases, as well as unexpected expenses.

Because of John's low income, he qualifies for food stamps and an energy subsidy. He manages a small apartment building, where he lives rent-free. Although his housing expenses are relatively low, he recently had to buy a new car when his old one started breaking down frequently: "All of a sudden I had a dollar or two problem, then some more. I ended up spending over five grand on it in one year... Just wiped out what [savings] I had, and then the car didn't still run right, so I had to trade it for another car. Now, I have car payments." He had to use a credit card to

pay for both the repairs and the new car deposit, both of which he is paying down on a monthly basis *“if I can grind away at it.”* He does not describe any major fluctuations in his monthly spending: *“I manage pretty good, unless it's something like the car...”*

In reflecting on his current financial situation, John says, *“I’m not happy. I’d love to have some money laying around.”* But he also notes that compared to when he was younger, *“I don't worry about it. I worried far more about money when I had a real estate office and the high overhead.”* Despite the decline in his level of financial security, he says he feels freer now because he has less money to worry about: *“I save less, but I also spend less money.”* John has scaled back his activities to live within his means: *“I don’t travel. I used to travel a lot. I certainly don’t eat out as much as I used to. Anything that costs money I don’t do as much. Don’t go to movies as much. That’s kind of limiting, but you got to be comfortable living within that.”*

Health Care Needs, Spending, and Insurance Coverage

Diagnosed with diabetes just under a year ago, John started swimming regularly and quickly lost 30 pounds. Soon after, however, he began experiencing pain in one shoulder, for which he received cortisone shots and underwent physical therapy. Now he has carpal tunnel in both wrists; he is not sure if the two problems are related. One was operated on recently, and he awaits surgery on the other. He reports taking a total of eight prescription medications for various conditions, including diabetes, high blood pressure, high cholesterol, restless leg syndrome, enlarged prostate, and gout. He spends roughly \$40 each month for medications and says he currently spends about \$150 annually for doctor’s visits.

John reports that his Medicare Part B premium is taken care of due to his low income: *“I’m low income, so they pay the \$90 for me”* (although he does not know whether he has Medicaid coverage). He also says he gets a *“low-income deal”* for his prescription drug coverage. His view of his coverage is positive, and certainly more so than compared to when he was uninsured prior to turning age 65: *“I’m very glad I’m insured and I’m being taken care of.... It gives you a lot of peace of mind. It carries over into everything else.”* When asked whether he thinks about what it would be like for him if he didn’t have Medicare coverage, John responds, *“I spent a lot of my life not having insurance. I very well think about it.... I’d be in a lot of trouble.”*

John is enrolled in a Medicare Advantage plan, with which he is very satisfied: *“I think they have a good group of doctors and they have a pretty good plan.”* With regard to managed care, he says, *“The gatekeeper thing is a little slow sometimes, but that’s fine.”* According to John’s thinking, the modest copayments for services that he incurs *“keep people from abusing the system.”* He also likes the fact that his plan pays for his membership at a local gym – though he pays an additional \$15 to use the pool.

Thoughts about the Future

Based on John’s recent health concerns, he imagines that in the future, *“A lot of what happens to me depends on my health, which I’m not in total control of.... I’m aware I’m not going to be in good health forever.”* His biggest worry is not being healthy enough to continue working on occasion to supplement his Social Security income: *“I have to stay healthy enough to work a little bit. If I work a little bit it's fine, but if something happened, God forbid, I couldn't work, I couldn't do a management job, or something, what do I do then?”* he wonders. When asked about long-term care and the possibility of having to go to a nursing home, he expresses some concern, knowing that he lacks the resources to pay for it, but figures that he would be taken care of: *“Let's say I was incapacitated. I assume the state would have to take care of me, or put me in a home, or something.”*

His more immediate concern relates to changes to payments for Medicare Advantage plans that were included in the 2010 health reform law. He is under the impression that the program is being *“abolished”* (it is not), or that he will be left with, as he puts it, *“a stripped-down version”* of his current plan, which he describes as a *“Cadillac plan”*. He has also heard about other proposals to reduce Medicare spending as part of current federal budget discussions, and while he expresses support for *“ways to do efficiencies,”* he is also concerned that some changes *“could be very detrimental to people my age.”* But he also adds, *“They can’t cut [Medicare] from people my age.... We’re sort of grandfathered in.... It won’t happen because everybody has a mom or dad that is in a similar position.”*

“We just have kind of been scrimping along here”

Family profile

Darlene and Bob, ages 69 and 70; married

Most recent annual income

\$59,280 (403% of the federal poverty level)

Sources of financial support

Social Security, Supplemental Security Income, unemployment insurance

Work status/history

Darlene stopped working due to disability, and Bob recently lost his full-time job

Insurance in addition to Medicare

Medigap, Part D drug plan



Typical Monthly Income = \$4,940
Typical Monthly Expenses = \$4,220

■ **Health care & premiums \$1,158 (27%)**

Expenses include premiums for Medicare Part B, a Medigap policy, and Part D drug coverage, along with dental and vision services, prescriptions, and chiropractor visits

■ **Food \$850 (20%)**

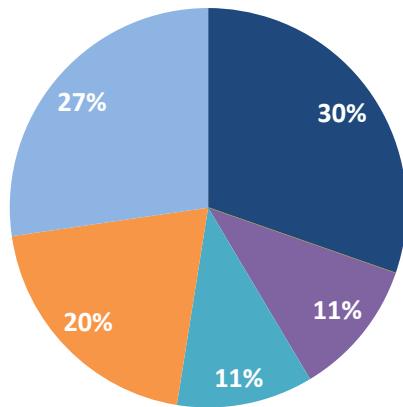
Their monthly food expenses are roughly evenly divided between groceries and dining out

■ **Transportation \$460 (11%)**

They own two cars, monthly bills are for gas, insurance, and repairs/maintenance

■ **Other \$475 (11%)**

Other expenses include clothing, gifts and some travel, but they are cutting back



■ **Housing & utilities \$1,277 (30%)**

Their mortgage is paid off; they face costly bills for utilities, including phone/cable, gas/electric, and home repairs/maintenance

■ **Debt/loan payments \$0 (0%)**

■ **Savings \$0 (0%)**

Income and Spending Overview

Darlene and Bob, ages 70 and 69, are married and live together in their own home. Bob was laid off from his full-time job late last year, and Darlene stopped working full time more than five years ago after being diagnosed with fibromyalgia and chronic fatigue, at which time she qualified for disability payments. When Bob lost his job, the couple’s income fell by half, and the experience has affected the couple both financially and emotionally. She says, *“I worry about [Bob] because he’s under so much stress now – he’s totally devastated by this, so [it’s] an ego thing and a financial thing.”* Their income currently consists of Social Security, disability payments, and unemployment insurance benefits. They also have money in savings and retirement accounts, which they have tapped into to cover a few minor bills since Bob lost his job. Having savings to fall back on has helped them avoid accumulating credit card debt during the past few months, but Darlene reports that the couple has always been careful about their credit card use: *“If we can’t afford it we don’t buy it... We just have been very responsible that way.”*

The couple own their home outright, yet still spend roughly one-third of their income on utility bills and home maintenance: *“Expenses are always there,”* says Bob. Spending on food, health care, and insurance premiums are other major expenses. When asked about having trouble making ends meet, Darlene says, *“I would say that we didn’t before [Bob] got laid off, but we just have kind of been scrimping along here trying not to overspend.”* It appears that they still have sufficient income to cover their monthly expenses despite Bob losing his job. Bob says,

“Right now on expenses we’re trying to hold our own. We’re bailing out and keeping the water out at an even level, trying to live on the income that we have from our Social Security.” But because Bob’s unemployment income will not continue beyond 2011, he says, *“If I can pick up any extra work, it would be great, that’s extra money.”*

According to Bob, the couple is *“adjusting”* to their lower income: *“You can enjoy yourself on a lower budget if you want to.”* They are trying to drive less, and *“when we go anywhere we try to line everything up so we’re not traveling excessively,”* says Darlene. They have cut back on dinners out with friends and decided against taking some trips to visit family. Bob says, *“I’m a coupon clipper, have been for years. I take pride in it.”*

Health Care Needs, Spending, and Insurance Coverage

The couple’s greatest challenges relate to health care. Both of them have a number of health conditions. Bob suffers from depression and anxiety brought on by his job loss, and had a cancerous skin lesion removed from his face last year. He also has asthma, allergies, prostate and esophageal conditions, an ulcer, and high cholesterol. Darlene has fibromyalgia, chronic fatigue syndrome, high blood pressure, high cholesterol, and osteoporosis. In addition, she is recovering from a benign brain tumor that was surgically removed two years ago but left her paralyzed on one side. Altogether, Bob and Darlene take more than 20 prescription drugs each month, including several brand-name drugs that don’t have a less expensive generic equivalent.

Darlene and Bob have multiple sources of health insurance. Darlene switched from Bob’s employer-sponsored coverage to Medicare last year. In addition to Medicare, she now has a Medigap supplemental policy, a stand-alone Part D plan, and dental insurance. Bob is currently covered under a COBRA policy that will expire in two months, at which point he will transition to Medicare coverage and purchase the same supplemental policies that Darlene has. The couple pays a considerable share of their income on insurance premiums and this fact bothers them. According to Bob, *“Medicare itself doesn’t do everything. You have to have a supplement. If you don’t...you’ve got problems.”* He concludes, *“That’s the biggest health concern now, is our insurance.”* Darlene is also worried about reaching the coverage gap in her Part D drug benefit, where she would have to pay more out of pocket for the cost of her drugs: *“That’s going to be a problem, because my medications are over \$1,000 a month.”* Darlene is disappointed in the financial protection provided by their insurance coverage: *“I feel like I’m paying a lot of money and I’m not getting a lot in return.”* As a result of the amount the couple spends on health care and insurance premiums, Darlene says, *“We have to really watch everything else that we do.”*

The cutting back on spending that Bob and Darlene are doing in many areas of their life extends to health care services as well. Darlene says she should be receiving more physical therapy to recover functioning she lost as a result of the brain tumor: *“Medicare will only go so far. You have to keep making a lot of progress and...I still can’t use my left side 100 percent.”* But she is not seeking more therapy, because, she says, *“I don’t want to put out the money.”* Darlene is also supposed to get an annual MRI of her brain, but skipped her most recent scan because, being relatively new to Medicare, she says she does not know what is covered and is reluctant to ask what her portion of the cost will be: *“I’m saying to myself, I’m going to hope everything’s okay.”* Bob has not seen a doctor about what he suspects is a broken toe: *“There’s not much you can do about it,”* he rationalizes. Also due to his enlarged prostate, Bob says he should be getting a prostate cancer test annually, but has put it off recently, saying, *“I’m on the optimistic side... It’s been false all along...and the odds are on my side.”* Both Bob and Darlene also need dental work that they are postponing due to cost concerns, including a root canal and fixing a broken crown.

Thoughts about the Future

The couple is still coming to terms with how Bob’s job loss will affect their future financial status. Bob says, *“I like working.... I’m not ready to retire completely. I have applied for different jobs [but] I think my age is a problem.”* Although Bob and Darlene have sufficient monthly income to cover their expenses, as well as retirement savings to fall back on, they still struggle with anxiety about the future and are reluctant to spend their resources on current needs. As Darlene explains it, *“I don’t want to deplete [the savings], because I don’t know how bad things will be in the future.”* Darlene is discouraged about their situation: *“I think it’s rough because you know, you get a set amount, which is not a lot, and then if you want any kind of medical care you really have to put out more money from your pocket.”* Darlene concludes, *“I’m trying to find some kind of place where I can feel good and try to keep that fear of not having money and not being able to take care of ourselves, trying to push that away.”*

APPENDIX A: METHODOLOGY

This report provides information on 16 Medicare beneficiary households, including a combination of single individuals and married couples, with varying incomes and financial resources, living in or around three urban areas: Washington, DC; Detroit, Michigan; and Los Angeles, California. The interviews took place primarily in English (one in Spanish) from February to April 2011.

Under the direction of Adrienne Dulio Research, local focus group facilities in the three urban areas recruited 12 individuals and 4 couples enrolled in Medicare, including 15 individuals/couples ages 65 and older and one 42-year-old woman with a disability who qualified for Medicare. For 8 individuals who were unable to participate on their own, caregivers knowledgeable about and primarily responsible for their finances were recruited to be interviewed on their behalf. Participants represented a mix of ethnic and racial backgrounds, family composition, housing arrangements, and health insurance coverage in addition to Medicare. Participants were also selected based on having relatively high health care needs and spending, and reporting at least some difficulty affording their insurance premiums and other health care expenses. Participants represented a range of incomes, from roughly 100 percent to 600 percent of the federal poverty level (FPL), which corresponds to annual income of \$10,890 to \$65,340 for an individual and \$14,710 to \$88,260 for a couple in 2011.

Participants were asked to complete a four-page worksheet in advance of the interview (see Appendix) detailing their income and spending for the previous two months (January and February 2011), as well as any major one-time expenses over the past year, including expenses related to a health care event such as a hospitalization or other facility stay. Expenses include housing, health care (including premiums and out-of-pocket costs), transportation, food, clothing, other insurance, entertainment/gifts, other household items, debt payments, and other expenses. Income includes Social Security, pensions, public assistance, employment, other retirement income, and other sources, as well as any one-time income payments received over the past year such as a tax refund or lottery winnings.

Interviews were conducted with the individual primarily responsible for managing the budget and finances of the beneficiary household, whether that was the participant, their spouse (if married), or a caregiver. During the in-depth interviews, which lasted approximately 90 minutes each, we asked participants a series of questions about their general financial and health circumstances and to describe in more detail the income and expenses they reported on their budget worksheets. We also asked participants to discuss their financial choices, challenges, and tradeoffs, paying special attention to their spending on health care premiums and services. Interviews were audiotaped and transcribed.

All participants whose information appears in this report gave written consent to use the personal and financial information they shared with us on their budget worksheets and during the interviews, as well as their picture and first name only.

APPENDIX B: FAMILY BUDGET QUESTIONNAIRE

Instructions:

1. This questionnaire asks you about your family budget for the past two months.
2. Please fill out the questionnaire as accurately as you can. It is fine to estimate your expenses if you do not have exact information. You can use your checkbook, receipts and bills to figure out amounts.
3. Please bring the completed questionnaire and your collected receipts, bills, bank statements or other documents that might be helpful with you to the meeting.

Thank You!

Name: _____ Age _____

Address: _____

Current or Former Employment: _____

Family members (include all who you support with your family budget):

Name _____ Age _____ Relationship to you: _____

Name _____ Age _____ Relationship to you: _____

Name _____ Age _____ Relationship to you: _____

Name _____ Age _____ Relationship to you: _____

(if you have additional family members, please continue on backside of page)

EXPENSES IN JANUARY 2011 AND FEBRUARY 2011:

January 2011: Please fill in expenses that you have paid for each of the following categories for the month of January. If you have receipts or other documentation, please bring to the interview.

February 2011: Please keep track of all expenses for this coming month and keep all receipts, bills and income statements that you receive this month for all categories listed below.

<u>Item</u>	<u>JANUARY 2011</u> Amount (in dollars)	<u>FEBRUARY 2011</u> Amount (in dollars)
1. Housing		
Rent/Mortgage	_____	_____
Gas	_____	_____
Electric	_____	_____
Telephone	_____	_____
Cable	_____	_____
Home Repairs/Maintenance	_____	_____
Help around the home	_____	_____
Home owners insurance	_____	_____
Renters insurance	_____	_____
2. Health Care		
Health Insurance premiums:		
Medicare Part B	_____	_____
Medigap supplement	_____	_____
Part D drug plan	_____	_____
Medicare Advantage plan	_____	_____
Long-term care insurance	_____	_____
Other health insurance	_____	_____
TOTAL INSURANCE	_____	_____
Doctor visits	_____	_____
Hospital fees	_____	_____
Prescription drugs	_____	_____
Over-the-counter medications	_____	_____
Eyeglasses/vision care	_____	_____
Dental care	_____	_____

Hearing aids _____

Medical supplies _____

3. Transportation

Car payment _____

Gas _____

Repairs _____

Public Transport (bus, taxi, etc) _____

Auto Insurance _____

4. Food

Groceries _____

Fast food _____

Dining out _____

5. Clothing

6. Entertainment and Gifts

7. Child Care

8. Debt Payments

9. Other

Describe:

Please also list major expenses in the last THREE MONTHS of 2010 or LAST YEAR (which you did not have to pay last month), such as medical bills for a hospitalization; furniture; home insurance; or taxes. List item, month and amount. Please continue on back of the page if necessary.

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

9. _____

10. _____

INCOME FROM JANUARY 2011 AND FEBRUARY 2011:

You will probably not have entries for every item – that is fine.

Item	<u>JANUARY 2011</u> Amount (in dollars)	<u>FEBRUARY 2011</u> Amount (in dollars)
1. Retirement Income		
Pension	_____	_____
Social Security	_____	_____
Other retirement income	_____	_____
2. Employment		
Wages and tips	_____	_____
Other	_____	_____
3. Public Assistance		
Cash assistance	_____	_____
Food stamps	_____	_____
Energy support	_____	_____
Housing support	_____	_____
Disability payments	_____	_____
Other	_____	_____
4. Other Income	_____	_____

Include child support, gifts, investment or rental income, profits from business, or any amounts you withdrew from savings to pay for any unexpected expenses. Describe:

Please also list major income items you had in the last year (which you did not receive last month) such as tax refunds, bonuses or gifts. List item, month and amount. Please continue on back of the page if necessary.

1. _____
2. _____
3. _____

Thank you very much for your time!

APPENDIX C: MEDICARE BENEFITS AND COST-SHARING REQUIREMENTS, 2011

PART A	
Deductible	\$1,132 per benefit period
Inpatient hospital	
Days 1-60	No coinsurance
Days 61-90	\$283 per day
Days 91-150	\$566 per day (for up to 60 lifetime reserve days)
After 150 Days	Not covered
Skilled nursing facility	
Days 1-20	No coinsurance
Days 21-100	\$141.50 per day
After 100 Days	Not covered
Home Health	No coinsurance; no limit on number of visits
Hospice	No coinsurance for hospice care; copayment of up to \$5 for outpatient drugs and 5% coinsurance for inpatient respite care
Inpatient psychiatric hospital	Up to 190 days in a lifetime
PART B	
Deductible	\$162
Premium	\$115.40/month; higher for those with incomes above \$85,000/single or \$170,000/couple; \$96.40/month for those held harmless from the premium increase since 2009; \$110.50/month for those held harmless from the premium increase since 2010.
Physician and other medical services	
MD accepts assignment	20% coinsurance
MD does not accept assignment	20% coinsurance, plus up to 15% above the Medicare-approved fee
Outpatient hospital care	20% coinsurance
Ambulatory surgical services	20% coinsurance
Diagnostic tests, X-rays, and lab services	20% coinsurance
Durable medical equipment	20% coinsurance
Physical, occupational, and speech therapy	20% coinsurance; certain limits may apply
Clinical laboratory services	No coinsurance
Home health care	No coinsurance; no limit on number of visits
Outpatient mental health services	45% coinsurance (phasing down to 20% in 2014)
One-time "Welcome to Medicare" physical exam	20% coinsurance; covered within first 12 months of Part B enrollment; Part B deductible does not apply
Preventive services*	
Flu shot, Pneumococcal shot	No coinsurance; limit of one flu shot per flu season
Hepatitis B shot, colorectal and prostate cancer screening, pap smear, mammogram, cardiovascular screening, abdominal aortic aneurysm (AAA) screening, bone mass measurement, diabetes screening and monitoring, glaucoma screening, smoking cessation	20% coinsurance after annual Part B deductible is met; however, Part B deductible and coinsurance are waived for some preventive services
PART D	
Information below applies to the standard Part D benefit; benefits and cost-sharing requirements typically vary across plans. Beneficiaries receiving low-income subsidies pay reduced cost-sharing amounts.	
Deductible	\$310
Premium	\$32.34 national average monthly premium (unweighted PDP and MA-PD plan average)
Initial coverage (up to \$2,840 in total drug costs)	25% coinsurance
Coverage gap (between \$2,840 and \$6,448 in total drug costs)	50% coinsurance for brand-name drugs, 93% coinsurance for generic drugs, phasing down to 25% in 2020
Catastrophic coverage (above \$4,550 in out-of-pocket spending)	Minimum of \$2.50/generic, \$6.30/brand; or 5% coinsurance

NOTES: This table does not include all Medicare-covered benefits or preventive services; for a complete listing, see <http://www.medicare.gov/Coverage/Home.asp> and <http://www.medicare.gov/Health/Overview.asp>. Medicare does not cover dental or vision services (including eyeglasses), hearing aids, and most long-term care services. Most beneficiaries have some source of supplemental coverage to help cover their Medicare cost-sharing amounts and, in some cases, services that Medicare does not cover.

SOURCES: CMS, www.medicare.gov, Medicare & You 2011, Your Guide to Medicare's Preventive Services.



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This report (#8200) is available on the Kaiser Family Foundation's website at www.kff.org.

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