The Financial Impact of Alzheimer’s Disease

There are approximately 250 million Americans age 18 or older; 53 million of these adults are caregivers. Buried in these numbers are the almost 6 million Americans with Alzheimer’s disease and their families. Alzheimer’s disease is the subject of this podcast.

Your clients, as they age, are either caregivers, care recipients or are afraid of the financial consequences of becoming either. It is time that planners learn a new skill set that will assist clients with planning for the financial consequences of being diagnosed with a chronic or terminal illness. This podcast is a part of that effort.

A working group of CPAs and other financial planners and wealth managers are working with the Alzheimer’s Association to educate their communities about the disease and its devastating impact on family finances. If you are interested in joining this effort, contact me, Julie Papievis or Jim Sullivan at 630-776-3767. Additional information on Alzheimer’s Disease can be found at the Alzheimer’s Association website at www.alz.org.

The question is, are we financial planners truly prepared for the aging of our clients? This question goes beyond the numbers and financial projections we prepare for our clients. It goes beyond the investment policy statements and portfolios we recommend.

Thirty years ago, concerns about the physical and cognitive issues surrounding aging were discussed only in general terms and “what if” scenarios projected broad estimates of the cost of chronic illness and nursing home stays in the distant future. Most of our clients were still in the accumulation phase of saving for retirement. Retirement and estate planning, college funding and insurance coverage were their primary concerns. Our projections and discussions centered on such matters as; would Social Security and Medicare still be available when our clients reached retirement age? Investment policies were built around long-term projections. Discussions about decumulation of the retirement nest egg were still years in the future.

In what seemed like the blink of an eye, baby boomers began turning age 65 a decade ago. An average of 10,000 boomers turn age 65 every day and the many of the planning skills we relied on to help our boomer clients prepare for retirement became outdated.

The oldest baby boomers are now nearing age 75. Just as our clients’ planning challenges are changing, so must our skill set. The upcoming challenge will be assisting our elderly clients with proper planning for the financial costs and vulnerabilities that accompany the physical and cognitive declines of aging. We must be prepared to understand and empathize with those changes. Almost one-third of those age 85 or older have Alzheimer’s dementia. Even those elderly clients lucky enough to avoid chronic illness will likely become frail and need some level of custodial care prior to death. How we interact with our clients will change as we adapt to their cognitive changes and physical decline. While the focus of planning will remain finances, more attention will be paid to improving the quality of our aging clients’ lives.
What We Will Cover in this Podcast
In this podcast we will study the financial planning impact of Alzheimer’s disease. Most polls show Alzheimer’s ranks second only to cancer as the most feared disease. But Alzheimer’s occupies a unique place among the top ten most common causes of death. Unlike the other nine, there is no effective treatment.

In this podcast, we will discuss what you need to know about the disease and how to begin developing a skill set that allows you to better work with your clients, not only after diagnosis but before any hint of the disease is on the horizon.

By the end of this podcast you will be able to:
1. Give a general description of what Alzheimer’s disease is, its pathology and progression.
2. Describe the new skills that will help you work with a client newly diagnosed with the disease and his or her family.
3. Summarize the value you can bring to an affected client and his or her family.

What is Alzheimer’s Disease?
Alzheimer’s disease is terminal. It is a type of dementia. Dementia is not a disease, rather it is a syndrome.

A syndrome is made up of signs (detected by health care professionals) and symptoms (experienced by the patient).

- Signs include: memory loss that disrupts daily life; difficulty solving problems or planning; difficulty completing familiar tasks; confusion with time or place; trouble understanding visual images and spatial relationships; new problems with speaking or writing words; misplacing things or losing the ability to retrace steps; decreased or poor judgement; withdrawal from work or social activities; changes in mood and personality.
- Symptoms include: having less energy and drive to do things; less interest in work and social activities; spending more time just sitting, watching TV, or sleeping; loss of recent memories, such as forgetting conversations and events that just happened; language problems, like trouble putting their thoughts into words or understanding others; mild coordination problems, such as trouble writing or using familiar objects; a hard time with everyday tasks, such as following a recipe or balancing a checkbook; mood swings that involve depression or a lack of interest; trouble with driving, such as getting lost on familiar routes.

These signs and symptoms can be caused by several different diseases including (but not limited to) Alzheimer’s, Parkinson’s, Lewy Body, HIV/AIDS and vascular.

According to the 2020 Alzheimer’s Disease Facts and Figures (page 6) the disease pathologies include “…the accumulation of the protein fragment beta-amyloid (plaques) outside neurons in the brain and twisted strands of the protein tau (tangles) inside neurons. These changes are accompanied by the death of neurons and damage to brain tissue. Alzheimer’s is a slowly progressive brain disease that begins many years before symptoms emerge.” Note that brain damage caused by Alzheimer’s damage begins “many years before symptoms…” Alzheimer’s
patients and others have suggested that planners should consider pointing clients of all ages to resources on maintaining brain health (for example, see https://www.alz.org/help-support/brain_health).

Even when clients may be diagnosed with the same disease – Alzheimer’s – the progression (or prognosis) will differ.

This fact – the difference in the progression of the disease for each client - is the key factor in developing the new financial plan. There is no “one size fits all” approach. The new financial plan must be adapted, as best as possible, to the progression of the disease expected for your client. The input of the family, caregivers and the health professionals can help you begin to construct the new financial plan.

Once the diagnosis is made, the variables that will impact planning include:

- The progression of the disease (slowly vs. rapidly). This will directly relate to the question of, if the affected client is able to continue to work or not.
- The impact on language and social skills.
- Anticipated loss of cognitive function that may require more extensive care earlier than would otherwise be necessary.
- Anticipated loss of physical function that may require costly custodial care.
- Where the care will take place, at home or in an assisted living facility or skilled nursing home; if at home, will caregivers have to be employed?
- The amount of care that may be available from family, friends and members of his or her faith community.

Note, these planning variables will impact, not only the cost of care and the financial projections, but also how and where you will interact with the client. In later podcasts we will consider interaction with your clients diagnosed with Alzheimer’s disease. When considering the prognosis, inquire as to whether the physician believes his or her recommended course of treatment may delay onset of cognitive or physical decline. At the very least, active management of the disease can improve the quality of life for the affected client and their caregivers. For more on this topic see page 12 of the 2020 Alzheimer’s Disease Facts and Figures available at https://www.alz.org/help-support/brain_health.

The affected client’s physician may recommend:

- Diet modifications
- Over the counter vitamin and dietary supplements
- Physical exercise
- Transcranial magnetic stimulation (TMS)
- Customized brain exercises
- Addressing other medical issues (high blood pressure, diabetes, thyroid dysfunction, high cholesterol)
- Improving behavioral health by addressing depression, aggression and anxiety
- Prescription drug regimen
Find out to what extent the physician believes these treatments may delay the need for care and incorporate those estimates into the budget. The cost of care planning by a health care professional is covered by Medicare. More about that later in the podcast.

With the diagnosis, the old financial plan is broken and must be fixed to accommodate the cost of care. That is where we will turn next.

**The Old Financial Plan is Broken – A New Skill Set is Needed**

The diagnosis of Alzheimer’s is, obviously, a very difficult time for the patient and his or her family. This is true even if everyone – including the person diagnosed- had suspected something was wrong for a long time. Among the many issues the family must contend with, they must consider how will the diagnosis change their financial plan? What should we be thinking about in order to adapt to our new circumstances? There are many more things to think about than just finances. But worrying about the coming financial challenges is natural and a cause of great anxiety.

In this podcast, we will only deal with the portion of the plan relating to budgeting. Our focus is on the family being able to meet the increasing out-of-pocket cost of care. Other financial planning issues, such as decisions about the investment strategy, income tax planning, charitable giving, estate planning, etc. will be dealt with in future podcasts.

A word about preparation. Many Alzheimer’s patients we have spoken to speak of the importance of keeping their financial plan up to date. They regret putting off taking actions that they should have taken before diagnosis. If the client procrastinates updating his or her plan, they will find their options are limited once they are diagnosed with a chronic or terminal illness. For example, they will be unable to purchase life or long-term care insurance. They may not be competent to make needed changes to their will or estate plan. That is why annual updates are so important and must be emphasized with all clients.

**The Care Budget and the Care Balance Sheet**

Shortly after diagnosis, it is important for the client to begin organizing their finances to account for the estimated future cost of care. This process begins with the creation of a Care Budget and Care Balance Sheet for the client. Keep in mind, this exercise has as much to do with number crunching as it does with helping the client reorganize their life around their new circumstances. It requires the client to take a new look at their financial resources and, at the same time, plan for the care of their loved one.

This planning process consists of two parts:

- The 12 to 18-month Care Budget. This is a monthly cash flow analysis. This short-term focus on monthly income and outflow is primarily an exercise to help the client first look at where they are financially before considering the costs of care. Next, they add in the estimated costs of care. This process also lets the client think through any issues and concerns that they may have and begin to address them. We will provide examples later.
The Care Balance Sheet. Once the monthly care budget is built, any anticipated shortfalls must be made up from existing assets and other resources. For example, previous sources of income not yet accessed may be triggered. These include Social Security, pensions and annuity payments. In addition, the Care Balance sheet is assembled with one goal in mind: to determine what assets can be drawn on if needed and the order to create additional cash flow to help meet care expenses. Several factors will determine which assets are drawn on and in what order. Tax considerations, market fluctuations, cash withdrawal penalties, etc. all play into the ordering.

Creating the Care Budget and the Care Balance Sheet can be done on a simple spreadsheet. Commercially available budgeting software can also be used but may not accommodate the type of detail a Care Budget entails.

The Care Budget and the Care Balance Sheet are ways of approaching a challenge that is often overwhelming for a family. They will need constant revision as the disease progresses. For the client and his or her family, however, your assistance is crucial to achieving a sense of normalcy in a difficult time.

The Care Budget - The Care Budget exercise begins by calculating the 18-month cash flow as it is currently, without considering the impact of the care expenses. This allows the client to establish a “baseline”. The resulting net cashflow excess or deficit helps provide the amount of income that will be necessary to draw from other sources.

Later the anticipated care expenses will be built in based on the prognosis developed by the health care professionals. Effective January 1, 2017, Medicare covers care planning for beneficiaries with cognitive impairment. For more information go to https://alz.org/help-support/caregiving/financial-legal-planning/medicare.

If the guidance from the health care professional is too general on which to build projections, the budget may have to be built around a “best”, “worst” and “mid” range scenarios. We won’t review the monthly household budget before taking care costs into account. The basic budgeting process is well known to planners. It does, however, require greater detail than we may normally include. In our example, we are working with a couple, both aged 70. They have two grown children who do not live nearby. The husband was diagnosed in August 2018 with “major neurocognitive disorder due to Alzheimer’s disease, probable, without behavioral disturbance.” The husband recently lost his driver’s license due to his poor reaction time during his evaluation by an occupational therapy driving rehabilitation specialist (go to https://www.alz.org/help-support/caregiving/safety/dementia-driving).

We will assume that based on the budget, the couple generates approximately $2,000 more monthly than is needed for regular expenses. Based on discussions with the clients, a list of
immediate care concerns was created, including the estimated monthly costs. The care concerns were raised by both the husband and his wife, who is also his primary care giver:

- **Issue:** The wife believes it is important that she get a respite from her caregiving duties. Because she is concerned about leaving her husband by himself, she also wants to be able to leave home and go shopping without forcing her husband to come along (which he resents).
- **Solution:** Schedule a caregiver 2 days per week, 4 hours per visit. At $25 per hour, the total monthly cost will be approximately $800. Occasionally, the caregiver will stay overnight to allow the spouse to take an extended break from her caregiving duties. The overnight stay costs approximately $250. The estimated total cost is $1,050.

- **Issue:** It would be better for the husband if he could get out of the house and socialize.
- **Solution:** The husband agrees to attend a nearby adult care center run by a local church. He will begin to attend 2 mornings a week. The cost is $60 per day or $480 per month.

- **Issue:** Mobility is limited. The husband would like to feel more independent. He would like to attend some activities that he still enjoys, such as going to the local health club and a local banjo club that he visits once a week.
- **Solution:** The wife worked out an arrangement with a local ride-hailing service for her husband to use when necessary. She estimated the cost at between $40 to $60 per week. She budgeted $240 per month.

- **Issue:** The doctor has recommended that the husband begins working with a therapist doing tailored cognitive (brain) exercise sessions. The cost is not covered by Medicare.
- **Solution:** The weekly session is affordable given the couple’s current monthly cash flow. The cost is estimated at $75 per session, 4 sessions per month, or $300.

**Total cost:** The total estimated cost of care is approximately **$2,070 per month**. The Care Budget shows positive cash flow of **$2,000 per month**. The costs exceed the after-tax cash flow by **$70**. Any changes, such as the need for additional hours of care from an outside caregiver or more days at day care may ultimately require even more additional income.

In addition, the doctor believes his Alzheimer’s is rapidly progressing which may require additional care costs within 18 months. The Care Budget will be revised as needed. The next step is to identify potential sources of additional income to cover the care costs. The Care Balance sheet is created with that goal in mind.

**The Care Balance Sheet** – In a minute I will list some alternative sources for additional income. Sometimes the client must make the best choice from a list of poor alternatives. For example, tapping the accelerated death benefit to help pay for current care may defeat the point of why the life insurance policy was purchased in the first place. It was meant to provide the surviving spouse or planning partner with a source of income. But for any number of reasons such as
federal and state income tax, liquidity, a downturn in the stock market, the “best” alternative may be to first access the accelerated death benefit.

I will now list some of the assets that may be available to draw on for income.

<table>
<thead>
<tr>
<th>Asset</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retirement pre-tax nest egg, IRA, 401(k) plan</td>
<td>Distributions are taxable and may increase income resulting in paying more for Medicare Part B and Part D monthly premiums (so called IRMAA or Income-Related Monthly Adjustment Amount). Consider impact on federal, state and local income taxes.</td>
</tr>
<tr>
<td>Retirement after-tax nest egg, Roth IRA, deferred annuity, after-tax savings</td>
<td>May be best to first begin accessing these assets because the distribution is not taxable. In our example above, the additional $70 needed per month will be withdrawn from the husband’s Roth IRA.</td>
</tr>
<tr>
<td>Long term care insurance policy</td>
<td>Pay close attention to when benefits may be triggered. Some policies pay a benefit for a limited period (e.g., 4 years). Thus, a delay in triggering the benefits may reduce the payout period if the insured otherwise dies before the end of the payout period. Even if you doubt the benefit was triggered, apply. All the insurance company can do is say no.</td>
</tr>
<tr>
<td>Hybrid annuity/life insurance policy</td>
<td>Such policies combine the regular benefits of an annuity or life insurance policy but provide added benefits if long term care expenses are incurred. Read the policies carefully to understand when benefits are triggered. Contact the insurance company if there is confusion.</td>
</tr>
<tr>
<td>Reverse mortgage</td>
<td>Accessing home equity may not be your first choice. Get help from a professional to understand how the policies work, the costs involved and whether they are right for you.</td>
</tr>
<tr>
<td>Government programs</td>
<td>These include Medicare (age 65 or older, if under age 65, the client may be eligible due to disability) and Medicaid (needs-based coverage provided by state and federal government). See additional comments below on Medicare.</td>
</tr>
<tr>
<td>Other real estate</td>
<td>A line of credit on a second home or vacation home may be possible. The household must have enough income to support repayment.</td>
</tr>
</tbody>
</table>
Medicare

Medicare is an asset? Yes, yes and yes. The key is knowing how your changing health needs may create an opportunity to change to better coverage choices. In addition, many Medicare benefits such as payment for home care are little understood and often go under-utilized. In addition, during the early days of the recent pandemic, Medicare recently expanded coverage for telemedicine. Remote care health monitoring is also covered. Understanding these benefits may delay the need to go into a skilled nursing facility. Keeping abreast of changes in Medicare care and coverage is important. Seek the advice of an expert.

Conclusion: The Value You Can Add

I hope that this podcast has demonstrated the value you can add when a client is diagnosed with Alzheimer’s disease. Let’s review what we set as objectives at the beginning of our podcast:

1. Give a general description of what Alzheimer’s disease is, its pathology and progression. Alzheimer’s is a progressive brain disease that slowly impairs the patient’s ability to function. It is terminal, but its progression differs from person to person.

2. Describe the new skills that will help you work with a client newly diagnosed with the disease and his or her family. With the preparation of the Care Budget and Care Balance Sheet you can help the client get organized and focused on their new financial plan. Because the disease progresses differently in each person, the budget approach cannot be “one size fits all.” The process also helps bring to light issues and problems surrounding the client’s care and the search for appropriate solutions can begin.

3. Summarize the value you bring to an established or new client and his or her family that must adapt their financial plan for what will become their new normal. Many clients and their families will describe their reaction to the diagnosis as “not surprising” since many of the related Alzheimer’s symptoms were already evident. The diagnosis confirms their worst fears and makes them feel vulnerable and directionless. The CPA planner can provide direction and give the family more time to focus on the care needs of their loved ones rather than wondering how the care bills will be paid.

We hope you learned from our podcast. For more information go to www.alz.org, the Alzheimer’s Association website. In future podcasts we will consider issues such as other aspects of working with Alzheimer’s disease clients and their families.

*Julie Papievis and Jim Sullivan both work at Fairhaven Wealth Management in Wheaton, Illinois. They can be reached via email at [jpapievis@fairhavenw.com](mailto:jpapievis@fairhavenw.com) and [jsullivan@fairhavenw.com](mailto:jsullivan@fairhavenw.com).*