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STILL STANDING

A Guide for Loving Through
Alzheimer's and Related Dementias



Still Standing

Version 10

November 2023

What's my job? How can I be who and what I need to be
for my loved one? ... for everybody else?

Your job is hard, but you can do this! You can learn to find balance in your own life as you love and honor your family member through this disease. You can develop the tools needed to protect your family, and yourself while protecting your loved one.

Foreword

As a facilitator of Alzheimer's/dementia caregiver support groups, my job, my privilege is to listen to fearful caregivers and their extended families; to help lead them to the knowledge and understanding that will empower them to survive. Each family is unique, but the concerns, the questions, the prayers are the same. Overwhelmed at the task ahead, some often do not even know what questions to ask.

The journey begins by becoming familiar with the vast resources available today—knowledge is power. Even so, while books, web sites, DVDs, etc. are important, I believe one of the keys to surviving the caregiving experience is coming face to face with others living the same life. There is power in being with those who understand. Support groups ... formal or informal ... offer this power. They offer help, hope, and a particular healing that comes only when heart aches and hard lessons are shared. They offer lifesaving laughter, forever friendships, and the peace that comes from knowing you are not alone. A support group can be the caregiver's greatest source of empowerment—the surest road to survival.

A handwritten signature in black ink that reads "Sheila Welch". The signature is fluid and cursive, with a large, sweeping initial 'S'.

So, where do you begin?

- Utilize this Guide, its resources and references.

Notes

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Notes

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Twenty-Five Common Questions

So Much Information – So Little Time

Answers to the Following 25 Questions...

The following pages contain the 25 most commonly asked questions by caregivers. I provide a brief answer. More in depth answers can be found in the 3 excellent resources below. Because your time is limited, I listed one or more of these books at the end of each question and provided the page numbers where each answer will be found.

1. *The 36-Hour Day: A Family Guide To Caring For Persons With Alzheimer's Disease, Related Dementing Illnesses, And Memory Loss In Later Life*: Nancy L. Mace, M.A. & Peter V. Rabins, M.D.
For good reason, this book is often referred to as the caregiver's bible. Every time you open it, you will find something new. For short video presentations by Dr. Rabins, go to YouTube.com and search "Dr. Peter Rabins".
2. *A Pocket Guide for the Alzheimer's Caregiver*: Daniel C. Potts, MD and Ellen Woodward Potts.
Daniel, a neurologist, and his wife Ellen have cared for eight family members with Alzheimer's. They offer an easy to use resource with bullet point answers to the most difficult issues in loving someone through Alzheimer's. www.dementiodynamics.com is the website of Daniel & Ellen Potts.
3. *The Alzheimer's Action Plan*: P. Murali Doriswamy, M.D. & Lisa P. Gwyther, M.S.W.
Recommended by the author of *The 36-Hour Day*, I find it helpful to use the two books together for questions on clinical matters.

Websites to Live By

lovingthroughdementia.org

Loving Through Dementia: Offering help, hope, inspiration, and dementia education to dementia families. Guiding communities of every faith to do the same.

alz.org

The Alzheimer's Association website is a wealth of constantly updated and helpful information. They offer a 24/7 Helpline: 800-272-3900. Do not hesitate to call for guidance.

teepasnow.com

Teepa Snow is a dementia care expert & lecturer who works tirelessly to educate caregivers on all aspects of dementia. Don't miss the opportunity to attend one of her lectures. Her website is a valuable resource, offering DVDs, books, advice, and a calendar of her lectures & workshops. Portions of her lectures are available free at YouTube.com.

careblazers.com

Dr. Natali Edmonds offers amazing educational videos.

When You Don't Even Know What To Ask

25 Common Questions

The bullet points following the answers indicate the source of that answer and often suggest additional reading on the topic.

1. ***What is dementia?***

Dementia is not a disease itself. The word describes a group of symptoms caused by one or more underlying disorders. These symptoms might include: confusion, memory loss, disorientation, intellectual impairment or similar problems. A doctor's evaluation is necessary to determine. There are more than 100 known causes of dementia. Some are treatable and reversible; some are not. See Questions 3 & 4 below.

- *The 36-Hour Day, pp. 5 - 10*

2. ***What is the difference between dementia and Alzheimer's?***

The most frequently asked question: Alzheimer's is a disease. It is the most common cause of dementia and is irreversible. Not all dementia is due to Alzheimer's, but everyone with Alzheimer's has dementia. The term *Alzheimer's* is often incorrectly used to refer to different types of dementia that impair memory and occur in older individuals.

- *The Alzheimer's Action Plan, pp. 4-8*

3. ***If it is not Alzheimer's, what might be causing these symptoms?***

Any of the following might cause symptoms that mimic Alzheimer's: depression; thyroid deficiency; diabetes; heart/lung/circulation problems; vitamin deficiency; liver failure; alcohol abuse; hearing & vision loss; delirium; infections; and types of dementia other than Alzheimer's. Some of these conditions are treatable, and successful treatment may lead to lessening of dementia symptoms.

- *The Alzheimer's Action Plan, pp. 22-33*

4. ***Something is wrong with Mother. She seems to be more forgetful, confused, and disoriented. At times her judgment seems impaired, and I just can't reason with her. How can I know if the behavior I see is Alzheimer's?***

Only a doctor can give you an answer. "When a person suffers from difficulty in thinking, remembering, or learning, or shows changes in personality, it is important that a thorough evaluation be made." There are many underlying causes with symptoms that mimic those of dementia. You must know the underlying cause in order to help. Begin with your primary care physician. Depending upon the findings, a neurological exam may be indicated.

- *A Pocket Guide for the Alzheimer's Caregiver. pp. 109-110*
- *The 36-Hour Day, pp.13-17*

When You Don't Even Know What To Ask

25 Common Questions

5. *My wife thinks there is nothing wrong and refuses going to a doctor. How do I get her there?*

A common problem for caregivers ... and a most difficult one. Creative lying may be called for. I told my mother that the doctors at Emory could help with her chronic back pain. This was the first, but not the last of the untruths I felt forced to tell my mother in order to protect not only her, but often my family and myself throughout her struggle with Alzheimer's. It is a perfect example of how caregivers so often are given only bad choices.

If you have already tried, and she has refused, back off. Solicit help from another family member, friend, or minister whom she trusts. Or...ask your wife's physician to write her a letter requesting that she come in for a check up.

- *The Alzheimer's Action Plan*, pp. 386-388

6. *What is the life expectancy of a person living with Alzheimer's?*

The Alzheimer's Association says average is 8-12 years following first symptoms.

- *A Pocket Guide for the Alzheimer's Caregiver*. pp. 117-118

7. *What does the doctor mean when he refers to the "stages" of Alzheimer's?*

Some doctors use the terms Early, Middle, and Late, to describe the progress of the dementia. Ask where your loved one is in the course of the disease. As dementia progresses, symptoms will change. Reassess needs as new symptoms occur.

- *Teepa Snow's free DVD, "Gems", p. 6 in this Guide*
- *A Pocket Guide for the Alzheimer's Caregiver*. pp. 33-37

8. *What medicines are being used for Alzheimer's.*

There are currently two categories of drugs in use:

For mild to moderate Alzheimer's:

- Donepezil (Aricept)
- Rivastigmine (Exelon)
- Galantamine (Razadyne)
- Tacrine (Cognex)

For moderate to severe Alzheimer's, often in combination with one of the above:

- Memantine (Namenda)

- *The Alzheimer's Action Plan*, pp. 106-119

When You Don't Even Know What To Ask

25 Common Questions

9. Do the available medicines help?

At this time there is no cure. The meds listed on page 9 may slow down the progression of symptoms for a while. Approximately one third will experience a slowing; one third; will see no effect; and one third will experience a negative reaction to the drugs.

- *The Alzheimer's Action Plan*, pp. 106-119

10. When I take Mother to the doctor, I don't even recognize her. She appears perfectly normal! Then, as soon as we leave, the old behaviors return. If she can control unwanted behaviors for the doctor, why can't she control them for me?

Dementia is variable: changes occur moment to moment and circumstance to circumstance. "Old social skills and the ability to make customary social remarks are often retained longer than insight and judgment. Thus, a person may sound fine to the doctor but in fact be unable to responsibly care for himself."

- *The 36-Hour Day*, pp. 22-25

11. Should I tell my father he has Alzheimer's?

Opinions vary on this question. Some choose to tell their loved one if the disease is in the early stage, thus allowing his participation in planning for the future. As the disease progresses to middle and late stage, learning or being reminded of the disease may only hurt, confuse and/or cause anxiety for your loved one. If in doubt, err on the side of kindness.

- *A Pocket Guide for the Alzheimer's Caregiver*. pp. 37

12. Should I be taking any legal and/or financial steps now that I have a diagnosis?

Definitely, and as soon as possible.

- *The 36-Hour Day*, pp. 243 – 252; 260 - 267
- *Financial and Legal Preparation* (page 43 in this Guide)
- Website for Georgia Advanced Directive For Health Care: <http://aging.dhr.georgia.gov> Click on "Publications" at top of page & scroll down.

When You Don't Even Know What To Ask

25 Common Questions

13. *What do I look for in a doctor?*

One of the most important factors in choosing a doctor is having one that you and your loved one feel comfortable with; one who listens and is willing to partner with you in the care of your loved one. Other important factors are the doctor's expertise in dementia, accessibility, and communication skills.

- *The 36-Hour Day*, pp. 17-19
- *A Pocket Guide for the Alzheimer's Caregiver*. pp. 139-142
- See: *Not All Doctors Are Created Equal*, p.32 in this Guide.
- *The Alzheimer's Action Plan*, pp. 389 -391

14. *What kind of doctor do I need?*

Typically, a Neurologist or a Psychiatrist specializing in dementia. It is very helpful if the doctor also specializes in Geriatrics.

- *The 36-Hour Day*, pp. 13

15. *What tests should I expect to be administered?*

A physician who suspects dementia will often administer a Mini-Mental State Examination (MMSE) or equivalent screening test. It is a brief 30-question test that takes approximately 10 minutes and is used to screen for cognitive impairment. This test alone is not enough to make an accurate diagnosis of dementia. Further testing is necessary in order to have a more definitive diagnosis.

- *The 36-Hour Day*, pp. 13-17

16. *My brother says its too hard to go see Daddy in the nursing home. It bothers me that I go and he doesn't. Also, I'm afraid he will feel guilty when Daddy is gone.*

Dementia families begin grieving the moment they begin to notice changes in their loved ones. You and your brother are grieving. Siblings often respond differently to that grief, making diverse decisions along this journey. More than ever, clear, loving, non-judgmental communication is necessary to preserve...even enrich relationships.

- *A Pocket Guide for the Alzheimer's Caregiver*. p. 143-144

17. *What is hospice. How and when could it benefit Mother?*

Hospice ... or end of life care ... seeks to address both the emotional, physical, and spiritual well being of the patient and his family. Generally begun when survival is predicted to be 6 months or less. The full focus is on keeping the patient as comfortable as possible during this time. It is generally covered by Medicare.

- *The 36-Hour Day*, p.115 - 118

When You Don't Even Know What To Ask

25 Common Questions

18. *My brother thinks there's nothing really wrong with Mother. She lives with me, and he offers no help. How can I make him realize the state she is in?*

Denial is common. Try this: explain that you have to have a break, and that he will need to take care of your mother for a few days. Walking a mile in your shoes may help him gain perspective. His opinion of her needs may be very different when you return.

19. *My husband is terrified of bathing. How can I help?*

This is both very common and very sad. Techniques for working through this problem can be found at:

- *Bathing Without a Battle* at <http://bathingwithoutabattle.unc.edu>
- *Teepa Snow, "The Art of Caregiving"* at *Amazon.com*
- *The 36-Hour Day*, p. 3, paragraph 2

20. *My father is in the middle stage of Alzheimer's and refuses to give up driving.*

Dementia is in charge, not your father. Dementia changes the ability to reason. Your job is to keep him and others on the road safe. Ask his doctor or other respected authority figure to reinforce the message about driving. His doctor may be willing to write your state's DMV recommending revocation of his driver's license; and / or prescribe a professional, simulated, cognitive driving evaluation.

- *The Alzheimer's Action Plan*, pp. 202 –203
- *A Pocket Guide for the Alzheimer's Caregiver*. pp. 66- 69; 177

There is a Georgia law that allows you to anonymously report your father. He will then be ordered by the state to have a physician evaluate his ability to drive. Find information at <http://www.dds.ga.gov/seniors/> Scroll to the bottom of the page to download form DDS 270: "Request For a Driver Review".

21. *My father is my mother's primary caregiver. How do I help him?*

Help him in every way he will allow. The tremendous stresses of caregiving—loneliness, isolation, depression, and guilt— put his own health at risk. Your father needs as much support, love, and understanding as your mother does. It is common for a primary caregiver's health to rapidly decline under such stress.

- *The 36-Hour Day*, pp.199-204
- *A Pocket Guide for the Alzheimer's Caregiver*. pp.137-138
- See: *Heroes*, p. 31 in this Guide.

When You Don't Even Know What To Ask

25 Common Questions

22. My mother begs, "I want to go home". How can I help her?

This is very common...and heartbreaking for all. Guilt can overcome us when our loved one begs to "go home". However, "As Alzheimer's disease progresses, often nothing looks familiar; nowhere is home ...". Reassure her she is safe and loved. Use redirection and diversion.

- *A Pocket Guide for the Alzheimer's Caregiver. pp. 48-49 & 186*
- See: *Going Home: Sometimes You Can't*, p.30 in this Guide

23. My mother is often angry with me; bitter; accusing; and using language she has never used before.

Unusual behaviors and inappropriate language are not aimed at you ... even if it does feel that way. Sadly, your mother's brain is failing, dying. As caregivers, we must understand this fact in order to decrease our stress and increase our patience. Less anxiety within ourselves usually means less anxiety within our loved one.

- *Teepa Snow's Positive to Care at <http://teepasnow.com>*
- *A Pocket Guide for the Alzheimer's Caregiver. pp. 50-58*

24. Mother's behavior has suddenly worsened. Is it simply because the disease is progressing?

Sudden changes in behavior often indicate an infection. Other causes include: pain; medication; and dehydration. A common culprit is a urinary tract infection. Run ... don't walk ... to her doctor for a urinalysis. The behavior will only get worse without treatment, often resulting in hospitalization.

Note: It is common for a trip to the emergency room or a hospital admission to profoundly alter for the worse, the behavior of a person living with dementia.

- *The 36-Hour Day, pp. 110-111.*

25. Is this disease coming to me?

Genetics and family history may play a part in increasing your risk. Research has shown that those who have a parent or sibling diagnosed with Alzheimer's after age 65 are more likely to develop the disease themselves. The greatest risk factor is age. Beginning at age 65, *anyone's* chances of having Alzheimer's double every 5 years, reaching 50% at age 85.

- *The 36-Hour Day. pp. 306-309*

It is only human to think,
"Is this coming to me? To mine?"

I know those thoughts. My mother, four of her siblings, and my beloved cousin were lost to Alzheimer's.

I refuse to dwell on a sadness that might come in the future. To do that would allow this disease to steal joy from my life today.

Dementia may come to me, but until that day I will live my life knowing ... this is the day that the Lord has made. I will rejoice and be glad in it.

Sheila Welch

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What's My Job Now?

Your Loved One Has Just Been Diagnosed

What Is My Job Now?

In an instant your life, your loved one's life, and your family's life is forever changed. Your role and your relationship have changed. You are now the advocate and caregiver. Your job is to love and protect your loved one and to protect yourself and your family at the same time.

Your Job Description

1. Understand and believe: "This is a terminal illness. I cannot fix it." Allow the Serenity Prayer to become your mantra:

*God grant me the serenity to accept
the things I cannot change,
courage to change the things I can,
and wisdom to know the difference*

2. Meet with the doctor to determine your loved one's care needs.
3. Read *The 36-Hour Day*.
 - Utilize this guide and its references.
 - Visit alz.org often to keep updated on the latest information.
 - Visit www.teepasnow.com, careblazers.com, and their associated YouTube videos.
4. Gather Your Team. Realize you cannot do this alone. Allow others to help.
 - Meet with your family to discuss your loved one's care needs. Form a team. Ideally, each family member will do his part according to individual strengths.
 - Find a support group. They are living the life you face.
 - Be honest with friends and family. When someone says, "I wish I could help", have your list ready. Ex: Occasional meals provided by neighbors are wonderful.
 - Have realistic expectations. See *A Pocket Guide for the Alzheimer's Caregiver*: pp. 117-121.
5. Communicate with your family on a regular basis. Keep everyone informed. They cannot know your loved one's needs ... or yours ... if you do not tell them.
6. Understand that dementia is progressive. Your loved one's needs will be constantly changing. What works today may not work tomorrow.

Your Loved One Has Just Been Diagnosed What Is My Job Now?

7. Keep Two Notebooks:

1. Keep notes for the doctor: Between visits, jot down changes you are seeing in your loved one. Make notes of any questions or concerns. Use these notes to communicate all that you have observed and any questions or concerns. One page or less.
2. Keep notes for yourself: People who are loving someone through dementia often find it helpful to write about their days. It may be only two or three thoughts each night before going to bed. You might write every day ... or only every few days ... or every few weeks. Some caregivers find themselves only writing following a difficult and heartbreaking day. Getting that pain onto paper can be cathartic.

What will you do with these notes?? You might store what you have written in a drawer and never look at them again, or perhaps throw them away ... or, you might use those painful memories to write your family's story one day... to help other families along their way.

8. Go into your loved one's moment. Do not argue or correct. For example: if your loved one believes you to be someone else, arguing and correcting will only hurt and confuse.
 - See: *In Her Moment*, p.33 in this guide.
9. Forgive yourself. You're going to make mistakes. Realize that often there will be no right answer—no good choice. Sometimes there will be only bad options from which to choose. In those times, loving may be the most that you can do. Make the best decision you can with the information you have at that time ... and throw away the guilt.
10. Follow this Guide. Use its resources.
11. Frequent LovingThroughDementia.org.

Become not simply a caregiver ... but an *empowered* one.

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So, How Do I Become an
Empowered Caregiver?

So How Do I Become an Empowered Caregiver?

Educate yourself

The 36-Hour Day is known as the caregiver's bible. READ IT ... and KNOW IT. Like the Bible, every time I read it, I found something new—a new perspective for the lives caregivers and their loved ones lead. Words that I have read before take on new meanings, are more applicable, more real.

Today there is so much information available: books; DVDs; lectures; workshops; YouTube; blogs; etc. You can be quickly overwhelmed. On page 6 of this guide, is a short list that I have found to be most helpful. Use that list. It will provide a sound, basic understanding of the life you and your loved one are living.

Protect Your Loved One

- Become your loved one's advocate, protector, and communicator.
- Recognize that your behavior, your tone and body language, affects your loved one's behavior. Do not argue; correct only when safety is involved. Go into your loved one's moment whenever possible. Meet loved ones where they are. As skills are lost, help your loved one use the skills that remain. See: *In Her Moment.*, p.33 of this guide.
- You and your team must manage all aspects of the following:
 - Medical care. Be aware that doctors and hospitals make mistakes, too. See: *Communicating With The Doctor*, p.39 of this guide.
 - All legal and financial concerns.
- Manage all financial concerns. See: *Legal & Financial Preparation*, p.43 of this guide.
- Recognize that no matter how much dementia may take from your loved one, no matter how different they become, your loved one is still here. *A Pocket Guide for the Alzheimer's Caregiver*; pp.43-44.
- Take breaks ... sooner rather than later ... for the sake of your loved one as well as your own. If exhaustion or hurt feelings prevent you from being loving and kind, stop what you are doing. Remove yourself from the room if at all possible. **Loved ones may not remember what we say, but they will remember how we say it.**

So How Do I Become an Empowered Caregiver?

- Protect your loved one's dignity. Example: Being in public (shopping, dining, etc.) with your loved one can become embarrassing. Some caregivers keep business cards that read: "My loved one is living with Alzheimer's. Thank you for understanding any inappropriate behavior." Slip this card discretely to whomever may be offended. Cards may be ordered at www.alz.org or www.teepasnow.com
- To further protect your loved one's dignity: Make family, friends, neighbors, and ministers aware of this illness. You need all the help you can get..

Protect Yourself

Most caregivers do not realize the risks they face—emotionally, physically, financially, and spiritually. They do not know what I mean when I say, "*Protect yourself*." Neither did I. Mother was the vulnerable one, was she not? Sacrificing for her as she had for me was only natural. Not sacrificing—unthinkable.

Your survival will depend upon learning to protect yourself while performing the seemingly impossible—caring for a loved one and meeting the ongoing needs of family at the same time. So, what do I mean, *Protect yourself*? The answer: Make whatever decisions necessary to avoid being consumed—suffocated by the caregiving experience. Today, there are 15 million people in the United States caring for a family member or friend with Alzheimer's. One expert says of this job, "No one (not even Superman!) can do it alone." Yet we—daughters and sons; husbands and wives; family members—do it everyday with little or no preparation. Overwhelmed. Afraid.

Afraid of not being up to the task. Afraid of how our lives are changing. Afraid that we will not honor our loved one as we should. However, the book, "How to Honor Our Parents", warns that a caregiver cannot honor a loved one by dishonoring himself and/or his family. He cannot take care of anyone if he becomes consumed by the caregiving.

Airlines instruct, "Place the oxygen mask on yourself and then on your child." The only way you could protect your child would be by first protecting yourself. Caregivers must ensure their own oxygen first.

So How Do I Become an Empowered Caregiver?

Get Help When You Need It - Sooner Rather Than Later

Protecting yourself and your loved one may mean seeking outside help. Seeking outside help does not mean that you have failed. As advocate you are providing the best care possible—the level of care that will keep your loved one safe. Such help could include additional family members; adult daycare respite programs; in-home professional care; placement in an assisted living facility; skilled nursing care; or hospice care.

- See *A Pocket Guide for the Alzheimer's Caregiver*, pp. 172-173.
- *The 36-Hour Day*, pp. 226-238.
- See: *Protect Yourself*, p. 34 of this Guide.
- Escape. Do something for yourself that takes you away from your caregiving experience; something that offers relief from isolation; an activity you enjoy. Contact with others can be your lifeline.

Find A Support Group

My work with support groups has taught me that a key to survival is meeting face to face with others living the same life. There is power in being with those who understand. Support groups, formal or informal, in your church or at a friend's kitchen table, offer this priceless opportunity. They offer help, hope, and a particular healing that comes only when heart aches and hard learned lessons are shared. They offer life saving laughter, forever friendships, and the peace that comes from knowing you are not alone. A support group can be the caregiver's greatest source of the empowerment necessary to survive.

So How Do I Become an Empowered Caregiver?

Seek Balance In Your Life

Today, four out of five families caring for a loved one with dementia succumb to the crushing load. Relationships are fractured, often never to be mended. In 1997, my family found itself where many of you are now. No one blew a whistle and called time out when the psychiatrist said, "Dementia". Yet in that moment, all of our lives changed. Mother was under attack, and I did not know how to help her. I would learn. I would acquire, then hone, advocacy and caregiving skills.

Constantly, dementia forced the question, *What is my job now?* As Mother's abilities were ever changing, so were her needs. Just when I thought I had a plan...dementia required a new one. The result for me was stress, frustration, and a feeling of impotence. As primary caregiver, I was overwhelmed by grief, duty, and fear, I was suffocating ... and didn't even recognize it.

Clearly my job, my privilege, was to love and honor Mother through this disease. *How will I ever do this when there are so many demands?* Like most of you, my plate was already overflowing. I had a husband I had promised to love and honor. I had two grown daughters who unexpectedly needed significant care. From the time of Mother's diagnosis to the end of her battle, life was full. Experience taught me that balance is critical. Without it I would have missed my own life: with my husband, my children and my grandchildren. Dementia would have stolen my life as surely as it stole mother's.

Finding balance was one of the most difficult tasks of my caregiving experience. In every decision, I had to learn to weigh the emotional cost to family and self against the potential benefit for my mother. What would my mother gain? What would my family lose? Needless sacrifice benefits no one. Guilt lurks around every corner. I wanted solutions that offered peace to everyone, including myself. Dementia does not allow that. I had to learn to accept the reality of the disease in order to be still standing at the end of the battle and in order for my family relationships to survive.

Notes

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I Wish I Had Known

I Wish I Had Known...

... the four basic truths of dementia

- At least two parts of the brain are dying
- It is chronic and cannot be fixed
- It is progressive: it will constantly change for the worse
- It is terminal

... that only in accepting the inevitability of Mother's disease would I find peace.

... to let go of mourning what she could no longer do, and embrace the things she could.

... how important a support group could have been to my father as he loved my mother through Alzheimer's ... how important it would become for me.

... that the person caring for a loved one with dementia needs as much care as the patient.

... Mother's needs would be a moving target. Even after soul searching and researching, I made decisions that I had to remake soon after. Caregiving is trial and error. Getting used to this constantly changing "new normal" is one of the most difficult aspects of the journey.

... as the disease progressed, there would be few good choices. Many times I would be caught between a rock and a hard place and find peace in neither choice.

... to forgive myself when I made mistakes. We can only make the best decisions we can with the information we have at the time.

... correcting my mother would only cause more anxiety and hurt feelings.

... that I was grieving as I progressively lost her to the disease. If we can understand that we are grieving throughout the caregiving experience, then maybe we can forgive ourselves when we do not love and care perfectly.

... I could not fix it. There would be no "right words"... nothing I could do or say would bring her back ... no words to explain away whatever state dementia held her in at the moment ... just as there could be no "right words" to cure a person dying from cancer.

... how to help my father understand that Mother's accusations, including infidelity, was dementia talking.

I Wish I Had Known...

- ... to be grateful for mother each day, and not mourn what dementia had stolen yesterday or would steal tomorrow.
- ... momentary glimpses of my mother before dementia would come and go quickly — Joys to be embraced for the moment and remembered always.
- ... how much my behavior would influence her behavior.
- ... balance in my own life would be critical in protecting myself and my family. I could be of little help to Mother if my family or I were falling apart.
- ... that a loving lie, or avoiding the whole truth, would become the loving thing to do.

Notes

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What I Learned From Caregiving

What I Learned From Caregiving

I learned that even in the darkest of times, lessons and blessings were there for the taking. Sometimes I saw them right in front of me; other times only in looking back. They lifted, fortified, comforted, and inspired. I learned to hold fast to the Serenity Prayer. My prayer for you is that you can do the same—that you can find the serenity, wisdom, acceptance, and strength to protect your loved one ... your family... and yourself throughout your journey.

Going Home: Sometimes You Can't

"Please take me home. I want to go home." ...

Of all the things Mother said during the last years of her illness, this was the most painful and the most pitiful. Although she could not tell me where home was, she was plagued by the longing to be there. I ached for her and felt guilty that I could not help her. Then, a few months before we lost her, something happened that would offer insight and absolution.

Mother's sister Polly had lived in the same house with her devoted husband Jake for more than forty years before Alzheimer's claimed her. No one could have been more "home" than Polly. Yet she, like Mother, begged over and over to go home. It was only then that I realized dementia would not allow even the peace that comes from the sense of simply being at home. Polly and Mother had not been looking for the physical place they called home. They longed instead for something now forever lost; that sense of security, familiarity, and comfort dementia had so cruelly stolen. Would Mother have experienced her longing even if she had been with Daddy in their longtime home? I now know the answer is yes.

What I Learned From Caregiving

Heroes

I learned that the primary caregiver of an Alzheimer's patient needs as much support, love, and understanding as the patient herself and that it is not unusual for that caregiver's health to rapidly decline under such stress. I learned that one whose health is already in jeopardy may be the first to fall. During this journey, I have known, loved, and been inspired by two very different men as they served as primary caregivers. One was my father, and the other my Uncle Jake.

For seventy-two years, my Uncle Jake and Aunt Polly had been wholly in love with each other. That never changed and was beautiful to witness. Mother and Daddy's relationship, on the other hand, had long been troubled and seemed far removed from theirs. I was privileged, however, to witness each of these men love his wife through the nightmare of dementia. Each withstood verbal abuse, paranoia, delusions, and the extreme isolation that dementia most often brings to the caregiver. Neither understood what was happening to his wife. Each lived with the guilt that comes from being the husband, the provider, the protector ... yet unable to hold back the disease that was consuming her. At times, these devoted men viewed themselves as failures, never realizing what they had achieved.

They loved their wives through this terrible illness—an utterly heroic act.

The lesson I learned through their devotion has, more than anything else, led me to the work I do today. Though each would show it differently, I witnessed love in its highest form. I saw strength gathered, exhausted, and replenished. I saw commitment honored, and I saw bravery personified.

What I Learned From Caregiving

I will be forever grateful to the many medical professionals whose skills and kindnesses benefited my mother. Experience, however, taught me that, despite the seemingly tireless efforts of doctors, nurses, and hospital staff, a person living with dementia might suffer without a trusted advocate present. While I have not believed any missteps came from callous negligence, they have occurred as the result of carelessness, inattention, and simple human error. In an effort to illustrate the urgency of every patient having an advocate, I offer the following cautionary tale:

The 36-Hour Day served as a valuable resource as I cared for my mother. If only I had read it sooner. It made me keenly aware of the mistakes I made in choosing her psychiatrist... Within its pages are these words:

The doctor you select for continuing care must ... be easily accessible. Some doctors have large practices and do not have time to focus on your problems ... you may have to talk with more than one doctor before you find one that is right for you. Discuss your needs and expectations honestly with him and talk over how you can best work with him.

Not All Doctors Are Created Equal

Dr. Carlisle was recommended by Mother's internist and well-known for his work with persons living with dementia. I neither talked with additional doctors nor discussed my expectations with this one. Serious mistakes. I did not realize the importance of having a doctor who would partner with me in caring for Mother. Additionally, a large practice and long hours made Dr. Carlisle not readily accessible. When I did speak with him, I rarely felt he was engaged in our conversations, and, even more troubling, he gave little appearance of having compassion or personal concern for Mother. It was not a good match.

A busy man, he often ran forty-five minutes to two hours behind schedule with his appointments. Untenable. Sitting with an anxious, angry mother, confused and suffering with back pain, created undue stress for both of us. Mercifully, after two of these extended waits, I arranged to call ahead in order to find out how far behind schedule the doctor would be. We arrived when he did. It was the only workable solution.

Why did I not switch doctors? I wanted to. However, it is not always a simple thing to do. I had begun to seek a new psychiatrist when Dr. Carlisle finally found the balance of medicines that offered Mother a more peaceful life. I was afraid to upset that delicate balance, so I held on, hoping, praying for the best.

Not until Mother was in nursing care and assigned a new in-house psychiatrist did I realize what a wonderful difference it would make to have clear communication with, and easy access to, her psychiatrist—a doctor who listened, who demonstrated compassion and concern for Mother's well-being. She made herself readily available, offered her cell phone number, and encouraged me to use it.

What I Learned From Caregiving

In contrast, when Mother reached an all-time low in assisted living, repeated calls and urgent messages to Dr. Carlisle went unanswered for twenty-four hours. By then Mother had been moved to skilled nursing—a dreaded decision that I was forced to make without her doctor.

In Her Moment

Not long after Mother's diagnosis, I awoke in the middle of the night, unable to fall back asleep. I headed for the den—hoping to be lulled by the TV. That was not to be. Instead, I received a gift that would shape my relationship with Mother for the rest of her life; Deborah Hoffman's documentary, *Complaints of a Dutiful Daughter*.

Wide awake, I watched as Ms. Hoffman candidly chronicled her mother's disease, beginning with bewildering behavior prior to diagnosis and continuing through the placing of her mother in an Alzheimer's facility. I watched, too, as this daughter came to accept the inevitable. Lovingly, tenderly, admirably.

Initially believing truth and reality to be important, the filmmaker corrects whenever her mother becomes confused. Realizing her action created even more confusion and anxiety, she had an epiphany. It really didn't matter if her mother said "May" when it was, in fact, "July." It didn't matter if the mother thought the daughter was a sorority sister from years past. Why couldn't she pretend to be that sorority sister for just a little while? Why couldn't she be *in her mother's moment*?

Going along with whatever version of reality her mother was experiencing changed both their lives for the better. Their time together was more peaceful. And far richer. The concept was liberating for Ms. Hoffman ... and for me.

I recognized myself as Ms. Hoffman tried in vain to guide her mother back to reality. While the film taught me that I should no longer correct Mother, I still wondered, "Why had I been so frantic to do so in the first place?" Why had I asked with such urgency, "Don't you remember, Mama, I told you ... ?" When Mother's forgetfulness and confusion was new to both of us, I found myself repeatedly correcting her with less and less patience. I was surprised. Ashamed. Why was I so short with her? This was my mother. And she had taught me better.

I soon realized my curt responses were born of fear, but what was I afraid of? My own epiphany would come in time. I had wrongly assumed that by correcting her I could stop what was happening. I could bring her back with just the right words—that it was my job to do so. By asking, "Don't you remember, Mama?" I was really saying, "Stop it. Please stop it. Why are you acting like that?"

What I Learned From Caregiving

lucid, to *remember*, to stay with me in *my* moment. Instinctively, I could not give credence or even respect to *her* moment. It was not a conscious behavior; rather a primal one. A fight to preserve all that I knew and loved in my mother.

Ms. Hoffman showed me that slipping into her mother's moment was the loving thing to do. I could see that loving my mother meant I must do the same. I saw clearly that reacting with frustration was selfish, even cruel. Further, I hurt her by merely posing the question, "Don't you remember?" I made her feel inadequate and, worse, frightened for *not* remembering—reminding her that the world she knew was fading.

My job then was to do better.

(Deborah Hoffman's documentary, *Complaints of a Dutiful Daughter*, may be purchased at www.alz.org)

Protect Yourself

My mother was one of seven children. Five of those children and my beloved cousin have been lost to Alzheimer's. Mother was the first to be diagnosed. My family and I loved her through this disease by the seat of our pants. Today, I know better.

In the Spring of 2004, while my father was having surgery, I walked into a hospital gift shop. My mother, seven years into her diagnosis with Alzheimer's, sat anxiously with my brother, just outside the door. The shop was tiny. I couldn't help overhearing the conversation of three women.

I heard one say, "Mother can't figure out what to buy at the grocery store and Daddy can't cook. I'm cooking all of their meals. Another said, "Mama's getting much worse, She's accusing Daddy every day of having affairs." The third woman, Jane, sadly said, "My daddy thinks I'm stealing from him ...

I knew this topic. I was living their lives. At that time, I knew no other families who lived with dementia. I needed to meet these women! They welcomed me as though I were family. And in a way, we all were.

One asked, "Do you ever think about what will happen if this disease comes to us? What if our children become the caregivers we are today?" Jane answered very seriously, "I'll tell you what I've told my daughter ... *Protect yourself*."

I listened, hoping that the comments from the others would help me figure out what in the world Jane meant. When that did not happen, I asked her to help me understand. I was stunned by her answer. She said ... "I know firsthand what this disease can do to the caregiver. I give my daughter my blessing to do

What I Learned From Caregiving

As I left them there, I remember thinking “that just doesn’t sound right.” In all the years of caring for my parents, it had never occurred to me that I would need protecting. *They* were the vulnerable ones. Sacrificing for them as they had sacrificed for me seemed natural. Not sacrificing for them? Unthinkable.

AND THEN ... my father died. I was now Mother’s Primary Caregiver.

From my kitchen I could see her in her bedroom, rummaging through her suitcase. Lost in Alzheimer’s. Lost without Daddy. I prayed out loud, “Please God, help me know how to care for her and the rest of my family at the same time!” Jane’s words echoing in my heart.

Protect yourself. But how?

Dementia would teach me.

1. It taught me that I would not be able to keep my mother at home with me. The anger, paranoia, and accusations that dementia had once helped onto my father were now coming at me. Those very stresses had contributed greatly to his death. Where would she live? Mother supplied us with the answer. “Please don’t take me out of Spartanburg.” Our home town. She moved into assisted living there. I commuted 350,000 miles over the next three years.
2. It taught me to hold even tighter to my faith and to the Serenity Prayer ...
*Lord, grant me the serenity to accept the things I cannot change.
The courage to change the things I can,
And the wisdom to know the difference.*
3. It taught me that humor would be my salvation.
4. It taught me that I knew nothing. In order to protect my mother and the rest of us, I needed knowledge. I bought, read, and re-read the only resource available, *The 36-Hour Day*. Today, that book, along with many other powerful resources, provide dementia knowledge. Knowledge that not only empowers us to better care for our loved ones, but commands that we care for ourselves.

Dementia Education is a driving force behind the conferences, workshops, seminars, and support groups offered by our *Loving Through Dementia Program* and its website, lovingthroughdementia.org

5. Dementia taught me that telling the truth ... the whole truth ... was not always the loving thing to do. So, I, who before dementia, had never lied to my mother ... often used “truth avoidance” to protect us both.

What I Learned From Caregiving

So, whenever my mother asked “Where’s your daddy?” and my father had been gone from us over a year... I avoided the truth ... and would do it again today. Anything less would have been cruel. How could it be loving to repeatedly remind my mother that her husband of 62 years has died? In her reality the most devastating loss of her life would be brand new ... all over again. So, my answer each time was a version of the following: “He can’t be here right now, but he loves you very much.” I love you, too, Mama.

My goal then was to divert her attention with something she really liked. Stories or pictures of the grandchildren were most often the best diversion.

6. Dementia taught me never to correct or contradict.

In the very beginning of this illness, whenever I noticed that Mother was thinking and doing and saying things differently, I instinctively wanted to correct her. I just knew if I could find the right words, everything would be as it had been. I found myself saying, “Don’t you remember Mama, I told you just a minute ago ...” One day when she asked for the third time, I heard myself answer... in a more frustrated tone. That’s when I saw a look that I would never have wanted to cause. I had hurt her feelings! I had made my strong, determined, capable mother feel confused, afraid, and childlike. She had taught me better! I must do better!

My job from that moment forward was to go into her reality... into her moment. She could no longer come into mine. What difference would it make if my mother thought pictures of my grandchildren were my children? Why couldn’t I let her think they were my children for a little while and share sweet stories about them?

Meeting her where she was protected both of us. Our time together was richer and far more peaceful. Today, “Meet Me Where I Am” is one of the most critical messages heard from our *Loving Through Dementia Program* and its website, lovingthroughdementia.org.

7. Dementia taught me that protecting all of us meant finding balance.

In every decision, I weighed the situation... How will this benefit Mother? What will the rest of us give up? Answers to those two questions rarely brought peace, and guilt lurked around every corner. I learned that dementia most often presents NO good choices ... only bad ones. Over and over again, I reminded myself ... “accept the things I cannot change.”

My mother loved me more than life and would never have thought or said or done anything to hurt me. Dementia on the other hand, absolutely would! Angry calls and letters came filled with accusations and paranoia. Visits were filled with more of the same.

What I Learned From Caregiving

Every part of this hurt. My family saw the change in my spirit and was concerned. I was determined to honor my mother, but I had a marriage vow to honor as well. I had two grown daughters with health issues, and grandchildren whose little lives I did not want to miss.

My prayer remained the same ... How on earth could I love mother and my family through this ... meet her needs, their needs, and my own at the same time??

I protected myself. I took breaks from mother. No calls, No letters. No Visits. This made me sick with guilt, but I was desperate to find balance in my life. I needed oxygen. My brother took over my visits, along with his own. Eventually, Mother received new medicines. The meds allowed her to be with me for short peaceful periods for the rest of her life. I am forever grateful.

8. Dementia taught me that I could not do this job perfectly. I made mistakes. You will, too. Which leads us to important number nine, below ...
9. It taught me to forgive myself.... to know that if I were to truly love Mother through this, I had to throw away the guilt!! At the end of the day I had to go to sleep knowing that I had made the best decision I could with the information I had at the time.
10. It taught me grief and acceptance.

Like most caregivers, I had begun grieving as soon as I saw the first change in my mother. And although, I had prayed that Serenity Prayer a thousand times, it was not until the last two years of mother's life that I truly accepted that I could not change what dementia was doing to her.

Only then, did I let go of grieving the person she could no longer be ... and love more sweetly the person who was still here.

My prayer for you is:

- that you will reach that acceptance sooner rather than later
- that you will seek and find ways to protect yourself while you are protecting your loved one
- that you will find balance in every decision
- that you will forgive yourselves for your mistakes
- that you will go to sleep each night knowing that you did the best you could with the information you had at the time
- that you will throw away the guilt ...

And that you will meet your loved ones where they are.

Notes

The background of the slide is a photograph of a blue sky with white, fluffy clouds. A solid green horizontal band runs across the middle of the image, serving as a backdrop for the title text.

Communicating With Doctors

Communicating With Doctors

Excellent discussions of preparing for a doctor's appointment, and getting the most out of that appointment can be found in these books on the Resource List:

- *The 36-Hour Day*, pp. 109-110.
- *A Pocket Guide for the Alzheimer's Caregiver*, pp 139-142

Prior to the First Visit:

Pre-register

If possible, register online or print out registration form to take with you for your first visit. Among other important information, this should include medical history, all medications, and all negative reactions to medications.

Filling out the registration in the office is still an option. You will just need to arrive earlier in order to do so.

First Visit:

Provide copies of health care forms, including Health Care Power of Attorney, Living Will or equivalent.

All Visits:

Provide for the doctor with no more than a one- page summary of changes/ symptoms which you have observed. Also, list concerns and questions. Note: If portal is provided, you may be able to upload this document onto the portal.

Take two copies of the above one-page document with you to the appointment. Discreetly provide the In-Take Nurse with a copy to give to the doctor. Have the other one available for you to refer to.

Listen. Always allowing loved one to answer the doctor's questions, when at all possible.

Address anything on your list that the doctor may have overlooked.

Take notes, or record the visit.

When loved one is prescribed medication, ask the doctor the following: What are its benefits and possible side effects? What is its cost? If expensive, are there effective substitutes?

Be aware of ineffective medications or those that have caused negative results so that you might inform the doctor, if necessary.

Communicating With Doctors

After the Visit:

Leave a written copy of any new instructions for any in-home caregiver involved. If loved one is living in a residential community, all meds and instructions require orders from the doctor.

Watch for any adverse reactions to medications and report to the doctor immediately.

Between Visits:

Please remember ... if there are sudden changes or concerns, or if there are unwanted behaviors that are troubling to you or to your loved one, please inform the doctor right away.

Notes



Legal and Financial Preparation



Gather Information

1. Do you know your loved one's:
 - Birth place & date
 - Social Security number
 - State of legal residence
 - Name & contact information for:
 - attorney
 - physician
 - financial advisor
 - Sources of income
 - Advance funeral arrangements, if any
 - Location of:
 - wills and the identity of the named "Executor" or "Personal Representative"
 - health care advanced directive
 - real estate deeds & vehicle titles
 - birth certificates and marriage license
 - copies of recent income tax returns
 - military records
 - Durable Financial Power of Attorney
2. Prepare a list, including location, and associated contact information for:
 - Financial accounts:
 - Banking accounts
 - Certificates of Deposit
 - Bank and retail credit card accounts
 - Investment accounts:
 - Life insurance policies
 - Annuities
 - Brokerage accounts
 - Insurance policies:
 - Homeowners' and Personal Property
 - Auto
 - Umbrella liability policy
3. Determine if he has, and obtain benefit and contact information on:
 - Long term care insurance
 - Medicare (Parts A, B, & D)
 - Supplemental health insurance to cover Medicare gaps
 - Tri-Care for military retirees

Legal and Financial Preparation

4. If he served in the US armed forces:
 - Locate Form DD 214. (If he separated from the service prior to 1960, the form may have a different number and/or name, such as "Notice of Separation")
 - Check with local VA office to determine benefits, if any

Financial Steps to Take

1. Have your loved one sign a durable financial power of attorney giving you the ability to carry out the financial transactions necessary when your loved one is no longer capable.
 - *Such a POA must be signed while he is still judged to have sufficient mental acuity to sign legal papers.*
 - Many investment firms offer a modified form of this POA which will allow you to make investment & administrative decisions but not to withdraw funds.
2. Consider consulting a professional financial planner or elder care attorney for issues concerning estate taxes; Medicaid eligibility; establishment of trusts; business property; legal issues that arise between family members. Go www.alz.org for a list of Georgia elder care attorneys.
3. A family member should consider obtaining "joint owner" status on the loved one's checking and savings accounts. This will prevent the account(s) from being frozen following death.
 - It is not necessary to add the new name to the check imprint in order for you to write checks. (Sometimes, adding a name to the check imprint is seen as a loss of independence by your loved one.)
 - A financial power of attorney will not meet this need, as the POA will cease upon his death.

Medical Care Issues

1. A family member should register with Social Security and Medicare / Medicaid so as to establish the right to access the loved one's account and records and speak on his behalf. (See information sheet on this process at the end of this package.)
2. For your loved one, you, as caregiver, should have a signed:
 - Georgia Advance Directive for Healthcare. See: <http://www.caringinfo.org/files/public/ad/Georgia.pdf>
 - *Like the Financial POA, this document must be signed while he is still judged to have sufficient mental acuity to sign legal papers.*

Legal and Financial Preparation

3. Primary caregiver and at least one additional family member should be named on the HIPAA form at each doctor's office and for any hospital treatment / admission. This will allow medical personnel to share your loved one's medical information.
4. Keep a chart of each medication taken, and take a copy to each doctor visit. Chart should include:
 - Name of drug
 - Dosage
 - Reason for taking
 - Prescribing physician

Important Document Copies

Copies of the following documents should be made and notarized to be a true copy:

- Powers of Attorney for financial matters
- Advance Directive for Health Care
- Final Directives
- Military Separation form: DD214
- Wills and any known codicils (additional notes)

Immediately Following a Death

1. Typically, the mortuary will make application for the official death certificate. It is wise to have them order 6 - 10 copies as they may be needed for a number of benefit applications and legal issues.
2. Be aware that Social Security and military retirement require that the recipient live the full month in order to earn the benefit paid during that month. If a recipient dies prior to the last day of the month, that month's entire deposit will be withdrawn from the account within a few days of death. Plan your use of the account accordingly.
3. Upon the death of a Social Security benefit recipient, it is possible that the surviving spouse will be awarded a portion of the deceased's Social Security benefit. It will be necessary for the survivor to make application for this benefit, in person, by phone (1-800-772-1213), or on-line at socialsecurity.gov.

Medicare Authorization to Disclose Personal Health Information

Go to: **www.medicare.gov**; scroll to bottom of page to the Take Action column and on click on: "**Get Medicare Forms**" or go directly to the page by typing: **www.medicare.gov/MedicareOnlineForms/**

On the next page you will be given the option to download a file you may fill in, have signed, and mail ... OR to fill in the form online. The questions are addressed as if the Medicare participant (your loved one) is the one filling in the form.

- Name as it appears on Medicare card
- Medicare number
- Date of birth
- Address
- Phone
- Indicate limited or unlimited information for the person sharing
- Indicate limited or unlimited time period for the sharing to be in effect
- Name & address of designated person (or organization)

Permission may be revoked at any time by writing to:
Medicare BCC, Written Authorization Dept.
P.O. Box 1270
Lawrence, KS 66044

Legal and Financial Preparation

Medicare Recap

Part A Hospitalization / Skilled Nursing Care (for limited time following hospitalization)

- Free for most 65-year olds
- Has annual deductible (\$1340 for 2018)

Part B Doctor visits, exams, preventative care, etc

- Participation is voluntary
- For 2018, costs \$183 monthly, usually deducted from the Social Security check
- Has annual deductible (\$147 for 2015)
- Typical copay is 20% of Medicare allowed amount

Part C Formerly known as Medicare Choice. This is a private insurance combination plan that provides both Medicare benefits and supplemental coverage for portions not covered by Medicare.

Part D Prescription drug coverage provided through private insurers.

Part D is described as “voluntary”, **but**:

A 65-year-old may pass on Part D under 2 circumstances:

1. He can prove that he has prescription drug coverage from another source; e.g. military Tricare or private insurance.

OR

2. He accepts that if he decides to sign up for Part D at a future time, a significant penalty fee will be added to his premium.

Legal and Financial Preparation

MediGap / Medicare Supplement Insurance is a private, supplemental policy intended to pay some or all of the charges not covered by Medicare. Plans may or may not include Plan D coverage.

Medicaid is health care for low income persons administered by the state. Eligibility is "means tested" based upon income and resources according to state law.

Extra Help for Plan D is a means tested program that varies by state and can significantly lower prescription drug costs. The application can be found at Medicare.gov when signing up for Part D. (see reverse side)

Medicare Part D Sign Up

Available plans vary according to state of residence, anticipated drug needs, and choice of retail source for your drugs.

Medicare.gov has an excellent plan finder which is located at:

<https://www.medicare.gov/find-a-plan/questions/home.aspx>

It features general Medicare supplement plans as well, but can be limited to a search for Part D plans only.

One can enter all current prescribed drugs and get a very personalized list, or enter without listing any drugs and receive a more generic list of plans.

You must enter a choice of prescription sources from among those in your neighborhood which are partnered with the plan you ultimately choose. This is an important choice, as the bottom-line annual cost of your coverage can, within the same plan, double based upon the retailer (Walgreens, CVS, Publix, etc.) you choose.

Having entered the required information, you will be presented with a list of all available plans in order of estimated annual costs for your drugs. The estimate includes 4 dollar amounts:

1. Monthly premium to the plan operator (may be deducted from SS)
2. Annual deductible, if any, paid by you prior to receiving coverage
3. Co-pay for each drug listed after deductible met
4. Annual out of pocket cost (estimate based upon the drugs you have entered)

What is the "doughnut hole" ... or Coverage Gap?

This amount is set annually (\$3750 for 2018). When the combined expenditures (you and your plan provider, but not counting monthly premium) reach this amount, all coverage ceases, and drugs become an out-of-pocket expense for you. In the Coverage Gap you will pay a significant portion of the retail cost of each drug, non-generic or generic. These costs could eventually reach a total that brings you out of the Coverage Gap and into Catastrophic Coverage.

Catastrophic Coverage

If your total out-of-pocket drug expenses reach \$5000, you will exit the Coverage Gap and pay only a small copayment for covered drugs for the remainder of the year.

The doughnut hole was planned to be eventually entirely eliminated under the Affordable Care Act (ObamaCare), but that issue is now unsettled.