



## Counseling Discipleship Training

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### **Ministering to the Forgotten Sheep: Men and Women Suffering from Dementia**

Today we are here because our hearts are burdened for the men and women in our churches suffering from dementia and family members who are desperate for answers on how to walk alongside their loved ones as they travel this journey. This topic came about from our personal journey with my dad who recently died from Alzheimer's on March 18, 2017. We often found ourselves, along with my mom, alone with no guidance or help as we struggled to care for his needs. We stumbled and at times failed miserably with our attempts to give him the best help in his desperate time of hardship. We also became aware that this is an often-neglected area of the church.

It is our goal to provide biblical and practical support to those in the early stages of dementia as well as those family members who suffer while they helplessly watch the decline of their loved-one.

- Our Journey
- What is dementia?
- What encouragement can Scriptures give to those who suffer from the debilitating impact of the various forms of dementia?
- What much needed perspectives can be gained for those who minister (caregivers, biblical counselors, church family, shepherds) to individuals with dementia.
- Practical Guidelines to consider for caregiver and family members.

#### **What is Dementia?**

- **Dementia is not a specific disease. Rather, it is a word used to describe a range or symptoms.**
- There are many factors that can cause dementia.
- It is important to know that dementia is vastly different from “forgetfulness or senility”.
- **It is important to understand that dementia is caused by damage to brain cells.** This damage interferes with the ability of brain cells to communicate with each other. If the brain cells cannot communicate normally, then thinking, behavior and feelings can be affected.
- **Many dementias are progressive**, meaning symptoms start out slowly and gradually get worse. If you or a loved one is experiencing memory difficulties or other changes in thinking skills, don't ignore them. ***See a doctor soon to determine the cause.***<sup>1</sup>

“First, we must understand that all forms of dementia are diseases; they are not part of normal aging. The victims cannot control what is happening to them, making it absolutely wrong to criticize or lose patience with them. When dementia gets frustrating, we must always recognize that the problem is the disease, not the person. Almost all forms of dementia can strike any person without any respect for place in society, state of physical health, or prior level of intelligence, though it is true that each of those factors can affect how the dementia impacts the victim.”<sup>2</sup>

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<sup>1</sup> Alzheimer's Association. (2018) What is Dementia from <https://www.alz.org/what-is-dementia.asp>

<sup>2</sup> Dunlop, John, MD. Finding Grace in the Face of Dementia (pp. 33-34). Crossway. Kindle Edition.

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### What encouragement can Scriptures give to those who suffer from the debilitating effect of the various forms of dementia?

- In 2006, a “MetLife Foundation survey found that Alzheimer’s disease is the second most feared disease among American adults, behind only cancer.”<sup>3</sup>
- “The progressive loss of memory leads people to believe that they will become unreachable and unknowable. Intentionally or not, many tend to believe that because people with dementia cannot contribute (in work, around the house, at church), they have little or no value. No hope, no identity, and no value...”<sup>4</sup>
- **As believers**, we certainly need to see that the Word of God tells us that we do have hope, our identity does not change, and we have immense value to our Creator God.
  - Romans 8:18-23 - We are all subject to disease, aging and decay.
  - Philippians 3:20-21 - We are pilgrims passing through this present world
  - 2 Corinthians 4:16 -18 – We have the hope that our “inner self” will not diminish but will in our affliction be renewed.
  - Caregivers, family members, and believing friends must remind their loved ones with dementia of this hope daily. Even when the loved one does not seem to respond, we must remember the Holy Spirit dwells within the believing person with dementia and He is the one who will bring this truth to their hearts. We are the instruments that God will use to provide His encouragement and hope.
- A powerful section of Scripture to remind both the one with dementia and those who are standing with that loved one of God’s personal presence and loving care is Psalm 139:1-6.
  - It is here we see an unexplainable value our Creator God places on us.
    - It begins with God’s intimate knowledge of our situation, our anguish, and our need.
    - Psalm 139:5 reminds us that God surrounds us from behind and in front and laid His hand on us.
    - Listen to how the great preacher, Charles Spurgeon describes this verse. “Shall we not alter the figure, and say that our heavenly Father has folded his arms around us, and caressed us with his hand? It is even so with those who are by faith the children of the Most High.”<sup>5</sup>
  - Psalm 139, verses 13 -16 lets us know that God’s intimate knowledge of us began before we were born.
    - Here the psalmist by God’s inspiration describes God’s blueprint for us was determined before our birth; even our allotted days for this earth.

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<sup>3</sup> MetLife Foundation, MetLife Foundation Alzheimer’s Survey: What America Thinks, (New York: MetLife Foundation, 2006)

<sup>4</sup> Mast, Dr. Benjamin T.; Mast, Dr. Benjamin T.. Second Forgetting: Remembering the Power of the Gospel during Alzheimer’s Disease (p. 57). Zondervan. Kindle Edition

<sup>5</sup> Spurgeon, Charles H.; The Treasury of David, Classic Reflections on the Wisdom of the Psalms, Vol 3. (Hendrickson Publishers, Peabody, MA) 260.

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- Ephesians 1 assures both the person with dementia and the caregivers that even this dreadful disease cannot rob any believer of their identity.
  - Our identity was God given before the foundations of the world.
  - In Christ, He has called us to be sons and daughters through His adoption.
  - We have in Christ redemption through his blood, forgiveness, we have been lavished with rich grace, and sealed by the Holy Spirit, our guarantee.
- God did not determine His plan for us spontaneously or on a whim, but one that came from the Triune Godhead in eternity past and will be complete in eternity future. (Eph. 1:4-5; Rom. 8:29-30; Deut. 7:6)
- Romans 8:37-39 assures us of His faithfulness. “No, in all these things we are more than conquerors through him who loved us. For I am sure that neither death nor life, nor angels nor rulers, nor things present nor things to come, nor powers, nor height nor depth, nor anything else in all creation, will be able to separate us from the love of God in Christ Jesus our Lord.”

Caregivers, family members and friends of the person going through dementia, once more, please remind and encourage them of these precious truths. God will never leave them or forsake them! (Deut. 31:8; Joshua 1:5; Heb. 13:5) Even when that person cannot respond, continue to speak these truths to them. “Alzheimer’s [*any dementia*] strips away our worldly identity, but a person is valuable for who they are, not simply for what they can contribute. We are more than the sum of our memories. Even when we have nothing left to offer others, we still have value to God, and nothing can change that.”<sup>6</sup> I would add to Dr. Mast’s wise words an important truth, no circumstance will come into the believer’s life that God will not use for good. It is vital for those who are coming along-side the dementia sufferer, to know that God will use the suffering not only for the good of the loved one, but others who are looking on and seeing how the gospel is displayed in earthen vessels. (2 Cor. 1:3-4; 4:7-12)

### **What much needed perspectives can be gained for those who minister (care givers, biblical counselors, church family, shepherds) to individuals with dementia.**

- “As one pastor said: ‘The church has an Alzheimer’s of its own.’ ... In the very times when they [*dementia sufferers*] are most in need, feeling isolated and alone, we tend to forget people with Alzheimer’s.”<sup>7</sup>
- Dr. Benjamin Mast in his book, *Second Forgetting: Remembering the Power of the Gospel during Alzheimer’s Disease*, provided import statistics that should cause our churches to realize that dementia is growing in numbers and is very likely impacting a significant number already, from caregivers to the ones with dementia. Please consider the following facts:
  - 14 percent people over the age of seventy have dementia, and another 22 percent have some other form of cognitive impairment.

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<sup>6</sup> Mast, Dr. Benjamin T.; Mast, Dr. Benjamin T.. *Second Forgetting: Remembering the Power of the Gospel during Alzheimer’s Disease* (p. 60). Zondervan. Kindle Edition.

<sup>7</sup> Ibid. (p. 105).



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- A large number of baby boomers (those born between 1945 and 1964) who may be spending a good portion of their retirement either caring for a parent with Alzheimer's disease or who soon will develop the condition themselves
- The Alzheimer's Association described Alzheimer's as the "defining disease of the Baby Boom generation" and estimate that as many as ten million baby boomers will develop Alzheimer's disease.<sup>8</sup>
- Caregivers, along with the individuals with dementia need the loving arms and support from the body of Christ.

### How can the church help?

- Trained volunteers can offer relief to the caregiver by filling in as they run errands or just take a nap.
- Trained volunteers can visit a sister or brother in Christ with dementia and the caregiver.
- Trained volunteers can assist with errands or transportation with a loved one with dementia.
- Musical volunteers can bring beloved songs and hymns that will encouraged the individual with dementia "Research studies show that music relieve stress, reduce anxiety, depression, and reduce agitation. Musical memories are often preserved in Alzheimer's disease because key brain areas linked to musical memory are relatively undamaged by the disease."<sup>9</sup>
- Are there needs of home repair or maintenance such as yard care? Individuals living on a limited income cannot afford to hire someone and they are often physically unable to keep up with the demands of their home. "In 1 John 3: 16 – 18, we read that we should imitate the love of Christ by caring for the practical, physical needs of people: 'This is how we know what love is: Jesus Christ laid down his life for us. And we ought to lay down our lives for our brothers and sisters. If anyone has material possessions and sees a brother or sister in need but has no pity on them, how can the love of God be in that person? Dear children, let us not love with words or speech but with actions and in truth.'"<sup>10</sup>
- Cards, notes, emails to both caregivers and the sister or brother in Christ with dementia.
- Some dementia sufferers love children. My grandchildren came regularly to visit great grandpa. They sang and made cards for him on the spot.
- Keep both the caregiver and the afflicted loved one in prayer by mentioning and praying from the pulpit and noted in the bulletin.
  - "Here are some suggestions offered by families for how to pray for someone with Alzheimer's disease:

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<sup>8</sup> Mast, Dr. Benjamin T.; *The Second Forgetting: Remembering the Power of the Gospel during Alzheimer's Disease* (p. 106). Zondervan. Kindle Edition.

<sup>9</sup> Graff-Radford, Jonathan M.D.; *Music and Alzheimer's: Can it help?* Retrieved from <https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/expert-answers/music-and-alzheimers/faq-20058173>

<sup>10</sup> Mast, Dr. Benjamin T.; *Mast, The Second Forgetting: Remembering the Power of the Gospel during Alzheimer's Disease* (p. 113). Zondervan. Kindle Edition.

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- Pray that the Lord will calm the confusion
  - Pray for relief from anxiety and for peace
  - Pray that the Lord will strengthen the person for what the Lord has for them that day
  - Pray that they will experience the Lord as their shepherd
  - Pray for comfort through the day and night
  - Pray for assurance that the person is a child of the King and that nothing can take that away
  - Pray that the Lord will be with us and carry the person's inner burdens
  - Pray for relief from pain and loneliness
  - Pray for a peaceful transition from this earthly home to the heavenly home (for those nearing death)<sup>11</sup>
- If our dear saints with dementia are in a residential home, visit in a team of two or three. Find out what they still enjoy doing. Simple things like walking with them, or looking at colorful books, or just simply talking to them and reading Scripture. Make sure you pray for them and remind them often how you love them and miss them. Go prepared by talking to family members or residential CNAs. who are with them often. This way visits are specific to their likes and needs. Don't worry about filling the whole time with talking as dementia sufferers do not always respond. Others will, and they may go off in a totally different direction than the initial conversation. That's OK. Join them in what they want to talk about.
  - Again, bringing children to a residential home is a wonderful way to bring sunshine to a dementia sufferer's day. Often bringing children to a residential home needs to be prearranged and children need to be prepared. Let children know what they will see and teach them to understand that this is God's way we come alongside the sufferer. Have something specific that they will do such a bringing handmade cards and coming to sing special songs. Scripture reminds us often to encourage and love each other in the body of Christ. What a wonderful way to teach our children what this looks like as we live this out. "And we urge you, brothers, ... encourage the fainthearted, help the weak, be patient with them all." (1 Thessalonians 5:14)
  - Pastors and Elders of a dementia sufferer's church, you too need to remember your charge as shepherds over your flock. Your sheep with dementia need to see you. I remember reading about how we can help the dementia sufferer with remembering Christ. One thing Dr. Mast brought to my attention that the purpose of the Lord's Supper was remembering Christ. I remember my dad praying often after the grip of Alzheimer's took hold of him. He would frequently ask for forgiveness. What better way to remind him of Christ's sacrifice and His great redemption than what Christ, Himself commanded, "Do this in remembrance of me." (Luke 22:19) We might wonder how someone with dementia could possibly remember when memory loss is his/her greatest problem. Using multiple sensory inputs with vision, touch, taste, smell, and hearing are avenues to remembering. This was something I was taught as a teacher and was

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<sup>11</sup> Mast, Dr. Benjamin T.; Mast, *The Second Forgetting: Remembering the Power of the Gospel during Alzheimer's Disease* (p. 143). Zondervan. Kindle Edition. (p. 143).

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encouraged to teach using diverse senses. “See it, hear it, do it” was a phrase I heard often. Sounds good, but with my dad I had to realize that the purpose of Communion was to do much more than jog memories. The Holy Spirit dwelt within my dad and due to this promise it was my hope and prayer that the Holy Spirit would minister to my dad’s heart giving him the much-needed assurance and hope we have as believers. It was my hope that the Holy Spirit would assure him that he was forgiven. (Rom. 8:13-16, 26-27; 15:13; Eph. 1:13; 2 Tim. 1:14; Titus 3:5)

Once more, Dr. Mast said it well.

“By being present with those who are hurting and confused, we become a concrete reminder that God is present. We come alongside families and journey with them, encouraging and supporting them, and demonstrating the love of Christ in a practical way. One practical aspect of this is that we get to know the person and their caregivers better and more appropriately begin to address whatever needs arise. You don’t need to know all of the right things to say. Just be present. Be quick to listen and slow to speak (James 1: 19). Weep with those who weep and mourn with those who mourn (Romans 12: 15).”<sup>12</sup>

### **Practical Guidelines to consider for caregiver and family members.**

Before we begin with considering different types of decisions and preparations, we must realize that more than ever we need the wisdom of God as we seek help for our loved one with dementia. James 1:5–6a tells us, “If any of you lacks wisdom, let him ask God, who gives generously to all without reproach, and it will be given him. But let him ask in faith, ...” As we cared for my dad, we often we experienced God’s help and His hand in guiding. “Start praying that God will fill you with love, wisdom, and strength for the job ahead. Recruit some close friends to faithfully pray with and for you.”<sup>13</sup>

If you suspect that someone close to you is showing symptoms of dementia it is important to act and help the person. “You will need to take stock of your current situation and then identify what needs to be done to help the impaired person and to make the burdens on yourself bearable.”<sup>14</sup>

### **Getting Medical Help**

It is important to see a medical doctor soon to determine the cause. “It is important that (the person with suspected dementia) undergo a thorough evaluation. A complete evaluation tells you and the doctors several things:

1. the exact nature of the person’s illness

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<sup>12</sup> Mast, Dr. Benjamin T.; Mast, *The Second Forgetting: Remembering the Power of the Gospel during Alzheimer’s Disease* (p. 115). Zondervan. Kindle Edition.

<sup>13</sup> Dunlop, John, MD. *Finding Grace in the Face of Dementia* (p.89). Crossway. Kindle Edition.

<sup>14</sup> Mace, Nancy L.; Rabins, Peter V.. *The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer Disease, Other Dementias, and Memory Loss* (A Johns Hopkins Press Health Book) (Kindle Locations 447-448). Johns Hopkins University Press. Kindle Edition.

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2. whether the condition can be reversed or treated
3. the nature and extent of the disability
4. the areas in which the person can still function successfully
5. whether the person has other health problems that need treatment and that might be making her/his mental problems worse
6. the social and psychological needs and resources of the person with a suspected dementia and the family or caregiver
7. the changes you can expect in the future"<sup>15</sup>

If there is a dementia diagnosis, get a letter from your physician stating to that fact. It will prove to be a valuable asset as you seek to get assistance for long-term medical care.

### Legal Matters

The time will come when individuals who have dementia cannot handle the medical decisions and legal or financial responsibility for themselves. With an early diagnosis, you and the person with dementia now have the opportunity to make decisions about the future together, including legal, financial, and long-term care planning.

**Legal documents help ensure that the wishes of the person with dementia are followed.** As the disease progresses it makes it possible for others to make decisions on behalf of the person when he or she no longer can.

- Durable Power of Attorney
- Power of Attorney for health care
- Living will
- Standard will
- Living trust (*Probate*)
- Guardianship / conservatorship

### Legal planning should include:

- Making plans for health care and long-term care
- Making plans for finances and property

It is important to discuss what financial resources they have or what debts they owe.

**There are a number of financial resources that may be available to help** cover the costs of care for the person with Alzheimer's or other dementia. Some may apply now and others in the future.

- Insurance
- Employee benefits
- Retirement benefits or pensions
- Personal assets
- Government assistance

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<sup>15</sup> Mace, Nancy L.; Rabins, Peter V.. *The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer Disease, Other Dementias, and Memory Loss* (A Johns Hopkins Press Health Book) (Kindle Locations 490-491). Johns Hopkins University Press. Kindle Edition.



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- Community support services<sup>16</sup>

### Be Informed

I highly recommend that you learn as much as you can about dementia. If possible you and the person close to you with the dementia diagnosis learn together what to expect. Most dementia diagnosis are progressive and will lead to future decline. “One of the most effective way of coping with adversity is education. Knowledge really is power! It provides the foundation to attack our problems, bolstering us with the assurance that we’re doing all we can to bring calm, sensible management, and comfort to the situation. So, the more we understand our adversary, Alzheimer’s disease, [*dementia*] the better we’ll be able to predict what’s coming and respond appropriately when it comes.”<sup>17</sup>

I have included a short list of books and other additional resources at the end of your handout. I will say that the Alzheimer’s Association Organization (website: <http://alz.org>) is probably the best help available and supplies solid information that will prove to be valuable throughout your journey. The information they provide will help guide you in the many decisions you will face, also they can assist with various support groups for both the caregiver and the person with early or mild dementia.

### What Kind of Care to Consider:

Determining the type of care for a person with dementia needs requires careful and thorough considerations. Early in the disease, an individual may be able to live independently, but only need some assistance with managing money, bills, and banking, taking medicine appropriately, shopping, driving, and housework or outside yard care. A possible option is in-home services that can help the individual function and still maintain independence.

“Not all in-home services are the same. Some in-home services provide non-medical help, such as assistance with daily living. Other in-home services involve medical care given by a licensed health professional, such as a nurse or physical therapist.

### Common types of in-home services:

- **Companion services:** Help with supervision, recreational activities or visiting.
- **Personal care services:** Help with bathing, dressing, toileting, eating, exercising or other personal care.
- **Homemaker services:** Help with housekeeping, shopping or meal preparation.

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<sup>16</sup> Alzheimer's Association. (2018) Planning Ahead Retrieved from <https://www.alz.org/care/alzheimers-dementia-planning-ahead.asp>

<sup>17</sup> Howard, Deborah; Howe, Judy. Help, Someone I Love has Alzheimer’s; (Shepherd Press, Wapwallopen, PA 18660) p. 12.



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- **Skilled care:** Help with wound care, injections, physical therapy and other medical needs by a licensed health professional. Often times, a home health care agency coordinates these types of skilled care services once they have been ordered by a physician.”<sup>18</sup>

As the disease progresses, you will notice that bathing and hygiene are deficient, weight loss due to not eating properly or at all, getting dressed appropriately, possibly incontinence, and sleep patterns will become affected. As the behavior and memory declines, this is the time to consider far more care. **“There is no one-size-fits all formula when it comes to Alzheimer's [dementia] care.** Needs change at different stages of the disease and each family's situation is unique.

### **Deciding on care can be a tough decision.**

Before you make the decision to bring a loved one with dementia into your home you must take into consideration many factors such as financial resources and are the much-needed support resources available. It is also important to consider the demands during the middle stages of Alzheimer's. It will become necessary to provide 24-hour supervision to keep the person with dementia safe. As the disease progresses into the late-stages, round-the-clock care requirements become more intensive. Making the decision to bring that loved one into your home or move them into a residential care facility may be very difficult, but you must consider that you may not be able to provide the level of care needed at your home. Here are some questions to consider in your decision.

- If the person with dementia is unsafe in their current home, will you be able to provide a safe environment?
- Is the health of the person with dementia or my health as a caregiver at risk?
- Are the person's care needs beyond my physical abilities?
- Would I neglect work responsibilities, my family and myself?
- Would the structure and social interaction at a care facility benefit the person with dementia?<sup>19</sup>

There may come a time when home care is not enough, and the difficult decision to pursue residential care is in the best interest of both victim and caregiver. One indication that the time has come is when caregivers have lost joy and feel spiritually dead, emotionally drained, and mentally or physically exhausted. Deep in their soul, they know they are not providing the type of care their loved one needs, and they become conscious that their motivation is no longer love but obligation and perhaps a little bit of stubbornness. In this case, it is time to pursue residential care if possible, and it may be the only recourse left for following Paul's exhortation to “not grow weary in doing good” (2 Thess. 3: 13).

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<sup>18</sup> Alzheimer's Association. (2018) In Home Health Care Retrieved from <https://www.alz.org/care/alzheimers-dementia-in-home-health.asp#types>

<sup>19</sup> Alzheimer's Association. (2018) In Home Health Care Retrieved from <https://www.alz.org/care/alzheimers-dementia-in-home-health.asp#types>

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Moving to a nursing home or similar facility becomes not a sign of weakness but of the strength to do what is right. The other person to consider in this decision, of course, is the victim of dementia. He may be at the point where he has no appreciation for the sacrifices being made to keep him at home. It's important for caregivers to know that after the patient adjusts to new surroundings, he might be equally content to live in a facility. In fact, he may actually be happier having others around. The move to a nursing home may be much harder on the caregiver than on the patient. If, on the other hand, he continues to derive obvious pleasure from being at home, other sources of help should be pursued, and nursing-home placement deferred. The final group of stakeholders in the decision to pursue residential or nursing-home care is children or teenagers in the home whose needs might require a higher priority than the wishes of the person with dementia."<sup>20</sup>

### Financial Concerns

- Begin first with the health insurance. There are those who have insurance that covers long-term care in case of a debilitating illness or accident.
- Some people opt for out of pocket to pay for medical assistance.
- Medicaid, a federal/state program can help with low income situations. Many do not have the insurance coverage or finances to cover the cost of long-term medical care. This was the case with my parents. Their insurance coverage was a basic Medicare plan that will cover certain short-term health care assistance, but it does not cover long-term health care assistance.

### Resources

#### Books:

*Second Forgetting; Remembering the Power of the Gospel During Alzheimer's Disease* – by Dr. Benjamin Mast

*Finding Grace in the Face of Dementia* – by John Dunlap, MD

*The 36-Hour Day; A Family Guide to Caring for People Who Have Alzheimer's Disease, Other Dementias, and Memory Loss* – by Nancy L. Mace, MA; Peter V. Rabins, MD, MPH

*Help for the Caregiver, Facing the Challenges with Understanding and Strength* - Michael R. Emlet

#### Websites Resources:

Alzheimer's Association - <https://www.alz.org/>

Alzheimer's Foundation of America - <https://alzfdn.org/>

Call our 24/7 Helpline: 800.272.3900

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<sup>20</sup> Dunlop, John, MD. *Finding Grace in the Face of Dementia* (p. 94). Crossway. Kindle Edition.



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Banner Alzheimer's Institute - <http://banneralz.org/>

Family Caregivers Association - <https://www.caregiver.org/caregivers-guide-understanding-dementia-behaviors>

### **Scriptures of Hope:**

*Hebrews 4:12 - For the word of God is living and active, sharper than any two-edged sword, piercing to the division of soul and of spirit, of joints and of marrow, and discerning the thoughts and intentions of the heart.* When our minds fail, we trust that God's Word will still speak to our hearts. Here is a list of Scriptural encouragement.

Psalms 20:1-8; 27; 28; 30; 34; 62; 63; 86; 103, 121; 130; 146

Isaiah 25:1-9; 43:17

John 14

2 Corinthians 1:3-11

I Peter 1:3-9