

# It's Alzheimer's Q

IT'S TIME FOR EXTRAORDINARY LOVE

A Christian Approach by Curt Seefeldt



PUBLISHED BY  
**THE LUTHERAN HOME  
ASSOCIATION**



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First edition, 2011. Second edition, 2013.

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# FOREWORD

## PURPOSE OF THIS BOOKLET

What kind of information would be most helpful to the people who just received word from their doctor, “It’s Alzheimer’s”? This question was the starting point as Michael Klatt, President and Chief Executive Officer of The Lutheran Home Association, and I considered the needs of people affected by this disease.

Many questions come to mind as families face the illness:

- n What is this disease?
- n How do we cope with the hurts? The fears? The questions about God?
- n How will we provide care?
- n How is our family going to deal with the legal and financial matters and everything else that is involved?

We have produced this guide to be a starting point and resource for families, caregivers, and their church families. Our goal was to cover a broad range of topics related to Alzheimer’s disease and to provide a Christian perspective as a foundation for care. We wanted the writing to contain a minimum of technical language and be understandable for a person who is just starting to learn about the illness.

With these thoughts in mind, we offer this guide to our Association members and friends. We pray that it is a blessing to you and those you love.

## USES FOR THIS BOOKLET

When a person receives a diagnosis of Alzheimer’s, it is always a shock. There is a lot going on. How can this guide be a help? It all depends. People are different and so is every circumstance.

In some situations, family members are looking for all the information they can find. They want quick answers to a wide range of questions. If that is the case, they might welcome this booklet from you as something to take home and read. In other cases, people may not be ready to look at everything it covers. If that is the situation, it would be best to refer them to specific sections as different needs arise. Your good judgment and sensitivity during a difficult time will be greatly appreciated.

## A NOTE TO BIBLE STUDY LEADERS

The Lutheran Home Association offers a variety of materials on Alzheimer’s for your Bible classes or discussion groups. Please see the resource list at the end of this booklet for information on these materials.

# ACKNOWLEDGMENTS

I thank the caregivers and family members who offered their personal insights and experiences: Maureen Giblin, Shari Nytes, Orville Taecker, and Diane Zellers. Their input was invaluable. Their care for the people they love provided great perspectives. They are truly special people. Special thanks to Sarah Beckius, BSW, LSW, and Tammy Dvorak, RN, both of whom work at The Lutheran Home Campus in Belle Plaine, Minnesota. Tammy was the Director of Home Health Services at Kingsway Retirement Living. As part of her duties, she supervised the assisted living/memory care area. Sarah is the social worker at The Lutheran Home: Belle Plaine's Special Care Residence where she provides social services for people with more advanced stages of dementia. Together, they held a monthly support group for families and caregivers, and graciously allowed me to participate. I also thank Pastor Ed Fredrich, Chaplain of The Lutheran Home Campus in Belle Plaine, for his experiences. I appreciate the insights and encouragement of Pastor Dallas Miller, Director of Spiritual Services for The Lutheran Home Association. Finally, I thank the staff and many friends of The Lutheran Home Association for their suggestions and assistance in developing the finished product. Their work is greatly appreciated.

Pastor Curt Seefeldt  
Director of Church Relations  
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“I haven’t told many people about this.”

There was a brief but agonizing pause. I didn’t look at his eyes. I didn’t need to. The sound of his voice told me that there were tears. “My wife has Alzheimer’s.”

Four simple words! They were labored, pained, and spoken with a deep love. I knew my friend was struggling to come to grips with everything that Alzheimer’s disease would mean for his wife. He knew that her life, his life, their marriage, and their entire family would be experiencing a profound and irreversible change. This disease was something they had never experienced before and certainly never wanted to experience.

Now it was their future together.

## What is Alzheimer's?

Alzheimer's disease is an illness of the brain. That makes it different from many other illnesses. While some conditions and ailments affect our behaviors and mental function, most of the time these changes are temporary. For example, stress or lack of sleep can affect our moods, our judgment, or our ability to remember information; low blood sugar can make us feel disoriented; medications in certain combinations can cause hallucinations. These conditions can and do change the way our brain

functions, but usually only for a short period of time. Once we get over the illness, get some sleep, or adjust the medications the symptoms disappear.

Alzheimer's is different. It not only affects the way the brain functions—it alters the brain physically, and it does so permanently. Deposits called *plaques* form on the brain itself. These plaques are accumulations of broken protein molecules. The disease also causes twisted protein fibers called *tangles* to develop inside individual cells.



These plaques and tangles are thought to be involved in a process that damages and eventually kills nerve cells. Over time, the brain actually shrinks in size (Alzheimer's Association, 2011). The plaques and tangles are the direct evidences of Alzheimer's disease.

The primary symptom of Alzheimer's is dementia. *Dementia* is a term that describes a loss of memory or other intellectual abilities to the extent that it interferes with daily living (Alzheimer's Association, 2011). Notice that dementia involves more than forgetfulness. It includes difficulty with abstract thought, language, judgments, or interpretation of what the eyes actually see.

It is common for people to call every form of dementia "Alzheimer's," but this is not the case. Dementia has other causes, and some dementia is only temporary. However, Alzheimer's disease is the leading cause of progressive and permanent dementia. While this booklet will speak of Alzheimer's disease, much of what it offers will be helpful for situations stemming from other forms of nonreversible dementia.

Alzheimer's is usually identified when family or friends notice a change in mood or behavior or an inability to remember events which occurred in the recent past (short-term memory loss). When that happens, it's important to schedule a screening. A doctor identifies Alzheimer's using tests to reveal memory loss and depression. A full workup can include brain scans. Even though, as yet, these scans cannot show conclusive signs of Alzheimer's, they are used to look for other causes of dementia such as stroke, tumors or brain trauma. Scientists continue to work to develop better diagnostic tools.

For now, no cure for Alzheimer's is known. No medicine is capable of stopping or repairing the progressive brain damage that it causes. However there are medications that slow the development of the disease, sometimes dramatically. They work best when introduced at the earliest stages of the disease, so early diagnosis is important.

Other prescription drugs can help people cope with some of Alzheimer's symptoms, such as depression, sleeplessness, or agitation. Results will vary from person to person. Research suggests that mental stimulation,

a healthy diet, and exercise may help to slow the progression of the dementia or reduce some of its symptoms (National Institute on Aging, 2011). A medical professional who specializes in geriatric care or neuropsychology can keep you informed of the latest breakthroughs in diagnosis and treatment.

Once a person is diagnosed with Alzheimer's disease, life expectancy is eight to ten years. This too can vary widely. In the United States, Alzheimer's disease and its complications cause more deaths each year than diabetes (Centers for Disease Control and Prevention, October 10, 2012)

At age 65, one in one hundred people will be diagnosed with Alzheimer's worldwide. At age 75 the number rises to one in ten and at age 85, it is one in five. Areas with high life expectancy have many more cases of Alzheimer's. In the United States, as more and more baby boomers reach retirement age, the number of Alzheimer's cases is predicted to increase substantially.

Some individuals with an Alzheimer's diagnosis are under the age of 65. Their condition is known as early onset, or younger onset, Alzheimer's.

It is usually identified in people who are in their fifties, but may occur rarely in people who are under 40 (David Shenk, n.d.).

All of this means that if you have a loved one who has Alzheimer's, you are not alone; many people are dealing with what you are experiencing. It also means that people and resources are available to help you. That is the good news. The challenge is that it will take some effort to find them, but it is important that you do. Alzheimer's disease, regardless of whether it is affecting you or a loved one, is not something that you will want to work through by yourself. People compare it to a journey. It is a long trip and full of surprises. Because you do not know what to expect, it is best to travel with people who have "been there"—people who have dealt with the disease and with individuals affected by it. The third chapter of this booklet, "Your loved one has Alzheimer's," offers some suggestions.

At the end of this booklet is a short list of resources and contacts. We hope you find them useful as you undertake your journey with Alzheimer's.

What, then, shall we say in response to this? If God is for us, who can be against us? He who did not spare his own Son, but gave him up for us all—how will he not also, along with him, graciously give us all things? Who will bring any charge against those whom God has chosen? It is God who justifies. Who is he that condemns? Christ Jesus, who died—more than that, who was raised to life—is at the right hand of God and is also interceding for us. Who shall separate us from the love of Christ? Shall trouble or hardship or persecution or famine or nakedness or danger or sword? As it is written: “For your sake we face death all day long; we are considered as sheep to be slaughtered.” No, in all these things we are more than conquerors through him who loved us. For I am convinced that neither death nor life, neither angels nor demons, neither the present nor the future, nor any powers, neither height nor depth, nor anything else in all creation, will be able to separate us from the love of God that is in Christ Jesus our Lord. (Romans 8:31-39)

## God himself walks with you

A note to the reader who has a loved one with Alzheimer's: Some days are better than others for dealing with sensitive issues.

The following section raises some of the questions that people ask when they are hurting. If today is not a good day for you to deal with these matters, feel free to turn to chapter three. However, do come back to these pages. The discussions provide comfort drawn from God's Word, the Bible. They express God's thoughts and have brought profound comfort to millions of people in situations like yours.

The Scriptures do not mention Alzheimer's disease by name, nor do they describe a disease like Alzheimer's. They do, however, have a lot to say to us when we feel abandoned, feel that our lives are hopeless or worthless, or feel angry, afraid, or guilty. If these are the thoughts and emotions held by people who are affected by Alzheimer's disease (and, yes, they are), then God in his Word has a lot to say to them. In his Word we find help from the loving God who invites us to address him as our dear heavenly Father.



## WHAT'S IN THE CUP?

In Mark 10, the Gospel writer records Jesus' words as he was preparing his disciples for his final trip to Jerusalem. This journey would end with his arrest and crucifixion. Two of his disciples asked for a special favor. Jesus refused to grant it and he explained why he would not do so with this question: "Can you drink the cup I drink...?" (Mark 10:38).

Jesus was using a figure of speech that was common in Jewish culture. To "drink the cup" meant to accept something that was, among other things, extremely challenging and painful (Paustian, 2004). Jesus went on to tell the disciples that they could not do what he was about to do. He was about to suffer and die to pay for the sins of the world. As Savior of the world, the work was his and his alone. The disciples could only observe him as he carried it out on their behalf.

However, Jesus went on to say to all of his disciples, "You will drink the cup..." (Mark 10:39). He was talking about their future. It would present them with difficult challenges. For most of those listening, the future included dying as martyrs because of their witness for the Christian faith.

Christians today "drink the cup" as well. The cup contains everything that is our future. Some of it we will call *good* and some of it we will call *bad*. It will include some difficult challenges. However, we do not know exactly what they will be or when they will occur. If we look into the cup, we cannot see to the bottom. Are there bitter dredges? Are there sour berries? Are there still pieces of sweetness? Until we take the cup to our lips and drink it deeply, we simply do not know.

If God has placed Alzheimer's disease in your cup, we know it will be your challenge. It will change your life dramatically, but no one knows exactly how. Nevertheless we do know this: the Lord knows your needs and he walks with you. That is his promise.

Yet when God asks us to drink a challenging cup, it is natural for us to have questions.

## IS ALZHEIMER'S DISEASE A PUNISHMENT FROM GOD?

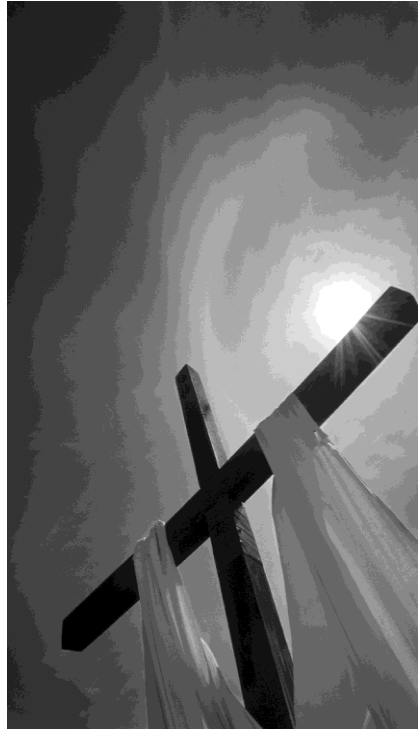
As Christians, we know that Alzheimer's disease is not a punishment. That is because God does not make people pay for their own sins on this side of eternity. Jesus has suffered all the punishment for every sin, for every person.

The Scriptures assure us, “The punishment that brought us peace was upon him [Jesus], and by his wounds we are healed” (Isaiah 53:5).

In this passage, the “punishment” Isaiah refers to is the horror which Jesus suffered on the cross. It was more than just the pain of the crucifixion. Jesus told us as much when he cried out from the cross, “My God, my God, why have you forsaken me?” (Matthew 27:46). His punishment also included being rejected by God, the Father. His own Father! Jesus was therefore separated from the Giver of all that is good. This is the punishment that we deserved, but Jesus willingly took our place to endure it for us.

Isaiah spoke about the result when he wrote that Jesus’ punishment brought us peace (with God) “and by his wounds we are healed” (Isaiah 53:5). The punishment that Jesus accepted in our place paid for the sins of the whole world. In his own words, Jesus called his sacrificial act a “ransom” payment (Mark 10:45). *Ransoms* are the prices people pay to provide freedom for others. When Jesus paid our ransom, he set people free from facing the punishment for their own sins.

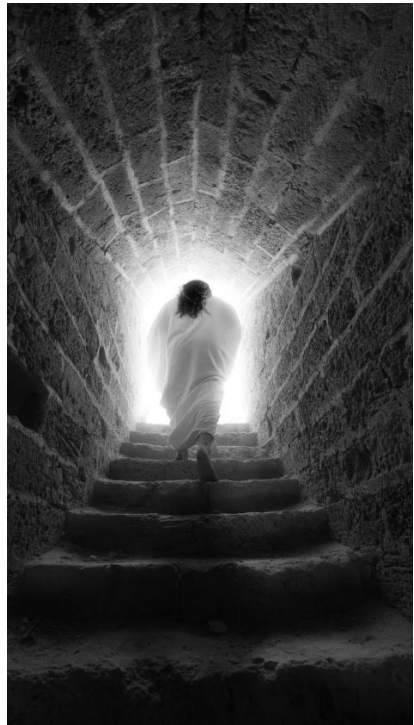
Since this is what Jesus set out to do as he went to die on the cross, the words he spoke just before his death are of the utmost significance. Jesus said, “It is finished!” (John 19:30). He was telling the world that the work of paying for sin was complete.



Jesus had drained the cup of God's wrath for sin, so all sin was now forgiven. All who trust in Jesus receive his forgiveness, and where there is forgiveness of sin, there is no more punishment for sin. Moreover, with his rising from the dead, Jesus showed in unmistakable terms that he was totally successful in providing salvation.

That is why we know that no disease, even Alzheimer's disease, is a punishment for what people have done. The Lord is in no way inflicting Alzheimer's on you or your loved one to make someone pay for a past misdeed. God says he does not operate that way, and God does not lie (Titus 1:2). His promise of forgiveness assures us that he pardons the guilt we have for every sin.

God wants us to have the peace that comes from knowing that our sins are forgiven. If we ever have any doubts, he invites us to just look to his Word. Saint Paul spoke in glowing terms about how extravagant God was in giving the undeserved gift of forgiveness: "In him [Jesus] we have redemption through his blood, the forgiveness of sins, in accordance with the riches of God's *grace* that he *lavished* on us with all wisdom and



understanding" (Ephesians 1:7,8, emphasis added). Jesus' forgiveness is superabundant. Never will it be that Jesus' forgiveness comes up short, leaving us to pay for even one of our own sins. So again, Alzheimer's is not given to us or our family to make somebody pay for sin.

#### WHERE IS GOD'S GOODNESS IN THIS DISEASE?

God is always by our side with his goodness, even if we do not see it or feel it.

Since Jesus predicted that his people would have challenging cups to drink, we know that sickness and sorrow are things that God permits to come upon us. But he does not allow them to come our way without good intention. God promises that his plans and purposes are good, even though we may find them difficult to accept. God assured his Old Testament people when they faced a serious challenge, “I know the plans I have for you...plans to prosper you and not to harm you, plans to give you hope and a future” (Jeremiah 29:11). God still has good in mind for his people today.

We have to admit that it is hard to look at Alzheimer’s as a “plan to prosper.” However, it is important to remind ourselves that God’s plan to provide good things for us is not a promise that life on earth will be pain-free or without problems. Nor is it a promise that, if I suffer now, I will eventually see God’s good things coming my way while I am still on earth. In Romans 8:28, Saint Paul assures us that “...in all things God works for the good of those who love him, who have been called according to his purpose.”

That is a passage worth rereading because it is easily misunderstood. All too often, as a Christian, I think

the passage promises that the good which God promises to work in my life will be both obvious to me and, ultimately, pleasant for me. The passage does not promise either. Rather, it simply promises that good will come, somewhere, somehow.

Yes, it may be that the good will be something that I experience personally, but it may also happen that the good will be only for the benefit of others. God will decide. It may be that the good will become obvious to me during my lifetime, but it may happen that I never see how God works out the good on this side of eternity. All of this is up to God.

Yes, in the Old Testament, God did reveal the good of his plan to Joseph. Joseph was the great-grandson of Abraham. He was sold into slavery by his own brothers, then falsely imprisoned, and finally forgotten in jail by everyone except God. But after years of challenges and misery, things changed. Joseph was elevated to a powerful government position. His job was to store food in anticipation of a seven-year famine and, when the disaster arrived, distribute it to the people. He fed the entire nation of Egypt and regions beyond.

Eventually Joseph was able to reintroduce himself to the brothers who had sold him into slavery. He joyously provided food and a livelihood for both them and their families. He was able to assure them that he forgave them for their hatred toward him. More importantly, he saw how God had turned his brothers' sinful deed into something good. He told them, "You intended to harm me, but God intended it for good to accomplish what is now being done, the saving of many lives" (Genesis 50:20).

Yes, Joseph's experience provided a happy ending to him personally. He held a prestigious government position. But look carefully at Joseph's words. He never pointed to his personal success as *the good* that God accomplished. Instead, he emphasized that his suffering put him in a position to help others. He referred to "the saving of many lives." That is what really brought him joy as he looked back at God's plan.

So what are the blessings that God may be choosing to accomplish through the Alzheimer's affecting you? It may be the steadfast witness that a Christian gives to a caregiver, family, and friends by living joyfully and confidently under difficult

circumstances. It may be the growth experience that results as a family comes together to provide for a loved one's needs. Or it may be the character building that the person with Alzheimer's undergoes as he or she deals daily with declining health and rises to the occasion with grace, confidence, and dignity. (Saint Paul speaks to this in Romans 5:1-5.) There are many "maybes," but one thing is sure: in everything in life, including Alzheimer's disease, the Lord promises to be working out his plan to serve his good purpose.

## GOD PROVIDES THE ULTIMATE GOOD.

Ultimately, the Christian will find blessing in his or her death. For the Christian, death is a victory. With death the Lord brings the believer's soul to heaven to experience its joys. The Lord also promises that at his return he will reunite the body with the soul and glorify both.

Yes, for those left on earth, death is a difficult time. There are sad realities: loneliness, feelings of loss, and questions about the future. But Christians in mourning are people who can also reflect on the promises the Lord gives to reunite all believers in heaven on the Last Day.

A Christian caregiver was visiting with her pastor. She was praying that God would send a miracle and cure her husband who was in the end stages of cancer. He offered her these words of comfort: “God will send a miracle, but it may not be the miracle that you are asking for.”

Every time a Christian dies, a miracle takes place. The soul enters eternal life in heaven, and God promises to raise the body on the Last Day.

Every Christian can look forward to that day. In heaven we will laugh and run and dance. We will live free of sin. We will live together and never misunderstand each other or be misunderstood. We will experience absolute joy. We will see God face to face and understand so much more than we know right now! Perfect blessedness in a perfect place—that is God’s promise. That is why the person who trusts in Jesus can always say, “The best is yet to be!”

#### **DOES GOD REALLY KNOW WHAT WE ARE GOING THROUGH?**

Yes! Since Jesus predicted that his people would drink the cup, he certainly knows the challenges that they are dealing with as they do. More than that, Jesus understands what human suffering is all about. He suffered too! Even though he was true God, he endured real suffering as a human being right up to and including the time of his death. His life was painful, and it was hard.

The writer to the Hebrews explains this when he writes about Jesus as our high priest: “We do not have a high priest who is unable to sympathize with our weaknesses, but we have one who has been tempted in every way, just as we are—yet was without sin” (Hebrews 4:15). Jesus was hungry. He was rejected by many people. He was misunderstood. He endured physical pain. He was tempted to sin. He was forsaken by his own heavenly Father. He even died. That is why we can say that he does know what you are going through, and he does understand how you are feeling. He experienced difficulties like yours and difficulties that were even greater.

The one who suffered is the one who promises to comfort you. He will send his holy angels to strengthen you. These are the same angels who strengthened him in his time of need (Luke 22:43).

### **HOW CAN GOD ASK US TO GIVE UP SO MUCH CONTROL OF OUR LIVES?**

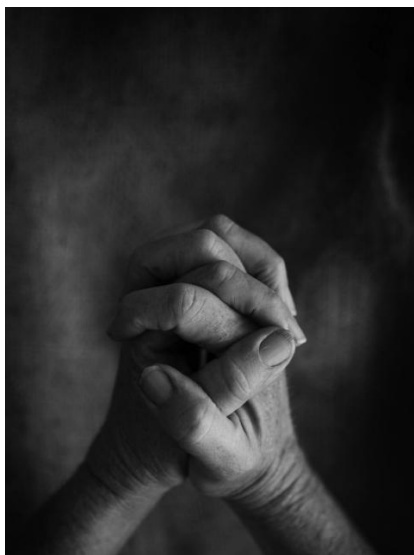
Diseases such as dementia teach us that ultimately, we don't have control of our lives. God does.

Saint James explains this truth: “Now listen, you who say, ‘Today or tomorrow we will go to this or that

city, spend a year there, carry on business and make money.’ Why, you do not even know what will happen tomorrow. What is your life? You are a mist that appears for a little while and then vanishes. Instead you ought to say, ‘If it is the Lord’s will, we will live and do this or that’” (James 4:13-15). In all of life, no one but the Lord is really in control. That has been true from our very beginning. We did not orchestrate our own conception, nor did we have a say in our own birth. Those were God’s decisions.

I know I like to think that I am in control of my own destiny. I like to think that when I make wise plans and when I work diligently to carry out my plans, I can expect that my plans will succeed. Saint James has a different insight. My plans may work as planned, but only if it is the Lord’s will. If the Lord decides to adjust my plans, the plans change. That is that!

However, I remember the promise. He works all things according to his good purpose (Romans 8:28). Yes, God may change my plans, but only and always when he has something better in mind. That is why I do not need to be in control of my life in order to be happy and secure.



## WHAT ABOUT SUICIDE?

The Bible teaches that we are not really in control of our own lives. Sometimes we still think we should be. It may be that this erroneous desire for control is what tempts some to consider taking their own lives when faced with Alzheimer's.

Sometimes Christians fight thoughts about suicide by reminding themselves of the guilt and pain they will impose on the loved ones whom they leave behind.

A stronger answer is found in God's Word. Consider the words of King David:

"You created my inmost being; you knit me together in my mother's womb.

I praise you because I am fearfully and wonderfully made; your works are wonderful, I know that full well.

My frame was not hidden from you when I was made in the secret place.

When I was woven together in the depths of the earth, your eyes saw my unformed body.

*All the days ordained for me were written in your book before one of them came to be.*" (Psalm 139:13-16, emphasis added).

The Bible teaches that God has a purpose for giving us our lives on earth and that he promises to work good things through them. King David points out that God has ordained when our lives were to begin and when he wants them to end. This being the case, do we dare change the time that God has determined for us to die? Of course not!

That is why anyone who ends his or her own life is taking God's decision away from him. Doing so dishonors God. This is wrong. It challenges God's wisdom and goodness. So when we Christians consider the end of life, we will always want to pray to the Lord the prayer that his Son offered as he faced the challenge of the cross: "Not as I will, but as you will" (Matthew 26:39).

## CAN A PERSON WITH DEMENTIA STILL HAVE FAITH IN JESUS?

Sometimes people worry that a person with dementia will lose his or her faith in Jesus. After all, Alzheimer's robs a person of the ability to remember. People also observe that Alzheimer's takes away a person's ability to communicate his or her faith. For example, a Christian man who has spoken openly about his faith all of his life reaches a point where he says nothing about it at all. Such a situation can make Christian loved ones feel uncomfortable.

Let us remember that it is not the ability to communicate our faith that makes us Christians. Rather, faith is simple trust in the promises of God. Said another way, faith means that we stand on the promises that God makes, relying on his Word. Saving faith is a conviction that was first given to us by God the Holy Spirit, and it is a gift that remains with us by God's grace through his Word and Sacrament.

Remember too that God worked saving faith in the hearts of many Christians through Holy Baptism when they were children. In Acts 2:38,39 Saint Peter proclaimed,

“Repent and be baptized, every one of you, in the name of Jesus Christ for the forgiveness of your sins. And you will receive the gift of the Holy Spirit. The promise is for you and your children.” That is why we are confident that infants believe, even when they possess limited mental capacity or do not have the language skills to express their faith. We are sure of this because Jesus himself praises the humble faith of little children. In this respect, he even uses them as an example for every Christian when he says, “Whoever humbles himself like this child is the greatest in the kingdom of heaven” (Matthew 18:4). People with Alzheimer's may not have the ability to express their faith, but we have every reason to believe that they still possess it.

Yes, it is hard to see a loved one lose his ability to speak of Jesus as he or she once did. The granddaughter of a person with Alzheimer's may ask grandpa to sing a familiar hymn. She remembers that he taught it to her years earlier while she sat on his knee. But now he looks at her with no clue of what she is talking about. It does not mean that grandpa has lost his faith.

Our faith remains even if we lose some knowledge of the Bible

For months a chaplain serving The Lutheran Home Association in a dementia care wing was bringing the Word of God to residents at their breakfast hour. As he left, a woman said, “Thank you for your devotions.”

She was a person who previously gave no indication that she was listening or even capable of understanding what was going on.

verses we memorized, the ability to memorize new ones, or the ability to be an active participant in devotions and prayers. We are happy to know that we rest securely under God’s promise of salvation even if we become more like a young child in our comprehension of Bible truths. We can also find comfort remembering how our loved ones expressed their faith in Jesus in their healthier days, before the disease.

It may help to know that many pastors and family members who have offered devotions to people with Alzheimer’s have seen them making

efforts to participate. They will pray along with some of the phrases of the Lord’s Prayer or mouth a few words of a favorite hymn. This can occur long after Christians with Alzheimer’s lose their ability to engage in casual conversation.

More than that, since many people with Alzheimer’s retain their ability to listen, we continue to lead them in prayers and read Scriptures. Caregivers notice that individuals with Alzheimer’s disease are calmed when they listen to music, including recordings of familiar hymns.

## ALZHEIMER'S IS A JOURNEY. GOD WALKS WITH YOU.

God will not abandon you or your family as you face Alzheimer's disease. His promise is that he walks with you in every trouble. "For I am the Lord, your God, who takes hold of your right hand and says to you, Do not fear; I will help you" (Isaiah 41:13). "I will help you" is the Lord's promise. He is paying attention.

God assures you that as he walks with you, nothing can separate you from his love. This promise is recorded by Saint Paul: "I am convinced that neither death nor life, neither angels nor demons, neither the present nor the future, nor any powers, neither height nor depth, nor anything else in all creation, will be able to separate us from the love of God that is in Christ Jesus our Lord" (Romans 8:38,39).

God invites you to come to him again and again to listen to his promises. So as a caregiver, make devotions and Scripture reading part of your care plan for yourself and for your loved one. Accept God's invitation to talk to him in prayer. He personally invites you, saying, "Call upon me in the day of trouble; I will deliver you, and you will honor me" (Psalm 50:15). Pray! He is listening.

Then look for his help! Of first importance, his help comes in the salvation that he provides. He assures you that this gift is yours as he leads you to repent of your sin and trust in Jesus for forgiveness. This gives you peace with God and assures you of the promise of eternal joys in heaven. But he does not stop there.

Some of his help will come to you in the form of other blessings. It may come from medical science, such as medication that controls the symptoms of the disease. It may come from medical professionals, friends, or family—Christian or non-Christian people who will support you and help you cope. The Lord's help to you may be the ability that he gives you to acquire new skills and develop innovative ways to support your loved one in this time of need. All of this assistance from the Lord is reason to give God praise and to tell others what God is doing for you.

Alzheimer's is a journey. As you walk down the road, know this: you are not alone. The Lord is going with you. He will provide you with people to help you. He knows your needs. He will never leave you. He is at your side to help you the entire way. That is his promise.

A nurse at The Lutheran Home was holding open a door to our memory care wing to enable a vendor to make a delivery. As she did, she heard this conversation:

Resident 1: Look, the door is open. Let's go and look at the basement.

Resident 2: OK, I don't think I've ever been to the basement. Where is the basement?

Resident 3: I don't know. I don't even know where I am!

Resident 1: You're with us, but we have no idea where we are either.

Then there was laughter.

Dementia is a life changing disease, but people with dementia can still enjoy their days and find fulfillment. So can their loved ones!



“When my husband learned he had Alzheimer’s, his first feeling was relief. Now at least he knew the reason he was doing the things he was doing.”

# Your loved one has Alzheimer's

## A PLACE TO START

Some of the most remarkable people in the world are the people who care for loved ones with Alzheimer's. I know because I have met some of them. Their steadfast love is amazing! So are their insights.

I often asked people this question: "What would you say if your best friend told you, 'My spouse has been diagnosed with Alzheimer's'?" The answers centered on one thought: "Get help!" They all found value in surrounding themselves with people who had "been there"—people who could answer their questions, help them work through their frustrations and assist them as they acquired new skills.

## YOUR STORY

Every family caring for a loved one with Alzheimer's has a story to tell. Every story has a beginning and moves from one turning point to another.

For one family, their Alzheimer's story involved two sisters. For months they were taking turns caring for their mom and dad in their home. Then the day came when one of the daughters left her parents alone, just for a moment. Suddenly, she realized that the house was too quiet. The front door was open. Both of them were on the street, walking in different directions.

For yet another family, the story began decades earlier as a wife witnessed the progression of Alzheimer's in her husband's siblings. Then one day she saw the symptoms in her husband.

If your loved one has recently been diagnosed with Alzheimer's, you have discovered the beginning of your own story. How the rest of it is written will be in large part up to you.

There are questions: What will I do? How will I cope? What is this going to cost? Can my loved one stay at home, and if so, for how long? What help is available?

So many questions! Where do we turn for answers?

While no two Alzheimer's experiences will be the same, being around people who are in your situation will help you get your arms around this new reality. They will help you understand the care your loved one needs right now and is going to need in the years ahead. This understanding is vital; as your loved one loses abilities to dementia, his or her quality of life will depend more and more on the quality of care that you and other caregivers provide.

Many resources are available to you. At the end of this document is a short list. It is brief by design. It is provided as a place to start.

One notable resource on the list is the Alzheimer's Association website at [www.alz.org](http://www.alz.org). It lists hundreds of support groups throughout the United States. It also identifies the symptoms of Alzheimer's disease, provides helpful suggestions for care plans, and offers a 24-hour helpline for support.

## WHAT YOU CAN EXPECT FROM THE DISEASE

Alzheimer's disease causes progressive, irreversible dementia. While no two cases are alike, Alzheimer's usually starts by attacking the area of the brain that enables the formation of short term memories, and then moves on from there. The video, *What is Alzheimer's Disease?*, produced by AboutAlzOrg (David Shenk, n.d.) outlines the following stages:

### n Short-term memory loss

The individual loses the ability to form new memories. During this stage a family member may hear the same story retold with exact detail three times in ten minutes. Some people will say, "I've caught myself doing that!" That may be true. But there is one thing different about the person with Alzheimer's: that person will have no clue that he or she is doing it.

### n Loss of language

As the disease progresses, it disrupts a person's ability to process language. The person finds it difficult to find the right word or to listen to a sentence spoken at normal speed. Caregivers frequently find it helpful to slow down their speech and to repeat what they say in order to be understood.



#### n Loss of logical processes

The brain loses the ability to solve problems, grasp concepts, or make plans. For example, a woman who was a teacher all her life knows that she should be able to tell time by looking at the face on an analog clock. But she simply cannot figure out what it means when the long hand points to the twelve and the short hand points to the three. The caregiver might solve the problem by purchasing a digital clock.

#### n Loss of emotional control

During this stage, the individual may cry for no apparent reason, exhibit fits of rage, or fill the room with inappropriate language. On the other hand, some people with Alzheimer's will laugh constantly. Sometimes during this stage, expressing emotion

may be the only way that individuals communicate. Caregivers may need to develop the skill of recognizing their loved one's needs by reading body language and emotions.

#### n Loss of the five senses

The mind loses the ability to interpret what the eyes see. Hallucinations may occur as the mind struggles to differentiate between dreams, memories, and what the brain is trying to make of reality. The seam where two pieces of carpet join may appear to be a stair step. A dark scatter rug may be perceived as a gaping hole, ready to swallow up all who move forward. The caregiver may need to remove scatter rugs, modify floor coverings, or change the lighting.

## n Loss of long-term memory

In this situation, memories of family and childhood prayers simply disappear. The person may stare at his or her spouse and seem to say, “I know I should know you, but I honestly don’t know who you are.”

In the last stages of the disease, the person loses control of muscles, balance, and coordination. Finally the mechanisms that manage breathing and heart rate shut down.

## ALZHEIMER’S CARE: HELP FOR HELPERS

These are hard topics to discuss, especially when we are seeing them in a person we have known and loved for many years. In their advanced stages, many diseases devastate the body. For example, when people have cancer, they may lose weight and grow weak; with diabetes, people may lose their eyesight or even limbs. However, Alzheimer’s confuses our loved ones’ memories and interferes with their ability to communicate, process thoughts and understand the world around them. This makes caring for people with dementia especially challenging.

That is why it is valuable for you as a caregiver to surround yourself with people who are dealing with the same issues. They can help you overcome burnout. Sometimes you may need someone who will simply let you vent.

A support group experienced with Alzheimer’s care can gather resources and discuss books and training materials that will help you master successful approaches for care. No doubt you will develop a good care plan from your own feel for the situation. Nevertheless, hearing what others are doing can give you new ideas that you can adapt.

## UNDERSTANDING THE SYMPTOMS OF ALZHEIMER’S

One support group reminds its members to view the words and actions of their loved one as symptoms of the disease, rather than behaviors (Jennifer Anderson, 2007). When a caregiver has this mindset, it provides a better understanding of what is happening and helps shape approaches to care.

For example, a loved one with Alzheimer’s may want to leave the building and go for a walk. But he forgets to dress appropriately for the weather, forgets to look for traffic when he crosses the street, and worst

One lady came to a support group where each person was asked to share a positive experience. Speaking of her husband, she opened with the same thought each week. With a twinkle in her eye she would say, “Well, I didn’t kill him!”

Those words may shock some, but it was this lady’s way of keeping balance. She valued the chance to share it.

of all, forgets his way back home. This activity is called *wandering*. It puts him in danger. A caregiver must intervene, but what should she do?

If she views wandering as a behavior, she is likely to think, “If I just explain why this is dangerous, he’ll make a better decision. He won’t wander anymore. He can get this under control.”

So she sits down to have the discussion. She explains calmly that it is dangerous for him to go for a walk by himself. He will probably agree, because he senses that it is important

to her that he does. She pleads with him, “Please, don’t leave the house without me.” He doesn’t really know what she means, but he will make the promise. He knows that it will please her.

She thinks, “Good, we’ve accomplished something.” Unfortunately, five minutes later she may find him at the door reaching for the knob. She will say, “Didn’t you just promise never to leave the house without me?” He will look at her like he has no idea of what she is talking about—and he doesn’t.

We are accustomed to thinking of activities as behaviors, so it is almost instinctive to fall into this pattern. But here is the problem: when we think the person under our care should be responsible for his or her actions and the response doesn't meet our expectations, we easily become frustrated. If our loved one senses this, he or she might react to our emotion with fear or anger. The situation can easily escalate to verbal abuse or worse. Many instances of elder abuse are related to scenes similar to this.

There is a better way. When we view the wandering activity of a person with Alzheimer's as a symptom, things change. We can think of the concept this way: wandering is a symptom of Alzheimer's disease; a fever and headache are symptoms of influenza (the flu).

Imagine as a parent you are caring for your young child. You discover that your child has the typical symptoms of the flu. You consult with a medical professional who confirms the diagnosis. What would you do? Would you go to your child and say, "I understand that you have a headache. I want you to make a decision to make it go away. While you are at it, I want you to promise to eliminate your fever too"? You would never talk like that! The child cannot control those symptoms by sheer force of will. No one can.

Instead you might say, "Your fever and headache are happening because you have the flu. This is what happens when we catch these germs. The doctor has told me about some medicines that will help. I want to give them to you. I also have a cool, wet cloth to put on your head. It will make you more comfortable."

Experienced caregivers remind each other,  
"When you argue with a person with dementia,  
you always lose" (Jennifer Anderson, 2007).

With this approach, the parent is showing an understanding of five important facts:

n Flu-like symptoms are typical of the flu.

n Symptoms happen for a reason.

n The child cannot make the symptoms go away by merely deciding to do so.

n The symptoms cannot be eliminated as long as the child has the flu, but they can be managed.

n The child will be more willing to accept direction in a setting that is calm.

Likewise, a person caring for a loved one with Alzheimer's will benefit from knowing the following:

n Wandering is a symptom that is common to Alzheimer's disease.

n Each symptom, even the most bizarre, happens for a reason.

n At some point the person with Alzheimer's will likely become unable to control his or her wandering, or the person may be in control some days but not others.

n It is the responsibility of the caregiver to understand that no one can eliminate the activity; the best anyone can do is manage it.

n The caregiver also needs to understand that reacting calmly to every stressful situation helps the person with Alzheimer's accept guidance.\*

When a caregiver understands these principles, things change for the better.

Hundreds of Alzheimer's symptoms have been identified, and each one is caused by some distortion in the brain's ability to process information. All people respond to their needs as they perceive them. If the thought process is skewed, the action to meet a perceived need will not make much sense to most people. However, if the caregiver can discover the need the person with Alzheimer's is trying to meet, it is often possible to provide an

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\* Of course, we cannot make a point-by-point comparison between all the symptoms of Alzheimer's and the flu. We have many medications to treat the symptoms of the flu. A number of them are available without prescriptions. Using medications for a symptom such as wandering is far more difficult. Often there are significant downsides to doing so. This treatment must be done under the care of a qualified medical professional.

alternative. By doing so the caregiver usually can reduce the incidence of the symptom or redirect the individual to safer activities.

A casual conversation might uncover what the wanderer is seeking to accomplish by wandering. Maybe the wanderer has a need for exercise. Once a caregiver knows this, the wandering might be managed by taking the wanderer for a walk a couple of times a day or by providing an exercise machine. If the wanderer simply feels bored, the caregiver can engage the person in household chores, playing a game, or doing a word search. In still another instance, a person may wander because he or she thinks it is time to meet with someone. In that case, the caregiver may call on an old friend to come for a visit, or maybe take the loved one to a “meeting spot,” such as a coffee shop, and explain that the person he or she is looking for did not show up.

Of course, it still may be necessary to secure the doors. However, when the caregiver looks at wandering as a symptom, he or she is more likely to keep the loved one safe with the least amount of restriction. Perhaps rather than placing a lock on the door, the door could have an alarm or a silent sensor that will alert the

caregiver when the door is opened. When alerted, the caregiver could head outside to walk around the yard for a few minutes and then guide the wanderer indoors.

The caregiver can also talk about these experiences with his or her support network. Other people who are also dealing with Alzheimer’s symptoms might have ideas that have worked well for their own wanderers.

### LIVING IN THEIR WORLD

A support group can help caregivers learn to *live in the world* of their loved one instead of trying to correct obvious misperceptions which are strongly held by the person with the disease (Jennifer Anderson, 2007). The following story applies the concept of *living in their world*. It comes directly from Anderson’s experience while working with a family.

A daughter heard her mother express concern that Dad was late coming home from work. Mom worried first about his safety. Then Mom worried that he might be with another woman. The reality was that Mom had been a widow for 14 years. At first instinct, a caregiver might try to help Mom understand reality. However, there could be some good reasons to avoid correcting Mom’s misperception.

One wife's story:

Before her husband came to The Lutheran Home, he was at a different home for care. While on an outing, he slipped away from the group. His absence went unnoticed.

"I don't know how he did it, but he traveled six miles. I found out about it when I got a call from the police telling me that they had my husband in the back of their squad car." The police were called when a clerk at a convenience store complained that he tried to buy a bottle of water with counterfeit currency.

When her husband had first entered the nursing home, it was important to him to carry a wallet containing large bills. Because that was not a wise thing for him to do, the administrator had suggested the wife provide him an inexpensive wallet and give him a couple of photocopied \$100 bills. That satisfied him and all was good, until he wandered away from his group and used his fake money to commit what in the eyes of the law was a felony.

"Fortunately the police officers understood the situation and brought him home to me."

Suppose the same conversation had occurred the day before. At that time the daughter had told her, “Mom, Dad died 14 years ago.” At the news, Mom had burst into tears. She reacted to the news of her husband’s death the same way she did when she heard it 14 years earlier. Or suppose Mom had not believed the daughter and had angrily accused her of lying.

On the other hand, when a daughter seeks to *live in the world* of her mother, she can try to redirect the conversation and trigger a pleasant memory about Dad. “Mom, did Dad ever surprise you with flowers or a gift?” If Mom recalls an occasion like that, the daughter could suggest that Dad might be late because he is doing some shopping for her. If Mom does not recall an instance, the daughter might remind her mother of a special present that she received from Dad. That is likely to elicit a response that is positive. The daughter then can close the conversation, “Yes, Dad sure is a thoughtful guy.”

The daughter knows that because Mom has lost her short-term memory, she may not remember this conversation after a few minutes. What her caregiver has accomplished is to leave her mother in a comfortable and pleasant state of mind.

At first, some might feel uncomfortable with the *living in their world* approach. It certainly would be inappropriate if it were used to harm or ridicule a person. Some might label it dishonest. Do not think of it that way. Rather think of it as an honest way to help. When motivated by love, a caregiver can use *living in their world* to help the person with Alzheimer’s deal with the life that she is living today. When Mom cannot understand reality, caregivers can put themselves in her world to help her live life as she perceives it, in peace.

#### FORWARD FOCUS

Finally, another part of *living in their world* is to help the person with the disease look forward to upcoming events. Caregivers can provide reminders that birthdays or holidays are coming or let their loved one know that family and friends will be arriving for a visit. It might be as simple as saying, “Remember, tomorrow is Wednesday. That’s when I will be bringing you your favorite, a bag of french fries.”

#### COMMUNICATION

At some point you as a caregiver may need to adjust your communication techniques. Alzheimer’s disease reduces the brain’s processing speed, so it is often necessary for caregivers

One family helped their loved one plan a vacation to Hawaii. This trip was something that they had always thought about, but like a lot of people, they were never quite able to get it done. The family brought travel brochures to the nursing home and talked to their loved one about the places they wanted to see and the things they wanted to do.

The family knew their loved one would never be able to take this trip, but the discussion was therapeutic. The planning gave each visit a forward-looking focus.

to slow their speech dramatically.

As dementia advances, it is usually helpful to signal that you want to talk by putting yourself directly in front of the person at his or her eye level, then reaching slowly to make contact with the person's hand. If he or she is comfortable, you can try moving closer. Use a gentle voice and short, simple sentences. Often statements of fact are better than questions.

It is okay to try asking questions, but use questions that will require only a

“yes” or “no” answer. Ask the question, and then wait—waiting even longer than you think you should. It may take up to a minute and a half for a person to answer. If there is no response, be prepared to repeat, patiently.

If you offer choices, offer only two. Instead of posing the question, “What shirt do you want to wear today?” ask, “Would you like to wear the blue shirt or the green sweater?”

In the later stages of the disease the person with Alzheimer's will lose the ability to verbalize desires. The caregiver will need to "read" the person's visual cues and emotions to determine his or her needs and wants. A nonverbal individual may growl when a caregiver comes near while he or she is eating. It may mean, "I think you want to take my food, but I'm not done eating yet" or "I think you want to give me a bath, but I don't want one now." Be patient. Listen carefully to the tone and emotion. Study the body language. Communication is more than words.

### **STAYING ACTIVE AND ENGAGED**

Over time the person with Alzheimer's will lose initiative. A caregiver will need to develop a plan that involves the individual in doing as much as possible independently. "What you don't use, you lose" is true, especially with Alzheimer's. It may take 30 minutes for a wife with Alzheimer's to brush her teeth on her own. Her husband could do a better job for her in less than five. But encouraging the individual to do as much of her own self-care as possible is essential to a good care plan. Helping with dishes, vacuuming, or dusting—any of these activities can improve the quality of life for a person with Alzheimer's (Jennifer Anderson, 2007).

Our caregivers working for The Lutheran Home Association have another guideline: "What is good for the heart is good for the mind." Diet and exercise are a good combination to make the most of the mind that Alzheimer's leaves behind. Social interaction with anyone, but especially family and friends, seems to help the brain "fight back" and may slow the progress of dementia.

Finally, encourage your loved one to be involved with as many decisions regarding the future as he or she can reasonably handle. In this way you respect your loved one's dignity as a person.

### **CREATING NEW MEMORIES**

Remember too that these years with your loved one are a time to create memories for yourself and for your family. Baking a cake with Mom and the grandchildren may take a lot of time and create a big mess, but it can provide your family with a cherished moment that all of you can recall for the rest of your lives. A support group can help you savor the good times. It can provide "outside the box" suggestions for interactive games, including activities with family members. Group dynamics can spark your creative juices to involve your loved one with the people she has loved all her life.

A wife cared for her husband with Alzheimer's. She said that during that time she became closer to him than at any other time in their married life. They discussed things they had never spoken of before he was diagnosed with the disease.

Yes, with Alzheimer's there will be times of sadness. But there also will be moments of laughter and joy. With some planning, you can put together events which will create memories for all involved.

### CARE OPTIONS AND HELP

A support group can also help you explore care options, such as in-home health services, respite care, or adult day care. These are just a few of the alternatives that are available in many areas. Your support group can help you get connected to your local senior center.

If your loved one needs residential care outside the home, your network will likely have a good knowledge of what is available in your area, whether it is memory care assisted living or skilled nursing residences with special areas devoted to dementia

care. Remember, your best options for residential care may have the longest waiting lists. There is no harm in meeting with potential providers early in the process. Waiting, however, may result in limited choices for placement if the need arises.

Your support group may also know contacts in state or county government who can provide assistance with veteran's benefits, finances, or legal help should any of these become necessary.

If it is likely that your loved one will need care away from home at some stage of the disease, think about allowing him or her to experience short stays in the residences that you are considering. Having a man with Alzheimer's, for example, spend a week in such a residence will give his caregivers a break and allow him to

see if the residence is a good fit for him and for his family. It will provide him the opportunity to build a social network with other residents and allow the staff a chance to get to know him, his preferences, and his needs at a time when he can communicate his wishes.

### LIFE WITH JESUS

As a Christian caregiver, you will also want to nourish your loved one's relationship to Jesus. This changes too.

Most adult Christians are eager to grow in their understanding of their faith by learning new information. With Alzheimer's it is different. Individuals lose their ability to form new memories and process abstract thoughts. As dementia advances,

caregivers serve their spiritual needs by finding new ways to draw out old memories instead of trying to share new biblical insights.

For many Christians, some of their most lasting memories will be the Bible stories, favorite hymns, and prayers that they learned as children. Even when people have reached the last stages of dementia, they often will join in speaking parts of the Lord's Prayer or keep the beat with "Amazing Grace." It may be that when these memories are reviewed, they are reinforced, so the person with Alzheimer's is able to retain them long after other memories fade. Just be prepared to be patient, to try different approaches, and to study the person's reaction for subtle responses.

A chaplain for The Lutheran Home Association was conducting a worship service. He observed a woman with an advanced case of dementia singing stanza after stanza of a favorite hymn. When he looked more closely he noticed that she was holding her songbook upside-down.

Dementia had blurred many memories, but not the recall of this hymn learned years ago. Hearing others sing it was all it took to trigger the memory of the song she held so deeply in her heart.

For as long as she could remember, a daughter knew her father as a man who was unable to tell her that he loved her. It just wasn't his way.

When she faithfully visited him in the nursing home, she would end each visit by giving him a hug and expressing her love for him.

One day he said it. "I love you!"

It is a memory that she will always cherish.

### **"IT'S ALZHEIMER'S"—IT'S TIME FOR EXTRAORDINARY LOVE**

Life brings changes.

We are happy about some of them. We look forward to new jobs, retirement, graduations, weddings, and the birth of grandchildren.

Other changes bring challenges that no one wants, such as diseases or life-changing accidents. When they occur, they require that we serve the people God has placed in our lives in ways we never dreamed and never thought we could. It takes extraordinary love and dedication.

Extraordinary love is not unlike the love that God had for us in sending Jesus, his Son. God is pleased when we express such love. When we love in God's way, caring for the body, mind, and soul of the people who are around us, we are sharing God's love. He will help us live up to the challenges that he places before us and will bless the work of all involved.

"To him who is able to do immeasurably more than all we ask or imagine, according to his power that is at work within us, to him be glory in the church and in Christ Jesus throughout all generations, for ever and ever! Amen" (Ephesians 3:20,21).

# A note for caregivers

On the next pages, you will find chapter 4: “I have dementia. Now what?”

It is written for a person with dementia to read for himself or herself.

It is offered to help the individual understand the disease and find comfort from God’s Word. It also outlines what he or she can do to help caregivers meet the challenges that dementia brings to the family.

It is directed toward the person with dementia to encourage that person to be involved in as many of the decisions about his or her care as possible. This is an important thing for you, the caregiver, to remember as you develop a care plan that respects the dignity and wishes of your loved one.

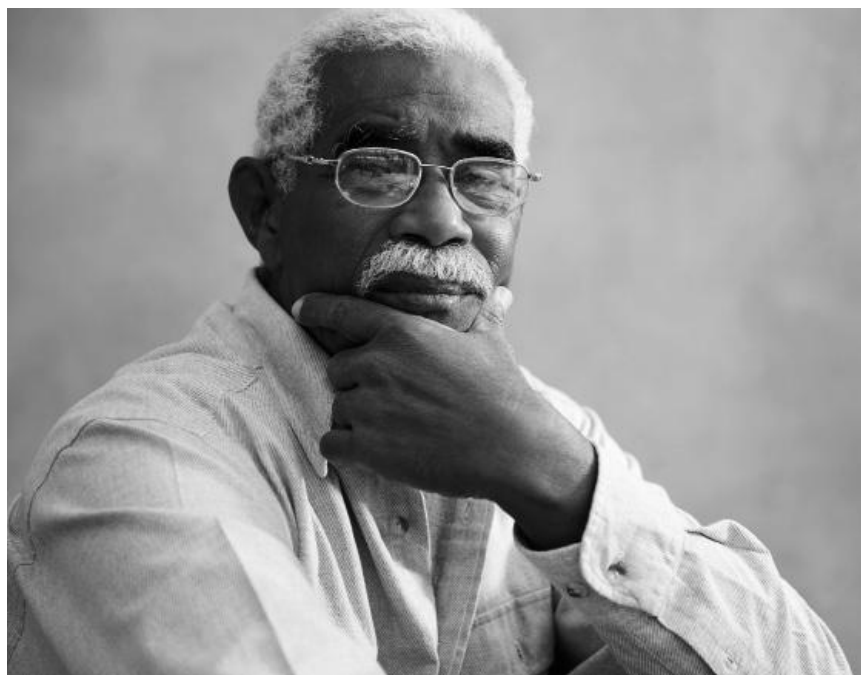
Of course, you as a caregiver will have to decide if your loved one has the ability to read this chapter and, if so, if he or she will benefit from reading it. You will also need to decide if some topics are too troubling to present at this time.

If your loved one is unable to understand this section, this section is for you, the caregiver. Use it to guide you on the steps that you will need to take to manage your loved one’s legal and financial affairs.

Representatives of The Lutheran Home Association’s Office of Mission Advancement stand ready to help. They can meet with you, your loved one, or other family members to discuss planning techniques for legal and financial matters. They will respect your confidentiality. They neither sell products nor represent those who do. They do not do legal work or offer financial advice. What they will do is offer guidance as you organize and coordinate your affairs. They will provide you with ideas to consider as you work with your own legal and financial professionals.

For more information contact:  
The Office of Mission Advancement at The Lutheran Home Association  
National Ministry Offices  
337 South Meridian Street • Belle Plaine, MN 56011

1-888-600-TLHA (8542) • (952) 873-6000  
E-mail: [info@tlha.org](mailto:info@tlha.org) • Website: [www.tlha.org](http://www.tlha.org)



## I have dementia. Now what?

If you have been given these pages to read, it's because your loved one wants you to have the comfort and guidance they provide. These pages will also outline some simple things that you can do to help your family provide you the best of care.

### **I HAVE DEMENTIA. HOW SHOULD I REACT?**

There is no “right way” to react to the news of your disease. There may be days when it all seems unreal. You may spend hours hoping you will wake up and discover you are just having a bad dream. There may be days when you are overwhelmed with unspeakable fear. You may feel as though you are the only person in the world who is hurting like you are hurting. You may have regrets for things you have done or said, or for something you have left undone.

There may be days when you look for someone to blame: God, the people closest to you, even yourself. Your moods may change by the hour or sometimes by the minute. You may become incredibly angry and then feel ashamed of your anger. The roller coaster of emotions may well be part of your journey. It is for many.

Or, you may feel nothing at all.

No one can tell you how you should feel. This is a difficult disease. You may have questions such as the ones that follow.

### **IS THIS DISEASE A PUNISHMENT FROM GOD?**

We know that dementia is not a punishment for anything you have done. God does not operate that way. Jesus has forgiven your sins, each and every one of them. He did it by taking onto himself all the punishment for every sin and for every sinner on the cross. No punishment on earth is left for you.



#### **WHY DID GOD LET THIS HAPPEN?**

Do not try to figure out why God let this disease affect you. Perhaps you are thinking, “Everything happens for a reason and I have to figure out the reason.” If so you can respond with this thought, “Everything may happen for a reason. Only God knows the reason. I am not God, so it is okay for me not to know why.”

Know this: God loves you. The proof of God’s love is that he sent Jesus to be your Savior. Jesus offered his life to carry out God’s plan to bring you forgiveness and the promise of heaven. Having this disease or any disease does not change God’s love for you. He will never abandon you. His love endures forever. He knows your needs and will continue to provide for you.

Here are some other important things for you to consider:

**THIS DISEASE MAY BE THE WAY THAT GOD TAKES YOU FROM LIFE ON THIS EARTH.**

As a Christian, God may be using your disease to bring you to the glories of life with him in heaven. When you die as a person who trusts in Jesus as your Savior, God makes sure that his angels carry your soul to heaven. When the time is right, Jesus will raise your body and unite it with your soul. The Scriptures promise that he will change “our lowly bodies so that they will be like his glorious body” (Philippians 3:21).

If you have been avoiding people who offer to talk with you about a loving relationship with Jesus, now is a good time to invite them to visit. A pastor or a mature Christian friend can describe the blessing of God’s love and his plan for your eternity. It is based on Jesus’ forgiveness and the promise of heaven to all who believe. This is a person who can pray with you and for you. Moreover, this will likely be a good person to talk to if you want to share your anger, fears, regrets, or anything else that is on your mind.

**YOU CAN HELP YOUR LOVED ONES CARE FOR YOU.**

The disease will require that you have a team of caregivers to help you. You will also need to identify people to make medical decisions for you and manage your financial and legal affairs when you can no longer do so for yourself. This planning is important for every one of us to do before there is a crisis.

Let helpful people help you! Inform your family of your desires. They will be much more comfortable and confident acting on your behalf when they have a firm understanding of your wishes. You will ultimately have more control over your living arrangements, your comfort, your health care, and your finances when you do the following:

- n Identify the people you want to be your helpers.
- n Express your desires to them.
- n Give them the legal authority that empowers them to carry out your wishes.

By doing this while you are still able to make these decisions, you will reduce expenses, legal complications, and confusion, and you will make it easier for the people you trust to provide you with the best care possible.

Here are some steps to consider at this time:

- n Set up a general durable power of attorney. This document names the person or persons you want to manage your financial affairs should you become incapacitated. Make sure they know where your documents and valuables are stored and will have access to your safe or safe-deposit box.
- n Set up a medical directive. This is sometimes called a *durable power of attorney for health care*. The document will ask you to name the person(s) you want to make health care decisions for you when you are no longer able to do so. He or she is known as your personal representative. You will want to make sure this person respects your moral values as a Christian with regard to end-of-life issues.
  - \* With this document, you can also provide guidance for the medical decisions you want him or her to make. Be sure to include instructions that authorize your personal representative to make decisions regarding long term care, such as moving to assisted living or a skilled nursing residence.
- n Review your plan for the final distribution of your estate. See if a will or living trust is the best way to pay your debts and obligations and to distribute your assets and possessions among your family, friends, and the charities you love. Discuss these matters with an attorney who specializes in estate planning.
- n Check to see that your beneficiary designations, transfer on death, and payable on death designations are in order. If done correctly, these will transfer your property to family, friends, and charities in a way that minimizes taxes and costs to your estate.
- n Review your insurance policies, investments, and retirement plans with the person who will hold your power of attorney. Tell that person where you keep your paperwork.
- n If you have long-term care insurance, ask the person holding your power of attorney to review the policy. Clarify under what conditions premiums need to be paid and the nature of the benefits to which you are entitled.

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\* More information is provided on the resource list at the end of this book, including a statement of beliefs that you can use to communicate a Christian perspective for end-of-life care.

- n Discuss your wishes for your funeral with your family and pastor. You can set aside money to cover these final expenses. Even if you spend all your assets to pay for long-term care needs, there are ways to preserve money to pay for funeral expenses. An attorney or funeral director can help you.
- n Finally, let people know how you want them to care for you if the disease progresses to the point where you cannot communicate your desires. Let your loved ones know if you want them to touch your hand when they visit. Write up a list of favorite hymns, music, and Bible readings that you would like to hear when you are no longer able to request that they do so.

This is a lot to cover. You aren't going to get it all done right now. However it is important to start soon and sort out what needs to be done first.

After you have expressed your *preferences*, let your loved ones know that they are preferences. Encourage the individuals you have empowered to use their best judgment in making decisions for you based on the circumstances.

If your family is providing much of your care, let them know that you want them to meet their own needs too. Consider asking your caregivers to explore care options in your area. Check on the availability of residences that offer you a place to stay for the day and return home at night. As you do, you will have the satisfaction of knowing you are giving your loved ones a break. You will probably enjoy the change of pace and have the chance to make new friends.

Also, you might ask your people to arrange short stays for you at a long-term care residence. This will enable you to try it out to see how it meets your needs.

Finally, make the most of your days. For us as Christians, the best is yet to be. We look forward to the day our soul arrives in heaven. However, while on earth, even with dementia, there will be plenty of good days. Make the most of them with your family and friends. God will be with you with his love. You can count on it!

# BIBLIOGRAPHY

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## RESOURCE LIST

The following materials provide an understanding of Alzheimer's disease as well as ideas for caregivers. The Lutheran Home Association provides this resource list, but does not necessarily endorse all the opinions expressed or implied in the materials.

*The Alzheimer's Project*, produced by HBO Documentary Films. The videos include the following segments:

*The Memory Loss Tapes*, in which viewers are brought into the world of seven individuals in different stages of Alzheimer's disease. *A note of caution from The Lutheran Home Association: These tapes include a segment in which a person discusses his intention to take his own life.*

*Caregivers*, a collection of five family portraits as they care for their loved ones in progressive levels of Alzheimer's disease.

*Grandpa, Do You Know Who I Am?* In this segment Maria Shriver provides ways for young people to understand a grandparent's memory loss.

*The 36-Hour Day*, a family guide to caring for persons with Alzheimer's disease, related dementing illnesses, and memory loss later in life. Authors: Nancy L. Mace, M.A., and Peter V. Rabins, M.D., M.P.H. Wellness Central, New York.

The Alzheimer's Association website contains a wealth of information including contact information for support groups throughout the United States. Phone their 24/7 Helpline for information on Alzheimer's disease, referral and support.

Phone: (800) 272-3900

Tdd: (866) 403-3073

E-mail: [info@alz.org](mailto:info@alz.org)

Website: [www.alz.org](http://www.alz.org)

EduCare Training - Dementia Series, developed and facilitated by Jennifer Anderson, Mirabelle Management, LLC. A five-part DVD series (also available online) providing practical solutions for professional and family caregivers including a disease overview and symptoms, communication skills and techniques, activities of daily living from a balanced perspective, changing the

mindset of looking at symptoms versus behaviors, and a touching look at the disease from the victims and family point of view. *Note: The Lutheran Home Association uses this material as a training resource.*

Phone: (952) 288-3800

Website: [www.mirabellemanagement.com](http://www.mirabellemanagement.com)

Email: [jmamirabelle@msn.com](mailto:jmamirabelle@msn.com)

Information about Alzheimer's disease is available on the website, [aboutalz.org](http://aboutalz.org). There you will find a series of helpful video clips under the title *A Quick Look at Alzheimer's*.

The Lutheran Home Association offers resources for Alzheimer's care and materials on Alzheimer's for Bible classes or discussion groups, including the materials listed below:

n A Bible study with discussion questions based on chapter 2 of

*"It's Alzheimer's"—It's Time for Extraordinary Love*

This chapter is entitled "God himself walks with you." It deals with the questions that people have about God's goodness and care when faced with a life-altering disease such as Alzheimer's.

n Lesson 7 of the Bible study is based on the first video segment of the *A Quick Look at Alzheimer's* series, "What is Alzheimer's disease?"

n *A Quick Look at Alzheimer's*, produced by AboutAlzOrg in partnership with The Alliance for Aging Research

*A Quick Look at Alzheimer's* contains a number of short video clips. It is available as a DVD or can be viewed at [www.aboutalz.org](http://www.aboutalz.org).

You can view, download, and/or order these materials at The Lutheran Home Association website, [www.tlha.org](http://www.tlha.org). Click on *Resources*, then *Aging Resources* and then on *Alzheimer's Resources*.

If you prefer to contact The Lutheran Home Association by phone, call (952) 873-6000.

# MY STATEMENT OF BELIEFS

## A Christian perspective on end-of-life care

1. I believe life is a gift of God (Psalm 139:13-18; Jeremiah 1:5) and that our times—birth and death—are in his hands (Deuteronomy 32:39; Job 1:21; Psalm 31:15).
2. I believe that because of sin, death has become an intrusion upon life and is the normal end of earthly life (Genesis 3:19; Romans 5:12; 6:23; Hebrews 9:27).
3. I believe eternal life is God’s free gift because Jesus’ perfect life and sacrificial death paid for my sins (John 3:16; Romans 6:23).
4. I believe that God takes life by his decision, and therefore I reject any attempt to lengthen my life when it is clear God intends to take it (Psalm 31:15; Matthew 4:7).
5. I reject any attempt to end my life when God would sustain it, regardless of a possible diminished state of quality to my life (Genesis 9:6; Exodus 20:13).

By this statement, I also wish to express my love for my God who created, redeemed and sanctified me, as well as my love and appreciation for my (spouse) and children whom I look forward to joining in the home that lies ahead with our God in heaven.

This statement of beliefs can be included in your medical directive or appended to the document and signed in accordance with the laws that apply in your state.

Christian Life Resources offers a Christian durable power of attorney for health care form with versions valid in all 50 states. You can contact them at (262) 677-5230 or visit their website at [www.christianliferesources.com](http://www.christianliferesources.com).

# THE LUTHERAN HOME ASSOCIATION



The Lutheran Home Association offers Christ-centered homes, services and programs, serving people's unique needs. We provide quality health care, housing, and support services in Minnesota and Wisconsin. Our Jesus Cares Ministries assists congregations in reaching out with the gospel to people with intellectual and developmental disabilities, their families, and communities.

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