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# Faith and Dementia

## SCOTT HOEZEE

In November 1994, former president Ronald Reagan wrote an open letter to America, and said: Nancy and I feel it is important to share with you that I have been diagnosed with Alzheimer's disease. In opening our hearts, we hope this might promote greater awareness of this condition. Perhaps it will encourage a clearer understanding of the individuals and families who are affected by it. Well, Reagan instantly became the most famous person in the world struggling with dementia; but it is a struggle shared by millions. Today on *Groundwork*, we want to ponder this painful reality, and dig into scripture for guidance and comfort. Stay tuned.

## DAVE BAST

From Words of Hope and ReFrame Media, this is *Groundwork*, where we dig into scripture to lay the foundation for our lives. I am Dave Bast.

## SCOTT HOEZEE

And I am Scott Hoezee; and Dave, we are, with this program, beginning a fairly short, four-part series—four programs—where we are going to look at how the Bible speaks to some deeply personal and stressful struggles with which a lot of us are quite familiar in our lives.

## DAVE BAST

Exactly; we have chosen some of the commonest physical, spiritual or emotional difficulties that most of us experience. Sometimes they become more pronounced and require professional treatment; but, there are also just kind of days when we feel depressed or we are dealing with anxiety or worry; or maybe our mental faculties are starting to slip; or even things like day-to-day chronic pain. So, those are the subjects that we would like to address, not so much from a psychological standpoint, but from the standpoint of scripture. What does scripture offer to believers as they deal with these things? And today, we are especially delighted to welcome a guest who will contribute to this program dealing with dementia or memory loss. She is Dr. Suzanne McDonald, a professor at Western Theological Seminary; and as you will hear in just a moment when she says hello, Suzanne did not grow up in America. She is a native of Australia. So Suzanne, welcome.

## SUZANNE MCDONALD

Yes, thank you. Great to be here; thanks so much for inviting me; and yes, I am an Aussie.

## SCOTT HOEZEE

Yes; well, Dave and Suzanne, as you just said, we want to go to scripture; and in this program, to deal with a very painful reality, and that is the reality of dementia. It is something that a lot of us know about. There are about five million Americans right now struggling with some form or another of dementia, but that number is expected to rise to fourteen million by the year 2060.

## DAVE BAST

So maybe, Suzanne, you could help us begin by explaining exactly what this is, and how...it doesn't mean as soon as you start forgetting things that you are on the path to this.

## **SUZANNE MCDONALD**

Yes, that is right. I think a lot of people worry about it. I mean, all of us do. The slightest blip in your memory and you wonder: Oh, my goodness, am I on the slippery slope to dementia? But all of us have that, right? I have junior senior moments all the time. I am always locking my keys in my office and so on. That is not what it is. I once had a really wise person say to me: How do you know, especially as you are getting older, when this has transitioned from kind of ordinary memory loss to something that is more serious? And this lady said to me: Well, it is kind of like when do you know your child is a teenager? It is not when they turn 13; it is not one thing you can just sort of pin down, it is a case of oh, now, you just feel it. You notice something is a little bit different. So, I don't think any of us should be anxious if we are just forgetful every now and again; but the kinds of things where maybe someone has been driving the same route for years and years, and then suddenly they are beginning to get confused—they are not quite sure where they are going; or when ordinary, day-to-day routine tasks...or suddenly you sense in yourself or other people notice in you that something isn't quite right—that you are more confused than you should be about stuff that, yes, we really find almost instinctive most of the time.

## **SCOTT HOEZEE**

Yes; we tend to think, most of us, of dementia as only being Alzheimer's disease, but physicians have actually now identified, believe it or not, 120 different forms of dementia. Alzheimer's is a very common one, but there are some other, really severe forms, like Lewy body, frontotemporal vascular dementia; and as you said, Suzanne, we also tend to think that dementia just is memory lapses, but it actually involves a whole range of things, doesn't it, that makes just the activities of daily living very difficult.

## **SUZANNE MCDONALD**

Yes, that is right; and especially as the disease progresses. I mean, one of the hardest things is actually for caregivers when, for example, there is significant personality change...personalities...maybe someone who has been gentle and quiet becomes a lot more aggressive...and when you think about what is happening inside of someone, just imagine the fear and the frustration inside of someone who is beginning to get fairly advanced dementia; where, you know, it seems like who you are is disintegrating from the inside. Everyday things confuse you and so on. It is not surprising that some people get perhaps very distressed, very aggressive...and then there are things like if your memory has lapsed and stuff, and you cannot remember where you put your wallet or your change, and you cannot find it anymore and you start accusing perhaps your family members or caregivers of taking it, just imagine the multiple layers of stress, not just for the person with dementia, but for the family members and the caregivers. It is hard across the board.

## **DAVE BAST**

There are physiological changes that contribute to this disease.

## **SUZANNE MCDONALD**

Oh, that's right. I mean, I am no medical expert, but I have seen the pictures and I have actually seen physically when someone who has died who has had advanced dementia; and you see the brain mass of someone who has advanced dementia, and the brain mass of someone who has died who is ordinarily healthy, it can be a third less brain mass, right? Your brain is literally shrinking through this disease, which affects all sorts of aspects of how your brain would normally function. It is a terrible thing, and at this stage there are no real prospects for a cure, and even the treatments aren't all that helpful. It is hard.

## **DAVE BAST**

I just think we should pause here and stress this point for anyone maybe who has a loved one who is experiencing this. This is not just a psychological condition. This is a real physical disease like cancer or like heart disease; and things beyond their control are happening to their brains, which affect, then, their behavior.

## **SCOTT HOEZEE**

Right; and their visual field narrows, they really cannot make good sense of what comes in through their ears; so they cannot see well, they cannot hear well. Older people generally lose feeling in their hands and feet; that is common of aging, but you combine all of that and you see the total disorientation that this can lead to; but all of this, also I think, raises other questions for us; and to get at some questions people have, let's turn to Genesis 1 and just be reminded of a core part of what it means to be human.

We are in Genesis 1:

<sup>26</sup>God said, "Let us make humankind in our image, according to our likeness; and let them have dominion over the fish of the sea and the birds of the air; over the cattle and the wild animals, and over every creeping thing that creeps upon the earth." <sup>27</sup>So God created humankind in his image; in the image of God he created them; male and female, he created them.

So, the image of God, Suzanne, is such a constitutive part of what it means to be human.

## **SUZANNE MCDONALD**

Yes; and one of the unfortunate things is that many of us, I think, leap to the understanding of the image of God as if it has to do just with our rationality or our minds; and as we have just heard in scripture, that is not scriptural, right? Nowhere in scripture is being in the image of God simply identified with our minds; and that is so important that we kind of let go of that; not just for folks, for example, with dementia, but a whole range of other folks who may be cognitively challenged in all sorts of ways. I think one of the best ways for us to begin to think about the image of God in dementia is to think about the image of God in terms of the relationship—the unique relationship—that God establishes with human beings. It is right there in the Genesis text; and if we take that as our priority—that God has established a unique relationship with human beings—okay, we are called in general to respond to God, but when you cannot do that, in the situation of dementia, maybe the image of God has been damaged by this disease, but it has not been lost. So, a person with dementia remains a beloved human being in the image of God, with whom God remains in relationship, even if that person with dementia cannot really express, or maybe even be aware of, their own relationship with God; keeping hold, as this person with dementia, as a beloved child of God, and the image of God is so important for how we then treat people.

## **DAVE BAST**

Even people who are perhaps born without any mental capacity. Maybe they have never been able to speak. They have never been able to respond in any deep way. They are still creatures made in the image of God; and this is something increasingly, I think, that will set us apart as Christians...

## **SUZANNE MCDONALD**

Yes.

## **DAVE BAST**

And other people of faith, frankly; that we believe in the preciousness and the importance of all human lives, regardless of how capable they are, regardless of how gifted or not they may be.

## **SCOTT HOEZEE**

Well, there is so much here in this program, both for people who may be listening who are maybe in the early stages of dementia, but also for caregivers and loved ones and family and fellow church members. So, in just a moment we are going to ponder some other pastoral and spiritual and personal aspects of all of this. So, stay tuned.

*Segment 2*

## **DAVE BAST**

You are listening to *Groundwork*, where we are digging into scripture to lay the foundation for our lives. I am Dave Bast.

## **SCOTT HOEZEE**

And I am Scott Hoezee, and today we are also being joined by Dr. Suzanne McDonald of Western Theological Seminary in Holland, Michigan; and Suzanne is helping us think about dementia, and various forms of dementia, and some of the spiritual aspects of that. Suzanne, when you have dealt with this and talked with adult education groups and the like about this topic, you have used an image of Holy Saturday, that day between Good Friday and Easter. Say a little bit about what that image says to you in regard to dementia.

## **SUZANNE MCDONALD**

Yes; it is kind of ironic, isn't it? Here is this day in Holy Week that we most often forget, right? We tend to move as fast as we can from Good Friday to Resurrection Sunday, and there is this day in between; and I sometimes think it is really helpful to think about Holy Saturday from the perspective of the first disciples, because although Jesus had told them that he was going to be raised on the third day, it clearly had not sunk in. So, when we get to their experience of Holy Saturday, what we have is Jesus has just been crucified; there is this desolation, there is this confusion, there is this fear—all these swelling emotions. They are not yet aware that something amazing is going to happen on Sunday; and I think this can be a holy space, not just, in fact, for people who are walking the dementia road, but for all sorts of tragedies and difficult times in our lives, that there is space in the scriptural story for the lament, the protest, the confusion. So, that is one aspect of Holy Saturday; and of course, we don't stay there. We know what happens on Sunday, there is that; but I think there are also some really specific things about what this day was like for the first disciples that connects so well with dementia. Think about it this way: There is actually no human hope on Holy Saturday, right? What is going to come? The resurrection. That is an almighty in-breaking act of God, but it seems humanly hopeless. We just said in the last session, there is no cure for dementia right now. Even the treatments aren't great. It feels humanly hopeless to be in this place. We are not going to stay there, but that is how it feels; and we need to give people the space for that; but think also about Jesus and the disciples...how Jesus seems to have lost his identity for them, right? Who they thought he was...the Messiah, the one who was going to redeem Israel, seems like he isn't that anymore...

## **DAVE BAST**

Like the disciples on the road to Emmaus...

## **SUZANNE MCDONALD**

Yes, exactly.

## **DAVE BAST**

We thought he was the one, but obviously he wasn't; even though it was Easter Sunday afternoon, they were still living in Holy Saturday.

## **SUZANNE MCDONALD**

That's right; because they hadn't encountered the risen Lord yet; and if you are the disciples, right, and you place the whole of your identity in who Jesus is and in following Jesus, and that seems to have disintegrated, then you are losing your identity, too; or it seems like you are. That feels so like what it is to walk the dementia road; when the person with dementia...their sense of self and identity is disintegrating, but especially the caregivers at some point here, they are watching that happen to a loved one, but also your identity changes in this situation. When your spouse of 50 years no longer knows who you are, what does that do to *your* sense of identity, right? And of course, we don't stay there, and that is part of the thing. Holy Saturday transitions into Resurrection Sunday, but I think it is so important to give the lament and the struggle space; but one of the other really neat things about the dementia road is that we also know there are resurrection moments...there is no cure, right, at this point...but you know what it is like, those of you who have walked this road. When all of a sudden, a piece of music will spark a memory—bring someone back; or you are looking at a photo album and suddenly a whole load of stories will come out. I like to call these resurrection moments...little glimpses of what it will be like when this person is fully whole again.

**DAVE BAST**

I think of a story our friend Jeff Monroe...I know you know Jeff...told about visiting his mother when she was pretty well gone, and there wasn't much there; she didn't really recognize him, but when he began to pray the Lord's Prayer with her, she joined in...

**SUZANNE MCDONALD**

Yes.

**DAVE BAST**

And that was such an uplift for him to know that that was still there.

**SUZANNE MCDONALD**

That's right; and I think the more that you know someone, you can, in a sense, be a guardian of someone's personhood, right? When they can no longer hold who they are for themselves, the more you know someone, the more things that you can hold for them that might be that trigger for a little resurrection moment, when they can recapture something of who they are.

**SCOTT HOEZEE**

And those could be moments that give us windows into something that we can read from scripture as well...two well-known passages that we can dig into here: Colossians 3 and Romans 8.

Colossians 3:

So, if you have been raised with Christ, seek the things that are above, where Christ is seated at the right hand of God. <sup>2</sup>Set your minds on things that are above, not things on earth, <sup>3</sup>for you have died, and your life is hidden with Christ in God. <sup>4</sup>And when Christ, who is your life, is revealed, then you also will be revealed with him in glory.

**DAVE BAST**

You spoke, Suzanne, a moment ago about being able to hold onto a loved one's life and their memories for them, but ultimately the one who holds our lives is Christ...

**SUZANNE MCDONALD**

Exactly.

**DAVE BAST**

And God; and the idea that although there is no hope for a cure, we still have a future...

**SUZANNE MCDONALD**

Yes.

**DAVE BAST**

Dementia is never the last chapter in any believer's life.

**SUZANNE MCDONALD**

Exactly so; and I mean, when you think about it, none of us yet knows who we truly are; only God knows that; and none of us will be who we most fully and truly are until we behold the Lord in glory and know as we are known; and so, in a way, dementia is holding up a mirror to us in that regard, but it is so important that who we are...our personhood, our identity, is kept for us with Christ in God even when we cannot hold on to it for ourselves. That verse is just a godsend for us.

**SCOTT HOEZEE**

And Romans 8: <sup>35</sup>Who will separate us from the love of Christ? Will hardship or distress or persecution or famine or nakedness or peril or sword (and let's add dementia? Shall dementia separate us?) <sup>37</sup>No, in all

these things we are more than conquerors...

I am convinced that nothing, right? There is nothing in all creation that can separate us from the love of God in Christ Jesus our Lord. That is a precious truth. This cannot separate our loved one or us from the love of God in Christ.

### **DAVE BAST**

Although, that knowledge is something we hang on to, it...as you say, Suzanne...it doesn't make the pain go away; it doesn't ignore the fact that we go through the dark valley of Holy Saturday; but there are some practical things perhaps that we can do as caregivers or friends or loved ones. We want to turn to that as we close in just a moment.

*Segment 3*

### **SCOTT HOEZEE**

You are listening to *Groundwork*, and I am Scott Hoezee.

### **DAVE BAST**

I am Dave Bast.

### **SUZANNE MCDONALD**

And I am Suzanne McDonald.

### **SCOTT HOEZEE**

And we are today in the first program of a four-part series dealing with some of the issues that come up in our lives...dementia in this program, and then we are going to look at depression, and then anxiety, and then living with chronic pain or incurable illnesses; but we are looking at dementia here; and Suzanne, we were just looking at Romans 8, the idea that nothing can separate us from the love of God in Christ Jesus; and what a comfort that is. You know, so often we hear people...loved ones who have someone with dementia in their family say why doesn't the Lord just bring them home? It can go on and on and get so difficult, but we cling to that promise.

When we were preparing for this program, Suzanne, you brought up another passage in Romans 8 that you think is very helpful, and you can read that and share it for us.

### **SUZANNE MCDONALD**

Yes; a little bit earlier in Romans 8, and it is verse 26 and 27: Likewise, the Spirit helps us in our weakness. For we do not know how to pray as we ought, but that very Spirit intercedes with sighs too deep for words. <sup>27</sup>And God, who searches the heart, knows what is the mind of the Spirit, because the Spirit intercedes for the saints according to the will of God.

I think this is so important for both the person with dementia and the people who love and care for them; especially when you get to the middle of the later stages, because if you are a person with dementia, by that point the words are going; and in the later stages, you have none. So, I like to think of this in the sense of if the person with dementia...if all that they can do now is groan...they have no words left...the Holy Spirit is in that groaning, and the Holy Spirit is lifting those prayers to Christ, who is interceding before the throne of the Father; and also for a caregiver. Let's face it, the words run out pretty fast sometimes. All you can do is sob your heart out. The Holy Spirit is in the midst; and the triune God does not give up on a person with dementia or on those who are loving and caring for them, and I think it is so important. Nothing can separate us from the love of God in Christ, and the Holy Spirit is in the midst, praying, groaning, interceding with us in these circumstances.

### **DAVE BAST**

What a great thing to remember as well; not just that we have a future hope, but the Spirit is still within; Christ is still joined to us by faith through the person of the Holy Spirit. So, even if that person becomes perhaps just a shell of what they once were, and hardly recognizable, that doesn't mean the Spirit has left them. It isn't like Saul in the Old Testament, you know, where the Spirit leaves for whatever reason. We have

that assurance: I will never leave you or forsake you.

### **SUZANNE MCDONALD**

That's right; and I think can actually become important, too. I know, I have had adult children of people with dementia who have been sobbing their hearts out with me because maybe their mother or their father with dementia had started saying some things like they have never said in their lives before. Words that are quite hurtful, maybe even blasphemous words, and that is where you have got to go back to Romans 8 and say nothing, not even what this disease is doing to someone, can separate them from the love of God in Christ. Christ has them in this, and the Holy Spirit is still at work, even when it seems like it is getting really hard in that sort of way.

### **SCOTT HOEZEE**

And it is so hard; and because it is hard, it is difficult to know what to do. None of us here on this program are experts, but there are experts out there who are giving really good advice; and this would be good advice for members of the congregation who help care for someone...certainly members of the family...and so, maybe we can draw the threads of this program together here in conclusion and just be reminded of what we said. This person still bears God's image; and therefore, they still deserve our loving care; and we want to approach them carefully. Again, we said earlier, their visual field has shrunk, they don't hear very well, so don't come up behind them; don't startle them; don't grab ahold of them and try to force them to do something you want them to do, whether it is getting dressed... You know, they deserve that care as an image-bearer of God.

### **SUZANNE MCDONALD**

Yes, that is right; and I think there are also ways that those of us who walk alongside folks can help. A time will come when it gets too much, all the personal care that a person with dementia needs, to help people to work out when is the time you need more help—when is the time you need other folks around you in all of this; but I also think, kind of more positively as well, there are some really good things people can do in the early stages of dementia that will help in the middle to later stages. So, put a scrapbook together; get some photos; get some church bulletins; get some pictures of maybe where someone used to go to church when they were younger. Put a list of favorite Bible verses down; work that out together...favorite hymns, favorite prayers, music...so that later on when the person with dementia cannot remember that, family members, people who visit, have something there that gives them a sense of, oh, this was important...this *is* important to this person. Maybe that will be a trigger to help them. And something else as well is a memory box, like a shoebox: twelve small physical things that have really important associations to someone with dementia; and these are the kinds of things that are actually fun to do, and positive to do in the early stages, that will be so helpful later. So, a bit of a story here: A guy who would always in a care home be holding a pocket watch and stroking it and smiling...it turns out, that was a gift from his grandfather to his father, and his father to him. Now, who knows in the depths of dementia whether he remembered all those details, but that physical thing was clearly something so important and beautiful for him, that brought back something of who he is. Simple things like that can be so important.

### **SCOTT HOEZEE**

And things just to preserve people's dignity...

### **SUZANNE MCDONALD**

Yes.

### **SCOTT HOEZEE**

Giving them just simple tasks: helping to sort the silverware when you are emptying the dishwasher, or just giving them some different types of screws to sort by type, just little things that can give people a sense of worth.

I think maybe the last thing to say is that in all of our Christian lives, we want to bear the fruit of the Spirit, but we really need to bear the fruit of patience and kindness and gentleness, I think, with people who have

dementia.

**DAVE BAST**

It is also important maybe...we've got less than a minute left...but, to say that the church is an important resource for caregivers, really.

**SUZANNE MCDONALD**

Yes.

**DAVE BAST**

And as the body of Christ, we need to be paying maybe a little bit more attention to this issue than most churches have...

**SUZANNE MCDONALD**

That is right; I mean, we obviously want to care for the person with dementia, but the time comes when frankly it is even harder for the loved ones who are family caregivers; and the ways that we can come around folks, maybe just give them a break. Help them to be more in their lives than just someone who cares for someone with dementia. Also be a place where they can vent and be honest about the struggles. So, walking alongside caregivers is incredibly important, and it is something we can all do.

**SCOTT HOEZEE**

As we said, this is going to become only more common; so we covenant together to pray for each other and support each other in these struggles.

Well, thank you for joining us on this program, Suzanne.

**SUZANNE MCDONALD**

My delight. Thanks again for inviting me.

**DAVE BAST**

Thanks for listening and digging deeply into scripture with *Groundwork*. We are your hosts, Dave Bast and Scott Hoezee, and our special guest today, Dr. Suzanne McDonald. We hope you will join us again next time as we examine the help scripture provides us when we struggle with depression, personally or in the life of a loved one.

Connect with us at [groundworkonline.com](http://groundworkonline.com) to share what *Groundwork* means to you; or tell what you would like to hear discussed next on *Groundwork*.

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