

## ***Still Alice: A Book (or Movie) Study* by Anne Saunders**

### **Objective**

This study has been developed to explore, from a faith perspective, issues raised in the book *Still Alice* written by Lisa Genova (2011) and the movie by the same name, released in 2014. The story describes Alice's experience of Alzheimer's Disease.

### **Study outline and themes**

The study includes four sessions based on these four themes:

1. Knowing and remembering
2. Opportunities and relationships
3. Autonomy and control
4. Self-worth and personhood

Using scripture readings, quotations from the book, discussion questions and prayers, the outlines encourage participants to take time to

- *reflect* individually and together
- *question*
- *share* stories, reactions and views
- *listen* to one another

There are no right or wrong answers to the questions and issues posed; but when considering them in community, there is God's way of being together in respectful and loving relationships. People will be speaking with emotion not only about the story, but also about personal experiences, hopes and fears. As you reflect and discuss, imagine someone like Alice in the room with you. Speak and listen with sensitivity to people's experiences of, and fears about, dementia. Living with Alzheimer's Disease (AD) – as the "patient" or as a family member – is almost always a frightening, tragic and devastating experience. It is an experience that can challenge and change one's faith. As theologian Peter Kevern put it, observing the progress of a dementia like AD can be "one of soul-crushing, painful struggle against the departure of a loved one, in which abstract philosophical and theological questions crop up in the most practical ways imaginable."

Many people today know someone living with dementia, and specifically with AD. The progression of AD is marked by losses – little deaths and endings – for the individual living with AD and for their family and friends. In our faith we believe that new life and new beginnings follow, but these are not easy to find and experience when considering AD. It may be helpful to think of this group's task as "wrestling" with issues, much as Jacob wrestled in the night, remembering that at daybreak Jacob received God's blessing (Genesis 33:22-30). It is hoped that through this study, participants might also receive God's blessing.

### **Study leaders and participants**

This study can be led by clergy or lay people, with leadership changing each session. Leaders are encouraged to be flexible in welcoming participants. While it is hoped that everyone will either have read the book or viewed the movie, it is possible that people who have only heard about the story will want to participate.

The book does not have chapters in the normal sense; it's more like a journal with 24 entries over the course of two years, beginning September 2003 through September 2004, and ending with the Epilogue. The study sessions are related to themes that run through the story so leaders may want to encourage participants to read the whole book or view the movie as soon as they can.

Also, participants can likely contribute to, and gain from, the group study experience even if they can attend only one or two sessions. However, this might be discussed at the first session to ensure that participants are prepared for this possibility and to clarify if others could be invited to the next sessions.

As a leader, feel free to adapt the material even further to suit the needs and context of the group. In particular, if during a session a theme emerges that is not part of this outline or that requires a lot more time to explore, then seek consensus to make it the focus of another gathering; and perhaps invite some participants to help prepare for it by identifying

- a) the parts of the story and/or relevant quotes pertaining to this theme
- b) biblical themes/scriptures/characters or stories that might relate
- c) personal connections
- d) resources like prayers from other sessions or sources for opening and closing the session.

On the last pages are some suggested hymns and a list of sources for further theological reflection.

### **Background to the topic of Alzheimer’s Disease**

An estimated 564,000 Canadians are living with dementia and that number is expected to increase steadily over the next two decades. With the average age in Canadian society rising and with our congregations aging, many of us know someone personally or know about someone who has dementia. Dementia refers to cognitive impairment and may be the result of a stroke, an accident causing brain damage, or a progressive disease like Alzheimer’s Disease. Alzheimer’s Disease is the most common of the large group of disorders known as “dementias.” Alzheimer’s Disease (AD) is not a normal part of aging. It is an irreversible disease of the brain in which the progressive degeneration of brain cells causes thinking ability and memory to deteriorate. AD also affects behaviour, mood and emotions, and the ability to perform daily living activities.

While AD is most commonly found in elderly people the main character of *Still Alice* is diagnosed with the rare Early Onset or Family Alzheimer’s Disease at the age of 51. Familial Alzheimer’s Disease (FAD) runs in families. At some point in the family history certain genes mutated and developed the abnormal characteristics that cause FAD. If a person has FAD, each of his/her children has a 50% chance of inheriting the disease-causing gene and developing Alzheimer’s Disease. These inherited genes differentiate FAD from the more common sporadic form of Alzheimer’s Disease, but the disease itself is nearly identical.

Since 1978, the Alzheimer Society of Canada has been dedicated to providing help for people with Alzheimer’s disease and other dementias and their caregivers. The Alzheimer Society offers a range of counselling and support groups that provide a safe place to share information, feelings and experiences for both people with the disease and their caregivers. The Alzheimer Society has developed a number of resources to help people living with the disease, their families and caregivers. Please contact your local Alzheimer Society to get free information sheets on various aspects of Alzheimer’s disease and caregiving and find out what services are offered in your community at 1-800-616-8816 or [www.alzheimer.ca](http://www.alzheimer.ca) .

The above background information comes from the brochure “What is Alzheimer’s Disease?” from the Alzheimer Society of Canada and available for download at <http://www.alzheimer.ca/en/About-dementia/Alzheimer-s-disease>. For information about the difference between Alzheimer’s Disease and dementia see <http://www.alzheimer.ca/en/About-dementia/What-is-dementia>.

## Session One: Knowing and Remembering

### a) Gathering

Go around the group asking everyone to introduce themselves. If people tend to know each other, ask each person to say something about themselves that others may not know.

Go around the group a second time and ask everyone, if willing, to say *what* they know about Alzheimer's Disease (AD) and *how* they know about it. Record this information in point form on a newsprint sheet and display it, keeping it for all session.

**Prayer:** Dear God, we are grateful for each person here. Thank you for this time and place where we can be together to talk about a story that raises profound issues about life and faith. Guide our thinking and our speech; and open our eyes and ears so that we may find you and experience the love and reassurance of your presence. Amen.

### b) Knowing and remembering in *Still Alice*

Memory loss is often identified as the first symptom of AD. But we all forget things sometimes. What do we learn from this story about the forgetfulness that happens with AD?

When does Alice first think that something is wrong – where is she and what has she forgotten? By the time she sees a neurologist what are some other examples that she gives him? What feelings accompany these experiences? What is the doctor's main concern?

Alice's memory lapses increase and become more apparent as she narrates her story right to the end of the book. She not only forgets words, but forgets her responsibilities, familiar surroundings, and how she is in relationship to people. What do you find challenging about this aspect of AD?

### Quotations from the book *Still Alice*

Use these quotations to help you consider the progressive memory loss Alice experienced. Share some of the moments that particularly struck you.

#### September 2003

"She simply couldn't find the word. She had a loose sense for what she wanted to say, but the word itself eluded her. Gone."

"She wanted to continue walking but stood frozen instead. She didn't know where she was..."

#### December 2003

"I've been having lots of problems remembering, and it doesn't feel normal. I'm forgetting words in lectures and conversation, I need to put 'cognition' class on my to-do list or I might forget to go teach it, I completely forgot to go to the airport for a conference in Chicago and missed my flight."

#### July 2004

"How can I be lost in my own home?"

#### October 2004

"She lay in bed and tried to remember what she'd been looking for."

"Alice knew that the young woman sitting across from her was her daughter, but she had a disturbing lack of confidence in this knowledge."

#### Summer 2005

Alice: "I think I've been here long enough. I'd like to go home now." John: "You are home. This is your vacation home."

### **c) Scripture readings and reflection**

There are passages throughout the Bible asking people to know and remember God.

**Read** Deuteronomy 5:15.

*Remember that you were a slave in the land of Egypt, and the Lord your God brought you out from there with a mighty hand and an outstretched arm; therefore the Lord your God commanded you to keep the sabbath day.*

**Read** Luke 22:19-20.

*Then he took a loaf of bread, and when he had given thanks, he broke it and gave it to them, saying, "This is my body, which is given for you. Do this in remembrance of me." And he did the same with the cup after supper, saying, "This cup that is poured out for you is the new covenant in my blood.*

Reflect on how "remembering" the stories of our faith has been part of your life. How do you think being unable to remember would affect your relationship with God? God's relationship with you?

There are also passages throughout the Bible saying that God knows and remembers everything about each of us.

**Read** Isaiah 49:13-15.

*Sing for joy, O heavens, and exult, O earth; break forth, O mountains, into singing!*

*For the LORD has comforted his people, and will have compassion on his suffering ones.*

*But Zion said, "The LORD has forsaken me, my Lord has forgotten me."*

*Can a woman forget her nursing child, or show no compassion for the child of her womb?*

*Even these may forget, yet I will not forget you.*

**Read** Romans 8:38-39.

*For I am convinced that neither death, nor life, nor angels, nor rulers, nor things present, nor things to come, nor powers, nor height, nor depth, nor anything else in all creation, will be able to separate us from the love of God in Christ Jesus our Lord.*

Reflect on how passages about God always remembering and loving us affect you. Read "Remembered by God." What might be the good news for people living with AD?

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#### **Remembered by God**

Goldsmith (1999) found good news for people living with dementia in what he called a "Remembered by God" model: "We are remembered by God long before and long after we make any recognizable response to God." According to Goldsmith, there is no responsibility on us to access God through knowledge or understanding; nor to respond to God. We may, but we are not obliged. The model "offers meaning which is unconditional," writes hospital chaplaincy visitor Hilda Flint (2004), "[and is] especially appropriate, not simply for a human race which is endlessly creating its own suffering, but for those in dementia who no longer have the cognitive powers to plan the present, remember the past or foresee the future coherently."

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### **d) Discussion**

According to the time and interest of the group, consider issues raised by the progressive loss of memory. Discuss one or more of the following questions and/or questions raised by participants.

What are the things you want to remember and know forever?

What role do you think memory and knowledge plays in the development of a person's faith?

What do you think it would mean for your relationship with God if you didn't know and remember all that you know now about God?

### **e) Closing Prayer**

All-knowing and all-remembering God, we praise you for being with us in beginnings and endings, in the in-between times, in the moments of joy and sorrow, and in death and new life. We thank you for your love and grace that know no bounds, that are given unconditionally, and that include and embrace every part of your Creation. Amen.

#### **Feedback on this session**

What went well?

What might you do differently for the next session?

What additional topics or questions were raised? How will these be addressed?

#### **Next session**

Think about the story of *Still Alice* and reflect on the effect of AD on Alice's opportunities and relationships.

## Session Two: Opportunities and relationships

### a) Gathering

If there are new participants, have everyone introduce themselves. Turn to the display of information that the group shared last session about Alzheimer's Disease (AD). Invite everyone to add to this list if there is something they know about the disease that is not listed. As information is shared, ask them, if willing, to say *how* they know about it. Comment on how the first session focused on how Alice began losing the ability to know and remember things. The focus in this session is on how Alice experienced changes in life opportunities and relationships because of the disease.

**Prayer:** Dear God, we are grateful for each person here. Thank you for this time and place where we can be together to talk about a story that raises profound issues about life and faith. Guide our thinking and our speech; and open our eyes and ears so that we may find you and experience the love and reassurance of your presence. Amen.

### b) Opportunities and relationships in *Still Alice*

AD is a disease that takes away life opportunities and changes relationships. How did Alice's activities and routines change as she became aware of the effects of the disease?

What were Alice's wishes and concerns about her relationships with her husband, children and grandchildren?

In the book we learn that Alice feels she "never developed a true faith", yet she went into a church seeking God. Do you think Alice experienced God as the disease progressed? Explain.

Eventually Alice does not know where she is or whom she is with. Describe her opportunities and her relationships with the people in her life in the last scenes of the story.

### Quotations from the book *Still Alice*

Use these quotations to help you consider the changes in Alice's life and relationships. Share some of the moments that particularly struck you.

#### March 2004

"He refused to watch her take her medications."

"She didn't have time for Alzheimer's today. She had emails to return, a grant proposal to write, a class to teach, and a seminar to attend."

"I can't stand the thought of looking at you someday, this face I love, and not knowing who you are...I don't know how much longer I have to know you."

#### May 2004

"... [Alice] wanted to live to hold Anna's baby and know it was her grandchild. She wanted to see Lydia act in something she was proud of. She wanted to see Tom fall in love. She wanted one more sabbatical year with John..."

#### June 2005

"...Alice applauded him, this student of hers whom she had no memory of."

## Summer 2005

“This place didn’t look like her home or sound like her home, and she didn’t feel relaxed. The man reading and drinking in the big, white chair didn’t know what he was talking about. Maybe he was drunk.”

### Epilogue

“Alice smiled and nodded back. She had no idea what she was agreeing to, but it was probably fine with her if the woman thought so.”

## c) Scripture readings and reflection

Perhaps the best known passage about the ebb and flow of our God-given life experiences is the Ecclesiastes passage about the seasons of life, titled “Everything has its time.”

### Read Ecclesiastes 3.

*For everything there is a season, and a time for every matter under heaven:*

*a time to be born, and a time to die;*

*a time to plant, and a time to pluck up what is planted;*

*a time to kill, and a time to heal;*

*a time to break down, and a time to build up;*

*a time to weep, and a time to laugh;*

*a time to mourn, and a time to dance;*

*a time to throw away stones, and a time to gather stones together;*

*a time to embrace, and a time to refrain from embracing;*

*a time to seek, and a time to lose;*

*a time to keep, and a time to throw away;*

*a time to tear, and a time to sew;*

*a time to keep silence, and a time to speak;*

*a time to love, and a time to hate;*

*a time for war, and a time for peace.*

A person diagnosed with a progressive, terminal disease like AD, becomes acutely aware of the constraints of time on the quality and range of opportunities and relationships. Reflect on how you’ve heard this passage in the past. What might it mean for a person living with AD?

Throughout the Bible we learn about all sorts of relationships, between people and between people and God. In this well-known passage from Luke, we glimpse Jesus and his relationship with God and with the disciples at a critical moment.

### Read Luke 22:39-46.

*He came out and went, as was his custom, to the Mount of Olives; and the disciples followed him. When he reached the place, he said to them, “Pray that you may not come into the time of trial.” Then he withdrew from them about a stone’s throw, knelt down, and prayed, “Father, if you are willing, remove this cup from me; yet, not my will but yours be done.” Then an angel from heaven appeared to him and gave him strength. In his anguish he prayed more earnestly, and his sweat became like great drops of blood falling down on the ground. When he got up from prayer, he came to the disciples and found them sleeping because of grief, and he said to them, “Why are you sleeping? Get up and pray that you may not come into the time of trial.”*

Reflect on Jesus' weakness – his vulnerability – at the time of this prayer, and on his relationship with God and the disciples. Read “God’s vulnerability and power.” What might be the good news in this theology for people living with AD?

### **God’s vulnerability and power**

Theologian Peter Kevern points out that our Trinitarian God is “constituted by relationships”, that these include very intimate relatedness to humans and participation in our very existence so that “to see the person is to see God, and to know God is to know the person” – even when the person has dementia. This means an all-knowing, all-remembering and all-powerful God who also shares in a person who has increasing ignorance, forgetfulness, and powerlessness. Kevern points out these opposites have always been part of the doctrine of the Trinity, suggesting that while “the context of dementia is new, the task is the old one, of ‘thinking together’ God’s vulnerability and God’s power.” Kevern suggests they are in relationship and inseparable.

### **d) Discussion**

According to the time and interest of the group, consider the changes people make and the priorities they set when they realize they have limited time left to live life to its fullest. Discuss one or more of the following questions and/or questions raised by participants.

What activities and relationships would you want to maintain as long as possible? What would you want to change? What would become your priorities?

Through life’s stages, how do opportunities, experiences and relationships with others affect how we live our faith? How does our relationship with God stay the same or change with time and circumstances?

What are the things we do and the rituals we practice that help us remember and share our memories and knowledge with others?

### **e) Closing Prayer**

Creator God, Jesus Christ, and Holy Spirit, we praise you for being three in one, for being both weak and strong, and for transcending all life and relationships. We thank you for your love and grace that know no bounds, that are given unconditionally, and that include and embrace every part of Creation. Amen.

### **Feedback on this session**

What went well?

What might you do differently for the next session?

What additional topics or questions were raised? How will these be addressed?

### **Next session**

Think about the story of *Still Alice* and reflect on the effect of AD on Alice’s autonomy and control over her life.

## Session Three: Autonomy and control

### a) Gathering

If there are new participants, have everyone introduce themselves. Turn to the display of information that the group shared last session about Alzheimer's Disease (AD). Invite everyone to add to this list if there is something they know about the disease that is not listed. As information is shared, ask them, if willing, to say *how* they know about it. Comment on how the first two sessions focused on how Alice experienced cognitive losses of knowing and remembering; the second session on changes in opportunities and relationships. This session focuses on issues to do with autonomy and control.

**Prayer:** Dear God, we are grateful for each person here. Thank you for this time and place where we can be together to talk about a story that raises profound issues about life and faith. Guide our thinking and our speech; and open our eyes and ears so that we may find you and experience the love and reassurance of your presence. Amen.

### b) Control in *Still Alice*

With the progression of a disease like AD, both the person with the disease and those closest to them struggle to maintain autonomy and control over their lives. In the following situations, who is trying to maintain control? How?

- Alice thought she would decide when she should stop teaching, but then the psychology department head shared with her some student evaluations of her performance.
- Alice prepares a suicide plan – the Butterfly file on her computer – in the hope that she can decide now when and how she will die.
- Two of Alice's three children decide to go for genetic testing so that they can ensure their offspring will not have the mutated gene that carries FAD. Anna has her embryos tested as part of her in vitro fertilization (IVF) treatment and ensures that her baby is free of the FAD gene.
- Alice's husband, John, makes a career choice that results in him living away from Alice. Alice had wanted him to take a sabbatical year to spend more time with her.

### Quotations from the book *Still Alice*

Use these quotations to help you consider the issues of autonomy and control that arise in this story. Share some of the moments that particularly struck you.

#### November 2003

“She couldn't remember which lecture she was giving today.”

#### December 2003

“In the future, you're going to have to bring a family member...you may not be the most reliable source of what's been going on.”

#### January 2004

“If she confessed to John what Dr. Davis had told her...it would become real. John would become the informant, and Alice would become the dying, incompetent patient.”

#### March 2004

“Ultimately her functioning would deteriorate to a level that would be noticed and not tolerated. She wanted to leave Harvard before then...”

**May 2004**

“She needed a plan that committed the future her to a suicide she arranged for now.”

**September 2004**

“I like our lives. I think it’s been a good balance between an independence to pursue our own passions and a life together.”

### **c) Scripture readings and reflection**

While we believe God is all powerful and sovereign, the power given to humans and our relationship with Creation have been sources of debate over the centuries.

**Read** Genesis 1: 27-28.

*So God created humankind in his image, in the image of God he created them; male and female he created them. God blessed them, and God said to them, “Be fruitful and multiply, and fill the earth and subdue it; and have dominion over the fish of the sea and over the birds of the air and over every living thing that moves upon the earth.*

**Reflect** on what you understand is the relationship between human beings and the created, natural world and on the power humans have been given with respect to Creation.

In the New Testament there are passages which reveal how little others understood about who Jesus was. They expressed desires to share in the secular power and privileges they anticipated he would have.

**Read** Luke 22:24-26.

*A dispute also arose among them as to which one of them was to be regarded as the greatest. <sup>25</sup> But he said to them, “The kings of the Gentiles lord it over them; and those in authority over them are called benefactors. But not so with you; rather the greatest among you must become like the youngest, and the leader like one who serves.*

**Read** John 14:8-9.

*Philip said to him, “Lord, show us the Father, and we will be satisfied.” Jesus said to him, “Have I been with you all this time, Philip, and you still do not know me? Whoever has seen me has seen the Father. How can you say, ‘Show us the Father’?”*

Reflect on how people today strive to set themselves apart and seek greatness and success, often competitively. Read “God-with-us.” What might be the good news in Kevern’s theology for people living with AD?

#### **God-with-us**

Peter Kevern suggests that some theologies make God’s sovereignty seem non-negotiable as though God is outside of, beyond or above – *not* within and part of – life situations like those created by AD. Alternatively Kevern wonders what the implications might be if “we are all in God’s image, then the world is not divisible into carers and patients in any stable way: the dividing line between these constituencies runs through each of us...[and then we] learn the truth of our experience by reflection upon God; and we learn the truth of God by reflection on our experience...the true God is the one who is present in extremity” – that is, God is present even in experiences of complete dependence and lack of control.

### **d) Discussion**

According to the time and interest of the group, consider issues related to personal autonomy and control over one's life. Discuss one or more of the following questions and/or questions raised by participants.

What do you have power and control over in your life? How important is this for you?

How are control, independence and power valued in our culture and society today?

What do you think of the desire to control how and when one lives and dies? Is there a point when you think a person's life has no value and/or is not worth living? Explain.

How do you feel about the increasing control that humans have over Creation, including their genetic make-up?

### **e) Closing Prayer**

Creator God, we praise you for the Creation we are part of; we praise you for Jesus whose life and ministry challenge us to understand the values and ways of being part of Creation. We thank you for your love and grace that know no bounds, that are given unconditionally, and that include and embrace every part of your creation. Amen.

#### **Feedback on this session**

What went well?

What might you do differently for the next session?

What additional topics or questions were raised by the group? How will these be addressed?

#### **Next session**

Think about the story of *Still Alice* and reflect on the effect of AD on Alice's self-worth and personhood.

## Session Four: Self-Worth and Personhood

### a) Gathering

If there are new participants, have everyone introduce themselves. Turn to the display of information that the group shared last session about Alzheimer's Disease (AD). Invite everyone to add to this list if there is something they know about the disease that is not listed. As information is shared, ask them, if willing, to say *how* they know about it. Comment on how the first session focused on how Alice lost the ability to know and remember things; the second session on the life opportunities that ended and relationships that changed; the third session on issues of autonomy and control. This session focuses on issues of self-worth and personhood.

**Prayer:** Dear God, we are grateful for each person here. Thank you for this time and place where we can be together to talk about a story that raises profound issues about life and faith. Guide our thinking and our speech; and open our eyes and ears so that we may find you and experience the love and reassurance of your presence. Amen.

### b) Self-worth and personhood in *Still Alice*

People whose loved one has AD, often speak about their loved one dying a slow death, as bit by bit the person they were slips away.

Describe Alice's characteristics and personality as you first come to know her in the story. Then describe Alice's characteristics and personality as she is encountered in the last scene. Talk about what has changed and what hasn't about who Alice is and her roles.

With AD, emotional reactions can continue in situations after knowledge and memory have been lost. Recount situations where Alice expressed different emotions (e.g. fear and insecurity, frustration and confusion, embarrassment, happiness and love). What and who contributed to these feelings? How do Alice's husband and children express their emotions? Describe times when they connect with Alice emotionally. How does this affect Alice?

With AD, Alice felt she was losing herself. Considering the title of the book/movie, at the end of the story how do you think that Alice was "still" herself?

### Quotations from the book *Still Alice*

Use these quotations to help you consider the issues of self-worth and personhood that arise in this story. Share some of the moments that particularly struck you.

#### May 2004

"Oh my gawd what if I have [the mutation]...I'll be a mindless zombie."

"Who was she if she wasn't a Harvard psychology professor?"

"Her mother had comforted her and told her not to be sad for the butterflies, that just because their lives were short didn't mean they were tragic. Watching them flying in the warm sun among the daisies in their garden, her mother had said to her, "*See they have a beautiful life.*"

#### Summer 2005

"But will I always love her? Does my love for her reside in my head or in my heart?"

"I miss myself."

"I remember I used to be very smart."

## **b) Scripture readings and reflection**

The experience of great loss and abandonment are often expressed through laments in the Bible, in experiences like being in the wilderness or in exile.

**Read Psalm 22: 1-6.**

*My God, my God, why have you forsaken me?*

*Why are you so far from helping me, from the words of my groaning?*

*O my God, I cry by day, but you do not answer;  
and by night, but find no rest.*

*Yet you are holy,*

*enthroned on the praises of Israel.*

*In you our ancestors trusted;*

*they trusted, and you delivered them.*

*To you they cried, and were saved;*

*in you they trusted, and were not put to shame.*

*But I am a worm, and not human;*

*scorned by others, and despised by the people.*

While different from the AD experience, reflect on how the underlying emotions of biblical laments might resonate with people dealing with the disease.

Contrasting with such laments is scripture, like Paul's letter to the Galatians, offering reassurance of God's, boundless unconditional love and grace that disregards any human-made distinctions, biases, or value judgments based on social context.

**Read Galatians 3: 25-29.**

*But now that faith has come, we are no longer subject to a disciplinarian, for in Christ Jesus you are all children of God through faith. As many of you as were baptized into Christ have clothed yourselves with Christ. There is no longer Jew or Greek, there is no longer slave or free, there is no longer male and female; for all of you are one in Christ Jesus. And if you belong to Christ, then you are Abraham's offspring, heirs according to the promise.*

Reflect on how, according to Paul's beliefs, there are no distinctions among people because we are all God's children. Read "What counts before God." What might be the good news in this theology of God's grace for people living with AD?

### **What counts before God**

In his book *Paul and the Gift* (Eerdmans, 2015), New Testament scholar John Barclay argues that Paul's view of God's grace was socially radical because Paul describes God's grace as being "given without regard to the worth of the people who receive it. God doesn't give discriminately to seemingly fitting recipients. He gives without regard to their social, gender or ethnic worth. Nothing about them makes them worthy of this gift... What counts before God is not what we pride ourselves on – or what we doubt ourselves on. What counts is simply that we are loved in Christ."

### **c) Discussion**

According to the time and interest of the group, consider the feeling of self-worth and the sense of personhood present in most of us. Discuss one or more of the following questions and/or questions raised by participants.

Talk about how memory, thinking skills, knowledge and achievements are part of our 21<sup>st</sup> century daily life. How are they valued? How are they part of people's identities and sense of self-worth?

Aware of all their losses in abilities and feeling a growing loss of self, people with a disease like AD sometimes ask what value they have anymore: "What good am I to anyone?" What words and actions could be offered in response?

How has this story and this study affected your understanding of God and how God might be present with people living with AD? How has it affected your faith and your relationship with God?

### **e) Closing Prayer**

God of generous and boundless love, we praise you for giving yourself to us so we are included and transformed; we praise you for asking nothing in return. We thank you for your love and grace that know no bounds, that are given unconditionally, and that include and embrace every part of your Creation. Amen.

#### **Feedback on this session and the study**

What went well?

What might you do differently if you were doing another session or study?

What additional topics or questions were raised? How will these be addressed?

Think about the story of *Still Alice* and the group study. Reflect on what you have learned.

## Additional Resources

### Worship and small group resources

Book of Praise hymn suggestions:

Hymn #64	Be still and know that I am God
Hymn #326	Give to the winds thy fears
Hymn #436	God, we praise you for the morning
Hymn #674	In the bulb there is a flower
Hymn #675	Precious Lord, take my hand
Hymn #785	“Abba, Abba, hear us,” we cry
Hymn #792	Let us hope when hope seems hopeless
Hymn #794	Abide with me
Hymn #828	You are holy, you are whole

*Worship in Long Term Care Settings and especially with Persons with Alzheimer’s Disease/Dementia* Jeremy Bellsmith (compiler) with contributions from Jean Morris and Dorothy Henderson, The Presbyterian Church in Canada. Available for order or download from <http://presbyterian.ca/resource-centre/> Along with suggestions for planning worship and ideas about content, this resource includes some sample services.

*Alzheimer’s Poetry Project* (APP) is a program of poetry and the arts with people with dementia. See examples at <http://www.alzpoetry.com/>

*Praying with Someone Who Has Alzheimer’s Disease* is a website where prayers are shared for and by people with Alzheimer’s Disease  
<http://onlineministries.creighton.edu/CollaborativeMinistry/Alzheimers/>

### Additional reading about a theology for dementia and Alzheimer’s Disease

(Annotations are from retail book sellers or the abstract of articles)

Barclay, John (2015). *Paul and the Gift*. Eerdmans.

Theology scholar John Barclay presents a fresh reading of grace in Paul's theology, studying it in view of ancient notions of "gift" and divine gift-giving, which for Paul, the author says, is focused and fulfilled in the gift of Christ. The author offers a new appraisal of Paul's theology of the Christ-event as gift as it comes to expression in Galatians and Romans and shows that a respectful, though not uncritical, reading of Paul contains resources that remain important for Christians today.

Flint, Hilda (2004). “All God’s Children: The spiritual needs of people with dementia” in *Care-Giving in Dementia: Research and Applications Vol. 3*, by [Gemma M. M. Jones](#) and [Bère L. Miesen](#) (Editors), Routledge, pp. 22-36.

Goldsmith, Malcolm (2009). “Dementia: A Challenge to Christian Theology and Pastoral Care” in Albert Jewell (Ed), *Spirituality and Ageing*. Jessica Kingsley, pp. 125-35.

Keck, David (2007). *Forgetting Whose We Are: Alzheimer's Disease and the love of God*. Abingdon Press.

Designed primarily for academic audiences, this book offers a Christian understanding of and a response to the difficult theological, pastoral, and spiritual problems raised by Alzheimer's Disease. The text examines the problems of Alzheimer's Disease from the perspectives of the theologian, the patient, and the caregiver.

Kevern, Peter (2010). "Alzheimer's and the Dementia of God" in *International Journal of Public Theology Vol. 4* (2010), pp. 237-253. Available at [http://eprints.staffs.ac.uk/61/1/IJPT%204,2\\_237-254.pdf](http://eprints.staffs.ac.uk/61/1/IJPT%204,2_237-254.pdf)

Recent developments in the theory and practice of care for persons with dementia have reopened questions, traditionally explored by theologians, to do with the nature of personal identity and its dialectical relationship to social recognition. This new perspective on classical theological questions serves as a potential theological resource in contemporary western society, where God appears to have withdrawn from the prevailing public discourses. The author explores the analogical potential of imagery of a "dementing God", as a way to describe the contemporary experience of western Christians.

Kevern, Peter (2010). "What sort of a God is to be in dementia? A survey of theological responses and agenda for their development." Available at <http://eprints.staffs.ac.uk/64/1/What%20sort%20of%20a%20GodTheology.doc>

Although a great deal has been written on pastoral responses to dementia, some of the theological questions it raises remain relatively unexplored. In this paper, the author argues that the widespread experience of living with someone with dementia has the potential to reshape our understanding of God's relation to humanity. He goes on to survey some key contributions to the existing theological literature on this subject and so to suggest directions for further theological work.

McKim, Donald (2003). *God Never Forgets: Faith, Hope and Alzheimer's Disease*. Westminster John Knox Press.

Sensing God's presence is difficult when faced with Alzheimer's Disease among family and loved ones. This book brings faith and hope to these trying circumstances, offering the witness of the Bible and the insights of theology to show how God continues to work in people's lives even in the midst of fearful disease.

Swinton, John (2012). *Dementia: Living in the memories of God*. Eerdmans.

In this book the author develops a practical theology of dementia for caregivers, people with dementia, ministers, hospital chaplains, and medical practitioners as he explores two primary questions: Who am I when I've forgotten who I am? What does it mean to love God and be loved by God when I have forgotten who God is? Offering compassionate and carefully considered theological and pastoral responses to dementia and forgetfulness, Swinton redefines dementia in light of the transformative counter story that is the gospel.