

Losing Our Story

Genesis 21:8-21

When one looks at our biblical ancestors, one shouldn't be surprised at some of the awful behavior one sees in their thoughts and actions. This morning's account of Sarah, the mother of our faith, casting out Hagar and Hagar's son by Abraham, Ishmael, is an act of unbelievable cruelty.

There's plenty of places I could go this morning with this text. Do we know of any situations where threats of expelling foreigners are made? When people of differing nationalities are falsely perceived to be a threat to one's own prosperity? When it's feared that they will displace the inheritance of our own children? Indeed we do.

But I chose this text this morning for a different reason, though I'm sure we will visit our current events in another sermon.

When Ken and I were planning this series on "Sharing our Stories," the theme for this week was "Losing Our Stories." And certainly in this Genesis text, Hagar and Ishmael are being cast out of the story. They are losing their story by acts and influences they cannot control.

What we want to note in this text, what we want to focus on, is how they are never "lost" by God. God herself finds them, sees them, hears them. God intervenes in their despair and hopelessness and makes a promise. God provides for their needs --- there is water in a parched place. God vows that they will not be forgotten, that they are valued, that they are still connected to the human family, to God's family. They are God's beloved and therefore cannot ever be "lost."

As I indicated during the Children's Message and in the worship preview that went out on Facebook and email, this affirmation of God's presence and power in the midst of someone losing their story is one that can be not only seen but emphasized in the situation that millions of people find themselves in...that is as persons who are afflicted with the disease of dementia, and the millions of caregivers who try valiantly and faithfully each day to help those people, those loved ones, live with safety and dignity and grace.

Dementia, let's note first of all, is "not a specific disease. It's the umbrella term used to describe a wide range of symptoms associated with a decline in memory -- "losing one's story." It describes changes in behavior, and decline in ability that interferes with daily life." So, it is a brain disease, one that most often affects older persons. It is a disease that comes in many forms, the most common is Alzheimers disease, which accounts for 60 -- 80 percent of all types of dementia. According to the Alzheimers Association, "every 66 seconds someone in the United States develops Alzheimers disease." It is predicted that in mid-century, "someone in the US will develop the disease every 33 seconds."

To put it another way: “An estimated 5.8 million Americans are living with Alzheimer’s dementia, and that number is projected to more than double to 13.8 million by 2050, barring the development of medical breakthroughs to prevent, slow or cure it.” (3)

When talking about Alzheimers, versus, say, vascular dementia which is caused by a stroke, we know that it is a progressive disease and “advances slowly through three different stages.”

Early stages are mild. People live independently. They can drive a car. Symptoms are often that of short-term memory, forgetting the name of someone they just met. Or maybe misplace items. Before you get too anxious here:

In one article I read, it described it being “common to misplace keys or eyeglasses or walk into a room with a task in mind and forget what that is. These are often attributed, it said, “to multitasking or stress and are considered part of normal aging.” “It is one thing to find your glasses on your head --- it is something else to find them in the freezer.”

In the middle (moderate) stage of Alzheimer’s Disease, a person will require more assistance. People may not remember important events, or the day of the week. They may have difficulty choosing the proper clothing for the season. Changes in personality might appear: sadness, withdrawal, episodes of paranoia and delusions might occur. (1)

Nancy Berg described the behavior she saw in her father, Bert Rose, long before he was diagnosed. “He was still working in his 80’s when (she) noticed small signs --- word retrieval problems and repeating stories. Then he began getting lost (when driving home to his own house) though it was a route he had driven many times before. He started “wearing sweaters in warm weather. In restaurants, he would ask family members what he liked to eat. And about a year before his diagnosis, he had trouble filling out a bank deposit slip, not understanding what the date was or how to enter it. (2)

In the late stages of the disease, the most severe, memory loss and ability may decline to the point where a person might need constant care. Help with dressing, bathing. A family member might require a special assisted living residence. And they become at “higher risk for fall/infections/ illness that require trips to the emergency department or hospital.” (1)

It’s a cruel disease, in many ways.

Given the amount of emotional pain this disease can cause the person with dementia and their family, it is not surprising that denial, pain and embarrassment can keep families “reluctant to broach the topic until far into dementia’s progression.”

This was the topic of a Washington Post article last month, that encourages families to speak up, to talk together about the disease.

It said that “ a survey released (that) week by the Alzheimer’s Association finds that nearly 90 percent of Americans say they would want others to tell them if they were showing signs of memory loss or other symptoms of dementia.” “Yet,” it continues, “nearly three-quarters of Americans say having that conversation would be “challenging” for them. (3)

The article highlights the benefits of talking together when signs are first observable. Initially, of course, Alzheimer’s or other cognitive-decline diseases can be ruled out. Something else could be causing the symptoms, something that is curable.

However, if the disease is diagnosed, in its early stages, it “gives people time to take care of legal and financial issues, make a long-planned trip, participate in their treatment plan or join a medical trial.” (3)

This is the part that appeals most to me: “it gives you a voice,” says Ruth Drew, who is director of information and support services at the Alzheimer’s Association. “If you know early on, you have a voice on how things go and who’s going to make decisions on your behalf.”

When I was doing a lot of reading in preparation for this Sunday, I noticed there’s a lot of first-person books and articles that are written by people who have been diagnosed with dementia. They describe their thoughts, fears, hopes. One of them, “Who Will I Be When I Die?” is by Christine Bryden, who was diagnosed with early onset dementia when she was 46 years old. In her book she offers insights into how it feels to “gradually lose the ability to undertake most tasks people take for granted.” How it feels...to lose one’s story.

At one point, Ms. Bryden writes, “Alzheimer’s disease is a terrible thing for us as a family to face up to – that slowly there might be less and less of ‘the old me,’ (p. 61). She was scared about the possibility of not recognizing her surroundings, not knowing who her daughters were, or being able to greet her friends. And she worried, too, about her faith. Will I still be able to communicate with God? Can I pray?

As we hear her struggling, asking questions, coming to terms with this disease and what it will mean for her and her family, she makes a very important observation. Quoting Oliver Sacks (who we heard Ken quote last week), he noted that “Alzheimer’s sufferers don’t lose their essential selves” (p 62). Oh, there’s no question that there is change. But Ms Bryden asks: “Am I really still me?”

She answers her questions like this:

“I believe that God knows us in our entirety,” she says, “each and every part of this kaleidoscope of who we are. “The centre of the being (will always be) there within. This unique essence of ‘me’ is at my core, that this is what will remain with me to the end.” (p. 64). (4)

As we continue to learn more about this disease, and how to care for persons with Alzheimer's and other forms of dementia, it is always essential to see them with the eyes of God. To remind ourselves always that they are not lost, but still known and loved...that God knows who they are and remains with them and part of them.

And I know, only in part, how challenging and difficult this can be. Because it's not only their story that gets lost, but our story too. When one can no longer be recognized as a daughter, a son, a partner, a spouse, a friend...it hurts. Our impulse is to say, "Don't you remember me?" And we are learning that this direct style of confrontation only causes anxiety and stress for our loved one. No. They don't remember. In the later stages of the disease, that's been lost.

But other options exist. Feelings remain. Communicating becomes different. One of my favorite books that I read is called, "I'm Still Here" by John Zeizel.

"My mother doesn't recognize me, what can I do?" he was asked one day. He inquired how they addressed their mother when they usually visited her. Did they say, "Hi, Mom, remember me?" which, he noted, was likely to elicit the anxious response, "No, who are you?" Or, do they hold their mother's hand in theirs, he asked, "put their face at her level, look her directly in the eye and say, "Hi, Mom, I'm your son Alex, we have wonderful times together and I love you very much".

This approach, he affirms, will be much more likely to elicit a smile and the response, "Oh, Alex, it's nice to see you."

I know that this style has served me well when visiting church members who have dementia. And I recommend it to our congregation, so that when our members with moderate symptoms of the disease can come to worship, we can put them at ease, and help them to experience those feelings that they associate with this community. Welcome. Comfort. The presence of God. The presence of friends.

There's no way we're going to cover all that needs to be lifted up in one reasonably short sermon.

So I'm going to sum up like this: first of all, don't be afraid of conversations when you notice some possible symptoms of a family member. Though Ronald Peterson who is quoted in one of the articles I've mentioned says: when initiating the conversation, be careful of jumping to conclusions.

"It's not something you want to jump into and say, 'Dad, I think you have Alzheimer's'. You might say, 'Dad, have you noticed, are you more forgetful than you used to be? You seem to be repeating yourself'. (2)

Don't let opportunities pass you by. If the disease is diagnosed, learn as a family what you can do, and learn ways you can cope.

Second, let's all try to let go of the shame and the denial. I am aware that there are members of Catonsville Presbyterian who no longer attend because they fear judgment about their condition, or the condition of a family member. We are children of God, and God does not abandon us. We don't need to be thrown out of the story. Let us support one another. Encourage one another.

Let's continue to discover how to be the family of God together. Let's explore ways we can be more welcoming as a congregation of families of persons with dementia. And discover ways we can support the caregivers, who are facing enormous challenges and losses of their own.

I'm going to close with the last two pages of the book we shared during the Children's Message, Grandma and Me.

"There will be a time in the future when Grandma will need more help. She may need help with getting dressed and eating her food. She may stay in bed a lot. Grandma may say or do things that she usually does not say or do. She may even seem like she is mad or upset with Mom, Dad, or even me. It is not Grandma's fault, or ours.

I know the changes are there because of Alzheimer's and not because of me. Grandma still loves me and I still love her, no matter what changes she goes through.

When Grandma can no longer tell me stories, I will tell her the same stories she always told me. I will let her hold the pictures while I tell the stories because I know that will make her happy.

When Grandma isn't able to talk to me anymore, I will hold her hand and talk to her like I do now. I know she will hear me.

Most of all, though (the) disease may change Grandma, it will not change me. Grandma and I together will always be Grandma and me. (1)

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(1: Grandma and Me: A Kid's Guide for Alzheimers & Dementia, Beatrice Tauber Prior & Mary Ann Drummond, 2018, Morgan James Publishing)

(2: WP, July 16, 2019 Susan Berger, 'Weird' Acts by Loved One May Signal Dementia.)

(3: Washington Post, June 7, 2018, Tara Bahrapour, "[Why it's important to say something if a relative exhibits signs of Alzheimer's](#)")

(4: "Who Will I Be When I Die?", Christine Bryden, 2012, Jessica Kingsley Publishers, London)

(5: p. 23 "I'm Still Here: A New Philosophy of Alzheimer's Care" John Zeisel, 2009, Penguin Group.)