

**The Tragedy (Discourse) Of Dementia by Sallie Tisdale, RN
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Start of Transcript

So, we're going to get into the gritty stuff now. I'm going to start with a quote from a 2016 article in the Journal of Neurology. "What remains is not another person, but the ruins of the former person. The loss of dignity, the knowledge that the lasting memory of their loved ones will be of a decomposed version of oneself causes them to suffer now, and that is considered to be unbearable. The tragedy of the disease is its destructive nature."

These blunt thoughts are not unusual. What's unusual is that this is a private thought spoken in a public square. The authors actually go on to talk about euthanasia for people with dementia. They question the pointlessness of letting nature take its course. Why go on and slowly disintegrate? Why not bring a halt to the merciless process? Now, dementia, of course is a group of diseases. You can actually have more than 1 kind of dementia at a time. They are all progressive. They are all terminal. But they're different, and the course is different. And yet, our communal response to the concept of dementia is one of deep existential dread. I have heard people with dementia described as less than human, as the living dead. I hear people say, "That's not my mother anymore, my mother is dead," or as in this article, decomposed ruins. So, what we end up with **[02:00]** as a community, as a nation is the only way we can talk about dementia, is what one group of researchers called the tragedy discourse.

When we think about the experience of other people, we imagine ourselves in their experience. And when you're thinking about dementia, that means you're thinking about being trapped in a failing mind. That's not what it's like for people with dementia. And we all experience a continuum throughout our life. What do we lose with dementia besides, we think, memory? Everybody always thinks, "Oh, you're losing your memory." What's really happening is that you're actually losing executive function; that's the biggest loss that people notice. And when I think about executive function, I think about how more or less able I have been throughout my life. I know that toddlers have taken executive function. I know that teenagers are very forgetful and have very poor impulse control. Babies can't balance. So, all throughout our life and at various times of stress, we experienced different kinds of executive function. And we tend to forget that these changes that we see with dementia are coming to all of us whether we like it or not. This is coming with aging; this is coming with illness. And for every one of us, dying means we will lose our physical function and we will lose our executive function.

If we look at people with dementia as less than human, then we are really looking at all of us as less than human. And I want to invite you to be able to see, not a broken life, but a whole life, a life that has a particular arc. **[04:00]** The quotes that you see are real comments from people with dementia. They will sometimes talk about revealing their diagnosis as a kind of coming out, and they mean all the fear that that phrase entails for people. When you reveal that you have a diagnosis of dementia, you create a black hole where all your independence goes away, where your power disappears, where your ability to make choices, to be an autonomous adult is taken away, usually right away. Now, self is a mystery. We don't really know where the self comes from, what creates the self. But one thing we know is that the self persists. As much as I have changed throughout my life, 'my me-ness' is persistent, and yet it's one of the first things we take away from people with dementia. Suddenly, they don't have a sense of self anymore, their 'me' is gone. We deny that persistence to people with dementia, and we shouldn't.

In fact, people with dementia feel very much like the same person they have always felt. They know they have a memory impairment; they know they're missing some pieces; they may be able to tell you exactly what they're missing, but they have not lost a sense of themselves at all. I've looked into a lot of the research on living with dementia, it didn't take me long, there isn't much. Researchers have been remarkably uninterested in what the lived experience of dementia is. They focus on cure, on palliation, on systems and so on. But they don't sit down and think about, "What is it like to live with **[06:00]** these illnesses?" And if you've looked like I have for in... for research on wellbeing and happiness and people

with dementia, it's very scarce; it is there, but it's very scarce. So, if researchers aren't interested in studying this lived experience, it leaves us with a very limited vocabulary. It leaves us largely with our own assumptions about dementia, our own perception of what we're seeing. When we have a limited view of something, we have limited words, and when we have limited words, we have a limited view.

Now, to approach other people this way breaks a fundamental scientific principle and it breaks a very important principle of caregiving, which is don't assume you know everything. Don't assume you know where it's going. Don't assume you know the end. Be willing to be surprised. What I want to do today more than anything is invite you to notice the possibility of happiness. In 1 survey of people with moderate dementia, (which means that some significant function has been lost and that people will need help with most... some of their activities of daily living), more than 2/3 of these people said they had a good or a very good quality of life. And they identified this quality as coming from friendship and attachments; exactly what disappears into that black hole.

What I see when I work with people with dementia, which is many days of the week, I see nuances that are never mentioned. I see intimacy. I see moments of startling clarity when it's least looked for. I have clients [08:00] who laugh and tell jokes every day. Whenever I see Laura, she's always going to have a pun. I see people who sing; whenever they hear music, they just stand up and sing. People dance; many people dance all day long. Another thing I see because people with dementia are vulnerable, they're physically fragile, and they're very socially fragile, and vulnerable, is a lack of defensiveness. Most of us in this room, we're on this... we're on this wheel of ambition and achievement and status and social role. And at a point with dementia, you step off this wheel, you stop defending your status, you become transparent in a way to relationship.

So, if you're from the outside looking in, when you look at a person with dementia, you may just see these losses. You may just see, "Oh my god, my mother can't tie your shoe anymore. Oh my god, my father's forgotten the names of the people in his family," it's all loss, loss, loss, but there's riches to be seen as well. I see brave people trying to figure the day out, just like me. I see that vulnerability that comes from having to trust people. I have a client named Jenny, she's kind of small and a little bit fragile, but like a lot of people with dementia, she's pretty busy. She walks all day long. She's always going somewhere. And sometimes, she carries a houseplant with her. She has this little house plant. And I don't know what that means to her, but I can look at her face and I can see that she's calm, she's composed. Sometimes, she carries it like a baby. She's pretty protective, [10:00] she's careful. I don't know exactly what it means, but I see love in her face.

People with dementia are like people who speak a foreign language. It's not bad, it's just different, and it requires us to pay attention in a particular way. When you're trying to communicate with someone who doesn't speak your language, you look at their facial expression, their posture, you look for all kinds of clues, the tone of their voice. You have to pay attention in a new way. My... my friend, Joe, moderate, moving on to a little bit more than moderate dementia, used to be a software engineer and a musician. So, he still loves his guitar, but he's forgotten the word for coats. So, when we went for a walk the other day, he... you know, he was showing me he knew he needed his code, but he... he didn't know the word. So, I helped him his coat, we went for our walk, and we walk a lot more slowly than we used to. That's partly because his balance is changing, but it's mostly because Joe is paying close attention to the... everything he sees. He is looking at each thing we pass, and he is attending to this moment, so it never happened before. And you know what? It never happens. He's onto something. How many hours have you spent, how much money have you spent trying to learn to live in the moment? Well, Joe's already got that.

Now, here's the caveat, this is a devastating, difficult, challenging set of diseases, in part because our healthcare system is so woefully inadequate [12:00] in providing the kind of care that people with long term illnesses need. It's pathetic. That adds to the suffering of families. The tragedy discourse also adds to the suffering of families. So, what I want to do is push against the belief, a kind of blanket belief that we have that dementia is always a disaster for the person with dementia, that the outcomes are always terrible, that tragedy is the only option we have for thinking about it.

One way that people with dementia suffer is from our pity. They suffer from our lack of attention, from our withdrawal of society, from our withdrawal of purposeful work. One study of happiness just generally said that the 2 things we need the most are intimate relationships and purposeful work. We take those away immediately. So, people with dementia suffer from our pity, which is distancing, very separating, and they suffer from our lack of attention. They suffer from the fact that we stopped listening. We say they have lost their dignity. The word dignity means worth, it means worthiness. We don't really mean that a person with dementia or aging or illness or a person who is dying has lost their worth. So, I want you to notice your assumptions. If you can just notice your assumptions, we often carry a dissonance between our beliefs and our actions. We believe that all people are equal, we believe our clients and our patients have worth and autonomy, but we don't always act that way. We are patronizing. We don't pay attention. We pity. **[14:00]** None of us have any choice but to meet our circumstances; that includes people with dementia, they have to face it. I want to live a life of grace. I struggle every day to live a life of grace. And to me, that means not just meeting your circumstances, but really learning to dance with them, really engaging with your life. I see this happening every day in my clients, and I want you to see it too. Sometimes, what I see is people literally dancing. Thank you.