

Contents

Introducing the Keeney's 00:56.....	1
Alzheimer's? No dementia. 06:03	2
CEO of someone with cognitive challenges? 08:35	3
Decision-making. Adjusting on the fly 13:05.....	4
A growing crisis. Rescue mission. 19:00.....	5
The first move 22:10	6
Healthy? Social connection! 27:41	7
Cascading craziness. Big decisions. 29:57	7
She was the love of my life 34:10	8
Reliving tragedy 34:40	8
Moving again. Another chapter. 36:19	8
Words of wisdom: Start the conversation now 39:11	9
It's a full-time job, taking care of myself 43:09	10
Reflections 46:37	10

Introducing the Keeney's 00:56

I've known the Keeney family for half a century. They were my second family and my safe haven during my high school and college years. I've paid the gift of them forward several times in my life. Gratitude! Jerry was my high school history teacher and Peggy, a feminist and artist. They folded me into their family, opened my eyes to Women's Lib, and nurtured me as I faced my dysfunctional family, drugs, the Vietnam War, and my confused self. I drove from Detroit to Zihuatanejo, Mexico, with Peggy and Jerry, the twins, Rebecca and Jennifer, and their sister Allison. I lived with them between travels and homes. I was living with them when my Dad died. I was 19. Becky and Jenni, twins, were 11 or 12, Allie 8 or 9 at that time. Jenni and Becky gave up their bedroom for me and moved in with Allie whenever I lived with them. I was so self-centered I didn't realize that until recently - 45 years later. They never complained.

Rebecca Archer is a nurse supporting people with rare diseases. We regularly speak about our families, nursing and advocacy. Jenni Keeney is a professional flutist and teacher. Allison Cofone works in Human Resources. I remember our trip to Mexico in 1969 or 1970. We lived there for several months. We partied one night, and Jerry got really drunk. He seldom drank more than a glass of wine. In the morning he freaked out when he couldn't remember anything about the previous night. Losing memory was his nightmare.

Several years ago, I heard *We're in trouble. Dad wonders off, gets lost, and Mom won't accept any help.* Jenni lived in Texas, Becky in Colorado, and Allie in Massachusetts. Peggy and Jerry had settled in Northern Michigan. Jerry was physically fit with progressing dementia, and Peggy chain-smoked and was an alcoholic.

Together (they're quite a team), Allie, Becky, and Jenni have gone through the gut-wrenching experience of trying to manage the physical and cognitive deterioration of their parents. How do you partner from a distance with reluctant parents? Do you intervene? How do you intervene? How much do you intervene? What's best for them? How do we maintain our boundaries as we help parents we love so much and make us so crazy? Becky, Jenni, and I sat down together after a long day to chat. You can probably tell how exhausted we were.

You'll notice in this transcript that sometimes I'll sometimes label Jennifer, sometimes Rebecca, and sometimes Keeney/Keeney. They complete each other's sentences, or I couldn't hear.

Health Hats: I'm sitting with two of my oldest friends - we've known each other for 51 years. How do you introduce yourself in a social situation?

Rebecca Archer: I'm Rebecca Archer, a mom of two sons, a nurse, a twin, and sister.

Jennifer Keeney: Hi, I'm Jennifer Keeney, a person on this planet. I love being a twin and a sister. I've been a musician for many, many years and a teacher, a flutist.

Health Hats: What do you remember first about our meeting?

Rebecca Archer: I don't know that I can remember exactly when I met you. I remember you hanging out with us, and I remember going on fun trips with you. And I remember being at the Unitarian Church with you.

Health Hats: How old do you think you were?

Rebecca Archer: I think that I was seven or eight?

Health Hats: What do you remember?

Jennifer Keeney: I remember having deep discussions with you. You were somebody I could talk to about things that I was thinking. I never felt weird talking about them.

Health Hats: Wow. And I was all of 16?

Jennifer Keeney: We knew you, too, when you were older, around 20. You were always willing to talk about anything.

Health Hats: Anything.

Jennifer Keeney: You were always a storyteller.

Alzheimer's? No dementia. 06:03

Health Hats: I'm here in Golden, Colorado, visiting. I came to visit you guys and your dad, Jerry, who's one of my oldest and dearest. I've been thinking a lot about what it means to be CEO of your health and your health care. You are managing Jerry's care. He has Alzheimer's. Being a selfish person, I'm delighted he remembers me. It's wonderful because he was so important to me. But it's been a challenge for you. You've been through a lot, managing.

Keeney/Keeney: We don't know that he has Alzheimer's. When I was running today, I was thinking, "God, how do you even know for sure that somebody has Alzheimer's right now or dementia or whatever it is that people have? How important is that? Or not important?" But he does have symptoms of cognitive memory loss? It was sudden for us. He was diagnosed in 2013 with dementia according to our health records. They were surprised that it was progressing very slowly. They didn't diagnose him with Alzheimer's because that usually is a change in personality. They still call it dementia because he hasn't gone to an extreme in his personality,

Health Hats: Yes. He's very much himself.

Keeney/Keeney: I agree. I think about it a lot. Having Alzheimer's would be so much different. It's not. They can't do much about any of it anyway, which is so frustrating to me.

Health Hats: You wish there were a pill or a magic bullet or something?

CEO of someone with cognitive challenges? 08:35

Keeney/Keeney: I wish there were some way to know when people have memory issues and better understand it with better ways to navigate. We should have conversations about it with our parents. We never got to have that conversation with them.

Health Hats: So, have that conversation before it happens?

Keeney/Keeney: Or even when it's starting to happen. Cause then you can't be CEO of your health.

Health Hats: Do you feel like you are the CEO of his health or do one of you?

Keeney/Keeney: I think all three of us are right now?

Health Hats: All three, including Allison, your younger sister?

Keeney/Keeney: We're all doing different things.

Health Hats: Say more about that. What are you doing?

Jennifer Keeney: I'm the daily care person, so I can see how he's doing daily, talking with the people that are caring for him there, and just manage his needs as far as daily living goes.

Health Hats: And what's your role?

Rebecca Archer: My role is to be a daughter to my dad and to provide a place for my sister to be here and for us to be close to my dad. And to make some big decisions as a trio.

Health Hats: Big decisions like where's he going to live?

Keeney/Keeney: We've all been doing that, trying to navigate three people with our specific roles. Then there are other roles, too. Allie takes care of the finances.

Health Hats: Interesting, my sisters, Jacky and Jessica, had a similar arrangement. I was the health care person, my sister, Jacky, the business person, and Jessica, who lived in San Diego, was the day-to-day spending time together. She took care of the day-to-day stuff. Jacky and I live in Boston. Our mom and Jessica were in San Diego. Once we realized and accepted that we had different roles, different

strengths, that made it so much more possible. We had a lot of tension before we figured out that we had different roles and that that was good. When we hoped the others would be different, we knocked heads. That was hard. But once we accepted that we have different roles, that was better. I can't expect Jessica to manage her healthcare. She was there as a companion. I didn't want to be my mom's companion. I didn't want to take care of the business stuff. Thank God, Jacky took care of business. It was fortunate that it naturally worked out. I don't know if it was naturally. It was arduous.

Jennifer Keeney: You think it's going to be this way, but then something else happens. Then you thought you were going to be able to do that, and then that didn't work out either. Or it worked out for a little bit, and then that person's life is stressful now. Just like Becky expressed, she's providing so many things, and I'm providing so many things. And Allie, too. I don't think anybody's not doing a lot to help.

Decision-making. Adjusting on the fly 13:05

Health Hats: What kinds of decisions have you faced?

Keeney/Keeney: If you'd go three years back, we knew and felt our parents weren't able to care for themselves well together. We tried to have that conversation with people that didn't want to have that conversation. No interest. She wouldn't let us in the door. They wouldn't let us visit.

Health Hats: So, first, it's knowing that there's something that's going on. And you feel for their health and safety.

Jennifer Keeney: The three of us were talking and trying to figure out whether we think this is a priority at this time? Is it our business to do anything about it?

Health Hats: The ethics of it?

Keeney/Keeney: Yes. That was just huge.

Health Hats: Say more about that.

Jennifer Keeney: I would have more of a desire to intervene than the others. So, we had to talk about that. Then maybe have the intervention to get some recognition from our parents. We finally got some recognition from our parents. Yes, this is something we're interested in. And the minute you leave, it's done, because we don't live near them.

Health Hats: You all lived a distance away. Your parents were not easy, living in Northern Michigan.

Jennifer Keeney: Was it tough getting into Detroit and driving six hours?

Health Hats: So, geography played a role.

Rebecca Archer: And we all don't live near each other.

Health Hats: Austin, Colorado, and Boston. That's crazy. So, there's something not right. Things don't feel safe. How do we love them and not be too overwhelming?

Jennifer Keeney: It seemed to me like the tipping point. Becky and I felt it's their life. They get to choose how they want to live it. We wouldn't want to live that way. We would want somebody helping us. Until I felt like my dad could not, because of his memory and stuff, care for him, make those choices for

himself anymore. When I felt like that, that's when I wanted to do something. He didn't get to make that choice. Mom was making all the choices, and her choices weren't his choices healthwise, ever. Other than that, they got along just pretty darn well. But he always wanted to go to the doctor. He wanted to take care of himself. He did take care of himself until he couldn't. When you say it like CEO of your health: do you know somebody well enough? Besides knowing yourself well enough to take care of your health, but do you know that? Have you really had that conversation with somebody and listened to them how they want it? We didn't have that opportunity. My mom for sure. Dad, a little bit just because he would talk about it. He liked doing his yoga. He liked to ride his bike.

Health Hats: So, knowing what was important in their lives and supporting them, meeting their goals. I find talking to Ann (my wife) about end of life or even what we want in our lives. That's always a challenging conversation. I might say I want just to go if I can't function and enjoy life. And I want to stay home. And she says, "I hear you, and I'll try to respect that, but I might not have what it takes." I was shocked when I heard that, and then I thought, "well, she's right, she's realistic. Sometimes you can do it, and sometimes you can't."

Rebecca Archer: You see us shaking our heads vigorously over here because you can't know what it's like until you're faced with that. So, she's very honest. She's doing her best to respect that in every way. But she also realizes that... We thought we would be able to do it - have our dad live here, but we couldn't stay up all night, waking up five times a night and always having to have somebody by his side.

Health Hats: Take a moment and recap that.

A growing crisis. Rescue mission. 19:00

Keeney/Keeney: What happened, less than a year ago, is we knew that my mom would not take phone calls. It got to the point where we couldn't call anybody. We had no idea what was happening with them. There was a huge, the worst storm with blizzard conditions. We knew they couldn't even get out. She wouldn't hand the phone to Dad. He couldn't use the phone. We hadn't talked to him in three months or more. We decided we needed a rescue mission to go and see what was really happening. So, we did. It was horrific. We were of the mindset; we're going out there to see how we can honor their choices, how we can make life simpler for them, if at all possible. But we didn't have any intention of moving, setting up, search for some services or something. Checking on Dad. We didn't know if we'd get to see her. But it turned out to be something good and bad all at once. We realized that they would not accept services. My dad would have, but Mom would not. She would block it. Oh gosh, it was just so bad, so bad. We had no idea that my dad's memory was so impaired. She was worn out. She was doing everything for him, and he relied on her 100%. She was just worn out. We finally got to the point where we're able to have the conversation and yes, she is worn out. She does want to move near one of us. She wants to accept our help, but she's scared to death. From that point we had help from the social worker, and the nurse was there and a PT person, an OT person, and everything like that. They were trying to do what they could. Mom would derail them. The social worker said he'd been working for 40 years and never seen anybody as strong-willed as my mom.

Health Hats: Yes, she was a force.

Keeney/Keeney: That's what he said. And he liked her too. She's never going to get with the program. So, we ended up having to make these decisions and work through all the legal parts and everything like

that. But my dad was very clear about one thing. He wanted to live by his daughters, and he wanted his wife near him. He was very clear that he wanted help. He wanted health care. He wanted to be going to the doctor. He wanted to live near family, and he wanted to be out of the snow. He was done with the cold. We ended up taking my dad first to Texas. Jenni wanted our parents to be there, and we wanted them to be somewhere warm. My mom agreed. She was going to wait until spring to come. And this was January.

The first move 22:10

Health Hats: So, then your dad came first.

Keeney/Keeney: My dad came first. We were setting up an apartment for them. We had to do all the legal stuff. We had to get a power of attorney signed and all that kind of stuff. So, we moved. Allie was going to take my dad. At the last minute she couldn't. I must've been on how many plane trips? I travel almost every week from work. I did like seven or eight plane trips in this year. We all took turns going there. Michigan during a snowstorm. We're stuck there in the blizzard. So, we got Dad back to Austin. Jenni in the meantime was looking at a million apartments trying to find places for them and setting up the apartment. We thought they could live on their own near Jenni. In the same apartment complex. I got him an apartment cause that's what they wanted. We gave Mom two choices. She wasn't able to make choices very well anymore. These are the two best choices: You can have an apartment near Jenni, or you can have this Assistive Care place. I looked at 27 of them.

Health Hats: This is massive project management. Plus, huge emotional exhaustion and disruption of everything in your life.

Keeney/Keeney: Thank you. And like you said, we all had our jobs. Jenni had her hands full with trying to manage. Allie quit her job and was full-time trying to help. And my job was calling my mom every day and coaching her towards making some teeny tiny steps towards getting ready to leave. That ended up with her leaving earlier. She was very, very depressed. We tried to set up all kinds of things for her. But she wouldn't accept any help except for one friend, Bill Twitty. Poor Bill, he would bring her wine and smokes and some food. We had this whole plan. Allie was going to go back to my mom and fly her back to Austin. That didn't work out so well. I had to fly back again to Michigan. She thought it was heartless, too hard. It was really hard because our mother who has never been to the doctor, we had to get a signature from a doctor. Talk about not being able to be CEO of your own health. Before she can go into assisted care, you needed somebody to say. And her blood pressure was 230/110. We have a genetic disease: polycystic kidney disease. We did not know seven years ago. We were 43. Our mom has it, too. She has never gone to the doctor. She didn't realize that she had this hypertension.

Health Hats: So, this is cascading.

Now a word about our sponsor, ABRIDGE.

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Store or Google Play Store. Record your health care conversations. Let me know how it went!"

Healthy? Social connection! 27:41

Health Hats: What does healthy look like to you now?

Rebecca Archer: I think there are health and wellness. Health is more physiologic. And wellness is how you feel overall. Health is a piece of being well, to me. It's what you think it is. Healthy is what it means to you.

Health Hats: So, it's your perception, and your perceptions are physical, cultural, historical, mental, spiritual, emotional? What do you think?

Jennifer Keeney: It's a personal thing for me - how I feel good, how I feel healthy? It has a lot to do with how I feel emotionally and mentally and spiritually. I feel my best when the physical part of my side is balanced out with the rest of it.

Health Hats: When the physical is balanced?

Jennifer Keeney: When I feel like I'm taking care of my body - not ignoring it.

Health Hats: Do you think your perception of that has changed this year?

Jennifer Keeney: I got to add one more thing to that - social connection. That's a huge, huge part of your overall wellness. That's what our parents lost.

Health Hats: They lost it because they were so isolated, both geographically and personally - from you guys?

Rebecca Archer: That was a big part of our decision that Dad had no ability to have any socialization.

Cascading craziness. Big decisions. 29:57

Health Hats: It's pretty dramatic what you guys have been through. You've had a cascade of craziness.

Keeney/Keeney: They lived the lives they wanted to live. However, not letting us in led to a house of cards falling when things went wrong. You and Allie would talk about that. You and Allie would say it's going to be a house of cards if we don't do stuff about it. Becky and I said, "it's going to be what it's going to be like." It's not our choice. We wanted to help. Allie wanted to try to do everything she could to prevent that from happening. To us, we've been trying forever. I don't see that happening. So, I think it gave me solace to think, and I have to be okay with this. These are the choices they've made.

Health Hats: So the challenge of watching people either make choices that you wouldn't make and seem unsafe while observing a decreasing ability to make choices at all - dramatically with your dad and then very suddenly with your mom? Then hitting that threshold, now we must intervene. Things have so deteriorated. It's time to intervene. Then you're trying stuff. It's a whole different experiment - an experiment of supporting them in whatever decisions are made? An experiment of what's the right situation now when you have more control.

Keeney/Keeney: What flipped my mom was that we said, "it's either the state's going to come in or come with us. I'm sure you'd rather have us come than the state. Of course, she told me I was threatening her and stuff. It did change her. She realized that somehow. So, she chose us.

Health Hats: I'm going to short circuit the story a little bit. Your dad moved to Austin. Then your mom came and was here for a week or two. How long was she in Austin?

Keeney/Keeney: She moved into assisted care with Dad and was there a few months before she passed away. She's still got to do what she wanted to do, which was be with Dad and be in a warm climate. It was spring. But she had COPD badly. She even tried to stop drinking and smoking. Then she didn't suffer that long. She was in the hospital for a few hours. And then she passed away.

She was the love of my life 34:10

Health Hats: Wow. That must've been flipped out for your dad. They were totally in love.

Keeney/Keeney: Yes. He always says, "she was the love of my life." I remember on the day that we had to tell him that she died. He just kept saying, "I've had bad things happen to me in my life, but nothing like this." He was howling and crying.

Health Hats: Oh, man.

Reliving tragedy 34:40

Keeney/Keeney: But then he'd forget.

Health Hats: To relive it over and over?

Keeney/Keeney: So, there was another decision. We were instructed in two ways. A lot of people think that when you have dementia that it's just cruel to keep telling them that somebody died because they were reliving it every single time like it was fresh. And then we just felt like he still understood enough to know.

Health Hats: I was there today, and we talked a bunch. We talked two or three times about Peggy, and he was pretty matter of fact.

Keeney/Keeney: I think he doesn't remember anymore. He asked once you guys left. When he's really, really tired, he'll say, "where's Peggy?" But he isn't as reactive anymore. But that was the choice. We still felt like he knew and that he had the right to grieve. Then we tried saying she was out on errands because it was so horrible for him. We did that for a while. Even before she got down there, "Where's Peggy? Where's Peggy? Where's Peggy?" We would tell him, but he didn't understand. So, then we had to say, "she's at an art class with friends. She went on a retreat." That's the only time she did stuff away from him. It was 15 times a day that he would ask about my mom.

Moving again. Another chapter. 36:19

Health Hats: So, then you had the bright idea to figure out what to do next? So, Jenni, you had a career and a life in Austin and Becky, you're here with a house. You decided to open your house to your dad and your sister.

Rebecca Archer: And I have two sons.

Health Hats: You uprooted your life, Jenni, and moved here to Colorado, thinking that he would live here. Then that was a challenging situation, too?

Jennifer Keeney: We were all so exhausted from January to May. Everybody wanted to live like a family and try to take care of them. I would be the main caregiver. That was our plan.

Health Hats: When my grandmother, Oma, moved to San Diego with my mom, she was really depressed and living in an assisted living place. We were living in West Virginia. We put an addition on the house and brought her to our place. Same thing, we were naive as hell and thought, "she'll be with family, and everything will be wonderful." We didn't know what it was like to live with a clinically depressed person. Oh my goodness, it was so stressful. I appreciate this. You were planning, and you figured that this was the right thing to do. You take a shot at something, and it doesn't turn out pretty much anything like you thought it would. Then, once again, you're exhausted, and you're making this really big change all three of you and your sons, and it's not the same.

Keeney/Keeney: It was the backup plan. If, for some reason, it doesn't work out, we know that there's this great place. Golden Pond Assisted Living Memory Unit.

Words of wisdom: Start the conversation now 39:11

Health Hats: If you were going to give words of wisdom to anybody else who's facing something remotely similar, what are your thoughts? What are the lessons that you've learned so far in this?

Keeney/Keeney: One of the first things would be to brainstorm with your siblings or whoever you think is going to have to make these decisions at some point for your parents. It could be lots of different people. But brainstorm and be willing to talk about what do you think this will look like? I know it might be a long time from now, or it might happen tomorrow. But be open to talking more about that and exploring options.

Health Hats: I feel like it doesn't really matter what you come up with because it won't happen. But grease the wheels of thinking about it, so you've had a cycle or two of chewing on a scenario, and you figure out how to talk to each other about it.

Rebecca Archer: A lot of my friends around here are ten years younger than me. They said, "what's your advice? I'm going to be there one day." I say that "If you're up for it, try to have these hard conversations with your parents. Really try. If only for your peace of mind. Try to get all their documents in place, because that is just like a major headache."

Jennifer Keeney: Allie - oh man, she's just done so many hours and hours and hours of work on that.

Keeney/Keeney: Personally, that's one of the things that helps me feel at peace. I feel like my sisters, and I really did brainstorm and work through this as well as we could and still are. I feel so fortunate that we are willing to have these hard conversations with each other. We did the best we could with my parents.

Health Hats: And you guys trust each other. That's apparent to me. You've always trusted each other.

Keeney/Keeney: When you talk to other people, that's what they say. It is a sibling issue. You cannot make somebody else do something, but you can talk to your siblings. And maybe find out, this is never

going to work out because we are so divided. How are we going to navigate? You try to have those conversations see if you can listen and get to know that person that you might be caretaking some time or helping with their life.

It's a full-time job, taking care of myself 43:09

Health Hats: How do you guys take care of yourselves? Frankly, both of you look exhausted to me. So how do you heal? How do you take care of yourselves? You're both busy. You have busy lives. You have careers.

Rebecca Archer: My friends are super important. My physical health is important to me.

Health Hats: I see you're out, and you're still running. You told me today, run and clear my mind."

Rebecca Archer: I remember my dad saying that, too, when he got to the point of retirement. "Dad, what are you going to do?" And he said, "it's pretty much a full-time job just taking care of myself. One of my hardest decisions is just getting out of the shower every morning." I remember that so vividly. Try to be gentle on myself, too. This has been an intense period. I'm finding the things I love to do.

Jennifer Keeney: I'm trying to learn what I can. I came here to help my dad because I wanted to. So, I'm trying to learn how to do that. How to start my career again and how to have enough energy to do those two things. As well as taking care of my dog and myself. I feel like I'm still figuring that out. It's different than just living by myself, taking care of me. It's a lot. And my relationship with my sisters, too. Because, because we are all caring for Dad.

Health Hats: So, your lives are turned on their heads.

Jennifer Keeney: They have their own families, too - their children. I'm figuring it out again. I feel like I'm learning.

Health Hats: You're learning.

Jennifer Keeney: You can learn so much in the last nine months.

Health Hats: Tell me two things.

Jennifer Keeney: Being patient, and I don't know anything. I don't know much about the disease state. I know a lot about my dad, but I don't know how his body has been affected by this.

Health Hats: He's frail. He's 88, so he has a right to be frail. Well, thank you.

Keeney/Keeney: Thanks.

Reflections 46:37

I love this family. I'm grateful that Jerry remembers me. When I see him, we cry and pat each other. He asks me every couple of minutes how long we've known each other *Fifty-one years, Jerry*. He nods. I read excerpts from *Roughing It* by Mark Twain to him. He chuckled at the passage about the jackass rabbit. He's a dedicated crossword puzzler. He corrects me on my distant memories. I send him a 60-second video clip every couple of weeks. The selective impact of dementia amazes me. Jerry has three daughters who love each other and care for him. My mom had three children who cared for her. Jerry

has some money. My mom had some money. We can all afford to care. So many can't. Making decisions for others is easier for some. It wasn't easy for the Keeney's. I tried to talk about end-of-life with my mom and her husband, Bill, twice a year for 15 years. No cigar. It was worth the try. When Bill got sick, my mom became a born-again end-of-life planner. Thank God. But it was still tough when she was dying. And she had all her faculties until the end. Physically healthy and cognitively absent has been a different puzzle. I'm grateful to be tangentially part of this one. Love you, Keeney's all.