

University

INTERVIEW SERIES

**Steps For Managing (And Delaying)
Alzheimer's:**

One Family's Journey

Dear Student,

I'm Michael Senoff, founder and CEO of HardToFindSeminars.com.

For the last five years, I've interviewed the world's best business and marketing minds.

And along the way, I've created a successful home-based publishing business all from my two-car garage.

When my first child was born, he was very sick, and it was then that I knew I had to have a business that I could operate from home.

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Now, let's get going.

Michael Senoff



Founder & CEO: www.hardtofindseminars.com

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Steps For Managing (And Delaying) Alzheimer's: One Family's Journey

Gary Reiswig, author of *The 1,000-Mile Stare*, knows firsthand about the struggle and science behind Alzheimer's. Just about everyone in his family has suffered from Early Onset Alzheimer's including his father, uncles, aunts, grandfather, and siblings. His family was instrumental in helping scientists uncover the genes that cause the disease, and now Gary's sharing everything he knows about it.

And in this audio, you'll hear all about his family's struggle with Alzheimer's, what to look for in order to catch the disease as early as possible, and the best plan for treating and caring for a loved one who's suffering.

You'll Also Hear...

- Telltale Alzheimer signs to look out for and how to confront a family member you suspect might have the disease (Gary says a loving personal approach is always the best way to bring up the subject, here's how)
- The best treatment that works to delay the severity of Alzheimer's now – and where treatment is likely headed in the near future
- All about the science behind Alzheimer's – the three genes that cause it – and the other lesser-known ways people contract the disease too
- The one big reason Gary says you shouldn't try to care for an Alzheimer's patient alone, how to set up "shared responsibility" for them, and how to know when it's time to let a nursing home take over
- Stories straight from Gary's life that illustrate how Alzheimer's can change a person's personality and decision-making capabilities
- Why it might be best to just go along with an Alzheimer's patient's delusional stories rather than try to correct them – and word-for-word examples of how to do that
- How to know if your forgetfulness is stress or menopause related – or if it could be the early signs of Alzheimer's

Gary says, when it comes to Alzheimer's, a person may seem completely normal one day and then not know you the next. Their personalities could dramatically change and they could even become hostile. Alzheimer's affects the brain, so it's a difficult disease to struggle with, and no two patients are alike. But there are strategies, support groups, treatment, and resources that can help. And in this audio, you'll hear all about them.

Hi, this is Kris Costello and I've teamed up with Michael Senoff to bring you the world's best health-related interviews, so if you know anyone struggling with their weight, with cancer, diabetes, ADHD, autism, heart disease, or other health issues, send them over to Michael Senoff's <http://www.HardToFindSeminars.com>.

Kris: Today we are talking with Gary Reiswig, author of The Thousand Mile Stare: One Family's Journey through the Struggle and Science of Alzheimer's.

Gary, thank you so much for joining us today.

Gary: I'm very happy to be here.

Kris: So you have quite a story. You have a very long family history of early-onset Alzheimer's. Your book is just a remarkable story of your experience in dealing with Alzheimer's. But I'd like to start with the science, because I know there are people out there who don't really know what Alzheimer's is, and can you kind of tell us what are some of the statistics, and what are some of the things that just stand out with this condition?

Gary: Let's start with some of the science facts and figures that have emerged and become evident to me as I've learned myself about this disease, as I worked on this book. Right in the book itself is a quotation from Dr. William Klunk at the University of Pittsburgh, who has worked on this problem, and naturally received a very prestigious prize for his work on Alzheimer's disease, the Potamkin Prize. And he says that by the time a person is 85 years old -- anyone who lives to be 85 years old -- has nearly a fifty-fifty chance of having Alzheimer's symptoms by that age. This is a startling statistic, when we stop to think about how many people are now living to age 85.

Kris: That is -- fifty-fifty is quite a roll of the dice there. What are the signs of Alzheimer's?

Gary: Well, the Alzheimer's Association, which is a marvelous organization, very well-organized and --run, and employs so many intelligent, smart, dedicated people -- I just can't believe it, every time I run into a new group of them at one local association or another. They have a website that lists ten signs of Alzheimer's -- ten things to watch for. So I would suggest either go to my website, the thousandmilestare.com and find a link to the Alzheimer's Association, or the Alzheimer's website itself is alz.org and find those ten signs.

But let me tell you some observations from my own experience, just living with family and watching first my grandfather when I was a boy, then my father, and nine uncles and aunts of his generation, and then my sister and brother of my generation, and a number of other cousins.

From watching them, here are some things I noticed -- simple things to keep in mind, not that you jump to conclusions when you see something like this, but let it raise your awareness a little bit.

Kris: And you started seeing these signs, Gary, when you were very young, right? You're talking about five years old, right?

Gary: That's the first time with my grandfather, when I saw the Thousand Mile Stare. Here's one thing I've noticed in my generation, and in the younger generations ... People who are normally good conversationalists and participate in the conversation, start either to withdraw because they no longer have the confidence to participate, or they may start telling the same story over again several times, in the context of one conversation. If this happens, this should raise a person's awareness. The loved one should ask, what's happening with this person? Why is this happening? So that kind of mental behavioral change that you might see -- either withdrawal or repeated episodes of doing or saying the same thing.

Kris: And when they say the same thing, is it almost verbatim, or kind of a different twist?

Gary: It can be a little bit of a different twist, like the person has forgotten they just told the story about Uncle Lou five minutes ago, and they're telling the same story again.

Kris: So it's pretty noticeable?

Gary: It is. It's very noticeable. You wonder, why, as he just told us this?

Then the common signs of forgetfulness. We all forget things, we go to the shopping center, we walk out of the shopping center, and you can't remember where you parked the car. But most of us can retrace our steps, and say, "Oh, now I entered from over there, and then I drove down sort of that way," and eventually we can get to it. But if someone has the moment of forgetfulness and can't retrace their steps, and they're having to call for help, this could be a sign that something is starting to go a little bit wrong with the mental processes.

Kris: And that's a very interesting question, Gary, because I know sometimes, is that hard to define for people? Because I know problems with memory

can sometimes be a symptom of stress or menopause. How do you know the difference with Alzheimer's?

Gary: Well, this is an appropriate question and a very good question, and it is difficult. And mostly, my thinking is, it's a matter of degree. If this starts happening so often, then the person needs to be taken to a doctor, to a clinic, and have some of that evaluated, so that all of those possibilities can be checked out. The good clinics that have a lot of experience in diagnosing Alzheimer's disease now are very, very accurate with diagnosing the illness. So, if things like this start to happen, the kind of things we've been talking about, and somebody's getting worried – some loved one, some acquaintance is getting worried, then the person who seems to be affected by these problems needs to be talked to and persuaded to get to a proper medical clinic and get an evaluation to find out what is happening.

Kris: And you've obviously experienced this a lot in your family, written A Thousand Mile Stare, your family's journey through Alzheimer's. What is it like when you confront a family member with this? I know we're getting a little off of the symptoms, but I'm very curious about, do people usually respond well, or how does that usually go?

Gary: Of course it varies with each individual, but it is a very touchy moment, when a child says to a parent, "You know, Dad, I've been noticing you've been doing this a lot. I'm concerned. I want to take you down to the clinic. And let's have this checked out to see if everything's okay." You know that kind of approach, that kind of easy, gentle approach, with a lot of "I" statements, saying "I would like to do this," "I would want to help you deal with this," instead of any blame about you're not doing something right.

Kris: So the approach is really important?

Gary: Yes, a loving personal approach. "I've been noticing this," "I'm getting concerned," "I would like you to go with me and let's look into this."

Kris: And so, Gary, what are some of the other symptoms?

Gary: In our family, getting into trouble driving has been a real sign of having problems. The first one was even before I was born, when my grandfather in his early fifties, drove a truck in front of a freight train at a wide-open crossing in the panhandle of Texas, and my grandmother was killed.

Kris: Oh, my goodness!

Gary: None of the kids could figure out why anybody would do that. It was just impossible to comprehend how he or my grandmother, or my 17-year-old uncle who was in the truck at the same time, couldn't see the train. And then in my brother – here's the kind of thing that happened to him – a good driver started making bad decisions. Now he fortunately avoided an accident. He never had an accident before his wife asked him to stop driving.

But he started doing things like suddenly deciding to turn left from the right-hand lane, instead of having the presence of mind to say, "Oh, boy, I don't want to do that, I might cause an accident. I'll just go up here and make two right turns and get back on the correct route." So mistakes in driving that requires that kind of reasoned almost instantaneous decision. If you start seeing a person make those kinds of judgment mistakes, that's something to watch out for.

Kris: And a scary thought with the over 85 and that fifty-fifty have Alzheimer's – scary thought for me out on the roads now.

What other things do people need to look for when they're wondering about Alzheimer's?

Gary: Well, I had mentioned this before. The gradual change in one's mental attitude, withdrawal from conversation, as I had already mentioned. A kind of heaviness and slowness that seem, at least in my family, to have developed in people suffering from this illness. And I wouldn't say that these things can noticed all at once, but have to be observed over a long period of time -- these more subtle behavioral changes, where a happy, normal, participating person and alive with life, over time starts to gradually become silent, and sad looking, and withdrawn.

Kris: For more interviews on health, mind, body and spirit go to Michael Senoff's <http://www.HardToFindSeminars.com>.

You have a very moving story in The Thousand Mile Stare, of your father – I guess you guys were on a cattle ranch, and he made a decision to take the horns, de-horn the cattle, I don't know the term for that ...

Gary: Yes, well, you got the term, "de-horn" the cattle. This was an incident in which he and I were doing something together that had started actually when I was nine years old. And it was my favorite part of the farm, and this was raising registered Hereford cattle.

And these cattle were just beautiful, beautiful animals, and part of the beauty was that by the standards of the breed, their horns were to be

trained to grow a certain way, to kind of frame their head, and give them a very special look. And it also trained those horns that were essentially, in the more primitive breeds used for fighting and dominance, it trained the horns so that they weren't as effective as weapons, but just for decorative purposes.

When I was in my teens, my dad got it in his head that he wanted to de-horn those registered cattle, and I just argued with him. I tried to reason with him, "But Dad, they don't hurt anything with them. Okay, so they get into a few head-butting incidents, but cows without horns do that same thing. And if you cut the horns off, it's going to depreciate their value – each one of those animals is going to be worth at least a third less than with the breed-appropriate horns on them." And I just couldn't persuade him.

One day, I got home from school, and he had taken both his animals and my animals – I had five or six registered Hereford cows myself – and he had cut off their horns. It was really a sad, sad, upsetting day. And of course, we didn't understand that there was a genetic disease in the family at that point. There was nothing to attribute this to, except that he just got something in his head that he couldn't let go.

And it was really an example of bad judgment, which is actually one of the Alzheimer's symptoms that is listed by the Alzheimer's Association. When rational people who have a long history of making good judgments start to make poor judgments, that's a warning sign.

Kris: It's as if they lose the ability to kind of rationalize and weigh decisions and things. They just make impulsive reactions.

Gary: That's right. That's exactly right. Cells in the brain are dying, and the normal rational processes start to get interrupted.

Kris: And that just must have been so shocking to you as a teenager, to experience that. And how old was your father?

Gary: Well, he then was in his forties.

Kris: Pretty young. And did you see other things after that, did it kind of snowball? Or how did that progress?

Gary: Well, yes, it did snowball, so one of the things that happened after that, and one of the things that I feel so badly about, because I participated in this – well, you know there were little things that would happen along, that we would laugh off.

Just one example of that kind of thing ... so we had a little rule in our family, that for the evening meal we always had homemade ice cream that we made, and we kept in a big pot in the freezer that was in the hall. And the person who went to get the ice cream and brought it to the table, if they were the only one who took any ice cream, they had to take it back. If somebody else took some ice cream, then one of the other people who took it, had to take it back, so the same person didn't have to go retrieve it and take it back.

And one evening, my father took the ice cream back to the freezer, and the next day, we couldn't find it. And it was just one of those mysteries. And about a week later, my mother finally bumped into this big kettle of by-then-melted ice cream, put in the hall closet, at the opposite end of the hallway. Well, then it just seemed like that's really strange. What caused him to do that? But then things just kept escalating.

And the thing that I wanted to tell you about that was more serious was, by the time I went to college and graduated, I was married and had two sons when I graduated college, and my dad volunteered to bring the truck from the farm, and help us move from where I was going to school in South Dakota, to Indiana where I had taken a job.

Mother objected by the way ... Mother didn't want him to do this, but both he and I insisted, "No, it'll be fine." I was in denial, you know, about how really serious his illness was, despite all the things that I told you had already happened ... the de-horning and all the other things. It's very hard to recognize this if you're not expecting it.

Anyway, he helped me get the furniture, get our chattel to Indiana, and then he had to drive back from Indiana to Oklahoma. And I carefully drew him a route out on a map, but he couldn't follow the map. He would get lost despite the map. Five days after he left, for a two-day trip, he had not reached home.

And the thing of it was, he forgot that we had a phone on the farm. We didn't have a phone until about two years before that, but I had talked to him on the phone when we talked about him coming to South Dakota to help, but by then, when we was driving back, he thought that they didn't have a phone, so he didn't call Mother. And she was worried, and I was worried, and we finally got the police from Oklahoma, and the police from Indiana to sort of converge and they finally tracked him down in Arkansas, miles off the route. And then gradually they helped him get home.

I saw that getting lost, that kind of thing, happens – this is even more toward the mid-stage of the disease in all honesty. And hopefully our whole culture is more attuned to these kinds of events now and will not let things like this happen. I mean, I should never have allowed him or asked him to come do that kind of driving out on the road, in his condition.

Kris: Ya, and you said, it's hard to let go and to realize the severity of it, probably in part because it is as you said, fleeting – you know, it comes and goes. There's moments when they come back.

Gary: Well, this is very true. There are times when a person, even in the mid-stages of Alzheimer's, can appear perfectly normal, and you think, "My goodness. Mom's feeling fine. Mom's great. Look, I think she's cured." And then the next time you see her, she will not know who you are.

Kris: It's such a roller-coaster ride, and I wanted to talk a little bit with you, Gary, about how do people care for someone with Alzheimer's. That must be a very difficult question for people, you know, whether the person needs to go in a home, or needs help at home. What have you seen works well for that?

Gary: Well, in my family, this has been a very difficult decision-making process. In my family, people will have tried to keep their loved ones at home just as long as they possibly can. In the case of my father, the disease actually affected one of his organs, and the part of his brain that was being most affected shut down his liver, and he officially died of liver failure.

Now in the case of others, you just have to be aware that this is not the same person that you once knew and loved. It isn't that you don't love them, you do still love them, you still remember how they were, but some dramatic personality changes do occur.

In the case of my sister, mostly she withdrew, mostly she became silent, but toward the end, where my brother-in-law was having more and more difficulty taking care of her, if he went to the farm to take care of the cows, he was afraid to leave her alone, because she might wander out the door, and have no idea where she was. And then he'd have to chase her down and find her. And if it was in the winter, she might have gone out even without her coat on.

So that kind of thing happened, but he was sort of adjusting and living with that, but what made him finally have to put her in the nursing home, where she could get professional care and unfortunately often medications are needed in these instances ... What happened was, one night, she woke

him up in the middle of the night, screaming that she was going to kill him. She thought he was a stranger who had snuck into the house, and had gotten into bed with her. She had no idea who he was, and he tried to say, "Remember me? I'm your husband, we did this, we did that," and all she could say was "I don't know who you are! Get out of my bed!"

Kris: Of my goodness ...

Gary: And she threatened to kill him, so he hid the kitchen knives because he was genuinely afraid.

Kris: You're listening to an interview on Michael Senoff's <http://www.HardToFindSeminars.com>.

Probably rightly so! My husband's grandfather had Alzheimer's, and he tells stories of how realistic when his grandfather would talk it was. He would visit him in the nursing home, and his grandfather would insist that the building was on fire, and I guess he was a young person at the time. It was almost believable because his grandfather would go on these long explanations of how half of the building had already burned. It was amazing, he said.

Gary: Well, interestingly enough, I've read some things and been around some people who have dealt with this phenomenon, and most people think that it's better to just to – without getting excited – participating in the ideas that are being expressed, to go along with it, and just try to reassure them. "Well, Grandfather, it's all right. We're safe. I'm going to take care of you here, so don't worry about it," that sort of thing. Even if the building is on fire, we're going to be okay.

So if you start disagreeing with them sometimes, they will get angry and belligerent and think that you're trying to harm them.

Kris: And so that question regarding Alzheimer's though, in making that decisions for nursing care or out of the home care, does it kind of boil down to when it becomes a safety issue?

Gary: That's exactly right. That's the perfect way to express it. Caregivers themselves and / or the ones needing the care – when the issue is the safety of one or the other or both, then it's time to get some professional help.

Kris: Does Medicare pay for nursing home care usually? Or how does all of that work?

Gary: In the case of my sister, yes it did. I'm not sure about all cases, but I know I have a cousin in a nursing home now, that is being taken care of by Medicaid.

Kris: Another thing that you talk about in The Thousand Mile Stare, is that your family, because you've had this incredible struggle with early-onset Alzheimer's, you said your grandfather, your father, and your sister and your brother – they played a pivotal role in the development of the EOAD genetic testing – did I get that right?

Gary: Yes, EOAD stands for Early-Onset Alzheimer's Disease, and let me just give you a little run-down on this, if I can. There are three genes now known that cause early onset Alzheimer's. I'm speaking of the genetic kind, of familial early onset Alzheimer's. Not every case of early onset Alzheimer's – and we're talking here about before the age of sixty or so – not every case is of this genetic familial kind.

But the causes of what's called "sporadic" or incidental kind of early onset Alzheimer's are not yet well known. An example of a new cause that's just now emerging is of course, the repeated head trauma. And that we're learning about from the National Football League, of all places. So anyway, not all cases are genetic.

When my family really started figuring this out, that this was a genetic family problem, one of my aunts, wife of one of my father's brothers, started pushing and praying, I would say, our family into a research program. And we started at the University of Colorado, and they published a few articles about the work they were doing with us. And then, the National Institute of Health started what was called "The War on Alzheimer's" when the US Congress woke up to the fact that when the baby boomers reached retirement age, there was going to be a big jump in the Alzheimer's cases. They knew that it was going to strap the whole healthcare system. And that's where we are right now, we're into that period.

So they founded that across the nation about 20 or 30 Alzheimer's disease research centers. And the center that was located in Seattle, WA at the University of Washington and at the veteran's hospital there designed a research study to study the familial kind of early onset Alzheimer's, where obviously a number of people in the same family were affected. And so we got located in that study.

And finally, after two other early onset genes were found at other institutions, the gene was identified that affects our specific family and at

least eleven other families from the same two villages -- seven miles apart, in a region in Russia, where many Germans had settled in Russia, leaving Germany in the 1760s -- living in those two villages of Walter and Frank in Russia. And so that gene was found, it's called PS2, presomal 12 and now people can get tested for that.

In our family, we can be tested for that, to find out who specifically who has the gene. But the primary value of these early onset studies, that's found a gene on chromosome one, PS-2 and the gene that affects our family -- and then there's another gene on chromosome 14 and a gene on chromosome 21. Those familial cases are being used in many of the research facilities around the world to study Alzheimer's. So we are happy that we were able to be a part of that from the beginning, and hopefully great progress is being made, which we believe that there is.

Kris: And that must have been an amazing day for you when you had the test and it came back that you did not have that gene, right?

Gary: I was 55 when I found out for sure, when the gene was found and I consequently found out for sure that I didn't have the gene. I thought I was past the age of onset, and I probably didn't have it, but I didn't know for sure. The usual age of onset in our family was in the early to mid-40s, although were some cases where it was not until the early 50s that symptoms began to appear. And it was both a tremendous sense of relief to find this out, that I didn't have the gene, primarily because if I don't have it, I can't pass it to my children. Because an autosomal dominant gene cannot be passed -- it doesn't skip generations. So that was a great relief.

There was a mixed response too, because by that time, both my brother and sister were affected. My sister was quite ill, and my brother was certainly in the mid-stages by then. And I just felt so sad for them, and so bewildered about how did I win in this lottery? How did I win this coin toss, when both my brother and sister lost?

Kris: That must be a really difficult question to struggle with. Now, I also want to ask you, Gary, about what have the treatments been so far for helping people with Alzheimer's and what kind of new treatments are coming around?

Gary: Well, there are now four or five drugs that, taken either singly or in combination with each other, seem to help in slowing down the progression of the disease. And that's why it's very important for people who may be developing symptoms, Alzheimer's-like symptoms, to get an evaluation as soon as possible. Because the earlier these drugs are

applied, the more effective they are in delaying the progression of the disease.

Now what's coming down the pike in the future is really still kind of unknown, but the pathology of the disease, as described by Dr. Alzheimer in Germany in 1906 who first observed and described the disease, the pathology of the plaques entangled in the brain. There are now many experiments being developed about how to stop these proteins that make up both the plaques and tangles, how to stop the abnormal development of these proteins in the brain. All three genes that cause early onset Alzheimer's are involved in the production of these proteins. And that's why the early onset cases have been so important in the research, because they're trying to figure out how to interrupt the abnormal process and keep these abnormal proteins from forming.

Kris: Before we finish up, Gary, I just wanted to ask you also ... People that are trying to help their loved ones with Alzheimer's – it's a huge task, a daunting task, I'm sure. What are some practical ways that caregivers can deal with the stress of dealing with Alzheimer's?

Gary: Well, one of the main things I think is try not to have to do it all alone, because it's such a lonely thing to do. This has to be a shared responsibility, because it's just impossible, especially when the disease advances even through the mid-stages – for one person to be responsible for the well-being of another 24 hours a day.

Going back to my grandfather, when I was just a little boy, my grandfather was moved around from married son or daughter to another. He would stay with each family a month at a time, so that there was shared responsibility. But I tell you, even a month at a time got to be long, and my mother and father would get me to take Granddad for walks out into the pasture, just to get him out of the house for a little while, because it's a really big, exhausting, draining responsibility to have to keep your eye on a grown man that's 62 inches tall, because he's behaving like a toddler of two, and can get into trouble in a moment. And this is exactly what happens to Alzheimer's patients.

And this was described so beautifully by my aunt Esther about her husband, my uncle George. The person just seems to go backward through development. She said first her husband became like an adolescent, overly opinionated, then stubborn and belligerent, then he just went backwards until he could no longer care for his bodily needs and this is another indication that it's time to get some institutional help, when a person loses their bath rooming ability. Because it's one thing to be doing

that for a child who's a year old, but it's another to be doing it for a grown 200 pound man. So this is what I can say about the caregiving -- beware of thinking that you'll be able to do this alone. You've got to get some help.

Kris: So reach out and get support, and as you mentioned, there are some wonderful groups out there.

Gary: Yes, again, check in with the Alzheimer's Association. They have support groups in most communities throughout the country.

Kris: Great, and also if people want to find out more, they can go to the [thethousandmilestare](http://www.thethousandmilestare.com) – that's S-T-A-R-E dot com. That's by Gary, whom we've been speaking with today, about Alzheimer's and the incredible challenge that his family has faced with it and his very illuminating new book, The Thousand Mile Stare. Gary, thank you so much for spending the time with us.

Gary: Thank you very much for having me.

Kris: That's the end of our interview, and I hope you've enjoyed it. For more great health-related interviews, go to Michael Senoff's <http://www.HardToFindSeminars.com>.