What Happens To A Relationship When You Become A Caregiver

This podcast does not provide medical nor legal advice. Please listen to the complete disclosure at the end of the recording. Hello, everyone, and welcome to Everyone Dies, the podcast where we talk about serious illness, dying, death, and bereavement.

I'm Marianne Matzo, a nurse practitioner, and I use my experience from working as a nurse for 44 years to help answer your questions about what happens at the end of life. And I'm Charlie Navarrete, an actor in New York City, and here to field questions you may have, such as, we don't need a will, right? I mean, it's just me and the wife. Well, when one of you dies and there is no will, your local government, and likely your state government, will investigate to confirm that.

The remaining spouse will have to pay a lawyer for that investigation. It will take you more time and money if you are not married. So get a will.

Make plans for the end of your life. Well. Well.

So. Yes. Please relax, get yourself something to eat and drink, and thank you for spending the next hour with Charlie and me as we talk about caregiving for a loved one who has dementia and how that changes your relationship with them.

In the first half, Charlie talks about wearing black to a funeral, and I have our recipe of the week. In the second half, I have part two of my interview series with Michael Porter, where we talk about the effect caregiving has on the marital relationship. And in our third half, Charlie has sort of kind of a poem-ish, right? Right? So I'm continuing our recipes from famous people by sharing the recipe for Mamie Eisenhower's chocolate fudge.

It's also known as million-dollar fudge, and this ultra-rich, creamy, and sweet fudge is a snap to make. With the help of some grocery store shortcuts and a few short steps, you will

have a swoon-worthy dessert to take to your next funeral lunch, 34th presidentially approved. Excellent.

So. So, Charlie. Yes? Something about black? Yes.

Funerals? Clothes? Clothes. Funerals. Black associated with death.

Oh! Oh my. You know what I just remembered? No. This.

God. This is season four. Actually last week started season four, and we never acknowledged it, and I almost never acknowledged it just now.

So I have my bell. Cow bell? We need more cow bells. Because I keep it with me.

Oh yeah. That was from that Saturday Night Live skit with Christopher Walken, it's like, cow bell. We need more cow bells.

We need more cow bells. Oh my God, Marianne. The beginning of year four.

This is like, holy smoke. Where'd the last three years go? Behind us. To the rear.

Well. And you know, and we, and we, and this, this started just when COVID started. You know, the, the, the, the, huh, how appropriate.

And I can remember when we started, I got a message from somebody on Facebook who said that really it was tone deaf of me to talk about death when COVID was going on. When people were dying? Yeah. That's really tone deaf.

And I thought, seems to me like it's like the perfect time to be chatting about this. So there you are. I don't know where that woman is now, but we're still here.

So why do we wear black at funerals? I don't know. Let me tell you about it. According to

artist and professor F. Edward Hume, since the sixth century, black has been utilized in the Christian church for a suggestion of the spiritual darkness of the soul.

By the 14th century, it was widely associated with death. What set black apart and solidified its status as the shade of mourning by Elizabeth the first funeral in 1603 was its expense. Creating the right black from specific roots, herbs, and flower petals cost a pretty penny.

Black clad funerals were political theater intended not just to console the bereaved, but to put on a show so over the top that it established a cultural split between commoners and the ruling class. Funerals were the red carpets of the day. And just like today's red carpets, unattainable for common folk.

For hundreds of years, it was illegal for commoners to wear certain colors and fabrics. England and much of Europe had

laws dictating that the colors and fabrics people could wear would be based on rank in society. This made one's social status evident at first sight.

Laborers were permitted to wear linens and most lower quality wools, but not embroidered silk, satin, finer furs, certain buttons, and threads of gold, purple, and silver. Supervisors of aristocratic funerals had to make sure that no social climbing upstart families displayed arms or carried out grand funerals to which they were not entitled. Oh, snap.

An English proclamation banned devising any new forms of apparel. So people were fine for wearing mourning clothing above their social class, but ordinary citizens with a strong feeling for greatness repeatedly broke the laws and just paid the fines. By the 19th century, production of cloth and the growth of synthetic dyes, which made the color black cheaper to produce, helped businessmen see dollar signs in death.

One entrepreneur turned mourning clothing into some of the first mass-produced fast fashion by opening Jay's London General Mourning Warehouse in 1841. Competing shops sprang up. These entrepreneurs helped create an entire industry around death.

Etiquette guides of the time defined distinct mourning periods, such as a man could avoid social scrutiny by wearing all black for three months following the death of his wife. Widows, however, were required to visibly mourn in a black dress for two and a half years. Jay's Morning Warehouse and other stores incessantly advertised of latest mourning fashions so that no self-respecting Victorian would be caught dead in last season's outfit.

When Queen Elizabeth's husband died, she wore all black all the time for 40 years until she died. Much of the show of wealth and luxury of the Victorian period intended to

impress or attract notice died with her. World War I, working in factories, and the Great Depression put more nails in the coffin regarding the number of days women remained dressed in black.

In 1926, clothing designer Coco Chanel, who observed, A woman can be overdressed, but never over-elegant, created the little black dress, which became a staple of late afternoon and cocktail hours, hmm, I wonder what time it is, making it fashionable to use the color on any occasion. Audrey Hepburn made the dress famous in the film Breakfast at Tiffany's. The all-black outfit evolved into broader worlds of fashion, including punk and goth subcultures.

Black at a funeral is as common as ice cream in July, and just as temporary. The TV show Ted Lasso observed, Funerals are weird. They're like a party but for sad people, where everyone knows they have to go and be sad.

Maybe you're not sad, but you have to go and act sad. Mourners, supposedly mourning, chat and laugh and mingle, ignorant of the bereaved who would like to have some quiet time. Those few will continue their state of grief in their own way.

For me, I grieve the dead in my life by way of a personal accessory. For example, the letter I wrote my father, not a demonstrative man, when I was seven, which he kept unknown to me until he died 60 years later. Then there's my son's second baseball glove, the gray one he insisted on.

These are enduring and I hold dearly, till death do us part, when all that will be tossed away. Hmm, that's really good. Thank you.

Thank you. Please go to our webpage. I was going to say, what do you want from me when I die? What are you going to want to hold on to? I say this, I haven't thought about it because the thought of you dying and how

close you came to it a few years ago, Marianne, so don't ask me.

Well, I'll put something aside for you. Okay. That I think you'll like.

Thank you. Maybe my cowbell. I'll give my cowbell to just anybody, Charles.

As long as I get to go before you, that's fine. So please go to our webpage for the recipe for former first lady, Maybe Eisenhower's million dollar fudge and additional resources for this program. You know, many of you have contacted Everyone Dies to say how much Marianne's years of experience with serious illness, dying, death and bereavement have helped you.

We ask you for your support in the form of a tax deductible contribution so that we can continue to offer you quality programming. Thank you in advance for going to our website to make your donation, as well as following us on Facebook and Instagram.

Visit us at www.everyonedies.org. That's every, the number one dies.org. Marianne.

Thanks, Charlie. Today, we're going to be sharing our second interview with Michael Porter regarding what he's learned about caring for his wife who has Huntington's disease and dementia. When we marry, we establish a pattern to our relationships that evolve over time.

When a spouse becomes a caregiver to the other, that relationship changes and will change in different ways depending on if the caregiver is male or female. But it will change. Michael talks about letting the relationship change in the way it needs to.

This is especially difficult for the caregiver because it's not the way they thought their marriage would be in their later years. The plans a couple make in their early years as they wait for enough money or time to do the things they want will not happen when a partner receives a dementia diagnosis. The

perspective of your role in the relationship will change as well as the reason you are in the relationship.

Letting go and changing the plan can bring great heartache and loss to the caregiver, which is why the perspective in approaching the caregiving role is so important. So, here's my chat with Michael. Today, we're going to be talking with Mike.

Mike was with us a little while ago and he is caregiving for his wife, Janet, who has really, at this point, end-stage Huntington's disease. And if you remember, Huntington's disease has a variety of symptoms that go with it besides the chorea, which is the movement. But there is depression, dementia, symptoms that are seen.

At this point, Janet is under hospice care, but Mike's been taking care of her for 12 years now. And so we thought that it would be good to do a chat about caregiving for someone with dementia and how to handle

certain situations. And Mike makes a great point.

He talks about how there's, you know, very concrete ways that people tell you how to do good physical care. But the moving target is always the emotional response. How do you deal with questions or comments or other kinds of issues that come up? So, welcome back, Mike.

I'm so pleased that you're willing to talk with us again. I have a feeling that you might be a regular for us because you're so articulate and knowledgeable about the ins and outs of this care. And I think that people who are caregivers really need to be able to listen to how, you know, how do people do it or what are some techniques or things to know? So you were just starting to tell me that you were reading about a woman was asking a question.

So what was the question she was asking? Well, this is a story that came from a post that

I saw on one of the dementia websites or dementia support forums. And the woman who was relating the story was telling that she got a phone call from her mother with dementia. And she was explaining that she was sitting on the front porch with this really, really nice man.

And the woman says, oh, is that your husband? Oh, no, no, no. This guy's name is Frank and he's really, really nice. You know, and the woman was asking, well, how do I deal with that? I mean, because Frank, I mean, that is her father.

That is her woman's husband. Yeah, so how do I deal with it? And one of the things that I told her is like, you know, if it makes her happy, you know, I mean, what harm does it make? I mean, maybe the best case is for, you know, a few weeks until this phase passes. It gives your mother a chance to fall in love with your father again and again and again and again.

And it's not a bad thing, you know. If it makes them happy, fine. You know, don't sweat it.

And it's these kinds of things that I think that, you know, there needs to be more general education with caregivers, you know, telling them how do you deal with this kind of stuff? Because, you know, people, they see things happening like that and they get confused and they get upset and they get worried. And it's like, well, how do I deal with this? What do I say? You know, what do I say when, you know, mom doesn't recognize her husband anymore, but she thinks she's falling for him? You know, how do you address stuff like that? And that there was a post that I saw a while back that said that, you know, thankfully, we've gotten past the stage where in medical care for dementia, where we used to think that if they said something wrong, we always had to correct them. Oh, yes.

Yeah. You know, like, you know, like this, like, oh, no, no, no, this is not 1945. We're now in the year 2020.

Oh, yeah. Or or or I'm your or like, what do you mean you don't know me? I'm your son. Or how can you say something like that? You know, I'm your wife.

I'm your wife or I'm your husband. And we've been together for 45 years. Or even I can remember back, you know, in the day I was, you know, working as a nurse when we were doing reality orientation and telling people, you know, the truth.

And it was so distrustful to patients that then we started saying, well, if you if you know, and this we're talking like I was in Massachusetts at Worcester State Hospital. So the state hospital that, you know, in the old days, it was called the state hospital for the insane back then. And this is 79, 80, 81 in that period.

They would put people with dementia in the state mental hospital. And so we would have we had a ward of people with all the different

kinds of dimensions. That's what they were there in the state hospital.

And so that was a group that I loved working with. And remember, there was this one guy who would, you know, like say, where's my wife? And people would say she's dead. And he would be like, oh, my God.

And sob and just and then, you know, 10 minutes later, where's my wife? And I said, this is ridiculous. Why does he need to grieve 10 times an hour? Oh, absolutely. I mean, you know, my mother had three strokes.

And after her last one, we were caring for her. And she was in Texas. And I would go and I'd be talking to her.

And and she said, and she would start saying, you know, she I wonder where mom and dad are her her parents. And she'll get halfway there. And she says, oh, wait.

They're dead, aren't they? And I said, yes. And she says, oh, she says, that's the worst part. This whole thing is you forget.

And then you have to go through over and over and over again. I mean, there were there were times when I when I I would be visiting my mom. And she and she would say things like, oh, where's where's Mike at? I've been I've been looking waiting for Mike to come by and see me.

And I said, oh, hang on. Hang on, ma'am. I think I saw him.

So I'm right outside. I'll be right back. And so I go outside, wait about 10 seconds, and I walk by and say, hey, mom, hi, how are you doing? And she's oh, Mike, you're here.

And I mean, just let that be OK. You know, yeah, I see on those posts, too, people get very distressed. My mother doesn't know me.

That's OK. She knows your heart. You know, she knows you're a nice girl or that you look just like her sister or whatever it is.

It's OK. Just be where they are. And there's no problem with that.

You can't expect, you know, like it's like if if you have a broken leg, nobody expects you to run a marathon. Your leg is broken. You can't.

And that's the same thing with any of these these dementias. It's like it's broken. Don't expect it to do something that it can't do, meaning the brain.

It can't do it. Right. Yeah.

And that is actually something that I tried to I've used as an assembly that I've used to talk to people. You know, if if you have a broken collarbone, you don't get angry with somebody because they can't reach the top shelf in the kitchen. You know, you say, oh,

well, that's part of having a broken collarbone.

And you deal with that. You work around it. And the same thing, you know, with this kind of a situation where you, you know, you.

You just let it let it be OK for them to be where they are. I mean, it's no big it's no big, horrible thing that people are going to be upset about or be angry about or or there's, you know, I mean, as long as you're not doing something, it's actually going to injure them or harm them or, you know. You know, it's fine.

Go for it. You know, it's and you sort of learn those things. And and the other thing I've sort of learned is to not take things too seriously sometimes or to understand, you know, that sometimes damaged brains say things.

For instance, when my mom was in a nursing was a nursing home locally here in Texas. She

was sharing a woman with a Hispanic lady on the other side of the fire. All right.

Well, one weekend, the family came to visit the lady on the other side of the room. And when I say the family, I mean the family. I mean, there was like, you know, three or four daughters, son in laws, kids, grandkids.

I mean, it's just it was I mean, it was just this wonderful insanity, right? And it was and like and like the old one of the oldest daughters, I mean, older daughters, her job was to, you know, wrangle the grandkids and and and decide who gets to sit next to a boy next. And, you know, these sorts of things, right? Right. Well, well, my mom, all she I mean, she's just recovering from this stroke.

Her mind is is half, you know, it's like Swiss cheese. And all she hears is all this conversation going on on the other side of the room in Spanish. And so her injured mind puts two and two together and comes up with five and decides I must have been on a

trip and I got into an accident and now I'm in a hospital and they're with these these Mexican people and they are and they're going to make me pay for their hospital.

Where all that came from, I have no idea. OK. Yeah.

And so and and so she starts getting upset and she starts saying these most horrible, racist sorts of things. Right. And and and my mom's yelling and the lady on the other side of the room is yelling, you know, in Spanish.

And finally, as you know, at one point, the oldest daughter starts to go out to do something and I stop her in the hallway and I says, man, I'm sorry. I really feel like I need to apologize for my mother. I mean, she just had a stroke.

She's hurt mentally. She's in a horrible shape. She doesn't know what she's saying.

You have to believe this is not the woman I grew up with. OK, and the daughter, she just started laughing and I said, why? What's the matter? And here I was over there, you know, worrying that you spoke Spanish. Because apparently her mother was saying the same things about my mom.

Yeah, but the thing is, we get each other through stuff like this, you know, and that's that really is the point of like the support groups is we get each other through stuff like this. And and we can share stories, we can share experiences. You know, one time somebody asked, you know, was asking a question and they said, I don't know if I should ask this question or not.

But then I said, all right, look, this is a deal. Any question that starts with is this common for X to happen? The answer is yes. Ninety nine point nine percent of time, the answer will be yes, it is.

Because, I mean, I guarantee you will find somebody else who's had the same experience, you know, the same occurrence happened with their loved one as happening, as happening with us. So just, you know, and that's how that's how we deal with this. We we we get each other through it.

You know, and. And by the way, given the whole topic of of, you know, everybody dies. I mean, one of the things that, you know, a lot of caregivers need to think about is what happens after your loved one dies.

What happens to you? And one of the things that I did a post a while back that was called Braindrain. And what it was about was. You have so many, you see so many posts where someone says, all right.

I've been on this forum for like five or six years. Thank you all for your support. My my husband, my wife, my child, my whatever died.

I'm not I'm not going to be leaving the group. I see that all the time, too. And I always make me wonder about that.

Yeah. And I and I and the purpose of the post was to say, no, don't do that. Is it? Yeah.

Maybe your need may need may not be there. But there are going to be other people who need to know what you know. They need, you know, they you have knowledge between your ears that, you know, could make somebody else's day.

They can save them from heartache and trouble and upset. I mean, I get too much. Oh, yeah, yeah.

Eating to all the things that, you know, just because the hardest job you'll ever have is that 24 hour. Caregiver of, you know, a parent or spouse, sort of like it's not how really it's supposed to be. And yet that's how it is.

And how do you get how do you get through that? You know, people struggle with is this really how I want to spend my life? You know, because in some situations, you don't really know how long is this going to go on? Yeah, yeah. Oh, yeah. I mean, it's like, you know, Janet, the first time she I mean, a year ago, it was almost exactly a year ago.

She said, she said, I've decided I'm tired of this disease. I'm not going to eat anymore. I'm just going to let myself go.

That was a year ago. And then she changed her mind and she didn't. And but the point is, is that over the past year, there have been four or five specific cases where she said, all right, that's enough.

I'm just going to stop eating. And I'm not going to eat anymore. I'm just going to go.

I'm going to die. I'm going to go be with God. And then and then sometimes and then it doesn't happen because one thing or another

intervenes or or as it turns out, you know, dying from dying, I guess is a lot harder than it would appear.

Well, it doesn't come if you stop eating and drinking. It's not like then the next day. Yeah, you're dead.

And we've done a podcast about this. You know, it can be three or four days or it could be three weeks. It's so incredibly variable.

Yeah. And it's like, well, I can remember in Boy Scouts, you know, you don't eat and you can survive, you know, two or three weeks if you don't drink down. Now you're down to about 48 hours.

But that's if your body that's if your body is healthy. Right. And that's if you can't you can't look at.

Sort of what you learned in Boy Scouts or what you know, people will Google and say, OK, how long can you go without eating and

drinking? Because they're giving you those numbers based on a healthy body and having different for semi normal levels of activity. You know, if someone is immobile, lying in bed, they're going to last a way of a lot longer not eating than somebody who has to get up and go to work every day. And people will also say, well, it's so uncomfortable for people not to be able to eat.

And, you know, it's uncomfortable for me not to be able to eat and drink and probably for you, Mike. But we're healthy. And, you know, if we were at the very end of our life.

It's not it's not uncomfortable. The body has a mechanism within it where, you know, when you go into that cathartic state, when you kind of have an eating and drinking drunk fluids for a while, natural opioids are released. So your body is very, very comfortable.

It's not an uncomfortable way to die if you're at the end of your natural life. You know, you and I who are healthy and many of our

listeners are healthy, you know, don't make me go more than two hours, please. But, you know, but our bodies are different because we have some health left in us.

So those those kinds of things, it's like I always feel very compelled to, you know, let's talk about what really happens with that. But that's not our topic for today. So if you had to, I don't know, you probably have a blog about this, Mike, but do you have like you're up to, you know, this year, 12 years now, like, are there the top three things that you've learned in terms of taking care of Janet or the big one, exactly one? You know, what do you what would you say to that? Well, the big one that I well, I mean, we talked a little bit about before about dealing with the changing relationships and being willing to let the relationship change as it needs to change so that your loved one gets taken care of, because I mean, at the end of the day, I mean, that's the whole point of the process is that your loved one gets the care that they need.

But beyond that, it's I think one of the big things is that I see that it's so damaging to people is when they get it stuck into their head that once my wife dies, once my husband dies, once, you know, whatever disease is runs its course that is currently ongoing, then, you know, then life will be will slowly get back to normal. And one thing that I learned a long time ago is that there is no back to normal. That whatever experiences you have, they change you.

And so that it's at the, you know, you can't go back to what you were before, particularly thing happened. Mm hmm. Because even if you go back to that place or, you know, say there's like a home you lived in or a town you lived in or a place you were from, even if you go back there, it's different because you're not the same person anymore as the one that who lived there, you know.

And because I was in the military, I sort of learned that pretty quickly early on that, you

know, you, you go into the military, you go through basic training, you go to your tech school, you go to get to your first duty assignment, and then you come to your hometown, come back to your hometown and leave it. Suddenly you realize this isn't my hometown anymore. And it's not because, you know, it's it's changed, but because I have changed, I'm not the same person anymore.

I mean, if you've ever watched the Lord of the Rings movies, I mean, at the end, the last movie, there's this great scene where all the hobbits are back and they're in this pub, back in Hobbiton, and they're all sitting there and they got their pints, you know, in front of them. And it's like, you know, and then there's this moment like, OK, we're home. Why doesn't this feel like home anymore? You know, and my son and I, when those movies were coming out, we went to see them every year.

And that was sort of our Christmas Eve thing, because they were always released on Christmas Eve. And when that, when that scene came on, he was in high school and I'm watching this and I start crying. And he says, why are you crying? And I said, well, someday you'll understand.

You know, the standard parent, you know, someday you'll understand life, right? Yeah. Well, my son went into, went to VMI, Virginia Military in Virginia, took his commission in the Army. And he came home at one point after he'd been on duty for a while.

And he got me aside. He said, Dad, you remember that scene out of out of, you know, the Lord of the Rings. And I asked you about why you were crying.

And you said, someday I'll understand. I said, yeah. And he says, I get it.

I get it now. You know, because, you know, you, you go through things. Well, you know, you, you always are changed.

You come out different on the other side. And that, and, and, you know, the bigger truth and the more fundamental truth is there's a reason for you to be there. Okay.

There's, there, there is a, there is a point to it all. And, and that, you know, as you are developing, as you, as you're becoming this different person, it's because the world needs that different person. It needs who you are as that different person.

So it's, it's, it's so much a matter of perspective. Right. Of things, of recognizing that, like in my case, Janet, she's going through changes.

Or in some ways, she's becoming a different person. But I'm also going through changes or in some ways, I'm a, I am a different person. And you, and you wouldn't be this,

and you wouldn't be this person without those 12 years of being Janet's care partner.

Right. Right. And I'm still figuring what that is all going to look like.

But on the other side, after, after Janet passes, who I am then, I mean, there's going to be a reason for that. I'm going to be needed somewhere. That's who I am.

As a result of this experience, there's going to be a spot for me. There's going to be a birth for me that I will fit perfectly. And that just, and so, you, you, it's, I mean, there's, there's a, there's a simile in scripture, which is, I talked about people, you know, saying, you know, you know, it's the, does the clay say to the potter, no, I don't want to be that kind of a pot.

I don't want to be that kind of a bowl. Yeah. Make me, make me, make me a different kind of a bowl.

Well, make me a different kind of a pot. And it's like, you know, that's, that's not what we try to do. That is people that when we say, no, I don't, I don't want to do this.

I don't want to do that. Yeah. Oh, yeah.

But, oh, yes, we do. You know, sometimes we need to surrender to it and just be. Yeah.

I mean, that's, that's like the whole story of, of Jonah was about, you know, where, where he was told by God, OK, I need you to go do this. He said, no, no, no, no, I'm not going to do that. And and through his experiences, he realizes that, yeah, you can just sort of work better if you if you do what you need to do.

But it's. So, yeah, so, I mean, that's that's the big thing is is to just realize that the relationship you had once doesn't exist anymore. You know, that's that's changing.

It's changing and it's changing irrevocably over time. Likewise, who you were is changing. You aren't the same.

You're at the other end of this caregiving experience. You aren't going to be the same person you were at the beginning of it. And change is hard, right? And, you know, none of us like to change.

None of us like to experience change. And yet we do. If if we're going to survive in the world, we have to be resilient and adapt and to change.

And either we adapt and grow stronger and and learn and become who who we're we're meant to be or we can push against it and fight against it and be miserable in our lives. Yeah, yeah. I think, you know, one of the great moments in the story of Jonah is he tries to get away and he's on this boat and the ship is being just tossed and turned and upside down.

And the other sailors on the boat, they're saying, all right, who PO their God? It's like, who's fault is all of this? And so and so they cast lots or something and they figure out that, ah, it was Jonah. Jonah's the one that and we're going to die because he upset his God. And so they pitch Jonah over over the side.

He gets swallowed by the giant fish. And, you know, the rest of this is true, they say. But, you know, it's that there's a point where, you know, you have to realize that in the very best of ways, I mean, you know, we are not you know, you're not the only person in the world.

I mean, you're you're one piece and it is this comprehensibly complex thing, you know, it's like and that I have no idea how this is all going to work out. And I mean, and Your Honor, I may never know how it's all going to work out. Exactly.

But it's going to because, you know, and we know that because we can look back and we

can see history and that, yeah, things work. Things get straightened out. Things get corrected.

Not on our not on our schedule and not in the way that we think they will be. But they will be. Yeah.

For instance, you know, 200 years ago, 230 some odd years ago when it was when a bunch of guys sat down in Philadelphia and wrote, you know, wrote, you know, we hold these truths you know, the self-evident that all men are created equal. Well, all men back then didn't include, you know, black men, brown men. Also, for the most part, didn't include women.

Well, it absolutely didn't include women. Yeah, and and that over over the past 200 some odd years, those things have been worked out. So that so that and we're still not perfect.

We're still reaching for the goal. We're still working on it, right? Yeah, but that's but see, that's the point of having a document like the Declaration of Independence is to set a goal out there that is too big that you will never reach. Because it is in the striving for the goal is where you find the real value.

You know, the reaching for it, you know, trying to measure up to this, you know, outrageous goal that of everyone is equal. Which is true, but it's so hard to implement. Yeah.

And I think that that's a great place to to leave our listeners in terms of thinking about how how you're approaching this caregiver role that you didn't ask for and you wouldn't have probably asked for. But Mike's helping us kind of get a sense of learning about how to approach that. And so, Mike, for that, I so appreciate you on the show and helping our listeners through that.

And I tend to get attached to this. You guys know this, I get attached to the people that I interviewed. Like, OK, well, then next time we'll talk about this.

But I think that, you know, if you're willing, Mike, I would love to continue to talk with you about these topics, because I think that being immersed in it, the way that you have been for the last 12 years is very beneficial for people to hear about how you process and learn from these things. So thank you, Mike. I appreciate that.

You're welcome. Thank you again, Michael, for sharing that with us. What follows is an anonymous reading about what someone with dementia would want if they could tell you.

If I get dementia, I want my friends and family to embrace my reality. If I think my spouse is still alive, or if I think we are visiting my parents for dinner, let me believe those things. I'll be much happier for it.

If I get dementia, don't argue with me about what is true for me versus what is true for you. If I get dementia and I'm not sure who you are, don't take it personally. My timeline is confusing to me.

If I get dementia, and can no longer use utensils, do not start feeding me. Instead, switch me to a finger food diet and see if I can still feed myself. If I get dementia and I am sad or anxious, hold my hand and listen.

Do not tell me that my feelings are unfounded. If I get dementia, I don't want to be treated like a child. Talk to me like the adult that I am.

If I get dementia, I still want to enjoy the things that I've always enjoyed. Help me find a way to exercise, read, and visit with friends. If I get dementia, ask me to tell you a story from my past.

If I get dementia and I become agitated, take the time to figure out what is bothering me. If I get dementia, treat me the way that you would want to be treated. If I get dementia, make sure there are plenty of snacks for me in the house.

Even though if I don't eat, I get angry, and if I have dementia, I may have trouble explaining what I need. If I get dementia, don't talk about me as if I'm not in the room. If I get dementia, don't feel guilty if you cannot care for me 24 hours a day, seven days a week.

It's not your fault and you've done your best. Find someone who can help you or choose a great new place for me to live. If I get dementia and I live in a dementia care community, please visit me often.

If I get dementia, don't act frustrated if I mix up names, events, or places. Take a deep breath. It's not my fault.

If I get dementia, make sure I always have my favorite music playing with an earshot. If I get dementia and I like to pick up items and carry them around, help me return those items to their original place. If I get dementia, don't exclude me from parties and family gatherings.

If I get dementia, know that I still like receiving hugs or handshakes. If I get dementia, remember that I am still the person you know and love. That's really, it's really so true.

Really, wow. I'm sorry we don't have this person's name. We don't know where this came from, but it's just absolutely remarkable.

I looked and I couldn't find an attribution, but I thought it was still worthwhile to share with our listeners. Yeah, and it's very true. I mean, you have dealt with more dementia, people with dementia than I have, or the few I have.

Well, I hang out with you, Charlie. Who are you? Where am I? Who am I? I've always depended on the kindness of strangers. And with that, please stay tuned for the continuing saga of Everyone Dies.

And thank you for listening. This is Charlie Naborette. And from writer and poet Charles Bukowski, what is terrible is not death, but the lives people live or don't live up until their death.

They don't honor their own lives. They piss on their lives. And I'm Marianne Matzo, and we'll see you next week.

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Always seek the advice of your primary care practitioner or other qualified health providers with any questions that you may have regarding your health. Never disregard professional medical advice or delay in seeking it because of something you have heard from this podcast. If you think you may have a medical emergency, call your doctor or 911 immediately.

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