

CAREGIVER COLLAGE

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From experiences and stories collected from participants at
The Caregiver Education Workshop
Organized by the Cleveland Clinic / Lou Ruvo Center for Brain Health
and the UNLV Gerontology Program

*(Each reader addresses the audience. They DO NOT talk to each other.
They are isolated on stage talking with the audience about their own crisis.
The only thing they share is their frustration about what is happening to their
relationship. When characters share a scene, it is noted by the word "Scene.")*

*(This first passage is spoken with anger and directness. There is an urgency to
get their point across.)*

HARRIET: I didn't choose this.

HELEN: This isn't my choice. I had no other options.

PAUL: We were supposed to grow old together.

KATHY: Instead he grew younger.

MARION: She became a child again.

VINCE: I have to do everything for her.

GAIL: This is my mother.

SANDY: My father.

PAUL: My wife.

HARRIET: My husband.

HELEN: My sister.

MARION: My friend.

- VINCE: When we got married, I never pictured myself having to take care of my mother-in-law.
- KATHY: Do you know how embarrassing it is to ask your own children to babysit their father? What if he messes his pants again?
- MARION : She never did anything wrong in her life.
- GAIL: She never drank.
- SANDY: He never smoked.
- PAUL: She was constantly reading – Always curious.
- HARRIET: When we got engaged, he used to talk all the time. He'd tell me what our future was going to be like. Where we would live; how he would open a furniture store...I know: A furniture store!
(She shakes her head.)

(Pause. Their pace slows down. The initial anger seems to have passed.)
- HELEN: Now she never talks to me at all.
- SANDY: He just sits there with a blank look on his face.
- KATHY: Sometimes I don't think he recognizes me. So he calls me —dear.
- MARION: I think she's scared.
- GAIL: She was the rock in our family.
- VINCE: It makes me so angry. I'm not an angry person.
- SANDY: Listen – I want to make one thing perfectly clear.
- HARRIET: I still love him.
- HELEN: I am outraged that this happened at such an early age. She's only 72!

KATHY: I'm growing bitter.

PAUL: Why would God do this to her? To me? To us?

MARION: She's scared and I'm growing anxious because I'm scared, too!

VINCE: And I don't know what to do to make it all go away.

GAIL: I want answers! She deserves answers.

SANDY: I want to make one thing perfectly clear: Of all the choices I've made in my life, I never chose this.

THE CALL

(A phone rings.)

PAUL: Hello?
 Yes?
 Oh, hi. I didn't recognize your voice. It's been awhile.
 You're where?
 You mean you're *here* in town? Well...what a...what a surprise.
 Yes. I'm very surprised.
 Oh, you don't have to do that.
 No, please don't.
 Well, I'm in the middle of things.
 Yes, she's doing fine.
 Yes, I'm doing fine, too.
 Listen, you really don't have to drive all the way out here. It's very thoughtful of you, but...
 No, she hasn't eaten yet but...
 Well, she's sleeping right now, so...Yes, she naps a lot these days.
 It's really not necessary, and the house is a bit...
 Okay, we'll see you in twenty minutes.

GAIL: C'mon...answer your cell.
 C'mon...I want to talk to someone.
(Her face falls as she's asked to leave a message. She puts a smile in her voice and goes forward.)
 Hi, It's Carol. I wanted to check up on Mom—see how she's doing. I just had a feeling that something was wrong – I don't know. And I also wanted to find out if you got that Emergency Folder I emailed to you. A friend of mine at work told me about it. I thought you could fill it out and email it back to me so I'd have it out here when Mom comes to visit at Thanksgiving. It's just—you know—prescriptions, doctor's numbers, current pictures, that kind of thing. Shouldn't take you more than ten-fifteen-minutes max to put everything together in a folder. Anyway. I'm stuck here until we get through the project presentation next week. I'm still the project manager and blah, blah, blah...But as soon as the presentation is—hello?
(She listens for another moment.)
 Hello?
(She's been cut off. She's run out of time on her message. She sighs.)
 Nice talking to you.

MARION: Hello? Bill, thank goodness you called.
I know. It's about Mom.
Just hear me out. Please?
I really think she needs to see someone. She's getting worse.
It's not just the keys.
She's getting thinner. I think she's forgetting to eat sometimes.
But the thing that really worries me is that she's having trouble with
names, now, too.
No, not my name. But names at church.
Her friends at the church.
Yes, she recognizes their faces, she recognizes that they're her friends,
but she doesn't know their names. Then she gets confused about where
the exits are.
Bill, I'm scared to let her drive anymore. I go with her to church now, so
she doesn't get lost coming home. I really think something is—
(Pause. She starts to get angry.)
No, I'm not over-reacting. This is becoming a real problem.
She's been going to the same church for five years, now. Ever since Dad
passed away. She shouldn't be confused about where the exits are. They
haven't moved them!
I know she's no spring chicken, Bill, but this isn't —
Why don't you drive up this weekend and see for yourself?
I'll make pot roast; you can come to church with us.
Why not?
All right. Okay. No, I understand.
It sounds like a lame excuse to me, but, sure, I understand.
Let me know if you ever DO want to come up and visit Mom. I'm sure
she'd be happy to see you. I just hope she remembers your name.

CHURCH

PAUL: We still go to church; my wife and me. She finds it comforting. Familiar.

SANDY: Before we come to today's scripture reading, I want to talk about something that I came across on the internet that I found interesting.

PAUL: We quietly hold hands in the pew.

SANDY: Like many of you, I was —surfing — or I guess the actual term is —blogging. Reading what's on other people's minds and what they want to share with the rest of us on their websites.

PAUL: It's a peaceful time for both of us. It's the one time a week that she's content to sit perfectly still.

SANDY: A man had written that all people act out of one of two reasons. I don't know if this was his idea or he found it from someone else. But he said that there are only two reasons that motivate us to do everything that we do.

PAUL: And when she's quiet like that, I can finally relax. I let my mind wander. To be honest, I'm really not that interested in what the preacher has to say. I've been going to church most of my life. And it seems like the minister just goes through the same things over and over. I figure if I miss something important, he'll bring it up again, sooner or later.

SANDY: How interesting: All of our actions are motivated by just two things. And do you want to know what he said they were?

PAUL: I remember when we were driving across South Dakota. Oh, she loved to go on trips. And I loved to drive. We didn't have to go anywhere special. She was just happy to see the world.

SANDY: He said it was either Love or Fear. Maybe you've heard that before, but think about it with me right now for a moment.

- PAUL: We'd stop at roadside attractions – Tourist Traps, I called them. And she'd eagerly scramble out of the car. Like the teenaged girl inside her suddenly woke up.
- SANDY: Love or Fear. It sounds too simple, doesn't it?
- PAUL: The girl I fell in love with five decades ago, waking up from her nap. Fresh and ready to meet the world.
- SANDY: But I was struck by the thought. And while I was meditating on it, the Lord brought me to this scripture: Second Timothy, Chapter one, verse seven. "For God hath not given us the spirit of fear; but of power, and of love, and of a sound mind."
- PAUL: She was so thrilled at the smallest, dumbest things. A homemade lollipop that tasted like a margarita. A giant metal statue of a Tyrannosaurus Rex that someone put up in their field. A meteor crater.
- SANDY: Think of that! God has given you power. And love. And a sound mind. Not the spirit of fear.
- PAUL: I became interested in so many things in my life, simply because she was interested in them. She was a powerful influence in my life.
- SANDY: So why should we as Christians act out of fear? Paul tells us very plainly that we've been given God's power and God's love. It's not something we're waiting to receive. We have it. It's been given. And Paul tells us in First John, —There is no fear in love, because perfect love casts out fear.
- PAUL: I guess I only go to church to dream these days. I let myself go back to those memories when everything in the world was exciting to her and therefore exciting to me.
- HELEN: Dear Lord. I'm scared. My sister is in the hospital again.
- KATHY: My husband wants to know when he can come home with me. He called me by his first wife's name.

- VINCE: Bless me, father, for I have sinned. It's been one week since my last confession.
- HELEN: She's only ten years older than me, but she looks fifty years older. I hate the way hospitals make everyone looks so ancient!
- VINCE: I took the Lord's name in vain with my mother-in-law twice yesterday, and I shook her arm. I was pretty rough. She fell down.
- KATHY: God, he told me he hated his first wife. He hated her!
- HELEN: And the nurses looked at my sister like "Here's another one with one foot in the grave."
- VINCE: She was yelling at me. She said I wasn't giving her any of her pain medication. She called me horrible names.
- KATHY: Why is he calling me by his first wife's name?! Why is this happening to me?
- VINCE: I feel so guilty.
- HELEN: I didn't choose this. You know I didn't choose this!
- GAIL: *(exasperated)* All right!
God?
You know I don't believe in you, so I won't be surprised if nothing happens – BUT! It would reflect well on you if you could get my sister up off her ass and have her call me. Or text me. Or fax me. Or email me. Or instant message me. Lord, I've got a million machines all around me and I can work every single one of them. But my idiot sister is technologically challenged! So if you're still up to working small miracles, could you please help her get in touch with me?! For the love of Pete, you know I deserve it. Amen. I guess.

MARION: I'm all alone.
My mother lives with me now, and I'm all alone.
When I ask her a question, sometimes she won't answer it. No matter
how many times I ask.
I'm all alone, Lord.
Bill won't visit.
People from church don't visit.
I don't ask them, but can't they see how alone I am?
One visitor.
Someone.
Anyone.
I want someone to...just...talk to.
It's too quiet.

HOME (*Scene*)

HARRIET: Oh my gosh.

HELEN: Would you just look at this place?

PAUL: Well we weren't expecting company.

HELEN: Apparently not.

HARRIET: Is she still sleeping?

PAUL: Yes, I'll go and wake her up.

HELEN: Oh don't do that!

HARRIET: She probably needs it. And you probably need the break, too, huh? I imagine it gets a bit hectic, doesn't it?

PAUL: I do enjoy the quiet times.

HELEN: Well, listen, I'm sure you're very busy and all; and I'm the last person to criticize a man in your position. But you really need to use the attachment on the vacuum cleaner to reach here along the back of the couch. There's so much dust back there. You wouldn't want someone coming to visit and leaning back to get a big ole pile of dirt in her hair.

PAUL: I think I missed that.

HARRIET: Are you two eating well? Is she getting enough salads?

PAUL: Yes, we get plenty of vegetables—

HARRIET: With fruit? You know I never really consider it a salad unless there's some kind of fruit in it. Like those little Craisins, or Mandarin Oranges? Do you have any of those?

HELEN: Look at that, we caught you in the middle of laundry day, too. I'll just put this pile in the washing machine for you.

PAUL: No!—those are clean—I just took them out of the dryer.

HARRIET: In fact, I have a recipe for a Romaine salad with strawberries that she will absolutely love. Strawberries have a lot of Vitamin C in them. Keeps you healthy.

HELEN: But look at this grease stain right here on her blouse. Did you pre-treat this stain before you washed it? Or are you using cheap soap?

HARRIET: And I've been reading about this raw food diet that you both should probably try. It's supposed to reduce stress.

HELEN: Oh, you are such a man. Why aren't you separating your colors? They're all going to run together and make everything dull.

HARRIET: But don't get your strawberries from Mexico. You never know where Mexican strawberries have been. It could make everything worse.

HELEN: I only say this because you're a man and don't know any better, but this collar could use a little needle and thread.

HARRIET: Oh my gosh, you're right. A stitch in time.

HELEN: Otherwise it's going to unravel completely and then where would you be?

HARRIET: Walking around looking like your front yard – which is being taken over by the clover.

HELEN: But don't go to Wal-Mart. All their lawn products have chemicals in them. I'll send you a catalog with all-natural weed killers.

HARRIET: Their weed killers don't work as well as the Wal-Mart kind, but you don't want chemicals all over your lawn. I mean, what if she fell down out there in a big pile of chemicals?

HELEN: I've seen it happen. And it could very well be all those chemicals that's causing her Alzheimer's in the first place.

HARRIET: Wouldn't it be awful if that were true?

HELEN: Well, we can't dwell on it now. No one knew. And everything's bound to kill you one way or another.

HARRIET: Oh my gosh, look at the time. I'm sorry we couldn't stay longer.

HELEN: We just wanted to come by and cheer you up. Help out if we could.

HARRIET: My niece is having a recital this afternoon at the school. If I miss it, I'll never forgive myself.

HELEN: You know, you should take up a hobby. Help take your mind off all that's going on around here with your wife.

HARRIET: See if the senior center is offering classes. Have you thought about learning French? It's very romantic

HELEN: Come on, sister-woman. We've got to get going. He'll figure it out.
(*to PAUL, almost a threat:*) Now you take real good care of her, you hear?
Bye now.

HARRIET: Bye!

PAUL: (*weakly*) Thanks for stopping by.

NOT HOME (*Scene*)

KATHY: Carol? I got your message. I didn't want to worry you. But it's about Mom.

GAIL: (*out of breath*) Hello? Oh thank God you called me back. I was in the back yard.

KATHY: I'm sorry. We've just been so upset here, and I knew you had your project presentation coming up and that it was very important.

GAIL: What's wrong?

KATHY: Listen. Mom wandered off again.

GAIL: Again?

KATHY: Somehow she's been getting out of the complex. I don't know how.

GAIL: Oh my God—where is she? Have you found her?

KATHY: Don't worry—she's safe—she's okay. We found her.

GAIL: Where was she? Why didn't you call me?!

KATHY: We didn't want to upset you. You've got your job thing – your presentation—

GAIL: Don't ever do that again! Do you hear me? Ever! I can't believe you! She's my mother, too! You can't just shut me out because I'm not there. For love of Pete, you DO have a cell phone, don't you? Is it too much to ask for you to call? Or do you need me to teach you how to work it again?

KATHY: All right! I'll call you the next time she wanders off since I'm obviously not doing anything else! But tell me something, Carol – What exactly are you going to do when you get the news? You're on the other side of the world, chained to your job, while the rest of us have to deal with Mom. I call you up and tell you she's missing. Then what? Are you going to snap your fingers and pull out some iPod or computer thingy and find her for us? I'm curious—What are you going to do from a thousand miles away?

GAIL: It's just...

KATHY: You think we're not smart enough to handle this problem without calling you for advice? "Oh my goodness, we'd better call Carol, because she'll know exactly what to do. Even though *we're* the ones taking Mom to the doctor, and the daycare and the store for the past three years. Quick – Call Carol and then lets run outside and throw dirt clods at the moon!"

GAIL: Okay.

KATHY: So what's your magical advice? What should we have done?

(Pause.)

GAIL: You should have called me and told me you were handling it.

(Pause.)

KATHY: You're right. I was...I was scared. I was embarrassed. I wasn't thinking. I'm sorry.

GAIL: I'm scared, too.

KATHY: I know.

GAIL: But Mom's okay?

KATHY: She's okay. But.

GAIL: There's more?

KATHY: Mom can't go back to the assisted living facility. They won't take her, now. She's wandered off twice and they're worried about legal responsibility. We have to move her somewhere else.

HOSPITAL

HELEN: Excuse me, Nurse? Hi, I'm Barbara – her sister. I wanted to make sure that I could bring in a few items from home. It won't be a lot, but I wanted to make the place a little more – what's the word? – homey.

No, of course, I won't bring anything that will get in the doctor's way. I'm thinking small things. A couple of pictures, maybe. Like this one – No don't go away, let me show you. This was taken last month when she visited her friends in Los Angeles. Doesn't she look young in this picture? She drove all the way there by herself. She has a perfect driving record, you know. Not a single accident. You'd swear she was still in her fifties, wouldn't you?

Oh! And I thought maybe I could bring in her trophy that she won last summer and put it over here. It's only about so tall. She placed third in the Senior Olympics in the Butterfly Swimming competition. Did you hear me? Third! That's a pretty good accomplishment, don't you think?

Where are you going? Of course, I know you have other patients to see. But, my sister is—Okay, stop right there! Before you take another step, I want you to look me in the eye.

She is not an old lady. Got that? Anyone can get a broken bone. Don't you dare look at her chart, see that she's 72, and dismiss her as being over-the-hill. She has 50 more good years ahead of her – Easily. So I will be in here every morning, putting on her makeup and telling stories about her swim meets. And if I catch you –or anyone else— treating her differently than you would treat a middle-aged woman, I will raise holy hell about it. You can count on that!

SANDY: He sits there. Staring toward the television. I don't say he's staring *at* the television, because I don't believe he actually sees it. So I knock quietly and enter the room. I say, "Hi, Dad." but he doesn't respond. So I tell him how my day was. I hold his hand, but he doesn't hold it back.

He just sits there. Staring toward the television. I don't say he's staring *at* the television, because he's never been interested in cooking – and that's what's on right now: a cooking show.

So I talk about a new recipe I got on the back of a soup label and how it reminds me of the chicken casserole his sister used to make at all the family gatherings. I tell him that his great-granddaughter got hired at the Pizza Hut this week. But he doesn't say anything back.

He just sits there. Staring toward the television. I don't say he's staring *at* the television, because he doesn't realize it's now showing a commercial about tampons. He used to be so embarrassed when those came on.

So, for some reason, I get brave and talk about tampons to him. Which ones I recommended to my daughter and why. What commercials I thought were particularly offensive. And then I talk about women things in the most graphic terms I can think of. I tell vulgar stories about body parts. I bring myself to the edge of nausea with my gutter language. And then I hear myself and stop. I'm embarrassed, and disgusted, and still desperate.

And he just sits there. Staring toward the television. I don't say he's staring *at* the television, because...because I know he's not seeing it. Not really.

And while I'm sitting there in silence, I remember how he took us to visit the home where he grew up in Elmwood Park, Illinois; I remember him teaching me how to make a grass whistle; I remember being embarrassed as a little girl the time he yelled at the county assessor.

And he just sits there. Staring toward the television. And I just sit there.
Staring toward my Dad. I don't say I'm staring at my Dad, because...

(Pause.)

I didn't choose this.

MOTHER

MARION: I left Mom on the sofa in the living room. I turned on the television, and hoped it would keep her occupied. She rarely spoke anymore, but she didn't seem to like the silence any more than I did. Then I went to my bedroom because I felt like crying and I didn't want to upset Mom. If I could get five minutes alone, and really cry it out, then I felt like I could keep going for another couple of days.

I sat on the edge of the bed and looked across the room at myself in the dresser mirror. I looked so tired and worn and my eyes were barely alive. I thought, this is a good reason to cry. I look so awful. But the tears wouldn't come.

I thought about all that I had done on my own in the last two days. I got no help from my brother, Bill who never calls and never comes to visit and check up on us. I got to all the doctor's appointments, I cleared up the mistake on her supplemental insurance, I got the shopping done at midnight while Mom was asleep, and even took her to the ice cream social at the church on Tuesday. She didn't speak the entire time we were there, and didn't say anything on the way home. No "thank you" or even "that was fun." And still the tears wouldn't come.

This was so aggravating. I needed to cry. Once I cried, I would be done with it and I could get back to taking care of Mom. I tried and tried, but still no tears. I was getting off schedule. I had to make supper in a few minutes and if I didn't cry soon, I'd be late. I'd gone to all this trouble to put five more minutes in my day and now it was wasted. I didn't choose this!

I heard music. Not music. Singing. I heard singing. Mom was singing. Something had to be wrong! I raced out of the bedroom and down the hall. I lurched into the living room and stopped. Mom was standing in the middle of the living room looking straight at the television. It was a rerun of Lawrence Welk on the cable station. I didn't even know Lawrence Welk was still offered.

They were playing “If I Loved You” from the musical *Carousel*, and Mom was singing with all her heart.

If I loved you, time and again I would try to say
All I’d want you to know...

And then I cried. For ten whole minutes I cried. I was completely off-schedule, but I didn’t care.

VINCE: That night I made a plan. I wasn’t proud of myself, but I made a plan anyway. My mother-in-law was still yelling at me. Telling me what a horrible son I was. At least, I think that’s what she was saying. She was screaming at me in Italian. My wife translated some of the words for me.

My mother-in-law still thought I wasn’t giving her any pain medication. I would draw a little line on the prescription bottle every time I gave her a pill, but she still didn’t believe me.

I guess I can’t blame her. By this time her mind had deteriorated so far that all she knew was she was in pain.

My wife was still working, but we couldn’t afford private care for her mother. It was up to me to keep looking after her.

Listen, I’ll be honest with you. My family was always calm. We never yelled at each other. Certainly not in Italian. The only way you could tell that my family was mad at each other, was that the house would get very quiet.

But living with my mother-in-law was like living in the monkey cage at the zoo. All that shrieking and yelling was driving me crazy.

So that night I made a plan. I would accidentally forget to put away the pain prescription bottle after I gave it to her. If she accidentally took more than she should...I’m not proud of myself...but it wouldn’t be my fault necessarily. And the house might be quiet again.

I could’ve done it.

I could've waited until my wife left for work and put the bottle right in the middle of the kitchen table.

It would've been merciful for everyone.

I could've made that choice.

But in the morning, I didn't choose to do this.

THE CHOICE

HARRIET: I didn't choose this. I had no control. He slipped on the ice in the back yard and broke his hip. There was nothing I could do about it except call 911.

Now I have to wait on him, hand and foot. When we got engaged he told me he would open a furniture store and make so much money that I would have maids running all over the place. I'd never have to do any housework. Men will tell you anything if they think it'll get them a little hmm-hmm-hmm.

No, I didn't choose this. If I got to choose, we would be in Barbados. He could do his crossword puzzles on the beach while I went swimming. Later we would dress for dinner and eat fresh fish right from the sea. As it gets dark we would sit on the patio of our villa and listen to the chirping of the tree frogs.

For a long time, this was my mantra – I didn't choose this. And one day I say it to my girlfriend and she says, "Okay, okay, we get it! This wasn't your choice. What is your choice? Are you just a total victim? You don't get to make any choices?"

And it got me thinking.

I can choose.

SANDY: All of our actions are motivated by just two things.

HARRIET: I chose him for a husband.

SANDY: God hath not given us the spirit of fear; but of power, and of love...

KATHY: I'm afraid of telling my sister when something goes wrong with Mom.

HARRIET: I chose to stay with him for better or worse.

KATHY: I feel guilty like it's my fault – and I know my sister thinks it's my fault. She treats me like I'm one of her employees.

SANDY: Two things motivate us: Love or fear

HARRIET: I can make the choice to love the crabby old man.

KATHY: In my mind I know there's nothing I can do, but that doesn't stop the way I feel. Sometimes it's easier to hide things from my sister.

PAUL: I have to take care of my wife, and the house, and the laundry, and the car, and the dog – why on earth did we get a dog?

MARION: My brother believes that if he doesn't visit, then he won't have to deal with anything. And I'm scared to do this alone.

HARRIET: I can make the choice to act out of love.

HELEN: She's not an old lady! She's still very young.

VINCE: I'm scared of who I'm becoming. I didn't choose this.

KATHY: I didn't choose this!

MARION: I didn't choose this!

HELEN: Well, my sister didn't choose this, either!

(Pause.)

PAUL: I know my wife didn't choose this.

(Pause.)

GAIL: What if I promise to stop calling because I think the worst has happened...and start calling because I love my family...?

MARION: To do all of this out of love seems impossible. No one can do that.

PAUL: Our pastor told me that when I realize that my own trip to the bathroom is the only quiet time I get during the day, it's time to get help for myself. He said I should join a caregiver support group.

KATHY: But what if I visit a caregiver website and it gives me a computer virus? That'd only be one more thing I had to take care of. I don't know how to get rid of viruses.

HARRIET: Love or fear. I can choose my motivations.

MARION: How can anyone make the choice to do all of this out of love? It sounds so exhausting.

HELEN: Why am I letting myself do everything out of fear? This is wearing me out.

VINCE: She scares me. How do I love someone like that?

GAIL: I promise to stop...

PAUL: At least once a day...

SANDY: And make the choice to do something out of love.

MARION: It won't be everything – I can't do everything out of love.

HELEN: But there will be at least one moment when I do.

KATHY: Otherwise, I don't know how I'll get through this.

HARRIET: There are so many things right now that I don't get to choose. But once a day, I will be in control.

VINCE: And I will say to that disease, "you haven't won – not yet!"

END