Revisiting 'The Mother Who Changed: A Story of Dementia'

0:01

hi everybody it's Sabrina I'm here because today we're doing something special we're revisiting a show from

0:08

earlier this year from January the story at the center of this episode which was

0:14

first a magazine feature by reporter Katie Englehart it just won a pullis prize for feature writing this past week

0:21

our team here at the daily including producers Luke Vander plug Clare tennis getter Diana win and Deputy editor

0:28

Michael benois worked with Katie to tell that story in audio both versions we

0:35

think shed powerful human light on a disease that affects so many people

0:41

dementia so we wanted to resurface it for all of you hope you'll give it a

0:46

listen here's the show amongst philosophers who study

0:52

dementia there's this story that gets told over and over again and it's about

0:57

a woman named Margot

1:02

Margot was a 55-year-old woman who suffered from early onset Alzheimer's

1:08

disease she couldn't recognize anyone around her she spent her days painting and listening to music she read mystery

1:15

novels too often the same book day after day the mystery always remained

1:20

mysterious because she would forget it but despite her illness or maybe even

1:27

because of it Margot was very happy the Margo Story presents philosophers

1:33

with this riddle imagine that years ago when Margo was fully competent she wrote

1:40

out a formal document explaining that if she ever developed Alzheimer's disease she would not want any life-saving

1:46

medical treatment and more than that she would want to be killed as soon and as

1:51

painlessly as possible this poses a question which version of the Margo should be listened

1:58

to the then Margo before she got sick the then Margo who never would want to

2:04

live that way or the now Margo who's sitting before us and who is by all

2:10

accounts [Music]

2:16

happy in other words who is the authentic

2:22

[Music] Marco from The New York Times I'm

2:28

Michael babbaro this is is the daily across the United States millions of

2:34

families are confronting a seemingly impossible question when dementia

2:40

changes a relative how much should they accommodate their new personality and

2:47

their new desires today Times magazine

2:52

correspondent Katie engleheart with one family's experience

3:05

[Music]

3:10

Katy how did you first discover this story so I've spent a number of years

3:17

reporting on issues related to older Americans and I've been particularly

3:22

interested in dementia and cognitive impairment and this story actually found

3:27

me because I've been writing about the subject I was receiving a lot of emails from people who had Dementia or whose

3:34

loved ones had it and there was one that really stood out to me and that was an

3:41

email from two women Chris and Julie nurelias who were writing to tell me the

3:46

story of their mother and what was the story that they told

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you the story that they described was effectively one of elder abuse in this

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case what they were describing ing wasn't physical abuse or um even kind of

4:04

direct Financial abuse but something a little softer more like psychological pressure or like

4:12

taking advantage of someone's cognitive weakness in order to convince that person that she wants something she

4:18

doesn't really but the more I reported on the story The more complicated it

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seemed this wasn't a straightforward story of elder abuse with good gu guys and bad guys this was a lot more

4:37

complicated we can all hear each other yeah yeah great thank you so much for

4:42

being willing to chat again so the first thing I did was call these sisters Chris and Julie nurelias and that really

4:49

started two years of conversation with them sure starting someplace

4:55

Works Chris and Julia are separated by a few years but they act almost like twins

5:02

were like that's wow they look similar they have virtually the same voice they complete

5:09

each other's sentences and they told me a lot about their family the nurelias family grew up in Dennis in Iowa a town

5:17

of around 8,000 people surrounded on all sides by cornfields their father bill was sort of

5:24

a prominent figure around town he was a lawyer and a land owner but we spent most of our time talking about their

5:31

mother Diane nelas my mom was

5:38

really the center of our family she the sisters describe their mother as really

5:44

the backbone of this happy American family dad worked all the time and so it

5:50

was up to mom to take care of everything else and it was a great childhood she was memor competent and you know a big

5:58

presence in the area she served on the school board she drove a school bus she

6:03

was on the State Library board but she was also a very traditional woman you know she was a woman of her time Mom and

6:10

Dad were married in 1957 so it was very much a 1950s wife at home with the children

6:18

husband working um and she was by her daughter's admission quite happy in that

6:25

role it was all it was very proper and mom took pride in that and probably would have continued that

6:32

way if things hadn't

6:39

derailed what exactly happened things for Dian really changed in

6:44

2011 her husband Bill died of complications from a broken hip after 53

6:51

years of marriage you have to remember that mom went to nursing school got out

6:57

and pretty much married dad I mean she was was in her early 20s when she had me so she had never lived alone been um

7:05

independent or anything so when she loses this man who has been there for her her whole life literally her adult

7:13

life I think she was like lost I mean she pretended like don't worry kids I'll

7:19

be fine but I don't think she knew how to do it by herself especially without a man and by do it you mean live her life

7:27

like she made it out like oh I feel kind of free now and I can go and

7:32

do anything I want but she really didn't she just watched television and then

7:37

Diane started losing more people to me the next thing was my brother's Health

7:44

crisis her son Eric died of cancer at 55 that's her only son that's one of her

7:49

children her daughter Julie who had lived next door divorced and moved to Colorado her support group has kind of

7:57

to her mind I think abandoned her she was seeing herself

8:03

alone and then almost all of a sudden a new man appears in her life and then

8:09

Along Came Denzel Denzel Nelson Denzel was known to the family

8:17

Denzel Nelson uh was my father-in-law when I was married to his son he was actually

8:25

Julie's ex-husband's father so a man she'd once been very close with but hadn't seen much of since her divorce uh

8:32

he always had cowboy boots and a cowboy snap down and a cowboy hat on he was

8:38

this kind of stocky Cowboy figure he'd worked as a horseshoer for most of his life but had since retired I mean it was

8:45

a completely different image you know in comparison to my father I mean they were

8:51

like opposites he was three times divorced

8:57

and actually because he had um no finances he asked if there was any

9:04

chance he could live in the hired man's house next door to my mom and coming off

9:10

his last divorce he moved into a little property on the nurelias farm plot in

9:18

exchange for helping maintain the yard like do the Mowing and help out with

9:23

yard work and things there that he could help with but by all accounts he and Diane weren't especially close well she

9:29

said he was disgusting he dressed like a hick mom used the word hick and she just

9:35

thought he was kind of repulsive she said he smelled bad she said he'd stop by for coffee sometimes and she wished

9:42

that he wouldn't so they certainly weren't close by any means until seemingly out of

9:48

nowhere Diane's views on Denzel completely changed it was a Sunday I called Mom and

9:56

the woman talking to me was not my mom she was like I need to tell you something and then

10:01

she went on to say I've invited Denzel to share my life and live in my house

10:06

with me I'm sure my mouth dropped open because I was like what is happening she

10:12

goes I need you to accept him and love him and welcome him into our family because this is what I want their mother

10:20

called them up and sort of presented this as a done deal Denzel and I are in

10:25

love he's moving into the house he's the love of my life it was hard it was hard

10:31

to swallow it really was but but Chris and Julie tried to be accepting of this

10:38

you know for mom's sake we all adapted so things were okay for a while

10:46

and Diane you know she seemed happy she and Denzel started spending their days

10:52

on on these drives they' drive around the state or to different states they' go to antique shows or horse shows or

10:58

quilt you know at age 80 Diane was finding a new way to

11:06

live but Diane's daughters also noticed changes in her that they found more

11:13

worrying my mom always was a fashionista she used to

11:18

make her own clothing suits and her mother had always been very well dressed very you know interested in her

11:25

appearance but then I I came home and she's wearing jeans with a big wide

11:31

cowboy belt and this old creddy horse breeders baseball cap all of a sudden

11:38

she was dressing like a cowboy and no makeup no makeup and I I was just like

11:45

who are you and some of the changes were deeper ones and she said to me one day

11:52

you know I'm trying to be more assertive Denzel's training me to be more assertive Chris and Julie really felt

11:58

like they're joyful joyous mother was growing mom wasn't sour assertive she was being aggressive and mean to people

12:06

even Diane's phone calls with her daughters were changing there started to be this the gradual isolation that um

12:14

Mom wasn't calling as much I'd call her and oh she'd be busy I'll have her call you back they're finding it harder to

12:21

reach their mother she's not answering the phone when she does answer the phone it seems as if Denzel's always beside

12:27

her always sort of coaching her almost on what to say but I think it was harder and harder for her to understand our

12:33

conversations when we would talk um they start to feel like their mother

12:39

is deteriorating in ways they can't quite understand from from far away

12:47

[Music] H but it's only in September of 2017

12:55

that a doctor finally gives shape to what Diane's daughters sort of both knew

13:02

and couldn't see I couldn't get a hold of mom and was worried about her and I got a phone call

13:10

from Denzel that said Mom was in the hospital he didn't think it was her heart they weren't sure denel had taken

13:19

Diane to the emergency room because she felt short of breath and at the hospital she was given a cognitive test um she

13:27

scored poorly she didn't know the name of the president for instance I

13:33

decided you know what I'm going back to Iowa and I got a plane ticket Chris actually got a plane ticket too but I

13:39

got back there before Chris so I went to the hospital um met with Mom then Dr

13:44

Ingram came in and explained to me that yeah you know your mother he had diagnosed her with dementia and it's

13:51

here at this time that Diane is diagnosed with dementia

13:59

that was the day we went to Vicky's house Vicky was kind of a friend to Mom and to us and we were so shocked we're

14:08

sitting at her bar crying and she's like well of course your mom has dementia we all know that we've known that for

14:17

years it's around the time that she receives that diagnosis that Diane starts rearranging her Affairs that's

14:25

when Denzel was added to the bank accounts she gives Denzel her financial power of attorney he was a a signer he

14:33

could co-sign on Mom's checks she redrafts her will so that if she dies

14:40

before Denzel he has the right to live on her property basically it gave Denzel

14:46

control of almost everything and she also dissolves her financial trust this is the trust that her daughter Julie

14:52

managed um which holds all of her assets and all of her Investments and when Julie checks dian's

14:58

bank statement she starts seeing cash withdrawals of hundreds of dollars at a time this was

15:04

especially worrying because they knew that their mother was worth around $4 million and that Denzel you know three

15:11

times divorced a retired horseshoer was worth basically nothing Denzel had taken

15:16

mom's phones away we couldn't talk to her on the phone we didn't know if she was dead or alive he wouldn't respond to

15:22

us anymore we were scared all of this just leads Chris and Julie to the

15:29

conclusion that they need to get to the bottom of what's been happening I was just sitting in the chair in my living room and it's like something swept over

15:37

me and said you need to go to Iowa right

15:44

now so what do they decide to do their first step is to call a lawyer and the

15:49

lawyer recommended that they obtain what's called a temporary protective order basically an emergency restraining

15:56

order that would force Denzel to move out of the house and stay away from Diane and the sisters hoped really give

16:03

them a chance to sit down with their mother away from Denzel's influence and really get to the bottom of what was

16:08

happening and that's what the restraining order would in theory do right it wouldn't get Denzel rested but

16:15

it would get him out of the house that's right so as a lawyer sort of working away on this paperwork Chris and Julie

16:23

got on a flight home to Iowa it was I think on a Thursday that we flew in to

16:29

Omaha it's October 2017 they drive up to the old farmhouse

16:34

our level of fear driving up that driveway was Unreal because we didn't

16:41

know how Denzel was going to react we didn't know how soon the police were going to be there walking up to that

16:47

door was the most frightening moment of my life they knock on the side door they describe their mother answering and her

16:55

initial response to them being there is to hesitate she just stood there and I said Mom can we come in and she goes oh

17:03

yeah you know like she was startled like of course you can come in when the daughters walk into the house they are

17:10

shocked by what they see this Farmhouse which was once scrupulously tidy now

17:16

just looks unkempt in the kitchen the landline phone is missing and the shelves are basically bare the only food

17:24

that Diane seems to have in the house is a freezer full of ice cream cones on the

17:29

stove there's this piece of masking tape with Denzel's handwriting on it it says do not use in big

17:35

letters on the door frame there's this piece of wood that's just blocking access to the

17:41

staircase when we go in we find our mom incapable of doing anything or

17:49

understanding why we were there or anything and their mother just seems completely out of it her curly white

17:55

hair which is usually perfectly styled and puffed is flat around her neck as if it hasn't been washed her watch is on

18:03

upside down her words come out slurred eventually Diane kind of gives up and

18:08

goes into the bedroom and just lies face down on her bed so Chris and I just tried to make conversation hoping and

18:15

praying that the police would come driving up the driveway and as expected for the daughters two sheriff's deputies

18:23

pull up and I looked at Chris like oh you know cuz I didn't know how he was going to react I was terrified

18:29

explained that under the terms of the order Denzel would be immediately removed from Diane's home and quote

18:36

restrained from committing further acts of abuse or threats of elder abuse charges that Denzel immediately

18:43

denied Chris went straight back to the bedroom so that she could be with Mom

18:49

because I said I don't want Mom to be upset or to wake up to any of what's going on you so in the sister's telling

18:55

Denzel runs into Diane's bedroom where she's sleeping and he's screaming at my

19:00

mom Diane Diane do you know what those girls have done do you know what they're doing to me starts screaming at the top

19:08

of his lungs it was utter chaos it was chaos sort of forced to leave the home

19:14

the look on his face when he walked out that door was I wish you were dead he was

19:22

[Music] Furious I don't think Chris and Julie

19:27

really had plans for what would come next and I think what surprised them most on that initial day was that none

19:34

of this seemed to register for Diana at all you know when the police left she fell asleep the first thing she said

19:41

when she woke up from her nap despite having witnessed you know this whole scene before her was where's Denzel and

19:48

she asked it again and she asked it again and all evening and in the middle of the night and the next day

19:53

too she didn't even know where he had gone and I think the daughter

19:59

you know they tried to explain to their mother what was happening H can I ask a

20:05

question yeah but you don't necessarily get an answer oh what later I listened

20:10

to this long conversation that Chris recorded on her phone did you terminate

20:17

my general power of attorney and you can hear Chris and Julie you know ask

20:23

questions of their mother what do you mean general power of attorney just I had a I know you ter my trust but did

20:29

you also terminate my power of attorney what is the power of not to my

20:34

knowledge what okay why and and Diane's responses are really shocking she says

20:41

you know what's the power of attorney and there a changes she doesn't remember

20:46

making you know I could grasp nothing about the trust all I know is it was there and you

20:53

you doled it up and that's I didn't I never doled anything from your well she's using

20:59

but while Diane clearly doesn't understand you know the precise financial and legal decisions that she

21:07

made her motivation is very clear um a long time ago when after dad died when

21:13

we did this you asked me you said Mom you know I would do you want to take

21:22

care of of their trust and and I looked at you and I said honey I don't know if I know the first

21:27

thing about that sort of thing uh do you want to do it and you said i' be happy to and I said okay go ahead okay so um I

21:36

can remember saying that but now I've got the feeling and has nothing to do with

21:43

Denzel he's got his own money I got my own money uh I want to be able to be my

21:50

own person before I die she tells her daughters I want to make my own

21:56

decisions I want to be in charge of myself until I die I knew that I had given you control of of it for me

22:04

because back before because I didn't have a clue and my mind wasn't working very well anyway um probably better than

22:12

it it is now but I want to be my own

22:18

person I'm realizing Katie in this moment that I don't really understand what the law has to say about this

22:27

complicated situation I mean here Diane is asking to see Denzel who has

22:32

just been removed from the house per that protective order and Diane is taking actions like giving him power of

22:39

attorney but she's been given a diagnosis of dementia and that recording

22:44

you heard suggests she doesn't even understand what power of attorney is at this moment both of which runs contrary

22:51

to the idea that she's really capable of being in control of her life and these kinds of decisions so what does the law

22:58

say about that yeah this definitely confused Diane's daughter and it

23:04

confuses a lot of adult children of people with dementia adult children often assume

23:10

that you know the moment a doctor pronounces a person to have dementia that kind of flips a decisional switch

23:17

and all of a sudden that person is now legally and medically incapable of

23:22

choosing for herself anymore the reality is that there's no such switch within modern medicine

23:30

patients are never declared completely competent or incompetent in some

23:36

holistic sense instead doctors are asked to look at individual choices and

23:41

whether or not a person is able to make a specific choice in a specific

23:46

moment this in practice can mean that a person with dementia can retain the

23:51

ability to make choices for many years and then lose the ability in stages so lose the ability to make complex choices

23:57

first and then simple ones later and this is important from a legal perspective too because it means that

24:04

people with dementia retain the ability to make legal choices even when they are

24:10

cognitively impaired but of course this often creates conflicts within families

24:17

because there's no clear-cut medical way to determine without error that a person

24:24

is capable of making a specific choice so Bas on what you to said the

24:29

daughter's options would seem to be pretty limited here so what is their next move it's clear to Chris and Julie

24:37

that their mother had been very effective at hiding the extent of her impairment from them

24:45

at this point Diana is still speaking well and she can be engaged in conversation so her daughters decide

24:50

that it's probably going to be important for them to get some evidence that their mother is actually very sick and their

24:57

decision has to bring her to the University of Iowa Hospitals and Clinic where they know there's a dedicated

25:03

geriatric Psychiatry unit where their mother can get a more formal assessment

25:09

and so we sat Mom down and explained it to her as best we could without having it sound scary like we're taking you to

25:15

a hospital and and they're telling Diana GRE to go she helps to pack her bag she gets into the car and they all start in

25:22

on this hours long drive to the hospital everything stayed quiet in the

25:30

car for quite a while we got to De Moine and my phone rang and it was our

25:36

attorney's mother who's a nurse it's sometime around sunset going and Mom

25:42

said who is that I said eileene well can I talk to her of course that Diane

25:49

starts getting upset so she gets the phone e I'm being kidnapped please call the police come and get me I'm being

25:56

kidnapped and ien at some point she throws a book at Julie she starts

26:01

hitting Chris and I had to grab her wrist to keep her from continuing to hit me she's screaming that

26:08

she's doesn't know where she is and is being you know driven somewhere against

26:13

her will yes it was terrifying physically it's the voice it's the body

26:19

it's everything that nurtured you before and suddenly it's like she's possessed

26:28

after a few minutes of this the sisters decide they're going to call an ambulance and have an ambulance Drive Diane the rest of the way to the

26:36

hospital when they get there Diane's given a cognitive

26:41

assessment and what's shocking is that you know while Diane has been operating

26:46

more or less normally in her life she actually has very significant deficits the neuropsychologist who tests her

26:53

describes deficits in almost every field that he tests for and decides that Diana's is unable to safely perform

27:00

tasks as complex as preparing a meal in his final report he describes

27:06

Diane as having significantly limited capacity for informed personal medical

27:12

and financial decisionmaking later a doctor helps to kind of interpret these findings and she

27:20

uses the phrase Alzheimer's disease for the first time in her view Diane is already at a late moderate stage so far

27:28

beyond the kind of mild forgetfulness that had started to worry her daughters so the kids wanted to know how bad

27:35

things had gotten for their mom and now they know I mean they have a very serious diagnosis now right and that

27:42

really convinces them that they need to take control of the situation in a more formal way so talking to their lawyer

27:49

Chris and Julie decide that they're going to focus on getting legal guardianship of their mother which will

27:55

effectively give them control over many of her personal and medical choices and

28:00

they're convinced that you know this will be a a fairly straightforward case and that once they get guardianship

28:07

they'll be able to kind of fix everything but it's also at this point

28:12

that their personal relationship with their mother really evaporates Diana's

28:19

moved from the hospital to an assisted living facility in Dennison and because

28:24

the elder abuse charges against Denzel have been dropped she's able to start seeing him again

28:29

and once that happens Diane quickly makes the choice to stop seeing her

28:35

children she tells pretty much everyone she knows everyone she sees that she wants nothing to do with them that she

28:41

doesn't want them to visit at one point she even tells a friend she doesn't have daughters

28:50

anymore hello hi Dental hi there's this recording of a phone

28:57

call not sure where to start so I'll tell you what I planned on saying and

29:02

that is that I would be happy to sit down and talk with you and Mana well I

29:09

don't know I'll have to get back to you please let me tell my grandmother the

29:15

same thing I'll let you tell her Julie's daughter Haley calls her grandmother

29:21

Diane and and tries to mediate the situation you hi Nana hi

29:29

over the course of the call you really hear Haley try to make the case that I

29:34

love all of my family I love you both I love my mother and Aunt you know this

29:40

has just got out of control Chris and Julie love their mother I need you both

29:46

to know and I need especially denal to know that from my perspective there are

29:53

opportunity for everybody to come together and everybody to be happy

29:59

especially Nana there's got to be some way to resolve this it's up to Nana

30:05

whether she accepts them again not them and Nana it's up to

30:10

Nana and she has chosen to write them off I have chosen to write them here and

30:19

Diane for her part she speaks very lucidly I I know think there's an easy

30:26

way out of this and there is not I can't handle much more

30:32

stress um and the only way I can get rid of that stress is to get rid of what's

30:37

causing distress which happens to be your family I'm sorry she says quite clearly

30:46

there's not a way to move on [Music]

31:00

and I don't know what else to do to save my life and that's the only thing I can do is for than I have I'm

31:11

sorry I want you to know I love you goodbye by

31:22

[Music]

31:35

we'll be right

31:45

back hello hi Mr Nelson thanks so much for uh for getting back to me again um

31:52

uh can you hear me okay yes okay great and thanks for those so Kati you eventually spoke with Denzel about how

32:00

he saw his relationship with Diane and with her family so in his mind how did

32:08

all of this play out so denel also describes falling in love as sort of

32:14

sudden and unexpected well one day I decided I was just going to go for a

32:20

drive and Diane was out working in the yard and she says what are you up to

32:26

today and I said you know it's a nice me and I'm going to get in the truck and

32:32

just go for a drive when I first got in touch with him on the phone he told me this long story

32:39

of about falling in love with Diane and his truck I said you want to come along and she said well where are you going I

32:47

said I don't [Music] know she says well yeah but she and that

32:54

day they took their first drive soon one drive became regular

32:59

drives and then longer drives they took trips to horse shows and quilt shows and

33:04

antique sales all around the state one of the first trips we made

33:09

M it always tickled me because her husband was an attorney and

33:17

and every trip they ever went on they had to be certain such of place because

33:22

they had a motel you know these trips were themselves kind of an entirely new

33:27

experience for Diane and the first trip we went on when we just took off she

33:33

says where are we staying tonight and I said well or do you want to St Dian said

33:39

was amazed to learn that Denzel never booked a motel room in advance he just got in his car and drove and drove until

33:45

he felt like stopping and then he'd stay at whatever Motel happened to have space so she liked how it was kind of more

33:51

spontaneous traveling with you theous deal was something that just really

33:56

tickled her and Denzel says that on those longer trips they would sometimes stay overnight at a motel in the

34:03

beginning of course they're just friends so they would sleep in two separate beds

34:08

he talked about leaving the room to go outside while she got dressed and he'd do the same for her but then one night

34:16

as he told it Diane just climbed out of her bed and into his arms and he thought

34:21

at that moment about how she was the gentlest person he'd ever met finally one day

34:29

well anyway we ended up in the big house and I was invited and so this

34:35

relationship just blossoms it was we had some really a couple three really good

34:42

years there from oh 2013 until they all the

34:50

fan when Denzel moved in you know he he knew that Diane's daughters weren't

34:56

really accepting the relationship Chris never did like the idea that I was living in her dad's house but he also

35:04

didn't really care you know it wasn't her dad's house anymore it was her

35:10

mother's house I think Denzel felt like you know Diane was a grown woman and she was entitled to make her own decisions

35:16

and it didn't really bother him whether a couple of daughters who lived out of state approved of him or

35:22

not but later I think Denzel started to butt heads more with Chris and Julie it

35:28

seemed to him that Diane's daughters were interested in controlling things for their mother you know he was

35:34

surprised to learn that even Diane's social security check went straight into an account that was managed by Julie and

35:41

he described being sort of disturbed to learn that whenever Diane wanted to do anything major like trade in her car for

35:48

one she liked better she had to go through Julie who was the trustee of her trust did it bother her that Julie was

35:56

kind of in in charge of things or did she like it because it was easier no she

36:01

hated it yeah she was perfectly able to take care of her own

36:07

bills and everything I'm curious what denzil's

36:14

interpretation and recollection is of the day that Diane's daughters show up

36:19

with that order forcing him to leave the house I think he was completely Amazed

36:27

by it I was home and I saw Chris and Julie come up to the door and I told

36:33

Dian I says there's going to be trouble he didn't see it coming at all and then

36:39

the sheriff showed up and they had a restraining order and they hauled me out

36:45

of the house and and I heard Chris tell Diane Denzel did something illegal and

36:53

you're never going to see him again in Denzel's version of events he doesn't resist at

36:58

he goes into Diane's bedroom to say goodbye to her I told Diane I said be

37:04

tough honey he gathers his various medications and gets into his car and drives away and I think Denzel was

37:11

completely taken aback when he heard the specific charges that he was accused of

37:17

they charged me with uh elderly abuse just one lie right after

37:23

another certainly the phrase elder abuse struck him as being entirely

37:30

inappropriate Denzel ended up giving me a copy of his diary from that time and he called them the sin sisters kind of

37:37

coming in and making up stories about him hurting this person who he loved more than anyone

37:43

else they said I wasn't eating right or we weren't eating right that's that's

37:49

the lies they told you know and he had his own explanation for things most of

37:54

the time we went out to eat because we could and Diana took all our

38:00

lives as for the cupboards being bare well Denzel said the cupboards were bare

38:06

because he knew that Diane had spent 50 years of her life cooking for other people and he thought it would be nice

38:12

for her to be taken care of they said there was some mold in there and there

38:18

was no mold as for the house being dirty again he said it looked okay to him but

38:24

anyway he didn't like to see Diane on her hands and knees rubbing the floor and anytime he did he told her to get up

38:30

and and not worry about it he would take care of things H so Denzel you know he left the

38:36

house as he was forced to do but I think from that moment he had every intention

38:44

to fight Diane's daughters for what he saw as as Diane's freedom and and

38:51

Liberation what about the decline of her memory which of course is that at the

38:57

heart of all the legal Maneuvers that his daughters are undertaking what does

39:02

he say about that he really denies that at this time Diane

39:08

was sick no he was not having any memory issues so that she didn't in your

39:16

opinion she didn't really have dementia right when this all started she got it later no no sure he noticed Diane was a

39:24

little less steady on her feet and you know maybe her memory wasn't what it was

39:29

at the age of 30 or 40 but he didn't see it as being some big serious thing a lot

39:37

of people have a bit of dementia and I think his view was that Diane was more

39:43

or less unchanged and certainly not changed to the point where she needed

39:48

someone to be caring for her all of the time he was prepared to care for her in whatever way he said she needed so what

39:55

does Denzel do after he and Diane are forcibly separated so the first thing he

40:02

does is leave the house as he's ordered to do he moves in with his son I just I

40:08

could have went nuts I mean uh couldn't connect with her couldn't

40:14

call her or nothing but once Diane's transferred to the assisted living facility he's given visitation rights

40:20

again and he starts visiting her every day most morning I'm an early riser

40:25

always have been I wake up at 4 :00 I don't care what time I go to bed and so I'd wait around till 7 when I could go

40:32

out there go to breakfast with her he shows up at 7:00 a.m. he stays 12 hours

40:38

he goes for little walks with her around the building he calculates that if they walk around the building 10 times it's a

40:44

mile they'll walk it twice he sits with her while she naps we played a lot of

40:49

cards and watched TV and set out in the porch swing and he says that often times in

40:56

the night he would get a call from the assistant living facility and a nurse

41:02

would tell him that Diane was crying 2: a.m. 3:00 a.m. that she was crying and she wouldn't stop and they'd ask if he

41:08

could come but many nights they'd call me that Diane was having a bad time what

41:15

was she was it just cuz she was sick or she was lonely do you think she she just

41:21

uh with what her daughters did to her and then maybe they tried to call

41:27

that day or something that she wouldn't talk to him and then she'd be thinking about it yeah how would you settle her

41:35

down hug her kiss her tell her everything was going to be

41:40

all right and as Denzel tells it you know Diana's very clear throughout this whole time that she loves him that she

41:48

wants to be with him and that more than that she doesn't want to see her daughters anymore and Denzel sees it for

41:54

himself he says you know when Chris and Julie call Diane's asked if she wants to take the call she always says no it's

42:01

Christmas approaches Diane sends word to her daughters through her lawyers that she doesn't want to see them at all and

42:08

I think Denzel really feels heading into the guardianship case that he has a really good chance of winning because

42:15

isn't it obvious Diana is telling everyone that she wants Denzel and shouldn't it be her

42:22

choice well eventually a court had to make that decision tell us what happened

42:29

during this trial over guardianship for Diane well in a way this kind of routine

42:35

trial in this small town in Iowa became this larger philosophical debate over

42:42

which version of Diane should be listened

42:47

to no Chris and Julie made the point that their mother had for years told

42:52

them if she ever got dementia they should be the ones to take care of her she trusted them to make the right

42:58

decision for her Denzel on the other hand argued that none of that really mattered because the version of Diane

43:05

who was sitting in front of them all was saying something very different she was saying she wanted him so in the end it

43:12

was a question of what does Diane really want is it what she's saying she wants

43:18

there in the moment in court or is it what she said consistently for all the years before her mind became impaired

43:31

and ultimately what does the judge decide in the end neither of those two

43:38

sides wins the judge decides that Chris and

43:45

Julie won't be suitable Guardians in part because they live out of state but also because they don't seem to be

43:51

taking their mother's wishes into consideration when making decisions for her on the other hand the judge thinks

43:58

Denzel will be unsuitable because he really seems to underappreciate how sick Diane is he says over and over in court

44:06

that she's not sick at all as far as he knows so the judge takes this middle course and appoints one of Diane's

44:12

friends Marshall L as the [Music]

44:23

guardian H and what do both sides end up making of that middle course starting

44:31

with Denzel I think he still feels liberated by the decision that's who

44:37

Diane wanted when they asked Diane who' she like to be her guardian she said Mara and of course he's friendly with

44:44

the woman who's appointed guardian and with her permission he gains the right

44:49

to see Diane whenever he wants also to move back into her house I was there three times a day to see her she was a

44:57

when I could three times a day and so he kind of continues doing what he'd been doing before visiting her every day

45:02

spending the day I mean I knew she was getting worse

45:08

that dementia only went one way yeah and I get realiz it when I get

45:14

there and he does start to notice at this time that Diane isn't what she used

45:22

to be well I'd help her put her makeup on and I think that was probably the first thing I no it sort of starts with

45:28

her makeup I mean she was a very attractive lady she was a real lady and

45:36

it bothered her that she couldn't her hands you know were shaking

45:42

and and that and so I actually helped her put her makeup

45:48

on I probably didn't do a real good job but but I uh I helped her put her makeup

45:56

on every morning and it

46:01

was and as Diane's dementia got worse she's moved to a different facility a

46:07

nursing home with a specialized memory care unit but Denzel keeps visiting her

46:13

there and his visits continue until 2020 the pandemic the

46:20

co yeah when the co started then you know I couldn't get her out of there

46:25

anymore Diane yeah some days seemed to understand what was going on but other

46:30

times seemed to know nothing of the pandemic and it got to her herel she

46:36

would uh a few times she said I know you can get in here you just don't want to

46:42

you know and that really hurt because she she understood Co at first but then

46:48

it got to where she didn't understand the co yeah she accused Denzel of

46:54

choosing not to visit her of being allowed to come inside but not wanting to we just had a really good few years

47:01

there but that all ended that dementia is to

47:07

me is worse than

47:13

cancer and then eventually it became less clear to Denzel that Diane always

47:19

knew who he was and it was around that time he says that

47:25

he stopped pH visiting and it's an untidy goodbye and

47:31

it's incomplete it's just one day a visit is hard and then that's the last that Denzel ever sees Diane

47:48

again so let's return to Chris and to

47:53

Julie what do they do after they they find out about the judge's decision in

47:59

the Guardian case so Chris and Julie go back to their respective homes and immediately they

48:06

start working on an appeal but they also continued this Relentless sort of effort

48:11

to get in touch with their mother but their calls wouldn't be put through they'd get friends to call too sometimes

48:17

and and just try desperately to get word of Diane and none of that worked until

48:22

this is Aon can I help you hi Erin can I speak to Diane n please yes just a minute okay one day

48:31

Julie's friend Mary calls the nursing home and to everyone's surprise she's put through to Diane hello hello Diane

48:38

this is Mary I called you last week yeah how are you doing

48:44

today I'm I'm getting better you're getting better

48:51

Mary and Diane were able to talk a couple of times and it was clear that

48:58

Diane's cognition was very diminished at this point she seemed confused a lot of

49:04

what she said didn't make a lot of sense but what was clear was that she was

49:09

unhappy where she was living in this basement unit of the local nursing home so so I called your daughter Julie and

49:17

she's finding you a different place to live oh really yes oh my goodness I was

49:27

able to listen to one of the calls and on it Mary tells Diane that she's been in touch with Chris and Julie and that

49:33

they're going to try to get her move to a different better facility don't know I don't know where

49:40

to to say well don't cry don't cry Diane just breaks down in tears and she says

49:46

it would be so wonderful and she's so happy to hear that her daughters are

49:52

maybe going to help her they're going to come and see you as soon as I can you know is that

49:59

okay yes absolutely absolutely have them coming to you but at the end of the call

50:05

okay Diane I'm gonna let you go I'm gonna call Julie right now okay and then and then I'll call you

50:12

back thank you sweetheart you're welcome you're the sweetheart Diane forgets to

50:18

hang up and Mary just sort of stays on the

50:25

line for a few minutes

50:34

and you can hear Diane crying softly in the background and then sitting in silence for a

50:43

while and then you can hear a nurse come in and she ask Diana if she's

50:49

okay she tells the nurse they hate me

50:57

of they call me bad

51:08

things so in September 2020 a court finally agrees to Chris and Julie's

51:15

request that Diane be moved to a more specialized facility in Omaha almost

51:20

immediately after arriving she is put on hospice care doctors decide that she is

51:26

dying and doesn't have very long to

51:32

live and it was then that a judge finally signs this order granting Chris and Julie the right to see their mother

51:38

for the first time in over two years because of the state Diane's in Chris's

51:43

immune compromise and decided that it wasn't safe for her to travel during the pandemic but Julie gets in her truck and

51:49

she drives 9 hours to [Music]

51:54

Nebraska walking through her threshold I mean the the anxiety the fear of you

52:01

know I haven't seen Mom for what Chris three years hadn't seen my mother and

52:06

she ends up spending four as she describes them completely Pleasant and wonderful days with Diane I

52:14

went in and and Mom was in bed she was very weak um but I sat beside her she

52:21

sat up we talked we hugged we kissed we giggled and

52:27

she was so happy and then we she laid down and I tucked her in under her little blankie and and she said oh stay

52:33

here by me stay here and so she held my hand and I just laid down beside her and

52:39

and sometimes Julie says Diane seems to maybe ask about Denzel she asks where's

52:46

that man where's that man a few times but she never calls him by name

52:51

I'm I can't tell you how hard it was to have to leave that last day

52:57

when I lefted the feeling I had was that this is how it should have been from the

53:03

[Music]

53:09

beginning in January of 2021 Chris and Julie

53:14

are granted guardianship of Diane and they call each other they can't believe

53:21

this has finally happened they start planning a trip together to see their mother but 4 days later before they

53:28

could take that trip Diane dies at the nursing

53:34

[Music] home we'll be right

53:50

back Katie it occurs to me that in the story that you have just told everybody

53:58

involved was hurt in some way and hurt

54:03

deeply the daughters Densel Diane so how do you think

54:10

about why there was so much pain in this

54:16

story is this really about bad decisions made by

54:21

the people that we have been talking about or is this about a bad system

54:26

that we have for handling people with Dementia or is it

54:33

both I think as a journalist I often write stories where there are in the end

54:39

good guys and bad guys and that's not how I felt in this case I I really felt

54:45

that everyone involved in this story was kind of arguing and fighting in good faith everyone loved

54:52

Diane I think you know in part there are we is in the system I mean if you look

54:59

at someone who has dementia that person might live with the diagnosis for years

55:06

slowly deteriorating and there's no clear and obvious and easy to measure point at

55:13

which a person with dementia loses the ability to do something for herself and

55:19

then loses the legal right to do it I think that's just an inherent difficulty

55:25

with the disease the medical system can try and the court system can try to locate that point but

55:30

it's not going to be easy and certainly a person with dementia a person like Diane can remember things and forget

55:37

things and remember again in the course of a day so what do you do with that mhm

55:42

but I think beyond that in many ways Denzel and Diane's daughters were

55:49

just living with different versions of the same woman and I think given how

55:55

they knew Diane this is understandable the daughters were committed to the then

56:02

version of their mother the pre-dementia version of their mother the one they'd lived with for decades the one who had

56:07

been clear about what she wanted at the end of her life and they felt obliged to

56:15

even when that woman seemed to disappear to recall her and to honor her what she

56:20

wanted and Denzel on the other hand only had the woman who was sitting in front of him at the moment and he felt that he

56:28

loved her and that the right thing to do was to listen to her to listen to what she was saying and to take it at face

56:35

value not as some pathological symptom of a cognitive impairment mhm and so he

56:42

was in a way advocating for the Diane who was diminished and I

56:49

think even amongst academics who debate this you know this is a contested

56:55

subject who's the authentic person who in this case was the real Diane I mean have you come to a

57:02

conclusion of your own after spending all this time with the family with

57:07

Denzel and with the documents I mean which one was the real Diane the one the

57:14

kids remembered and wanted to honor or the one who fell in love with

57:19

Denzel I think it's hard to say who the real Diane was but I do know that as a

57:25

society as with our medical system and our legal system as they are we're

57:30

moving in the direction of honoring Denzel's version of Diane it used to be

57:37

you know in the early 20th century that just having a diagnosis of dementia basically meant that you were stripped

57:43

of all your decision-making power stripped of all your civil liberties and put under the control of other people

57:50

and we've moved away from that system and we've moved towards a world in which

57:56

we hope even people with significant disabilities and impairments can live

58:01

with some autonomy and in the case of dementia that means increasingly listening to what a person

58:08

with dementia says she wants even if it's different from what she said she

58:15

wanted for decades and Decades of her life and I think that

58:21

is understandable from a you know political or legal standpoint but very

58:28

very challenging for the adult children of people with this disease right

58:35

because they have to live with the reality that the now version of their mother or their father or their sister

58:41

or their brother is the one that the system Privileges and

58:47

prioritizes yeah [Music]

58:56

and I think it can be terrifying for you know the rest of us too we can tell our

59:01

children what we want to happen to us when we're older in the event that we get sick we can write out documents

59:08

outlining our wishes but in the end they might just not be listened to because in

59:14

the throws of the disease we might change our minds and that can be very

59:19

scary you know I feel like I know who I am and it's it's frightening the thought

59:24

that some different impaired version of me might actually have both the

59:31

ethical and the legal authority to usurp what I decide I

59:39

[Music]

59:49

want well Katie thank you very much we appreciate it thank you for having me

59:56

[Music]

1:00:16

today's episode was produced by Luke Vander PLO with help from Claire tennis

1:00:22

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1:00:43

[Music]

1:00:52

wonderly that's it for the daily I'm myor see you tomorrow

1:01:01

[Music]