

Keynote Address at The National Lifespan Respite Conference
Huntsville, Alabama Thursday October 12, 2017, Jill Kagan, Dir.

Begin with the song “Oh No, I’m Looking For My Glasses Again”
3 min

I wrote that 20 years ago at the tender age of 45. The song isn’t completely true since I didn’t find the glasses because they were on top of my head — I found them when I looked in the mirror — I was WEARING them. I knew at that moment I had crossed a line. I crossed a line. I’ve crossed so many lines since then, but we keep going because that’s what we do.

I’m here first and foremost to thank all of you for what you are doing to care for our elders. I have limited experience doing this — but what experience I have has taught me so much, and one of the things I have been taught is that very often caring for our elders is a thankless job. It brings out the best — and the worst — in families. And too often caregivers neglect their own health when they are so focused on their elders.

In 2010 I gave up my apartment in NYC and moved to a small upstate town to live with my mother, who at the time was 90 — she is now 98, has no short term memory, and back in 2010 she had some short term memory, but not much. I lived with her from January 2010 til September 2012, doing way fewer concerts because it was much harder to travel from that small town, plus it quickly became clear when she was alone she was at sea.

For the 2-1/2 years I lived with her, I went out socially THREE times without her — saw the movie “Moneyball,” and two concerts. That was IT. I could see how anxious she was left alone — even for 5 minutes — so I was with her every day from noon til bedtime, and then I would work on my computer on the

couch within sight of her room til 3 or 4 AM. One brother was with her at breakfast time, from 7 - 9:30. On Saturday afternoon my younger sister would take Mom out, and on Sunday afternoon another brother did. So there were gaps, but I did as much as I could to ensure she had company most of the time.

I have 8 brothers and sisters, 2 of whom live in the same town, 2 live within an hour's drive, the rest scattered around the country. We've been doing family "tag-team" care— but for anyone who thinks having that many children means better hand's on care, it's not always the case. So much can fall between the cracks. Seven of the 9 have spouses who also have a relationship with our Mom, and have their own opinions on her care, so family discussions get complicated — and sometimes heated — very quickly.

I managed to take my Mom out a lot — she is very social, loves good food and especially ice cream — and we made many many visits to local restaurants and our local Wegman's grocery store. I let all the Wegman's employees in the sit-down area know that Mom had very little short term memory but she loved the store, so could they stop at our table and say hello whenever we were there?

The Wegman's employees were wonderful — they understood she would never remember them, so they introduced themselves to her every day like it was the first time meeting her. We bought scratch-off cards, had coffee, very often had dinner there — but we also would go to nice restaurants in town — admittedly, when I moved back to NYC in 2012 I was way in debt from the combination of few concerts and spending on restaurants. But it made her so happy. I'd do it all again.

I learned how to make videos while I was living with my mother — I taught myself using an iPhone and iMovie on my laptop. I would film everyday activities that Mom took part in, just so she could watch them and remember, since her brain couldn't remember for her anymore. She loved watching these little videos, and soon I knew enough to make videos for my own songs — but I learned simply to help her remember.

During this time I was so focused on my mother that I didn't pay attention to my own issues until one day, while packing to go to Texas for a music festival, I passed out. I have a stent in a vein in my chest — no big deal now, but it was a big deal then — but it's one of the reasons why whenever I do interviews prior to my concerts I mention that I hope caregivers will take a night off and come out and have some fun. I don't know if all caregivers end up being as isolated as I was, but I know that isolation contributed to my worsening situation. While I was living with my mother I told all the local siblings that I was there to help give them a break, so take advantage of my presence. If I had spent more time with them they would have noticed something was wrong with me — something I didn't realize until I actually passed out that day.

In July 2012 Mom fell, fractured her pelvis, and her shoulder, went into the hospital where her memory deficit was observed and they would not allow her to return home, more for the memory issues than for the fractures, which would eventually heal. She didn't have 24/7 care at home — we had those gaps — so I moved back to NYC in September 2012 to keep my career moving forward, but visited as often as I could. Few of my siblings are able to spend hours at a time with Mom, so I know what I do matters when I'm there, though when I leave there are more stretches of her being alone, but at least she's alone in a setting where she is looked after.

Now one of our siblings has dementia, lives on the west coast, so we are trying to include visiting her into our schedules. It's complicated things exponentially — this summer one my younger sister flew from Rochester, NY out to California to escort her back for a week-long visit. The next day they flew back east, everything was going fine til later that day my younger sister's husband suffered a heart attack and needed emergency open-heart surgery, so we all had to pitch in, taking care of our mother and our sister that week — understandably, they wanted to be together as much as possible — and my younger sister who had arranged this visit and had planned to 'babysit' our older sister 24/7 was suddenly dealing with her husband's heart surgery.

With both our mother and our sister we find ourselves more and more dependent on the staff at the facilities where they now live. When I am with her I spend at least five hours a day with Mom, knowing that short 'pop-in' visits are fine, but when it's someone with no short-term memory, those visits don't do all that much — they do more for the visitors than for the residents, in my opinion. In August 2016 I again moved from NYC back to the small town, lived there til April of this year. She always does so much better when she has a relative she still knows. But I moved back to NYC this April after it became clear that Mom thought of me as an employee of the facility, and I HAD to get back to my work for financial reasons. But I live with the daily guilt of knowing there are now long stretches where she is on her own, but at least in a staffed facility.

I learned as much as I could to do things that freed up the staff from doing them— walking with a gait belt around her, helping her in and out of the bathroom, getting her ready for bed. I've also seen the rapid turnover at the facility.

From what I can see there are two kinds of people who work with the elderly — those for whom it's a calling, and those for whom it's a job, or a Plan B or Plan C. Since you are here I guess most of you are the ones who choose this as your life's work. It's heartbreaking work. Someone asked me how I could spend so much time at the nursing home with my Mom, and I tell them, "it's like hanging out in a college dorm — except everyone's a senior, and no one wants to graduate."

There's cliques, feuds, friendships, constantly adjusting expectations — but spend enough time there and there's always ways to make it rewarding.

A good way to keep the family connected is by creating a private group Facebook page —

MATT — [SHOW FACEBOOK PAGE AND SCROLL AS I AM TALKING]

Mom has her own page, though she doesn't contribute directly to it — anyone in the group can, so over the past four years we have an ever-changing gallery of photos and videos — most are of Mom, but sometimes other relatives post photos or news from their family. It's a very good way to stay connected, and if you do it via facebook instead of a dedicated website, it costs nothing.

By limiting it to invited members you control who can see it and contribute to it. It's something one of your younger family members can do in a snap, and it's a way to make them part of their elder's care.

Our mom can spend a long time looking at the photos and videos and postings and reminiscing. I even have made videos of her scrolling through her facebook page, enjoying it immensely. This

helps to get more relatives to post things there, seeing that she does enjoy looking at what is there.

We also text a lot — the siblings — photos of her sitting outside, eating ice cream — but the beauty of a facebook page is that everything stays in one place, and over time you can get a grasp of the person's state of health and welfare by scrolling through the pages.

We probably have over 100 videos of Mom — most very short, more like moving snapshots — and we'll have these forever — made with an iPhone and a Mac Book — no special software. Again, this is something that for young people is second-nature. It's harder for us to learn how to make videos — not impossible, but harder — but for young people they already know how to do it. Over time these photos and videos will mean so much more.

MATT, PLAY VIDEO: Good night from Mom, where Mom lists the names of all nine children

2 min <https://vimeo.com/192718219>

Our Mom was a great scrabble play til recently, but there's a game called "Mobi" that she played a lot — til recently, when this is now beyond her reach. She was a math major in college, so her math skills are skills she still has some of — in a way it's like Scrabble, you start with 7 tiles, except there is no board, and no need to keep score. There are blue tiles with numbers on them, and white tiles with plus, minus, divide and multiply signs. The first person who uses up all of their blue tiles shouts "Mobi!" wins.

MATT, PLAY: Mom plays Mobi in bed

1 min <https://vimeo.com/141495228>

I have a dozen Mobi games that the inventors let me have at a deep discount so that I could give them to 12 of you today. You probably already know who at your facility still has decent math skills — and you don't have to be a math whiz to play this game at all — so I encourage 12 of you to grab these while they are here.

I would often bring my guitar and after dinner have a little 'sing' in the dining room at my mom's place. I put together a songbook of a dozen songs that seniors like to sing — and in one case — “You Are My Sunshine” — I rewrote it so that it has a happier ending than the original. I learned that singing, “You'll Never Walk Alone” is too much for some seniors, so maybe don't sing that one.

However, there was one man there who hated my singing, would run out of the dining room covering his ears. I found that often if I just sat next to one of the residents and sang them a song after they were in bed but still awake, that they liked that very much.

And there was one woman there who just sat in her wheelchair and said, “Mommy . . . mommy . . . Mommy . . .” all day long. All day long. She was parked at the nurse's station for many hours. One day I got out my guitar and sang her, “Somewhere Over The Rainbow,” and the effect was remarkable. She stopped saying, “Mommy . . . Mommy . . . Mommy . . .” she sat silently and listened, and when I was done she looked at me and said, “That was a beautiful song. Thank you for singing it.”

The staff at the nurse's station was stunned — they told me nobody had ever heard her speak anything but “Mama mama mama” til that moment. So whenever I was there with my guitar I would find her and sing it to her, and it always stopped her from babbling, and she always said something nice.

I made a “songbook” with the lyrics and the chords to 12 songs that were hits with those seniors — this link is in the email I sent to Jill Kagan, who will forward it on to you later today — You will have six days to go to that link where you can download the ‘songbook’ and print it out. If you have folksingers who come and entertain they might find it useful, or you can just have them sing the songs a cappella since most of the songs are very well known and easy to sing.

That link also includes an mp3 file of my brand new album, SPAGHETTIFICATION, and the 48 page PDF for that which includes lyrics to the 15 songs on that album. I have a limited number of physical copies of my album here, but I have to charge \$10 for them since I haven’t paid it off yet. But the digital copy is free. So look for that email being forwarded by Jill Kagan to arrive later today.

During one of the stretches where I was living in NYC I got a call from the former owner of the nightclub “The Bottom Line.” He and his wife, Eileen are now both residents at The Actor’s Home, which is in Englewood, NJ. His name is Allan Pepper, and he is so grateful to the caregivers there that he wanted to thank them for what they do, especially for his wife Eileen, but he wanted to thank them in an unusual way. He asked his friend Henry Gross, one of the original members of “Sha Na Na,” to write a song about the place.

Henry did, and Allan sent it to me asking if I had an idea of how to get the song in circulation? I suggested making a video for it — so in the spring of 2016 I made six trips to The Actor’s Home, filming Allan’s wife Eileen, along with her two best friends there, Janet, a retired stage director, and Teak, a retired dancer. The Actor’s Home is open to families of people in show business, and a number of current Broadway stars’ relatives live there. Because

of HIPPA laws, of course, I can't say who they are. But with Broadway royalty visiting, you best believe the entertainment there is first rate.

Because of privacy laws, the home's administration wasn't sure about this idea of us creating a video. Absolutely NO ONE could appear in it except for the three principles, and their spouses. I had filmed a shot where you could see the reflection of a resident for one second in one of the glass doors as it closed — that had to be edited out. They take these rules very seriously.

The Actor's Home has a fantastic collection of sheet music, gold records, film and Broadway posters and photos, artwork by renowned artists — it was founded by Lillian Gish and her family — but after I had shot much footage of all of that, word came down that none of it should be included. We were a bit dismayed, but did what they wanted.

Allan Pepper is nothing if not persistent, and when we were working on the 10th draft of the video, he was able to get the head of The Actor's Home to look at it — and he changed his mind completely. He became our biggest ally and when it was finished he had it run in-house on the message boards on every floor IN HEAVY ROTATION.

So here's Henry Gross, formerly of "Sha Na Na," then as a solo had a huge hit of his own in the 1980s called "Shannon" — still singing for his contemporaries, though now many of them are in Assisted Living and Nursing Homes.

PLAY VIDEO "Come On Home" Henry Gross
4 min <https://vimeo.com/168849555>

Once a year Teak hosts a sale of all the scarves they knit — some of it goes to charity, and it's a fun project that Teak, Janet, and Eileen take part in all year.

I have a song that I only sang once in concert, at The Guthrie Center in Great Barrington, Massachusetts. I knew about halfway through that it was upsetting to some in the audience, and I wished I hadn't sung it. After the concert I was approached by a woman who was in the audience who asked me if that particular song was on any of my albums.

I told her no, it wasn't, and I don't think I will ever play it again in public because I felt that it brought the audience down. She insisted that I had to record it. "I'm in eldercare," she said, "and you MUST record it."

Even though I never performed it again, I did record it, because that woman was so insistent. This will only be the second time I have ever performed it for an audience, and I am hoping this is the right audience for this song.

CHRISTINE SINGS: "They Are Not Done"
8 min

THEY ARE NOT DONE
by Christine Lavin

"Oh what a lovely family!"
he heard that all his life
though he was quite distant
he had a cheerful wife
all the children went to college
each earned a degree
but he died before

he knew what kind of adults
they would be

his wife lived on many years
At the age of 85
Her short term memory
All but gone
but still very much alive
like so many elderly
Who cannot live on their own
she's now in a facility
so she is not alone

“God’s waiting room”
Is what some call this kind of place
Some are like high end hotels
Some are a disgrace
Some are run by angels
Who love the work they do
Others staffed by lost souls
Whose other plans fell through

No matter -- good or bad
The family gets involved
In helping make decisions
Getting any problem solved
One is chosen Health Care Proxy
Though laws differ in each state
When this family chose theirs
Did they made a mistake

At the time they didn’t know it
But by the end of that first year
their mother’s needs were not being met
that was very clear
Despite no short term memory

The rest of her was strong
She read the daily newspaper
loved Scrabble, singing songs

She was curious and eager
To engage in conversation
But those beside her nodded off
parked at the nurse's station
Where she now spends much of her day
dozing in and out
The family grew quite worried
Worry mixed with doubt

Two schools of thought emerged
As the grown children now took sides
Half wanting her to be moved
The others said, "Let it slide
she doesn't remember anything she's done
at the end of the day
no need to keep her entertained
why bother – let her stay"

But as the arguing grew heated
the Health Care Proxy took the reins
dismissed any talk of changing things
saw more losses there than gains
refused to fill out paperwork
to get her on a waiting list
ended all discussions
with his hand curled in a fist

For months the arguing
among the siblings grew much worse
they now think living this long
is not a blessing but a curse
Most live far away

Though the proxy lives nearby
And decided he would not tell them
If anything went awry

And when it did he'd keep that news
As quiet as he could
Eventually they would find out
The news was rarely good
And they'd beg him to let their Mom
move to another town
Where there'd be lots more family
she would be around

They'd say, "At least let's all meet
To discuss the situation"
But he'd refuse
Delete their emails
Shut down communication
So the family called a lawyer
that's where things stand right now
Everybody knows we've got to fix this
But nobody knows how

If you walk into a nursing home
See a sad silent display
Of old people parked at the nurses' station
Day after day after day after day
Do not assume a thing
About each one's circumstance
and hope someone there is trying
to win them another chance

To get back in the game
for some it is not over
They're in wheelchairs they use walkers
but they sleep above the clover

They want to make connections
They want to sit out in the sun
They still have things they love to do
They are not done
They are not done
They are not done
They are not done . . .

“Oh what a lovely family!”
he heard that all his life
though he was cool and distant
he had a gentle, cheerful wife
all the children went to college
each earned a degree
he died before he saw
what kind of adults
they turned out to be
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CHRISTINE SINGS: “The Armchair Based Lifestyle” with
audience participation — MATT PLAYS BACKTRACK
5 min

CHRISTINE SINGS: “GRANDFATHER ISAAC” by Daniel Cainer
7 MIN

CHRISTINE SINGS: “GOOD THING HE/SHE CAN’T READ MY
MIND” 5 MIN.

Thank you for all that you do for our elders. To sum up, think of creating a private group facebook page for your elder, or suggest it to young family members who are skilled on computers. If you own an iPhone and a Mac Book, you, too, can teach yourself how to make simple videos that your family will cherish for years to come. If you need help in learning, find someone in your town

who knows how to do it — they will be more than happy to teach you. When people get good on the computer teaching themselves, they are usually very happy and proud to share their knowledge.

Understand that caring for elders brings out the best and the worst in families, but the good ones will make themselves known to you pretty easily.

And most importantly to everyone here — make sure you take care of your own health. You are so valuable to your community, but if you are out of commission, you can't help if you become one that *needs* help. I know what that feels like, and it doesn't feel good.

And if you're only going to see one movie in 2-1/2 years, choose something better than "Moneyball." I mean, it was OK, but something like "Hidden Figures" is much more inspiring.

CHRISTINE ENDS HER PRESENTATION with "Dream/Summer Song" — MATT PLAYS BACKTRACK
TOTAL BLACKOUT FOR THE ELECTRIC BATONS AT THE
END.

THANK YOU ALL!