

Creating a Movement By Alicia Garza End Well Symposium, December 6, 2018

Start of Transcript

[Crowd Applauding]

My mother died April 30th of this year. It was seven weeks from diagnosis to death. I had just flown in from wherever I was and I got a text from my dad, said he needed to talk to me about something important. I was running around, doing other things, rushing to another event and I said, "Okay. I will call you when I'm finished." When we talked later that evening, he told me that my mom hadn't been acting like herself. Having grown up as the "grownup" in the family, I thought maybe they had had an argument and that something had happened and I wasn't really sure but as he began to describe her [00:01:00] symptoms, I felt a tightness in my chest.

You see, my mother, my world, my heart, the strongest woman I have ever known, a woman who was in the military and believed that there was a place for everything and that everything had its place, was suddenly putting towels in the refrigerator. I immediately called my bestie, she's a public health nurse in Alameda County, we call her "night nurse" and asked her all of the questions about anything health-related, whether she knows it or not. She asked me a lot of questions which I didn't have answers. We started to narrow down what can possibly be happening. Did she have a small stroke? Was it possible she was displaying some of the early signs of dementia or Alzheimers [00:02:00]?

I patched in my dad on three-way, and we agreed on a plan. What we said was that my dad would do is call the doctor's office first thing in the morning and demand that my mother be admitted for an MRI. They had done that already. The doctors didn't wanna do it, they felt like maybe it was an unnecessary procedure. In the morning, I learned that they had been successful in advocating for what it was that they wanted. Later that day, again, rushing to get to another event, I grabbed my shoes, I grabbed my speech, moved my skirt, I'm walking out the door and my phone rings, I picked up and all I hear on the other end is sobbing. They found a mass in my mom's brain [00:03:00]. My mom was on the phone and so I had to explain to her what was happening.

"Mom," I said, "they found a tumour in your brain."

"Oh!" She said, child-like.

A woman who I had known as so capable, so intelligent, suddenly I couldn't tell was she processing what I was saying to her or was she really unaware of what was going on? Either way, it was terrifying.

The next seven weeks were a whirlwind. It started with learning how to adjust our lives. You see, my mom was the caregiver of the family. And as the girl child, I of course was raised to know how to care — but behind my mom [00:04:00]. She had a way to do it. My dad had recently developed a chronic spinal condition which meant that he had to take medication, he was constantly uncomfortable, and it was my mother who made sure that he went to doctor's appointments. It was my mother who made sure that he did the physical therapy he was supposed to be doing. It was my mother who made sure that he took medication when he was supposed to take it, with the food he was supposed to take it with. It was my mother who was trying to convince my father for months and months to maybe just try that surgery and maybe that doctor wouldn't actually kill you like he thought he might.

But now it was my mom that needed care. And we quickly found out that she needed care around the clock. She got disoriented really really quickly, looking for the bathroom outside. She moved in silence like always, which meant that we had to adjust **[00:05:00]** our attention spans because she's creeping around and then you look up, and she's outside next to the swimming pool. We all had to quickly learn how to pay close attention to the woman who paid close attention to us.

Now a week prior, I had just launched an organization, focused on building black political power. Everything had to be put on hold. I spent a week in Northern California cooking and cleaning, talking to relatives about what was going on even though I had no answers. Soothing my father who was faced with the prospect of losing his partner of more than 30 years before he thought it was time. I had to teach him how to use the washing machine, how to use the dishwasher. We had to find a doctor and trust me, internet searches are not great **[00:06:00]** when your loved one is suffering and you can't tell who's who. Who's an expert? Who's not an expert? Who's gonna be the best for her particular case?

One day my mom was walking and she was talking, the next day she was not. A scheduled MRI turned into a rush to the emergency room as there was bleeding in her brain likely from the tumour... and she'd lost consciousness. She needed immediate surgery to stop the bleeding and drain the fluid that was building in her brain, she needed a shunt installed and then she needed another MRI but under sedation. We spent four weeks in the hospital. Two of those weeks in the ICU, meeting new doctors and nurses, meeting families some of whom had success stories. Others who were losing their loved ones, and each moment **[00:07:00]** in a place like that is uncertain and it's a rollercoaster. Some days my mom would be lucid, and she would be herself. Other days, she would be unconscious or sleeping. We had no real answers as to what was going on with her for four weeks.

The day the doctor told us that my mother was dying, that there was no treatment that she could survive that would deal with the localised cancer and the cancer that had spread across her brain, was the day that our lives changed forever. You see, moving my mom, just 63 years old, not a wrinkle in sight, into hospice care, was unlike everything I'd ever experienced. Now we all know that we're gonna die eventually. And we do a lot of things to prevent that day from coming sooner **[00:08:00]** than we think it should. Botox, exercise, or like my partner's 95-year-old grandmother, her solution, is eat nothing light.

[Crowd Laughing]

But hospice was a dimension that was completely new to me. For our family, hospice became about embracing death. Embracing the life that we have left with as much agency and dignity as possible. For my family it wasn't possible for my mom to die at home. They lived three and a half hours away. My dad did not know how to be a caregiver and we couldn't imagine in having a caregiver move in to their home three hours from the rest of my family's support system. Working closely with a palliative care team at UCSF, who I will forever be grateful for, we were welcomed into this zen hospice centre **[00:09:00]**.

Now you might know that Zen hospice was established in the mid 1980s to afford dignified care for people who were dying on the streets, were dying in SROs and certainly during the height of AIDS crisis here in San Francisco, Zen hospice project took care of people with AIDS whose families had abandoned them. When we entered Zen hospice, I'm pretty sure I cried with relief. So did my momma when she arrived later that day. I have a picture of her wearing one of her signature big-brimmed hats. She had become accustomed to wearing those hats because she was very self conscious about the stitches on the top of her head. She was

wearing a t-shirt that said “Phenomenal Woman.” It was the first time in four weeks that she had worn regular colts.

Hospitals are not fun environments [00:10:00]. Now of course I’m grateful for every doctor who would explain something to me for the hundredth time about what was going on with my mom or who made sure that we as a family didn’t kill each other before my mom passed away. I’m also grateful to every single overnight nurse who chased my mom up and down the hallways of UCSF during many of her manic moments.

At Zen, though, my mom had a shift that would make anything she wanted. She had her own bedroom that overlooked the garden. There was only six residents there at any given time. No fluorescent lights, no constant noise, and she could actually sleep. Zen let us experience an experiment with what was best for my mom to meet the needs that she had at any given moment. Sometimes that meant cannabis whale because she wasn’t eating [00:11:00] or because she needed to sleep. Sometimes what that meant was a signature lemon pound cake to satisfy her sweet tooth. Other times it meant giving her access to a glass or three of wine that she became accustomed to over the last 30 years... or so. Sorry mom. It was also close so I could visit where I needed to.

You see hospice wasn’t just for my mom. It was for the entire family. We all became intertwined. And we all received the care that we needed to embrace the moment that we were in. The bond here is where I learned that my mom loved to have her nails done. So once a week, they would do her nails. She was really self conscious about how she looked because I told again, she had this scar in the shan’t thing and she was dry and had tape marks all over her. So we brought [00:12:00] in a stylist to make her feel beautiful again.

You see I talked with hospice nurses at least once a week to get updates on her prognosis. Mom always had a big smile for everybody that she loved and even people she didn’t know. But there was times when she was withdrawn and deep inside of herself. One day a hospice nurse told me that my mom sobbed the night before. She remembered that her own mother had passed away. She became conscious that she was passing away. And she said to the nurse, “I’m not ready to die.” And they sat and they held each other in the middle of the night. What would we have done without a caregiver to be there for her in that moment when she needed them the most?

My mom died on April [00:13:00] 30th. Seven months of the last week, I was holding her hand when she took her last breath. I imagined that’s how it should be. Taking your last breath on your own terms, surrounded by the people that you love and that love you. I miss my mother terribly and I remember when she was sick, I felt like every single cell in my body would split. But I can say and stand here before you to tell you that we experienced angels in the care that our family received. What it meant for my mom to die with dignity, our experience of care and caregiving, was essential and it is not the experience that so many families have across this nation.

I spend most of my days [00:14:00] trying to get people to take action around things that are important to our collective well-being. I’ve done that through the *Black Lives Matter* global network, ensuring that black people are able to live full and dignified lives and not have those lives cut short by inadequate policing, by disinvestment, by criminalisation or by the myriad of other issues that make black lives disposable.

But before BLM and to this day, I worked with the *National Domestic Workers Alliance*, one of the nation’s premier organisations, fighting for the rights and respect of caregivers. Child caregivers, elder caregivers, house cleaners, people who support independence for folks with

disabilities. You see, domestic work and caregiving in this country is rooted in the legacy of slavery **[00:15:00]**. And now the vestiges of that awful, terrible arrangement still exist in the industry itself. We work to make sure that caregivers can also care for themselves. That the work that caregivers perform is considered work. And we work to make sure that that work is paid like it's valued for.

[Crowd Applauding]

We work to make sure that caregiving is affordable, that it's quality, while also making sure that caregiving can actually be valued for the incredible contribution that it is.

In the 1930s domestic workers and agricultural workers were excluded from basic labor protections that other workers enjoyed. That was a result of a racist compromise between **[00:16:00]** union leaders and southern lawmakers. They were unwilling to ensure that black workers and brown workers that compromised the vast majority of the sector, would receive the same rights and protections as white workers.

Today we fight state by state to win rights and respect for the people we care who care for the people we care for the most and we have won rights and protections for caregivers in eight states across the nation. My family could not have made it without the care that we received. Caregivers are the backbone of our society and the backbone of our economy.

[Crowd Applauding]

Many caregivers in this country don't have the protections they need to make a wage that will allow them to care for their own families. More than a million caregivers in this country **[00:17:00]** are not covered by basic labor protections, even though caregiving is one of the fastest growing sectors in our economy. Every eight seconds in the United States somebody turns 65. And we don't have enough caregivers to care for our ageing population.

Now my mother was not old. She was 63. She had not had a long illness, she had not even retired yet. She and my dad had just bought a house in Northern California where they planned to live out the rest of their days together. They were talking about retirement. Now that both of their children were grown and at least one of them was self sufficient.

[Crowd Laughing]

And yet more and more people, like me, are in a position where they are caring for children and caring for their ageing or ill parents. My story is **[00:18:00]** a story like many others. An illness that seemingly comes from nowhere and lays even the best laid plans aside. But my family had resources. My mother was meticulous about planning and it paid off when she can no longer make decisions on her own behalf. We did not run into complications with insurance companies that didn't want to cover procedures. Even though both of my parents were covered under the Affordable Care Act. We got into a facility with a week's long waiting list and the reason was because the nurse recognized me and respected my work.

[Crowd Applauding]

Don't cry. [Laughing] She pulled strings to get us there. My family lives here. We're fourth generation in San Francisco, we are a quickly dying breed. We all lived within two hours of **[00:19:00]** where my mother came to die. I had miles, I had money to be able to fly her twin brother out from Georgia here twice to be able to spend his best friend's last days with her. My family was just not fortunate, we had and we have privileges. Many people who need

caregiving don't have access to those privileges and not only is that unfair, it's criminal. My mother's death has impacted me in ways that I can't grasp and I had yet to know. But I can say that I had everything I needed available to me. What about those who don't? What did they do to die with dignity? What do their families do? And as I said before, this [00:20:00] work has always been personal to me. My mother cleaned houses when I was younger to make ends meet. My grandmother was a caregiver for a family for 30 years. It was always personal to me. But it became even more personal when I needed to rely on caregiving. When I needed support and caring for my mom. When my mother was dying and I could not be there at every second like I wanted to be. Bless the caregivers who held her when she cried. Bless the caregivers who chased her around the hospital during manic moments of her illness.

Caregiving is the work that makes all other work possible. So why aren't caregivers being cared for in return? Now as a sidenote, the home that my mom died in, she was the last resident. A few short weeks after her death, I ran into her caregivers at a film festival for another friend who was then dying of cancer [00:21:00]. My friend Alona valiantly fought for two years a rare form of gastrointestinal cancer before dying a month ago. When I saw those caregivers, I hugged them for a very long time and they told me that they were given just a couple of weeks' notice that soon they would not have jobs there anymore. That the house would be closing. And I recently learned the house is put up for sale. Now it breaks my heart when I think about it, I was just getting up the resolve to go back, to go through the voluntary program and give back the care that my family received. I can't do that anymore. And it raises the question, why does our care infrastructure get left to not profits that rely on philanthropy and goodwill? Why is it not an embedded part of our city's infrastructure [00:22:00]?

Now my friend, Alona, died a month ago. She did home hospice. And I can tell you her experience was not at all the same as my mother's. The caregiving was different. Process more formal and isolating. There wasn't family care. Just the bare minimum of patient care that was allowed by her insurance. I wished so much even after her death that she had that same level of care that my mom received.

This is why movements are important. Movements have become the buzzword over the last few years and people often wanna know how do I just add water to create a thing like you did? And I keep telling people you can't add water and start a movement. Movements are not built from hash tags and they're certainly not built [00:23:00] from Twitter followers. They aren't built from small circles of people who already agree with each other. Movements are built by people who care. People who are directly impacted by an issue. People who come together to understand why is this happening to us and what are we gonna do about it? In movements, we learn how to work together across difference for the sake of our collective liberation. In movements, we learn how not to leave anyone behind. We learn how to interrupt the wedges that are placed in between us.

I've been a part of the *Domestic Worker Movement* for about five years. I've been a part of many other movements for about twenty years — don't let the baby face fool you. But I walked unknowingly and somewhat unwillingly into this movement around dying with dignity [00:24:00]. A movement that seeks to change how we understand the role of death in our society. A movement that seeks to break the silence and the isolation of dying. This movement cares for people when they need and deserve care the most and yet families, and caregivers, and those of us straddling both minds, don't have the things we need to die with dignity or to support dignified dying.

So here's my call to action. Keep going. Don't let caregiving be available only to the people who have access to financial services and resources. Don't let caregivers and their vital role be erased. Bring the different parts of this movement together so that we can be stronger and

more dangerous together. *The Dignified Dying Movement*, *The Domestic Worker Movement*, the movement for affordable healthcare, the movement to end racism **[00:25:00]** and sexism and homophobia, anabolism, they're all connected.

[Crowd Applauding]

And we need each other. Desperately. Caregiving is facing a crisis in this country and our voices are not loud enough alone. This room has to be multiplied by a thousand, by a hundred thousand, by a million. We need each other to be successful. We need to change the composition of what these rooms like and who was sitting in them. We need to ensure that the people who are doing the work are sitting in these seats, and informing us of what a caring economy can be. We have no choice but to prevail because what is at stake is dignity for all of **[00:26:00]** us.

Every single one of us is going to die at some point. Every single one of us needs and deserves care. So what's at stake? Being able to reach toward that which is our birthright. Please, keep going. Thank you.

[Crowd Applauding]

End of Transcript