

## Taking it to the Streets By Randi Belisomo End Well Symposium, December 7, 2017

### Start of Transcript

The voice at the other end of the phone stung. It burned me more than the sun that was beaming on my balcony just west of Chicago's loop where I sat concocting what I thought was a halfway decent plan. Her words shouldn't have bothered me so much. After all, this colleague told me the truth in which I intimately aware. "Randi, what you don't seem to realise is the fact that you're white." Breaking news! They're not gonna like this message because black folks die differently. That's just the way it is. Race wasn't something that I had taken for granted. I knew I looked out from a more privileged perspective on a [00:01:00] on a city cut in stark racial lines.

I grew up in Memphis, Tennessee, but it wasn't until I moved to Chicago I felt I had a really good understanding of what segregation is. In more than a decade in Chicago as a broadcast journalist, I've worked as what we call a street reporter, covering streets that at a street level are straight lines of color. Black, brown, white. I've knocked on countless doors, and asked moms to describe unspeakable pains. "Tell me about your son. What will you miss the most?" Traditionally reporters don't hug those they interview, but I've had more than a few grieving women collapse in my arms.

While neighbours don't mix with each other [00:02:00] across racial lines that you won't see on a city map, they typically mix with me and that's a fact that's due entirely to my role. They're eager to speak up and share with the rest of the city what matters most. The details of one young life who had gone unnoticed and I thought that instinctively human desire could drive be it halfway decent idea that I referenced earlier, to some level of success.

What was the idea? Lightbulb moment! To develop a pilot program that opens access to residents of one neighbourhood to comprehensive, structured and trustworthy planning services. So residents can consider, communicate and document their end-of-life preferences. To build a culturally competent system built on trust and community respect in multiple public places so these discussions will flourish [00:03:00] and be normalized. All this so residents can experience end-of-life care that lines with their values, goals and beliefs because they have been shared, understood and most importantly honoured by loved ones and providers. Maybe this neighbourhood could emerge as a community model for meaningful end-of-life dialogue.

That's the reason I called here in the first place, an African-American minister's wife who was keenly familiar with the care challenges in her own congregation but she reinforced stereotypes that if you were my friends in medicine, sometimes lamented, "My people," is what she said, "will always do everything." I feared responding the wrong way because there were plenty of facts that don't support her claim. African-Americans [00:04:00] report worse symptom-related suffering at the end of life, poor communication with doctors, less than adequate pain assessment... and overall lower satisfaction with the quality of their end-of-life care. Most a the end-of-life want I thought what we all want through at it, to be heard. To live in accordance with our values, to matter. I was too off kilter to say any of that to her and the notion of her people got me right off the phone. I knew that they're not her people anymore than those on the near west side of Chicago is mine. Either the Puerto Rican's a black's further west of me, those of my late husband's Carlos.

Chicago was my city. Chicago is still my city. His death from colon cancer drove my decision to enter end-of-life education [00:05:00]. He was the sweetest soul with the kindest eyes. He was an enthusiastic husband who was devoted to his role as a local political reporter. He was mourned by seemingly an entire city, and officially from the floor of the United States Congress,

and the West Wing of the lighthouse. Carlos was a great man. His death was not. He was in the ICU, a setting I am certain he would not have chosen but his death is the reason I guess I am here today and started *Life Matters Media* with his oncologist, Dr. Mary Mulcahy. The non-profits roots trace to a conversation we had shortly after my husband's death. My instincts as a reporter led me to a quest to figure out what happened and why. I asked her, "Why didn't you ever tell me that Carlos was dying?" She said [00:06:00] something similar but with a subtle difference. She said that his cancer was incurable but it was treatable so we focused on that latter reality and went full steam ahead doing whatever we could to elongate whatever time we had left. No matter what Mary has said, it would've never been enough. Nothing could've prepared us for the ugliness that was ahead.

I was getting ready for work the day Carlos suffered his ultimately fatal P.E. He was sitting with me while I was putting on my makeup, convinced I needed to go and save my days off so things get worse down the road. Things were already worse but we didn't acknowledge it. Perhaps [00:07:00] we didn't really even know that day I was preoccupied with how I was gonna get him to his chemo appointment the next day. We never paused to consider whether those four ours and an infusion room were the best use of our time. I spent the day of that chemo appointment I was concerned about at a funeral home conference table, numbed by the events of the prior 24 hours.

About two years later, our new organisation began community education with a program called *Starting the Conversation*. We did this in conjunction with the city's department on ageing, at every city of Chicago senior's centre. We also asked participants to complete a survey asking about their considerations of end-of-life care, discussions [00:08:00] with family members, their documentation.

We found that there was no difference in planning as a factor of race as commonly believed. We did find a big difference based on income. Those who lived on higher income neighbourhood were more likely to have thought their care preferences, talked about those thoughts and documented them all. What we also realised is that it would likely be more beneficial to provide more frequent programs in one area than doing a lot of education spread out throughout the city. That way, residents in that one area could get to know us, our colleagues, our issue and we can get to know them, their families and their values. With the help of the retirement research foundation, we launched our first neighbourhood initiative in [00:09:00] Chatham then earlier this year. It is home to one of the most solemnly middle class black communities in the city with one fo the oldest populations. In that survey that we conducted the first time around, Chatham residents got our attention. More than 80% of them said that they had thought about the care that they wanted at the end of life, but more than half of them had not discussed those wishes with anyone. Older population thinking about their future care, but not talking about it. Combine those facts with the presence of what we called "bright spots." Business associations, busy libraries, health committees, embedded in vibrant churches maybe Chatham was ready to start the conversation.

Focus groups at the beginning of this year overwhelmingly affirmed this fact and helped us shape our objectives of providing cultural [00:10:00] -ly relevant information, increasing community knowledge, normalising planning as a routine health behaviour, and fostering local expertise. Through tailored messaging in appropriate channels, Chatham residents learned about the initiative more frequently from reading the *Chicago Citizen* than in the *Chicago Tribune*. They figured out where to show up, what senior centre, from AM gospel radio than our recurring segments on *MPR*.

What do we do? We partnered with ten sites to provide about 33 programs so far this year. Close to 500 neighbors have participated. Mostly by taking part in our standard four-program

series. We talked about living well at the end of life by thinking about what gives our life meaning now [00:11:00]. We also talked about why they think only 3% of residents have had a physician first broached this topic with them. We talked about how well executed advanced directive reflects a really good conversation, but we also talked through wishes with the residents who do not want a document and often for really good reasons. We introduced the topic of palliative care and discussed how somebody would know it may be time for hospice. But we also talked about how to access that much needed support with keeping the presence of strangers in our home to a minimum. We talked about how —organ donation and stories of local donors and talked about the many good reasons neighbours don't donate and separate those reasons from abuses in past history and current myth. We also explored [00:12:00] the most economical of disposition options and sparked conversation about what it's in these when attempting to bury loved ones.

They learned more from each other than they do from any program facilitator. Some have emerged as what we call our conversation champions who expand this initiative and take it to their club or their church, where living well and dying well was the subject of several Sunday sermons this November. Pastors in Chatham are burying at higher rates than they're baptising or marrying and can make the most influential of allies. These champions invited their friends to a screening of the *Defining Hope* film, many of you saw and *Hospice Month* and a theatre full of neighbours stayed for the documentary and for a discussion following with African-American hospice specialist.

We're able to survey about 200 people who took part this year. A population of healthy seniors, the average participants is 70-year-old woman in good health and average household income \$50,000 [00:13:00] or less. 50% of them lived alone. We know that 80% know who will speak for them in a medical crisis. About half have discussed the wishes with that person and about 30% have an advanced directive. This data shows us a lot and shows us what we have to do from this point forward. We will stay in the neighbourhood next year to provide facilitation services to residents in their ages to result in informed advanced directives, we're going to train neighbourhood champions who are signed up to become respecting choices of advanced care planning facilitators. They have received this gift and looked forward to giving it to others, in their church or senior club, and it's a movement that's growing organically — because it must. Unfortunately we have neither the staffing nor the resources to meet a demand in a population many people would write off as unwilling [00:14:00].

Betty Anne, she thinks it's crazy that people would think that she doesn't want to have the conversation. She's in the same circumstance of too many moms on the city's Southside caring for a son who was left a quadriplegic due to trauma that should never have happened. Every day, for the past 26 years, she has travelled 44 miles each way to visit her son in a nursing home. He's on a ventilator. Her son is waiting the miracle he is praying so faithfully for and would like all treatment to extend his life. But Betty Anne says at her age, that is too much. And hoped for hospice care if she becomes ill. She's relying on her niece to make that happen because her son is her only child.

Then there's Cleo. Cleo has come to four community programs this year with a combined total of 17 relatives. Quality end-of-life care is a priority [00:15:00] for her and you would think — I would think, that she has others more pressing. Ten years ago, her neighbours who ran a thriving drug operation broke into her home. Since then, to scare Cleo from turning them in, they have vandalised her property, killed her dog and left the bloody path on her porch and regularly fire shots outside her window. She's wearing dark glasses in this photo because she has a black eye underneath. She got it falling from bed trying to take cover.

When we met Gwendolyn Lee, she wanted to clarify her wishes because she worried about her future care. She'd never been married, and she lives alone. A month later she came back to check in with her nieces and she had news for me. She had a new flame...who was really an old flame from high school. They had reconnected through Facebook. 50 years later, there's still hope for me [00:16:00]. [Crowd Laughing] She said that if he would be willing to listen to her care wishes, she would know that this time it's for keeps. Well, four months later, I ran into her holding hands with him at a Jazz festival and she gave me a wink and said, "I had a conversation. It went really well." I hesitated to look at him because I said surely, only Gwendolyn I could think that conversation remotely romantic. But he said, "No, no, no! This was great! I'm planning to be there for Gwendolyn, so I really need to know." By sharing what matters most later, they can focus on what's meaningful now like the Hawaii cruise they're taking this spring.

Though many Chatham neighbours have told us this process is the most valuable gift their family has ever received, they've taught us just as much. One is that all those taboos and stereotypes so often associated with dying are our own hangups, not those [00:17:00] of others. Don't put them on other people. And if there are theories, they're usually not what you would expect. Andy won't know until you ask.

This isn't cutting-edge stuff but this is the design of a program that is working in a population that many would've considered unlikely to design a better end-of-life experience for themselves. This isn't a life that I would've designed or expected for myself either or Carlos certainly wouldn't have expect it from me, but I think that he would be really happy that my life is in some way connected or trying to fortify an often vulnerable time for a vulnerable population of seniors. He was the kind of guy who would dance with every older woman at a party especially if she were there alone [00:18:00]. But for Carlos, I'll always remember him at 36. And that's an age that I will somberly turn next week. And what sustained me through the pain of losing him is the deep faith that he has seen the face of God... and that I was left here for some purpose and I thank you for allowing me to share that purpose with you.

[Crowd Applauding]

End of Transcript