2019 INFLUENCERS IN AGING
Meet Next Avenue’s 2019 Influencers in Aging. These 12 advocates, researchers, thought leaders, innovators, writers and experts continue to push beyond traditional boundaries and change our understanding of what it means to grow older. [https://www.nextavenue.org/showcase/meet-our-2019-influencers-in-aging/](https://www.nextavenue.org/showcase/meet-our-2019-influencers-in-aging/)

Sandy Chen Stokes: Helping Chinese Americans Navigate End-of-Life Decisions
Founder of the Chinese American Coalition for Compassionate Care

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During its 14-year existence, the CACCC has provided education and translated materials for Chinese Americans related to end-of-life issues. It also has provided training for health care professionals, volunteers and caregivers in helping Chinese Americans navigate end-of-life health care decisions. The organization has active partnerships with [150 local, state, national and international organizations](https://www.nextavenue.org/showcase/meet-our-2019-influencers-in-aging/).

[READ OUR INTERVIEW WITH STOKES](https://www.nextavenue.org/showcase/meet-our-2019-influencers-in-aging/)
IF YOU COULD CHANGE ONE THING ABOUT AGING IN AMERICA, WHAT WOULD IT BE?
“To make the community more friendly in talking about end-of-life issues so Chinese Americans will be able to share their thoughts, ask questions and receive end-of-life services. So, hopefully, they can have a better death.”

**Sandy Chen Stokes: Helping Chinese Americans Navigate End-of-Life Decisions**

Her father's death led to the landmark work of this 2019 Influencer in Aging

- By [Edie Grossfield](#) Health and Caregiving Editor September 24, 2019
Sandy Chen Stokes is the founder of the Chinese American Coalition for Compassionate Care (CACCC), a nonprofit based in Cupertino, Calif., dedicated to providing support and education related to end-of-life issues for Chinese Americans. During its 14-year existence, the CACCC has provided education and translated materials for Chinese Americans related to end-of-life issues. It also has provided training for health care professionals, volunteers and caregivers in helping Chinese Americans navigate end-of-life health care decisions. The organization has active partnerships with 150 local, state, national and international organizations.

Stokes grew up in Taiwan, came to the U.S. in 1977 and pursued a nursing career. She is a registered nurse and a certified public health nurse with a master's degree in nursing. During her nursing career, she specialized in geriatric psychiatry. Today, her work is focused on the CACCC’s mission, including traveling in the U.S. and beyond to provide education and training in hospitals, hospice facilities, universities and senior centers.

One of Stokes’ most recent collaborations was with the AARP’s Multicultural Leadership department to create a series of videos on various aspects of end-of-life health care planning and broaching the topic with loved ones. Her awards include: the 2017 Compassionate Care Innovator award from the Coalition for Compassionate Care of California; a 2011 AARP Inspire Award and a 2009 American Cancer Society Lane Adams Quality of Life Award.

Next Avenue: Why did you first start working on end-of-life issues related to Chinese Americans?

Sandy Chen Stokes: I had just received my master's degree in nursing and was working in the hospital. My master's project was related to Chinese-American seniors, so I saw the needs in the community and that nobody was talking about Chinese seniors suffering from depression and anxiety. And there were quite a few suicidal cases going on.
“End of life, obviously, is the biggest taboo for the Chinese community. And later, I found out, it’s not just Chinese; it’s everybody. Nobody wants to talk about end of life.”

So, I thought I’d like to look into that area ... it’s kind of like a taboo. End of life, obviously, is the biggest taboo for the Chinese community. And later, I found out, it’s not just Chinese; it’s everybody. Nobody wants to talk about end of life.

And you said you were also motivated because of the way your father died in the hospital.

Yes, I went back to Taiwan to visit him. He had prostate cancer and, eventually, a complication from a gastrointestinal condition sent him to the hospital. Then, he caught pneumonia while in the hospital. Later, he had respiratory failure. And during that time, the worst part was that he was already in very bad condition, but because of [the respiratory failure], they started putting in a tube and everything and he ended up staying in the ICU (intensive care unit). You would probably never imagine this, but he was in the ICU for over a year.

He went through all the suffering and all the tests and everything. At that time, Taiwan didn’t have legal documentation, an advance health care directive or POLST (physician orders for life-sustaining treatment). So, the doctors had to do cardiopulmonary resuscitation for every single patient, even if the patient had died or the patient already expressed not wanting to receive that. They just have to do it because it would be illegal if you don’t do it.

And that’s part of what motivated you to ensure that Chinese Americans would know about patients’ end-of-life options and rights?

Yes. Even though we have the opportunity to be able to speak for ourselves and make the decisions — all the documents are there — Chinese seniors don’t
know that exists. They don't know what it is, they don't want to talk about it. So, I said, 'Hey, how about I do that with my volunteer work?’

So, we started the translation work, we had the advance health care directive translated into Chinese. A few years later, we started translating other materials related to end of life. And we eventually formed this coalition, back in 2005.

As you said, just about everybody finds it difficult to talk about end-of-life issues. But is there something about the Chinese culture that makes it especially taboo?

I think it's because we Chinese are more into the family decision — it's not an individual decision. So, if you make a decision that's not the family decision, the family will point their finger at you and say you are a bad son or daughter or whatever. And the spokesperson normally is a guy, the oldest son or the husband — they will make that decision, even if the daughter cared for her mom and her mom told her many times what she wanted. But if she didn't write it down, it doesn't count.

If you're the daughter-in-law, you have no position to talk because you cannot say anything. So, the people who really know the patient the most may not be able to express the patient's needs. Because of that, it becomes even more taboo to talk about.

In working with doctors and nurses in hospitals helping Chinese Americans with end-of-life decisions, you said there has been a kind of disconnect between what the doctors see happening and what you find people really want for end-of-life care. And, you've been able to learn this because of your “Heart to Heart Café” activities, which use cards that have end-of-life issues and options written on them to help facilitate discussions. Can you elaborate on this?
With the Heart to Heart Cafés, we have the data collection for the past four years, and we've had twenty-three hundred people complete the cafés. So we said: 'What are the top cards picked?' Lots of people pick like, 'I don't want to be put on a machine, just let me go.'

And the doctors and nurses all say, 'Sandy, it's not accurate, because in our hospital the Chinese patients always ask us to give aggressive treatment until the very end. Even if the patient only has a few minutes, a few hours to go, the family will ask to put everything on I want you to save my mom.'

We told the doctors, it's very accurate and we feel very confident about this, because we do the cafés and guess who is in the cafés? The persons themselves. So, you ask the person — and it doesn't matter if it's a senior or a non-senior — what do you want the most? they say: 'I don't want suffering.'

But when they're in the hospital, the patient is already comatose, they are already so weak and so sick, and the decision makers are all family members. If you wait until there's a crisis, it's already too late. You have to prepare yourself, because you will say, 'Save my mom,' that's it.

If you can talk about it when you are healthy, write it down, have people witness for you, and you share that with your family members, the family members will honor your wishes. So, you're happy because they will do whatever you want to do. They are happy because they don't have to make the decision.

Yeah, because that's an excruciating decision for family members to have to make.

Oh my. I've seen the family members split, fight with each other, they hate each other. They all love their mom, but they have a different way to show their love. And they won't talk to each other.
So, I say, ‘Think about your mom. Do you think your mom would be happy to see that you guys don’t talk to each other? She will know you all love her in your way, so please don’t do that to yourself or to your mom.’

And we will tell the seniors, ‘If you really love your kids, this probably is the best last gift you can give to them. Get the decision resolved. Write it down. Don’t wait for them to make the decision, because they don’t know what kind of decision they should make.’

By Edie Grossfield

Edie is Next Avenue’s health and caregiving editor. In this role, she reports on the information people need to make sound decisions about caregiving, their health and the health of their loved ones. She has been a journalist for more than 20 years, reporting and editing for newspapers and magazines. Edie has a master’s degree in journalism from the University of Wisconsin-Madison. Reach her by email at egrossfield@nextavenue.org.