

Ageing Matters: "Handling a Long Term Care Crisis"

Jason Kong: Well, let's get into the first topic for this evening Nicole and you know, we talk a lot about caregiving and a lot of times people don't find us or think about caregiving until they're thrown into a crisis or a situation that they're not prepared for and you know you're, you're scrambling so hard to do this and it's hard to be prepared for what you may be in for as a caregiver and the levels of care that your loved one may need.

Nicole Clagett: Exactly and especially if we're talking about an illness that is probably not going to be short term. More of like a long term illness such as a dementia diagnosis and often times as caregivers, we really underestimate the length of time we're going to be caring for someone. The degree to which we're going to be caring for someone and then how those needs change over time. So, I'm super excited today to be talking to Gina Murray who is the Founder and Director of Aware Senior Care and they are a private duty in-home care company right here in the Triangle serving older adults in our community and their caregivers. So, welcome Gina.

Gina Murray: Thank you. Thank you for having me. Glad to be here.

Nicole: So I know that you work a lot with families who are caring for older adults with a cognitive impairment. Talk to us a little bit about what you find that they're discovering as they finally reach out to you for some assistance?

Gina: Well, as you alluded to many times, the families that come to us, they're in a crisis. Something has happened. They may have had the dementia diagnosis for a couple years. But everything was fine. Going along fine, they had a little bit of support. But then you know they left the pot burning on the stove mom walked outside in her bed clothes and um, they come like "Oh my gosh ,what am I gonna do?"

Nicole: Mm-hmm.

Gina: So, they're in a crisis and we we need to step in and see what we can do to help them.

Nicole: And we know you know typically most people want to age in place wherever they call home and a lot of times families are really in support of making that happen. What do you think we should be doing as a society, Gina, to really prepare ourselves for the needs of the older adults in our lives? Because I really don't think we give a lot of thought to what folks are going to need in the future. We just basically kind of all go along in our happy little rosy ways and and not really think about, number one, that we're aging and number two, that our parents are aging.

Gina: Right and and there's things you can put in place now at any age. If you're looking at your home, even if you're in your 50s or 60s, you don't consider yourself old. But you can look. Do you have wide enough doorways if something happened and you needed a wheelchair access? Are you on one level? Just different things that you can put in place. Do you live where you can take public transportation if you can no longer drive? Can you walk to the supermarket? So there's things you have to think about now before, before something happens.

Nicole: And I think we're just basically wired to really not want to see what's going on with our loved ones or, or perhaps we just aren't educated enough just because there's so much to understand about the aging process. And people often times will notice things going on with their loved ones. Like that they're isolating themselves as they're becoming forgetful or they're forgetting to pay a bill. People are just you know thinking well that's just normal for a person who's aging. But, the reality of it is is a lot of these things are not.

Gina: That's true and the things that changes happen are so subtle and you can kind of chalk it up to "*Oh Mom just forgot that*" or "*My husband, he usually gets lost when he's driving.*" The changes that happen are so subtle that you don't even realize that they're, that these are going on. It could be a friend who hasn't seen them for a while or a family member that comes from out of town and hasn't seen this person in six months. When did this happen and you're talking like when did what happen? And the folks with dementia do a really good job early on covering up.

Nicole: Yeah.

Gina: They're working so hard to, to not let anybody know that they're struggling.

Nicole: And they're scared I mean I think we're really, really what it comes down to as a hu-, as a human race is that we are wired to survive no matter what. So, whatever we have to do to pull ourselves into the core of our being to make sure that we're gonna keep on plugging along, we do. And then there's the whole issue of losing control.

Gina: Right and they don't want to admit when they get a diagnosis if I say it out loud, then it's true and if I never admit that I have dementia or I'm having forgetfulness, then it's not going to happen. It's, it's putting your head in the sand.

Nicole: Oh yeah, I mean or not and I'll be the first one to say I'll do that with my little minor ailments as they go along. Oh this tooth kind of hurts. Oh I think I'll be fine. Oh it feels better this week I'm fine they're really probably isn't a cavity there and then the next thing you know you could have dealt with a little filling and now you need a root canal. I mean and that's unfortunately

Gina: That's true.

Nicole: Such a small example of how we handle things in our lives most of us, you know, then you have the other end of the people that go to the doctor when they have a pimple on their face. But, but most of us are not wired that way.

Gina: We're not, we're not. We're like it'll go away and, and unfortunately dementia won't. It's, everybody's journey is unique but it's going to progress one way, unfortunately.

Nicole: So, what are some of the things that you hear from family members when they're first calling into Aware Senior Care, reaching out for help? Kind of what gets them to that breaking point?

Gina: Like I said, **usually it's a crisis or they're just exhausted. Mentally or physically, exhausted.** It's not uncommon for people with dementia to have their days and nights flipped. So, their spouse, their loved one is up all night. And so the person caring for them is sleep-deprived and then they're trying to maintain the house. They're still trying to work. So, they've just gotten the point of complete exhaustion.

Nicole: And then they finally reach out to you and a lot of times I'm sure when they're reaching out to you, they still haven't even broached this topic to that family member. So, what's some advice that you can give to families listening right now that might be saying yeah this is sounding an awful lot like what's going on in my life? How do you have that difficult conversation with a loved one?

Gina: Oh, we'll talk to the family. We do meet in their house to see the environment and what I'll tell a loved one is you know, this can be helpful for you. Not necessarily your husband who has dementia. You know we provide support because you need help, some help with the household tasks. So, it's not his caregiver. It's assistance for the family. We can also say "Will you allow this person to be here so that your wife is comfortable going out?" and they're just gonna make the meals and do the cleaning so she won't have to do those things when she gets back.

Nicole: Mm-hmm.

Gina: And they're more accepting that way. I'll do this for the person that's taking care of the person that I love. I'll do it for them.

Nicole: Exactly. Instead of doing it for yourself and that's one of the big tips that we give folks at Transitions Guiding Lights is when we're talking to the families, you know, sometimes that person, I don't care if they're 95 years old. They're just not ready to receive that care. They're never gonna be the consumer of care. They've always got this. But, if you can have an open conversation and discuss your feelings with that individual as that family member and just let them in a little bit. Not to make them feel guilty, but help them understand how this is impacting you and how this would help you.

Gina: That's right.

Nicole: Then, a lot of times that person is a lot more willing and frankly, a lot of older adults are still very, very concerned about leaving money for their children. And so they're so worried about tapping into that little nest egg that they have to provide care for themselves...and they, they want to leave for their loved ones. So, they'd rather suffer.

Gina: Right and they would, they're like *"Oh I don't want to spend this money..."*

Nicole: This is for you.

Gina: Right, this is gonna be for you. You know, we've had adult children say *"But, I'm gonna lose my job. I'm gonna lose my livelihood because I keep skipping work you know, to go to*

doctors appointments because there's been a crisis, because there's been a fall." And so we'll say, oh, when we meet with families we'll say tell us you know, tell us how what your day is like and describe this. And they'll say *"Oh, that's okay my daughter does that. Oh that's okay my son does that."* But are they leaving work to do it? Do they have children you know, are they missing things in their own children's lives that you know, let us do some of the tasks and let your children be family again.

9:40 Break

10:08 Return

Jason: You're listening to aging matters, care and comfort that surrounds you. A service of transitions life care on Newsradio 680 WPTF Jason Kong here with the lovely Nicole Clagett.

Nicole: Ah, that's right.

Jason: See, I'm a quick learner, Nicole. I know my place. And we've got a special guest here in the studio and that is Gina Murray. She is founder and director of Aware Senior Care and we're talking about some unexpected items and occurrences that folks may not think of when they're in a caregiving said, caregiving situation dealing with someone with an Alzheimer's or dementia diagnosis. Nicole and I know the, we're knee deep in this conversation and we've got another segment here. So, let's get right back to it.

Nicole: Yeah so you know, I think one thing that people perhaps underestimate is really the changing roles. When you're a family caregiver and you have a loved one who becomes, um, incapacitated by an Alzheimer's diagnosis or a dementia diagnosis and your role suddenly have to change. Um, that can really be overwhelming.

Gina: It really can I um, I have a dear friend whose wife has Alzheimer's and what surprised him the most was he was so focused on what, what she would need in her care. And he realized he had never done the laundry. He had never made the shopping lists and made all the meals. They had traditional husband and wife roles for you know, the 40 years they've been married.

Nicole: Exactly.

Gina: And he says, *"This is exhausting running a household!"* *laughs*

Nicole: At least the kids are out.

Gina: That's right. The kids are grown. But he was like *"Wow, this is a lot."*

Nicole: Yeah.

Gina: So.

Nicole: It can be really overwhelming. I mean, just picturing my old life you know, we have a farm in Johnston County and I'm like yeah if something were to happen to my husband...I mean I've been on the tractor a couple of times. So, as far as that goes...

Gina: You're ready to take that over?

Nicole: No, not so much. I haven't even unlocked the chicken coop before. I don't even know where that key is. But, the reality of it is that on top of worrying about that loved one and providing that care then you really have to figure out, you know, how am I gonna maintain the household it in the way that it was? And then of course, you know, you know me now in my 40s thinking about that. That's one thing. But, if I were in my 70s that would be a whole other ball of wax.

Gina: Right, right. It's and it's really hard you know, the older we get it's harder to learn new things.

Nicole: Yeah.

Gina: And you may not want to do that.

Nicole: Exactly. I may want to binge watch something on Netflix that day.

Gina: That's right.

Nicole: Not that I get to do that that often but it's, it's a thought. You know I think another thing that we often underestimate and sometimes we bring up, but it's super important is the real, the grieving process. You know it's similar to somebody with a traumatic brain injury. You know, they don't wear their injury on the outside. They're not walking around with a sling, right?

Gina: Right

Nicole: And so their injury is really inside of their brain and, and their loss is really inside of their brain. So that person may look okay and eat may even talk okay seemingly you know at first blush. But that family member is really grieving and it's a very, very, very long goodbye and one of the things that I often talk to families about is, is really a part of that grieving process. Where the very first stage is where that individual has the dementia and they realize that there's something wrong and different and difficult about it. That's really the most difficult part for them because they're spending a lot of time trying to cover it up. They're scared to death about the loss, the future losses that they're going to have and then when we move into those middle stages and those later stages. That's the hardest time for the family when they are, you know forgetting loved ones names and really needing that physical care and all that support and they're a shell of who they once were.

Gina: Right it's, it's really difficult. My mother-in-law does have dementia and it's hard people say she looks wonderful. And she does, but you can't see that her brain is broken on the inside and she no longer recognizes her grandchildren. Um, she still recognizes my husband which is

Nice. But it's, it's painful, it's painful to watch and it's just and everybody's journey is unique. It's, that's the, I think that's the hardest part if you know one person with dementia you know one person.

Nicole: That's right. We're all so different.

Gina: It's true.

Nicole: We're all working in our own ways

Gina: I always recommend getting support, joining a support group even having someone to talk to. My friend doesn't want a support group. But he does have a friend who has a spouse and they just, they have that mutual time together that they can just say I understand.

Nicole: And you know the other piece of all this is there is so much information out there on the web. And I often ca-, caution people. A lot of people after they go through a dementia journey with a loved one to your point: it was one person with dementia. And these were the tricks and tips that worked with that person may not work for your loved one. So you need to be very, very careful when people are out there blogging and posting about you know, what they do that it's actually something that is typically accepted and reasonable to care for that individual with dementia. So, we like to often say that we really need to stick to some of those main websites like the Dementia Alliance, like Alzheimer's Association, the Mayo Clinic, Johns Hopkins. Some of those real reputable organizations.

Gina: Right, we that that's really good advice because you can get information overload or “Well my neighbor said this and like I said well stick to the people the real resources that know.

Nicole: And to your friend you know who doesn't particularly care to go to a support group, support groups are very tricky. You know I've been running them for my entire career and um, similar to having children you know you get you find out you're pregnant. You fall into two camps: You're either the type of person who wants to know everything to expect as soon as that sperm and egg gets fertilized all the way to what does the afterbirth look like? And you want to know day one where other people literally want to only know what's going to happen the next day or that day. And they don't want to know all that information down the road. So, support groups can be very scary to people if they walk into one where it's a bunch of people that have loved ones with various different parts, phases of the disease process. And so you really need to know who you are. And then reaching out to organizations that have the support groups. It's okay to ask you know, what types of family members are in the support group? What stages are their loved ones in? Because support groups can be very, very beneficial. But they can also scare people off if it's not the right fit for you.

Gina: That's a good, that's a really good point. And talking about the right fit when you're looking at families, caregivers, different adult children, spouses, everybody has a different ability in caregiving. I might be very comfortable giving my mother a shower, doing personal care or my sister's like no. I'll handle the bills but I am not helping with any of the personal care. So, not assuming that everybody can play every role.

Nicole: Right.

Gina: In the caregiver, well, they've got this huge family. Why aren't they helping?

Nicole: Right.

Gina: People need to help in their own way.

Nicole: Exactly and you know another thing that you know, we often run into as family caregivers is that superhero mentality where you've got your cape on and you've got this and you're gonna handle this. And you're doing fine for a while there. But at some point there is not an infinite amount of energy you have to put forth in caregiving and you're gonna smack and hit a wall. So it's super important even in the very beginning stages of your caregiving journey to really build in that time for yourself. Whether or not you need it on in the first weeks of your caregiving journey is it really doesn't matter if you don't build it in. It's just like building in an exercise routine. It's never going to happen and consider that exercise for your mental health. Allow people to help you in the beginning when that diagnosis happens and people are rallying around you because after a while if you keep saying no. It's not that people are being mean. You've just said no a lot and people aren't just going to keep offering if you keep telling them no.

Gina: Exactly, exactly and it's hard to say yes because you do feel like I can do this. But, unfortunately we see the caregiver, the one going down and then you're really in crisis.

Nicole: Right.

Gina: So, we've had a family, the husband took care of the wife until he had a stroke.

Nicole: And then...

Gina: And then the family is in a crisis.

Nicole: Exactly. So talk to us a little bit about Aware Senior Care, kind of who you are and where are you operate and how folks can get in contact with you.

Gina: Aw, thanks. So, my husband Tim and I started Aware Senior Care almost five years ago and it came out of experience of taking care of our dads and wanting, just wanting to do it a better way. Um, it comes from a love of caregiving and that caregivers have to have the right heart as well as the right skills. Um, so we serve the triangle. They can give us a call. We have a website, awareseniorcare.com. We have, you want more information, we're happy to do it. We have skilled, we have tools online to help you see where you are in your journey.

Nicole: Mm-hmm.

Gina: So and you don't have to put your information in. All of that is easily accessible.

Nicole: We're not going to call you.

Gina: We're not going to call you. We'll contact you if you'd like us to. But, but please we have a number of people in our village. We love to support. We're one piece of the pie that helps the seniors and if we can't help you we would love to help you find somebody who can.

Nicole: One piece that is often confusing for people is kind of how these types of services get paid for and so typically private duty in-home care is a private pay scenario?

Gina: Right and unless the client has purchased long-term care insurance and qualifies under their policy. So, if they do have long term care insurance we can file everything and, and take care of it that way. But, typically it's private pay.

Nicole: And folks can receive this care literally around the clock if needed?

Gina: We do, we take care of folks 24/7.

Nicole: Awesome.

Jason: That's great to know. Again, that website awareseniorcare.com, awareseniorcare.com. The phone number (919) 436-1871. (919) 436-1871. Gina Murray, Founder and Director of Aware Senior Care, thank you so much for coming in this evening.

Gina: Well, thank you for let me be here.

Jason: Absolutely, it's our pleasure.

END 20:21