

Aqualyn Kennedy:

I was a freshman at Spelman College. It was Friday, September 28th. I was walking across campus when I felt a "Pop." I wasn't sure if it was a pop or I made it up, if it was a bone popping in my arm, leg, what have you. But I knew something had happened and I noticed that everything looked a little bit different. Like kind of glassy, so I walked to my first class, which was a computer class. We were standing outside. The doors had not been opened yet, and I tried to ask someone, "Why are we standing outside?" Because I wanted to know why we weren't in, it was almost eight o'clock. They didn't understand me, "Excuse me?" "Why are we standing outside?" "Excuse me."

Aqualyn Kennedy:

Finally, I realized, when I listened to myself. I sounded like this ... Nothing was coming out. I ended up spending the whole day trying to hide it because I'd never been sick a day in my life. I went through classes, I took a philosophy test. I did all kinds of things until the next day my roommate convinced me to go to the doctor, sent me to the hospital, and the hospital that I went to did not have a neurologist on staff and sent me home. So I waited for two days before I actually was seen. I then was diagnosed with a stroke and within four days I had open heart surgery to remove a myxoma, which is what caused the stroke.

Carey Pena:

The COVID pandemic has made matters even more difficult for many stroke survivors and their families, especially financially. You just heard a powerful story directly from heart attack and stroke survivor, Aqualyn Kennedy, who knows firsthand what it means to be confronted with financial and health challenges simultaneously. Stroke can already be financially devastating. It can cause stroke survivors of working age to be disabled and unable to return to work. According to a survey conducted by the American Heart Association, American Stroke Association, nearly 43% of stroke caregivers said being a caregiver had significantly affected them financially. Family caregivers also report spending \$5,531 out of pocket in annual direct costs for such items as assistive devices, modifications to the home, and more. Now, add on top of that COVID-19, which may be causing stroke survivors or their family breadwinner to lose their jobs or income as a result of the drastic actions that have been needed to slow the spread.

Carey Pena:

Hi, everyone. I'm Carey Pena and here's a power bite of what you'll learn in today's show, financial challenges posed by stroke and COVID-19. You'll hear more from Aqualyn Kennedy about her journey to physical and financial health. Plus, we'll be joined by Sharon Epperson, a CNBC senior personal financial correspondent and a stroke survivor. You'll hear from them both about what stroke survivors and their families can do to endure a financial crisis.

Carey Pena:

If you don't currently have health insurance, what can you do to get it, and what other kinds of assistance may be available to help patients and their families? But first, Aqualyn Kennedy had a stroke at age 18 as a freshman at Spelman College. She's confronted financial challenges as a result of her stroke and two subsequent heart attacks. She's become a passionate advocate for helping to provide stroke survivors and others with preexisting conditions with the financial security that health insurance provides. Aqualyn, thank you very much for being with us today.

Aqualyn Kennedy:

Thanks for having me.

Carey Pena:

Emotionally, what was that like for you?

Aqualyn Kennedy:

Terrifying. I'd never been sick a day in my life. My mind was just racing the entire time trying to figure it out for myself because I realized I couldn't communicate with anyone. Even writing was difficult. It was a very, very scary experience. But what I will tell you is, by the time I got to the hospital, it was Emory that actually ended up diagnosing me. I'm so thankful for Emory, but within an hour they did a number of tests. They diagnosed me and I finally had a name for it. I finally had a feeling that, "Okay, there is something that can be done to fix this," and I was thrilled.

Carey Pena:

Were people around you, your friends and family, shocked? Because you were so young.

Aqualyn Kennedy:

Yes. Everyone was extremely shocked. They didn't understand, neither did I, how this could have happened. There's only one person who wasn't terribly shocked, and it's my grandmother. My grandmother, unbeknownst to me, and I don't think most [inaudible 00:04:43] family knew this, she was the youngest of 10 and all of her siblings had died of strokes. So at that point when my grandmother heard that I'd had a stroke, she immediately connected that it was something in our family, but we never knew what it was. We just knew it was a stroke. We found out later it was related to lupus, and so that's what I ended up being diagnosed with.

Carey Pena:

You are such a fighter and I understand that often on since you had your stroke, you've also been forced to go without health insurance. Can you talk a little bit about the financial security and peace of mind that the insurance obviously provides?

Aqualyn Kennedy:

Oh my goodness. It provides so much peace. I will definitely say, at that time I was a freshman in college I was on my mother's insurance, which was great. My whole goal after that moment was, "Make sure you get a job when you graduate that has wonderful insurance." That has been my top goal throughout my life. It's making sure I have health insurance. But however, I went to business school and during that time I was on the school's insurance, which was fine. I started with a company, Proctor and Gamble, which was great. Then I started my own business, and that was the time that I actually had the experience of, "What do I do about insurance?" This was in 2006, so this was before the Affordable Care Act, but there was a lot of interest and research going into healthcare reform and what we needed to do. So it was kind of in line.

Carey Pena:

Aqualyn, I would wonder, how has your experience suffering this unexpected crisis as an 18-year-old having a stroke, how has that helped you to prepare yourself financially for the financial crisis that COVID is causing so many people?

Aqualyn Kennedy:

It's been unfortunate, but it has been so eyeopening. I will definitely say, and I think anyone who has lost a capability or what have you. For me, I lost my speech, I lost feeling in half my body. I think when you lose that, you really start to recognize how important these things are. So coming forward to, "How do you stay prepared," as I mentioned before, my goal was always I have to have health insurance. Even outside of that, "What other kinds of insurance or what other kinds of support can I have so that I'm not a burden to the people who love me and who are around me?" Some of those things have included, I've had great jobs, I've always had my health insurance, I've always had my life insurance. One of the things that I had never thought about before, but as I learned more was, our life insurance at work doesn't typically go with you when you move to the next job.

Aqualyn Kennedy:

And so, we don't really think about, is that life insurance portable? Because what I'm not realizing and what I didn't realize at the time was I'm really not attractive to insurance companies. [inaudible 00:07:35] already I learned that, I didn't know that about life insurance. I didn't know that about other types of insurance. So those are some things that were very important. I think when it comes to COVID, being a preexisting condition from the time I was 18, we don't know how insurance companies are going to look at us if we've been effected by COVID or not. We don't know enough about it and it's very concerning. And so, that's one of the things I talk about with my clients today is, "Make sure you have something because you don't know what's coming down the road."

Carey Pena:

Let's talk a little bit more about the advice that you have for stroke survivors and their families to help them endure the financial challenges they're faced with.

Aqualyn Kennedy:

Sure. Well, one of the things is, knowing your family history is my takeaway or the thing I like to leave behind whenever I tell my story and do any kind of speaking engagements is, I had no idea that my grandmother was the youngest of 10 and all of them had strokes. Had I even had a clue about a stroke, then when that happened I may have at least ... It may have like, something had clicked and said, "Oh, you need to go get some help. This is not something you can fix on your own."

Aqualyn Kennedy:

It's pretty significant to understand your family's history and what the propensity is for certain types of diseases and whatnot, and in keeping that in mind, making sure that, okay, when you have children born into the family, things of that nature and you know what's in your family, you know what you tend to pass away of, to plan ahead of time. When you look healthy and when things look good in your labs, then you are relatively attractive to insurance. We are all going to pass away of something one day and there's no reason why you should be a denied like I am because they know what this is likely going to be.

Carey Pena:

We're going to turn to our expert here in just a moment. But before we do, I'm just amazed by your story. Can you just talk very quickly about where you get your strength?

Aqualyn Kennedy:

God, that's a really good question. That's a really good question. I draw on the Lord, and I drawn people that he places in my life and the people whose hearts are in the right place. I'll tell you, my heart is with the American Heart Association and the American Stroke Association. When I decided to start my own business, the reason that I started was because I felt that I was supposed, I had a story and I was supposed to get the story out. Hopefully, it helps people. Hopefully, it inspires them or helps them seek out their answers. But I felt that it was, when you think about that purpose-driven life, I felt that this was part of my purpose, to try to bring that forward and I haven't looked back.

Aqualyn Kennedy:

I have definitely suffered a lot, but in my suffering, God has always been there and he's always led me through these things. I do believe the reason I'm come out is because he knows I'll talk about it. I am happy to testify and I am happy to share whatever I know and I'm happy to listen to people when they go through their situations as well. I find the biggest challenge has been, I can make it through all of these things, but I tell you, that whole financial situation is just a pain. However we can make it easier and just be more informed about it, the better. That's why I'm doing what I'm doing now.

Carey Pena:

Aqualyn, I thank you so much for sharing your strength and your story with all of us. Now I want to turn to Sharon Epperson, a CNBC senior personal financial correspondent and a stroke survivor. She's an award-winning journalist and writer who can be seen regularly on CNBC Television and as a contributor on NBC's Today, NBC Nightly News and so much more. Sharon covers the many facets of how people manage, grow and protect their money. Sharon was 48 years old when she began experiencing the worst headache of her life while exercising in September of 2016. She was suffering from a stroke caused by a ruptured brain aneurysm. Fortunately, she experienced a full recovery and had also prepared financially for a crisis and was therefore able to weather the 13 months she spent recovering and unable to work. Sharon, thank you so much for being here today.

Sharon Epperson:

Thanks so much for having me.

Carey Pena:

Can we start with that, just your experience? Have you done since your recovery?

Sharon Epperson:

Well, my experience, similar to Aqualyn, I was completely healthy or so I thought. I had no idea that I had a small balloon that had developed on one of the key arteries in my brain that, when I was exercising one morning before going to work, it just burst. I've had the worst sensation that I've ever had in my head and knew something was wrong. I immediately contacted my husband, who came to pick me up from the exercise studio, but he took me home. Now I know I should have gone straight to the emergency department, but he took me home, told me to put my feet up and tell work I wouldn't be coming in until I felt better, but I didn't feel better. And so, he took me to a primary care physician who thought about the worst case scenario of what could be going on with me and suggested I get an MRI at the local hospital.

Sharon Epperson:

That showed that I had bleeding in the brain, and that showed I was having or had had a hemorrhagic stroke. From there I went to another hospital for emergency surgery and was out of surgery before midnight that same day. So from 9:00 AM to probably about 9:00 PM on one day, my life changed forever and the person that I was before went away. I had to spend several weeks in the hospital in ICU, not walking, not being able to sit up. I had to learn how to walk again, how to speak and communicate effectively, how to balance a checkbook for financial journalists. That's a very important thing to be able to do, and it took me about a month in hospitals to recover, but several more months of recovery at home. I think it's an ongoing process.

Sharon Epperson:

I think Aqualyn would agree that being a survivor of a stroke or a heart attack, yes, a survivor from that and your surgeons will say that you're completely healed, but there's a long process to recovery. It's not a several months process. It's not even sometimes a several year process. It's a lifelong process. That's for your your physical health as well as for your financial health.

Carey Pena:

Well, as you just described so eloquently, you are a survivor. I'd like to talk about the recent steps that have been taken that stroke survivors should know about that can help protect them financially.

Sharon Epperson:

Well, let's start with what can help you cope financially. One of the things that's going to help you cope or help many people who are fortunate enough, and I say fortunate because it's not always easy to qualify, to get social security disability insurance and to get supplemental security income, you are automatically going to get a \$1,200 check coming from the IRS into direct deposit into your bank account or to your address wherever you get federal benefits. That is something that many people have been advocating for and wondering, "How's that going to happen? How am I going to qualify? When will I know?" Those checks and those payments should start being made this week or next week.

Sharon Epperson:

One of the things to keep in mind is that if you want that payment quickly, you need to go to the IRS website and look at the non filers form there to put in your bank information to make sure you get that information. If you have a spouse or a partner who is not getting SSDI or SSI but you still have the qualifications based on income, which is for individuals under \$75,000 and for married couples under \$150,000 to get a full payment, then you need to fill out that information so that your spouse will be able to get that payment of \$1,200 the full payment for an individual as well. But that is going to come to you directly, so that is something that's important to know.

Sharon Epperson:

The other thing that is important to know is that there have been some really important changes to Medicare. Go to medicare.gov and see all of the things that are listed that are covered. One of them that I think is great and I use quite often is Telehealth. If you have access to be able to reach a medical provider online, you can do it by the phone. It's going to be covered often by your insurance if you are covered by insurance or by Medicare. That's something to really take advantage of at this time when we're all sheltered in place and we need to check in with our medical providers. This is not the time, again, it's a long process. This is not the time for survivors to stop seeing and being in communication with their doctors, their therapists or anyone that is helping you with your care. This is the time to stay

in close contact to make sure that you're hitting the targets and doing what you need to do to continue to improve.

Carey Pena:

Sharon, let me ask you, if you don't currently have health insurance, what can you do to get it?

Sharon Epperson:

One of the key things to do is to look at the Affordable Care Act exchanges and the health insurance marketplace and see what's available. Go to [healthcare.gov](https://www.healthcare.gov) and see what may be available there. There are certain things to keep in mind because when we talk about the cost of recovery and cost of surviving a stroke, we're talking about ischemic stroke care, estimated \$140,000, and hemorrhagic stroke care, even higher than that. The direct cost to a patient can be \$8,000 on average, but often can be even higher than that. So that's important for people to understand and to know that there is help available to you, but you do need to access if you can, the marketplace and also find out if there are other types of plans that you may qualify for. If you qualify for Medicaid, if you qualify for the children's health insurance plan, if you have dependents. There are a range of things to look into, but I think the first place to go is [healthcare.gov](https://www.healthcare.gov) and see what may be available to you in your area and what you qualify for.

Carey Pena:

If you've lost your job and your health insurance coverage during the crisis, you are eligible for a special enrollment period through [healthcare.gov](https://www.healthcare.gov) or your state's health insurance marketplace. Can you talk a little bit about that?

Sharon Epperson:

Yeah. The 22 million Americans over the last several weeks that have applied for jobless claim benefits, that doesn't tell the full story of how many of those people really are in desperate situation, because they're now also not able to get any insurance from their former employer. So what's key to know is there is a special enrollment period with the health insurance marketplace. It only lasts for 60 days, but it will help to make the premiums, the idea is to make the premiums for your health insurance more affordable. If you think you're going to lose your job, if you've been furloughed, if your hours have been reduced, if your pay has been reduced, and I think many people feel that they're on shaky ground, even if they are fortunate enough to be working, then you can still apply for this special enrollment period because you don't want to have any gap in coverage.

Sharon Epperson:

So sign up now and find out about ... Bookmark these places, find out, know where they are so that you're not one of those people that is last in line to try to sign up and get these things done. The other thing that you want to look at is, again, whether or not you would qualify for Medicaid. The one thing that you may not want to do is to take advantage of extending your current job insurance benefits through Cobra, because Cobra can be very expensive. So it may be less expensive for you now to look into what you can do with this special enrollment period through the health insurance marketplace. Again, everybody's situation is going to be different, but know that if you continue the employee benefits that you have for healthcare coverage that might be quite expensive and you are going to have to pay that on your own.

Carey Pena:

Let's talk for a moment here about what other kinds of assistance may be available to help patients and their families.

Sharon Epperson:

You want to look at what you can do in terms of prescription drugs, what kind of pharmacy discounts and things that you can get. Places to look, like medicineassistancetool.org or rsassist.org or places to go. You also just want to simply look at your local pharmacies, the Walgreens, the CVS. I love coupons, and anytime I see a coupon for my local CVS, I bookmark that, put that into my account on my app and make sure that I'm never going to be purchasing anything, or I try my best not to, that doesn't have a coupon associated with it. So wherever you're doing you're getting your prescriptions from, whether it's Walgreens or CVS or another pharmacy, see if they're also discounts there that you can take advantage of.

Carey Pena:

Well, you're a financial expert for a reason so the coupon thing makes perfect sense. Can we talk about what kinds of other steps should stroke survivors and their families consider right now to help them weather future emergencies? Because you, obviously, are someone who has been really good about planning ahead.

Sharon Epperson:

Well, in terms of in terms in future emergencies, I think the most important thing to do is save, save, save as much cash as you can and have that on hand. I think that this is a time where if you are fortunate to be working right now and fortunate to have a savings plan at your job for your retirement, 401(k), a 403(b), that's wonderful. Put money into that regularly and you don't have to think about it, it comes straight out of your paycheck. But now may be a time that if you don't have emergency savings, if you don't have cash savings, that you dial that back just a little bit to make sure that you're starting to develop an emergency fund of least three to six months worth of your living expenses. You may want to have even more than that in there. I think this unexpected COVID-19 has highlighted how important it is to have that emergency fund. I think Aqualyn and I haven't gone through our experiences, already had an unexpected experience that was financially destructive to us.

Sharon Epperson:

So we know that you need to have that money, but it's important now to focus on how you're going to do that and get the discipline in doing that. Having that taken automatically from your paycheck, putting it into a high yield savings account, an online savings account, not associated with where your checking is so that you're not tempted to dip into it, that's the best way to really develop that discipline and to save that money. The other thing that I would say that's really important to do is something that Aqualyn mentioned. That is to have the family talk. I think the money talk is something that people find very uncomfortable to have, but now is a time, where we're all in a different financial situation than we ever thought we would be. There is no shame. There is nothing wrong with being humble and admitting where you are to your family members. I have a 14-year-old and a 17-year-old, so I'm including your children and I think even toddlers can kind of understand needs versus wants versus, "You just can't have that today."

Sharon Epperson:

This is the time to have that conversation, have that conversation with older parents as well. "What have you done? Do you have a will? Do you have estate planning documents?" "What? What are you talking about? I don't have that." We need to have that conversation about what is happening because, like Aqualyn, I also had several instances of hemorrhagic stroke in my family. I'm the fourth generation to have had a hemorrhagic stroke and the only person to survive. If I had known that my great, great grandfather, my grandfather and my aunt all suffered from a hemorrhagic stroke, I probably would have maybe thought about being tested, thought about having an MRI. I'm vigilant about making sure that I take care of myself to prevent breast cancer or try to and have my mammograms and my ultrasounds. I should've done the same with my brain and I didn't think about that. So it's important to have the talk about your family health history, as well as your family financial history, and let's not romanticize it. Let's be real with one another about where we stand so that we know where we need to go in the future.

Carey Pena:

What about for those who haven't had a stroke but want to be financially prepared in the event of a significant medical event? I mean, as you guys have both talked about today, you ladies have explained that neither of you were expecting what happened. That could frankly happen to any one of us at any time, so what do you say to people who've not walked in your shoes but might be thinking about, "How do I plan just in case"?

Sharon Epperson:

Two aspects of planning that are critical and were critical for me. One is having disability insurance. You are more likely when you are working to become disabled than to pass away. I quoted that statistic time again during my career as a financial journalist and then it happened to me and it was so true. So that money that I thought, "Why am I putting this money into disability insurance? Why am I paying for a private disability insurance policy on top of what my employer is offering so that I have something that," as Aqualyn said is portable, that will be mine no matter where I am, "why am I paying this money?" Well, let me tell you. Not working for 13 months, that disability premium and that coverage saved my financial life.

Sharon Epperson:

So it's very, very important to have disability insurance and to pay for that. You're not going to maybe get the terrific TV that you want, the home remodel that you want, this is something you absolutely need to factor into your budget. So get longterm disability insurance. The other thing that I would say, and this is really, really painful and very difficult for people now who are dealing with loved ones who are in the hospital and need medical care, you need to have certain estate planning documents. A will, no one wants to think about it, no one wants to talk about it, it's important to have.

Sharon Epperson:

It's important to name guardians if you have minor children, but what's really critical for people right now who are being hospitalized and by themselves, no family members going with, no friends going with you, you need to have a document that says what your wishes are. What do you want? Do you want to be resuscitated? Do you want to be intubated? Is that something that's not something that you would want to happen? Do you want to be resuscitated? Those things can be in a living will and in a healthcare proxy that you can assign a person to make those decisions for you so that the hospital doesn't have to try to find a family member or a friend to be in touch with, but you've already

designated who that person's going to be. So you need to have that living will about your wishes. You need to have the healthcare proxy to designate someone to carry those wishes out.

Sharon Epperson:

Then, you also need to grant someone that you trust your financial and legal power of attorney, your durable power of attorney to make those financial legal decisions for you. I think those things are something that everyone should have, especially now. Even though, again, we're at home, we're sheltered in place, we can't go to a notary, we can't necessarily find a witness, there are many states that are now allowing you to do all that online, through video. So there are places that you can go starting with just going to a website, like ARP has good information about that, about where you can go to get these documents online for free and get these documents in place. Because you never know what can happen and you're hoping you're not hospitalized during this time because of complications with your stroke or anything else. But if you are, you want to make sure that the person that you want to make those decisions for you if you're unable to do so, is that person that is going to make the decision.

Carey Pena:

You shared so much excellent information. Just before I close things out here, I'll just ask you on a personal note, I know you have this incredible career as a financial journalist, you've gone through your own personal struggles. So many people are afraid right now and I know you all hear from them at CNBC, from your viewers, and you have an incredible following. What words of inspiration could we take right now? I just think there's so much fear out there.

Sharon Epperson:

Right.

Carey Pena:

What can you tell people about staying inspired and forward thinking?

Sharon Epperson:

Like Aqualyn, I think my faith trumps fear every time. That is what guides me every single day. But very practically what you can do is focus on what you can control. There is much out there that you cannot control. No one expected COVID-19, and I shouldn't say that. Very few of us expected COVID-19 to occur. Aqualyn and I had no idea that we were going to suffer a stroke, but it happened. But what we were able to have in place, her mother had a great insurance policy, a medical insurance policy that helped her when she was 18. She knew too as an adult, have proper insurance, for when she was a heart attack survivor. So it's important to make sure that you look at these things that went by the wayside for so long. Now we have time to focus on it.

Sharon Epperson:

Now is the time that we need to think about what our legacy is going to be. Not because we're so afraid of contracting a virus passing away. No, because we want to have a legacy of financial strength. To do that, you need to focus on what you can control. You can't control the financial markets. Those are topsy-turvy every other day, and so what you can control are things like your insurance policies, things like how much money that you put into cash savings and things like the documents you need to have in

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place to make sure the loved ones and the people that you trust and care for are the ones that are going to be caring for you and making decisions for you if you're unable to do that.

Carey Pena:

Sharon, thank you so much for spending some time with us.

Sharon Epperson:

Sure.

Carey Pena:

I really appreciate your words today of information and empowerment. Aqua Lynn, we thank you very much. Continue doing great things out there, we know you will. To all of you for listening, thank you so much for joining us. Please remember to share this entire stroke and COVID-19 series with someone who needs it. Wash your hands often, stay home as much as possible and learn more at stroke.org. Or you can call our stroke warm line at 1-888-4-STROKES. That's (888) 478-7653. I'm Carey Pena. Thanks for listening.