

**NEVER STOP LIVING: The Adaptive Community Theatre**  
2017-2018

*(opening music)*

**Tanisha:** The Adaptive Community Theatre launched in the Fall of 2017.

**Christina:** During this time, UCF volunteers met with participants at the Aphasia house.

**Danielle:** Aphasia is a disorder that results from damage to parts of the brain that control language and speech.

**Sharon:** Many, though not all, of the individuals at the Aphasia House are survivors of stroke.

**Anjel:** The volunteers spent time getting to know the people at the Aphasia House and learning about their lives.

**Tommy:** Their stories were written into this play, along with the reflections from the volunteers about their own experiences.

**Annette and Chitra:** These are our stories.

**PART ONE: HOBBIES**

**ALL:** Part One: Hobbies.

**Voiceover:** The speech generating device (SGD) allowed me to learn a lot more about Jack. It really empowers him. I learned about his family, stroke, education, career, likes and dislikes.

**Jack's SGD (Danielle):** Barbara is my wife.

My daughter Amy is an attorney for the FBI in Washington DC.

Mark is my grandson. He is 13

Jason is my 2nd grandson. He is 10 years old

**Voiceover:** Jack uses his speech generating device to tell jokes, but after each punchline Jack says out loud: "Jesus! Oh!"

**ALL:** These are a few of his favorites:

**Jack's SGD:** Why is there a gate around cemeteries? *(pause)* Because people are dying to get in.

**Jack (Tommy):** Jesus! Oh!

**Jack's SGD:** What do you call a waffle in the sand?*(pause)* Sandy eggo.

**Jack:** Jesus! Oh!

**Jack's SGD:** What did the man do to stop farting? *(pause)* He ran out of gas!

**Jack:** Jesus! Oh!

**Voiceover:** Jack's subtext is rich and his intellectual presence is apparent.

**Tanisha:** Ginny loves eating at restaurants. Her favorite is First Watch. She also loves going on the computer,

**Christina:** hanging out with her friends,

**Danielle:** Taking pictures and

**Sharon:** Watching movies.

**Anjel:** Jill played the oboe in marching band and went on to become the drum major. She loves different kinds of puzzles, whether it be Sudoku or Crosswords or regular puzzles. She loves to read, especially fiction.

**Tommy:** Tom spent a lot of time being involved in sports. He was a quarterback at FSU as a student there and continued to be involved in sports like baseball, basketball, football, and weightlifting (he could lift 225!) He even hit a homerun when he was 47 (before his stroke).

**Christina:** Annette has many interests, and was eager to tell us about them and share pictures of her crafts and garden.

**Annette:** I enjoy gardening, cooking, and eating.

**Christina:** Spaghetti is her favorite dish.

**Annette:** Craig and I have tomatoes, beets, carrots, and pineapple in our garden.

**Tanisha:** Chitra's garden is all flowers.

**Chitra:** My favorite flowers are roses.

**Danielle:** Religion means a lot to Dave. He thanks God for letting him live through his accident.

*(lights shift)*

**Dave (Sharon):** I didn't have a stroke -- I was in a motorcycle accident when I was 27. I asked my friend to borrow my bike after work, and I fell while riding it. I was in a coma for two weeks. Now I have apraxia of

speech; I understand what people say but I have a hard time finding and formulating the words to respond. I gained 100 pounds after my accident; but lost it all this year! I just turned 34 years old.

**Danielle:** One of the clearest ways in which David physically communicates conveys his love for God. He kisses his fingers, points toward the sky, and smiles.

***(All demonstrate.)***

*(lights shift)*

**Theo's Wife (Anjel):** On July 22, 2010, Theo turned 40 yrs old. As I gave him a kiss goodnight, I laid my head on his chest and noticed he was getting congested. I remember telling him he couldn't get sick because I had a big party planned for him Saturday night. Little did I know, it was too late. By Saturday, Theo had a fever of 103. On Sunday, his fever was up to 104. He didn't want any medicine and wouldn't let me take him to a doctor because we didn't have insurance. I was going to the store and wanted to bring home stuff to make him homemade chicken noodle soup, but he said no. I left, went to the store & came back home. When he was helping me put the groceries away, he said, "I thought you were going to make homemade chicken soup". He had no recollection of the entire conversation we had. By that night, he was stumbling when he came to bed. I was still not sure how bad he really was at that point.

*(lights shift)*

**Jill (Christina):** I don't remember having my stroke.

*(lights shift)*

## **PART TWO: FAMILY**

**ALL:** Part Two: Family.

**Voiceover:** Jill is a really wonderful lady. Jill definitely dedicated a lot of her life to her family, specifically her husband Jim.

**Jill (Christina):** I love my husband, Jim, very much. It is my goal for both of us make it to our 90s. I also has a cat named Pepper. Pepper usually sleeps under the bed but went missing one day. Jim and I noticed our back door had a hole in it. After searching for a long time, we ended up finding Pepper in our guest room.

**Voiceover:** She told us the story of Pepper disappearing a few times, which according to her worker, May, meant she was tired.

**Sharon:** Jill has daughter that lives in Seattle.

**Anjel:** Annette has an amazing husband, Craig, who takes her everywhere.

**Annette:** He was patiently waiting while we conducted our interview.

**Anjel:** Craig has a three-wheeled motorcycle and a hot rod he enjoys working on. They also have two grandchildren.

**Tommy:** Dave has a cat named Calle. His family lived in Puerto Rico; Dave was born there and then moved to the mainland. His mom helps him, and he loves her a lot -- he fake cries when she leaves.

**Anjel:** He doesn't rely on his mom,

**Anjel/Tommy:** she just helps.

**Tanisha:** Chitra has two children,

**Chitra:** A boy and a girl

**Tanesha:** And two granddaughters. Her husband passed away from cancer.

**Christina:** Ginny has two grandchildren named Cameron and Sammie.

*(lights shift)*

**Ginny (Danielle):** I suffered a stroke in May 2007 and developed Broca's Aphasia. Broca's Aphasia is a condition that makes it difficult to read, write, and speak. But I don't let it get in the way of doing the things I want to do.

*(lights shift)*

**Theo's Wife (Anjel):** Monday July 26, 2010, I got up to go to work and woke him up before I left to take his temperature. It was 105! I called 911 for an ambulance to come help me. By the time the ambulance got there, Theo's vitals were ok, but he still had a fever and was pretty much unresponsive. It appeared he had a stroke. After we arrived at the ER and had a series of tests, then the waiting game began. If there was an "ologist", Theo had it. If there was a test with letters, they did it. Still no answers could be found. They had tubes everywhere they could put a tube. Theo had to be strapped to the bed because he kept trying to pull the feeding tube out of his nose. We waited 5 more days not knowing what was wrong and how to get Theo better! On Tuesday, the Infectious Doctor came in and told us Theo had West Nile Virus that caused Encephalitis. The swelling put pressure on the part of the brain that controlled his motor skills and he was basically an infant in a 40 year old body.

*(lights shift)*

**Cindy (Tanesha):** My first stroke was in 2001 and my most recent stroke was in 2008 on New Year's. I was able to go back to teaching after my first stroke but was unable to after my second. I developed Anomic Aphasia which makes it difficult for me to express my words. I know what I want to say, it's just hard for me to say it. I work on workbooks for spelling and vocab to help me with my aphasia. Being a teacher has really helped me with my Aphasia.

### **PART THREE: CAREERS**

**ALL:** Part Three: Careers.

**Danielle:** Cindy studied at Kent State University to become a teacher. She taught for nine years before she had the first of three strokes.

**Sharon:** Theo was a new construction plumber when the downturn in the economy inspired him to change careers and become a chef. In May 2010, Theo was hired by Hilton Garden Inn as a chef. The restaurant had previously received bad reviews for service and food quality. Under Theo's leadership, they completely turned the reviews around. People raved about Theo's cooking!

**Anjel:** Jack got his doctorate degree in Biology at Oklahoma State. He was a professor and assistant dean at UCF

**Tommy:** Prior to her stroke, Annette worked for 15 years as a waitress at Denny's, and also at Longhorn Steakhouse for three years.

**Annette:** I worked the day before my stroke.

**Danielle:** Dave was a break dance instructor for kids.

**Tanesha:** Chitra was a secretary in New York

**Chitra:** And in Florida.

**Christina:** Tom was born in Queens, New York but moved to Miami, Florida when he was about 5 where he stayed until he left for Florida State after turning 17. Several years later, he moved to Wichita, Kansas for his position in intelligence and security administration where he served our country for 21 years!

*(lights shift)*

**Tom (Tommy):** It has been 5 years since my first stroke. I had the first stroke 8 months into Iraq. It was not so bad because I began to recover until I experienced the second stroke 2 weeks after the first, setting my recovery back. However, I have made some great improvements since then given that I was unable to walk and talk for some time. Dr. Whiteside helped me come to the Aphasia house and my experience here has been great so far. At the Aphasia House I became very good friends with Larry. Larry is a really great guy and has been a very important part of my recovery.

*(lights shift)*

**Theo's Wife (Anjel):** At one point, the nurse told me they were going to have to do a tracheal tube if he didn't start breathing better on his own. Theo and I talked before he got sick and he made me promise to never let him live by a machine. I didn't know how I was going to find the strength to make this decision on my own. I went into his room and climbed up on the bed. I put my hands on his shoulders and made him look me in the eyes. I said: "You need to take all the fight you have on the outside to the doctors and put it on the inside so you can come back to me! The doctors want to put you on a machine to help you breathe and you made me promise to never do that! Please do not make me have to make this decision; I am too

young to be a widow!! When I got home, I got on the floor of our bedroom and prayed to GOD to give me the strength to accept whatever HIS will was for Theo and to be strong enough to make it through this. Then I climbed into bed and cried myself to sleep. Thursday morning I went back to the hospital and the nurse said: "I don't know what you said to him before you left last night, but he did a complete 180 and is breathing on his own."

## **PART FOUR: FUN FACTS**

**ALL:** Part Four: Fun Facts.

**Voiceover:** Chitra had trouble getting her words out, especially when she had to pause to cough or catch her breath at the beginning of the interview. Her helper reminded her to pause and swallow, and then she seemed to relax more and didn't have as much trouble during the rest of the interview.

**Chitra:** We have a Travel and Food club. We talk about a country and eat food from there, and then have a quiz on the country. I was born in India. My husband and I were married there and then moved to America in 1970. When we talked about India in the Travel and Food club, I brought in some clay figurines of Indian men dressed in cotton clothes that I'd had for twenty-five years.

**Voiceover:** Chitra printed her name for me at the beginning of the interview, and it was very clear in large letters. After that though, when I had trouble understanding what she was trying to tell me, she wrote in cursive.

**Danielle:** Ginny has a daughter named Wendy who was an Olympian in 1992 where she won a bronze medal

**Sharon:** Jill was born in New Zealand, South Island. She moved to England and met her husband

**Anjel:** Dave met Michael Jordan at the restaurant he worked at. He has a sandwich named after him in Miami!

**Tommy:** Tom enjoys Bruce Springsteen's music and considers himself to be his #1 fan.

*(lights shift)*

**Theo's Wife (Anjel):** One of Theo's speech therapists suggested we contact the University of Central Florida as they have a clinic that specializes in Adults that have lost their speech due to illness. We filled out the paperwork and Theo got accepted into the program. He began speech two times a week. Theo fast became a favorite in speech and students from all levels would schedule time to observe Theo's sessions to learn. UCF asked his permission to film him to be used for other classes that didn't have access to the clinical settings. On July 22, 2011, we had a one year recovery and 41st birthday party to celebrate how lucky we are to still have Theo around. Every day is a struggle, but he continues to make progress.

*(lights shift)*

## **PART FIVE: ANNETTE**

**ALL:** Part Five: Annette.

**Annette:**

My stroke.

Hello, my name is Annette.

I had my stroke on April 10, 2004, 13 years ago.

I worked for Denny's for 15 years and Longhorn Steakhouse for 3 years.

I worked 7 days a week.

Craig and I were married Feb 23rd 2004.

I worked before my stroke.

Everything was great.

I just fell over, no warning at all.

Craig had Matthew, my son, call 911.

Best thing he ever did!

We spent 46 days in Florida Hospital, our honeymoon!

The stroke got my right side,

arm and leg,

plus my speech.

I used to smoke,

not anymore.

I was right handed,

not anymore.

Craig was happy I remembered him!

So after 46 days we were on our way home,

with a wheelchair in the trunk.

My world was ready to completely change...

But I had no way to know how much.

I couldn't speak,

I needed help with EVERYTHING!

After my first year home with very small improvement, I started at UCF.

I spent my first 5 years of speech therapy with my clinicians and Mrs. Jane Hostetler.

I knew what I wanted to say,

but I couldn't say it.

I would cry and get very upset.

I had a problem with saying yes and no.

Then I started to write my name with my left hand, it was very very hard to do.

I did it!

At least now I can walk.  
Dr. Whiteside asked me to go to the Aphasia House.  
It's called the Friday's Only Club.  
Now, I'm starting my seven years in the Friday's Only Club.  
We have fun in the group!  
It's an AWESOME group of people in it.  
Craig and I did everything together and still do!  
I'm the same person after my stroke.  
Now it is harder to do everything.  
Patience  
patience  
and patience!  
Now my NEW hobby is to never give up on my recovery  
and never stop LIVING!

## **PART SIX: IMPACT:**

**ALL:** Part Six: Impact.

**Danielle:** Annette is a lively, outgoing, people person. She was used to working hard as a waitress, so it isn't surprising that she worked hard on her recovery too. It's clear that Aphasia House means much more to her than a place she comes to for therapy.

**Tommy:** Cindy told me of her amazing idea where she thinks that a school for people with Aphasia should be created. She thinks that people with aphasia need help re-learning how to do all the things they have trouble with now. It seems that Cindy will always be a teacher.

**Christina:** It was nice sitting down and chatting with Jill. She is a nice lady and from her stories she seems to be a great friend as well. Jill seemed very excited to share things about herself with new people and it was just nice to give her the opportunity to do so.

**Danielle:** I was nervous at the beginning of my interview with Chitra. I'm more of a listener than a talker to begin with, but I had to really focus on listening to what Chitra was trying to say. I felt bad when I couldn't understand and great when I could. Chitra is a warm, caring woman.

**Sharon:** Despite his accident, David really has a positive and bright spirit. He had a smile on his face the entire time we interviewed him, and he played many jokes on us (all of which were fun). I admire his positivity and gratitude.

**Anjel:** Tom served our country for twenty-one years. That's a very long time but I can tell that there is absolutely nothing that can stop him from doing anything.

**Tommy:** I think what affected me most was the fact that Jill does not remember having her stroke. Jill doesn't really let aphasia define her experiences, though. She was very thankful for the opportunity to tell her story, which I think speaks volumes considering many people with disabilities are often sequestered to their own areas and surrounded by the same few people most of the time.

**Tanisha:** After our time at the Aphasia house, it was clear that everyone there has a story to be told. The problem is, most people don't take the time to slow down and listen.

**Christina:** In December, the Adaptive Community Theatre Project shared the first draft of this script with Aphasia house patients and clinicians, and these were some of the responses we received:

**Danielle:** People were amazed at how brave Annette was to share her story.

**Patient (Anjel):** *(to Annette):* You! You! I bow down!

**Clinician (Sharon):** Thank you for portraying our clients because this is what we want everyone else to know about them. We want them to have a voice. A broader voice.

**Tommy:** We were emotional too.

**Volunteer 1 (Danielle):** Afterwards, I said, It made me emotional, I can't talk. When I said that, Dave took my hand and kissed it.

**Volunteer 2 (Christina):** You hear about their lives before and they're kind of like our lives right now, and then they changed so dramatically. It's overwhelming.

**Volunteer 3 (Tommy):** When people meet these individuals, they only see them as people with aphasia, and they don't know their whole life before.

**Clinician (Sharon):** It's amazing that we can represent where they are now. They never gave up. And this a true testimony to the strength that they have.

*(music)*

**Anjel:** Thank you, to the patients of the Aphasia House and the members of the Adaptive Community Theatre Project.

**Tommy:** Thank you to the clinicians who make this work possible.

**Annette and Chitra:** Thank you all.

**Tanisha:** For your stories.

**Christina:** For your vulnerability.

**Danielle:** And for your inspiration

**ALL:** To never stop LIVING!

### **INTERACTIVE DISCUSSION:**

**MODERATOR (Christina):** Thank you for attending today's staged reading of "Never Stop LIVING" by the Adaptive Community Theatre. Before we shift into the second part of our programming, could we please have one more round of applause for our performers?

*Recognize the volunteers who worked with the Aphasia house participants in the Fall by applause.*

*Recognize the clinicians at the Aphasia House by applause.*

*Recognize the patients at the Aphasia House by applause.*

We are so thankful to have the opportunity to bring everyone together not only to hear the stories of these participants, but to dialogue about these stories and today's performance. We are going to take a moment to shift into small groups for these discussions, and we are going to make an effort to ensure that every group has a blend of participants of varying abilities and life experiences. If you are able and willing to separate from whoever you came to this performance with, we would encourage you to use this opportunity to get to know someone new. We are aiming for each group to have roughly 5-6 participants in it.

We would also like to ask for a group of audience participants who are physically able to come on stage to volunteer to join Annette onstage for a group discussion. Don't worry, we won't ask you to perform!

*Give audience members time to break into groups and facilitate as necessary.*

Now, before we begin our group discussions we have a few guidelines we'd like to put forth:

1. Honor Every Voice!: We have a diverse group of experiences and abilities here today. Recognize that some participants may need more time to communicate their thoughts, or may need to communicate in nonverbal ways. Please exercise patience and share the floor with others.
2. Speak Slowly: Similarly, we are with individuals who have varying processing needs as well. Please speak as slowly, loudly, and clearly as you are able.
3. Step in and Step Out: You do not have to answer every question. If you do not have a response, or do not want to respond, you may pass and rejoin the conversation whenever you wish.
4. Listen with Curiosity and Wonder: If someone says something you do not agree with, you are encouraged to consider their perspective with curiosity and wonder, by asking them to further explain their thoughts, or by simply taking the time to ask yourself why they hold this belief.
5. The Learning Goes, The Stories Stay: If someone shares a personal story within your group, please do not share that story with others. We encourage you to share about today's experience, but the stories that are shared belong to those that tell them. Along those same lines, we encourage you to think carefully should you choose to share a personal story, to make sure it's a story you feel comfortable with others knowing.

First, let's take a moment to go around within our groups and briefly share who you are and what brought you to today's performance.

*(Two minutes)*

Now, I'm going to ask three questions. Discuss each questions in your small group, and after you discuss each question, I will then see if anyone would like to share with the whole audience anything from your small group discussion.

1. What moments from the play most resonated with you, and why?

*(Five minutes to discuss, three minutes for volunteers to share something their group talked about with the rest of the audience)*

2. In what ways does today's performance connect with or challenge your views about the ways in which people with physical or neurocognitive disabilities are viewed or treated in our society?

*(Five minutes to discuss, three minutes for volunteers to share something their group talked about with the rest of the audience)*

3. What are the needs of individuals with physical or neurocognitive disabilities, and how can we as a society address those needs?

*(Five minutes to discuss, three minutes for volunteers to share something their group talked about with the rest of the audience)*

Now, for closure, I'd like for you to think of one word that encompasses your experience with today's performance and talkback; for example: Hope or Determination. Take a moment and think of your word, and then let's go around our small groups and share.

*One minute.*

Would anyone like to share the word you said, or a word that you heard from one of your group members?

*One minute for them to share -- probably too challenging to pass the microphone around that quickly so encourage participants to shout it out and then you can repeat it into the microphone.*

Thank you to everyone for participating in today's community discussion, and for attending the performance. We will now move to the plaza to have a short outdoors reception. For those of you that might prefer to reflect on your experience in writing or visually, we will have paper and markers available for you to write or draw your response to today's event. We will also have a videographer circulating the reception if you would like to create a video response as well. Thank you, and enjoy the rest of your day.

Reception notes:

- Hang chart paper with question: What did today's performance make you think?
- Markers
- Videographer capturing responses/photos