

Welcome to YASS!

Bill Monroe – has been to two or three meetings

Gerrit has been facilitating for 13 years

Bill has agreed to “take over the reins”

Bill has a background in corporate training and is going to be a great speaker

Bill is 9 months post-stroke.. June 3rd, basal ganglia stroke

I’m really looking forward to helping with the group

I’ve worked with other groups and this is the best one for sharing resources

Last month I started a podcast about my stroke story

I explore rehab and recovery, one-handed banana peeling

My background is in retailing and marketing

Bill@strokecast.com

I’m really excited and looking forward to working with you all

Gerrit will still be involved with the group!

Any achievements this month??

Steve has ALMOST stopped losing things.

Bill: that gives you more time in your life because now you don’t have to look for things

Steve: I don't know how I accomplished that, but I have a partner that helps a lot!

I still have moments of frustration but maybe I'm getting better at accepting that I lose things.

Bill: It's amazing how much of that stuff is still in our heads, and we just have to find all the information we lost access to

Mike: Sometimes it's hard to tell how much of the changes we experience are age-related or stroke-related. Some things are very obvious, but some times it's hard to tell if I'm just getting old

Gerrit: Well a stroke is nice because then you could just blame your forgetfulness on the stroke!

Mike: Yeah, sometimes it's hard to know if it's age or stroke.

Bill: Yes, sometimes it's hard to tell, but at the end of the day, does it matter? Whatever is causing the trouble, you still need to figure out how to get things done at the end of the day. If you notice a lot of BIG changes, then you should probably go to the doctor, but for smaller changes, it might not matter what is causing the problem.

Mike: I'm wondering because I notice some things my friends go through and it's not the same as what I'm going through, so I have to ask myself, "What's causing this change?"

Bill: It can be hard to tell if a problem is stroke based or dementia based. If you put cookies in the oven and later smell something

burning, then maybe that's a stroke problem. If someone else comes home and noticed the cookies burning, that may be a dementia problem.

-when I got my new car, the technology changed and its harder for me to operate the cars since my hands are not as stable as they were. Now, I have to be more aware of what I'm doing in the car

Other achievements?

-Mike: when the weather seems to get better, I have to drive my car more because its a convertible !

-Whitney: I just finished my second quarter of graduate school! I am getting a PhD in clinical psychology. It is challenging because I had to limit my course load the previous quarter but now I was able to take all of my classes. I noticed my cognitive speed and processing is not the same and I can't take notes like I used to, so having to learn to advocate for myself has been a huge learning adjustment. Learning to advocate has also taught me to want to teach others to advocate for themselves.

-The brain is a work in progress!

-Do you find yourself compensating in school?

-Yes, I do audio recordings now during the lecture. Reading is so time consuming now so I had to learn to take in information a lot differently

-Yes, it's all in the compensation!

-One thing that can be hard is asking for help when we used to be very independent. Sometimes, letting people help is doing them a favor. A lot of people want to help and give assistance and so one thing we can do is accept it and take the help

-Question: Has anyone had any embarrassment or shame about needing extra help? And how do you deal with that?

-In my experience, it is amazing how fast I found going from modesty and embarrassment to then being able to ask for help to go poop!

- I think there are many things that can happen. Shame, embarrassment, anger, but an important thing to remember is we are all part of a community and if we do not take the help, we are making it harder for others to receive the help. We are all part of a community and so this may impact other people.

-Some people equate brain damage to mental illness and so I kept it hidden but then I realized it was an invisible disability. I was later forced to use a rolling cane in public and it was amazing how this physical cue made people more likely to offer assistance. So once I accepted that I need to let my disability show, it made it easier to get help from others. I don't know if I would classify this is shame or embarrassment but I did not want to show vulnerability or weakness.

- I was in the hospital almost a year ago and it was difficult to go to the grocery store. I felt like it was difficult to go back out in the community and so it's just something you have to work your way

through and figuring out how we are going to get through this. We often feel like if we are different from the “herd” people will look at you differently and treat you like a “wolf” and so the hard thing is figuring out that it is okay to be different from the “herd”

-I had my accident at such a young age that there were a lot of things I didn't learn (what to wear, what not to wear). I heard terms like “retard, freak” and I know that I am not those things. I still resent those terms. I know I look different and people need to accept that this is tough. It is their problem not mine

- We are never going to be able to control other peoples reactions or how they deal with these things. It is important for us to learn how to deal with this. We have to remember, this can happen to anyone

-There's a fear that they dont understand that this can happen to them and it scares them to death.

- I think participating in this group has for me, gotten rid of these feelings of embarassment. We all share these feelings and to me, this ameliorated the problem. I was able to meet others who had the same accident that I had, and that helped me.

- I think this had made me become humble. I was at the grocery store and couldn't load my groceries into the car and someone came up and asked if they could help me. This didn't make me feel embarassed, instead it showed me, “wow, there's good people out there”. I don't feel embarassed, to me its like, “hey, I can walk and feed myself and so it's one step at a time”. I find if I get angry or

frustrated with myself, I feel more motivated like “ok, now I’m going to accomplish this.” The more I do, the stronger I get!

- If I go to the restaurant, I can’t cut meat, so I just ask the kitchen and they can do it with no problem. I don’t feel embarrassed at all.

- I volunteer for a medical place and I’ve met a lot of people whose relatives have had a stroke, and I can help people feel less alone.

- there are a lot of people who have strokes. 800,000 people a year, and people are having strokes younger, too.

- asking for help can help you bond with the person providing help.

- and asking can help remove the stigma

- you can use your anger and frustration to help push you forward. I’ve been refused a lot of things (housing, insurance, cars) because of my disability. But if you remember that by refusing you, that person doesn’t get your money, it can help you feel better about giving your money to someone who respects you.

- there are two things you can get stressed out about: things you can change and things you can’t change. If you can’t change it, then there’s no point in getting stressed out. If you can change it, then get to work.

- a few years ago I took a medication that messed with my brain. I started using luminosity and it really helped me to retrain my brain.

- we have a link to luminosity on the website. Sometimes the best way to rehabilitate your brain is to keep it working.

- if you feel like you have an ongoing problem with shame, anger, embarrassment, be sure to seek help from a professional.

Depression is very common in stroke survivors and it makes sense because you've had a major change in your life. Depression can change your whole outlook and make it that much harder to get better from your stroke.

- There are a lot of talented people who can help you!

- Gerrit got a telescope from his brother-in-law in New Mexico. it's huge, so it was in the living room for a long time. I finally took the time to take it into the backyard but I was really having a hard time to figure out how to work with this huge telescope. I built a dolley to help move the telescope around, but I still have a hard time looking through it.

- so I started doing astro-photography, which eliminates the problem of craning to see through the telescope. Now I can move the telescope around, aim it and see through it using a camera, and share the pictures. I can do astronomy now!