

Stroke Patient Perspective

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cerebellar ischemic
12/19/22

October 20, 2023




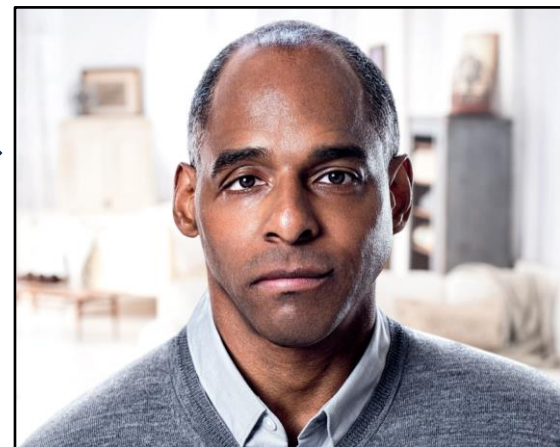
- 53 years old
- Lifelong good health; well-managed BP/cholesterol
- No family history of chronic conditions
- Married 26 years; 2 grown daughters
- Live in Midlothian
- Work in post-acute healthcare services

Disclaimer

Every stroke is different & I was very lucky. I'm here because the healthcare system as a whole both propelled & inhibited my recovery process; I believe there are addressable gaps that could improve outcomes for many people

About My Stroke

- 12/19/22: bolted upright in bed 1:30am
 - Mostly extreme dizziness
 - Had no “airport guy” symptoms 
- Initial CT/CTA negative; 1st PT asked to speed up MRI, which confirmed stroke
- Testing confirmed undiagnosed PFO
- 60 hours in hospital regarded for strokes
 - Wife listened to 14 hrs of Christmas carols
 - “Annoyed my way out” early via self-PT
- Last contact w/hospital was wheeling to my car with discharge packet
- **My goal:** help improve stroke outcomes via better-coordinated post-acute care



How Life is Different Post-Stroke

- **Very lucky in my recovery:** 90% back to normal; expecting long/healthy/normal life with limited impairment
- **First experience with visible disability:** people treated me differently & I found it frustrating. Know what paralysis feels like.
- **First experience with invisible disability:** opposite issue...people treat me as “normal” when I’m not. Deficiencies blur w/life in my 50’s.
- **Work:** changed jobs...was very open about stroke w/former company, but hide it from current company. Learning how to work around fatigue.

Recovery Process Highlights

Q1

- Initial shock
- Rapid progress
- Overly-ambitious

Q2

- Temporary adjustments
- Progress plateau
- Worries emerge

Q3

- Permanent adjustments
- “Daily life is my PT”
- Renewed determination

12+ Post-Acute Providers* ...What Would Have Improved the Process?

- **Like an “Unrehearsed Symphony”**: each provider great at their own instrument, but clearly never play together. *On our own to connect dots.*
- **No preparation**: most providers seemed semi-surprised about my stroke after walking into exam room. *Those appts are a big deal!*
- **Check-box feel**: *Neuro*: checklist approach to first Neuro appt...couldn't ask questions. *Ophtho*: had to ask for my prognosis after 3 hour exam.
- **Appointment headwinds**: Neuro office tried to schedule first post-acute appointment in 4 months. *Who could help fast-track?*
- **No involvement from PCP**: very hands-off at a pivotal life moment. Was my primary for 15 years; shopping for new PCP. *Who quarterback?*



How Was Spouse Critical?

- **Pushed through constant headwinds:** getting appts set
- **Follow-Up:** ensured all instructions followed for meds, PT, etc.
- **Nutrition:** good/regular meals I would never have prepared for myself

Wish We Would Have Known?

- **Less common stroke symptoms:** Googling during & after episode wasn't helpful
- **Aspirin is a no-no:** 911 instructed taking; EMTs administered on arrival

What Gives Me Purpose?

- **Gratitude:** stroke was a “dodged bullet” that fundamentally changed trajectory of our lives; adjusted life plan to now retire at 60
- **Purpose:** got my life back; plan to live well, but help people who didn't

What Would I Recommend to Stroke Coordinators?

- **Assess patient's ability to project manage & problem-solve throughout a prolonged recovery process:** everyone's accountable for their own care, but most would likely shortcut and/or give up without assistance
- **Pre-schedule a 30-day check-in:** help catch problems & dysfunction while there's still time to course-correct
- **Intervene w/providers:** at least within your own health system!
- **Seek clinical "ratings":** only satisfaction survey I received was for food service. Spoiler alert...it was horrible!
- **Offer guidance re: mobility aids:** other than the walker, had to figure everything out on my own (e.g. DME/shower chair, cane, etc)

Thank You!