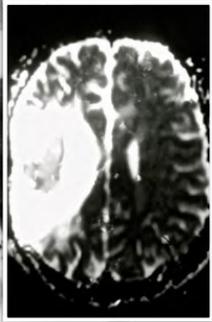
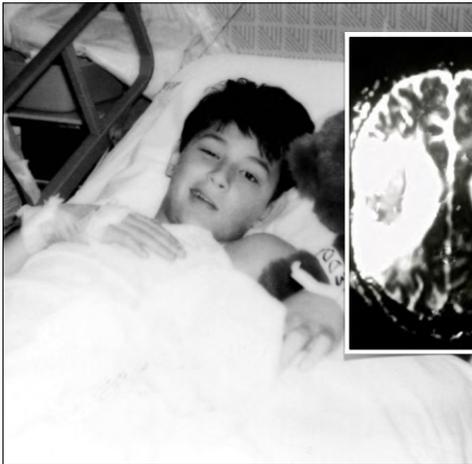




My Recovery From Stroke

David Dow
Age 10



My MRI
1995

“Consider Nursing Home Placement.”

- He can't talk, read, or write
- He doesn't understand commands
- He can't walk
- Right arm paralysis
- Swallowing difficulty
- No bladder control
- Strokes may continue
- DX: Advanced Moyamoya Disease



Global Aphasia Total Right - Sided Paralysis



4

Hospital Neurosurgeons:

“This case is inoperable.”



5



6



Dr. Takanora Fukushima

7

SURGERIES

May
Nov.
1995



EDAMS

(encephalo-duro-arteriomyosynangiosis)
is an indirect method of revascularization.

It combines the technique of EDAS and EMS.

8

- **EDAS (encephalo-duro-arterio-synangiosis)** procedure is an indirect method of revascularization in which the superficial temporal artery is placed in contact with the brain surface. A hole is cut in the skull directly beneath the artery. The artery is then sutured to the surface of the brain and the bone replaced. Over time, angiogenesis results in the formation of small arterial vessels to the brain. The integrity of the STA is maintained; the vessel is not harvested, as in the direct bypass technique.

EMS (encephalo-myo-synangiosis) procedure is an indirect method of revascularization in which the temporalis muscle on the side of the head, is dissected and, through an opening in the skull, is placed onto the surface of the brain. Over time, new vessels form between the blood-rich muscle and the brain.

9



My Pediatrician brought me a gift.

G I Joe Watch

Be a Fighter.

10

Back to School

- One handed & in wheelchair
- Can't read or write
- Can barely say my own name
- I was moved from the gifted program to a classroom with kids with developmental disabilities.
- Kids thought I was "stupid."
- Teachers called me "lazy."
- Lost friends - isolated



11

Psychosocial Issues



- Depression
- Loneliness
- Suicidal
- Hopelessness
- Frustration
- Anger

12



Challenges Are Not Just Aphasia or Mobility

93% of stroke survivors with aphasia experience high **psychological distress** compared to 50% of those without aphasia. Loneliness and low satisfaction with one's social network are particularly important and contribute to long-term psychological distress.
- Hilari et al

13



Psychological Distress

- Affected my well-being
- My coping skills
- My motivation
- My willingness to try
- My outlook of the future
- My life seemed hopeless

14

Why Bother? I was losing the fight.

Recovery was so slow.
4 years post stroke I could write the word, "GO."
I could say 3-5 words at a time.
I could barely read.
Public school was torture for me.

I HATE MY LIFE.
IT IS HOPELESS.

Special School

Brehm Prep School, Carbondale , IL

Started here

5 years post stroke



- Small Classes
- Assistive Technology
- Speech Therapists
- Friends & Leadership Roles

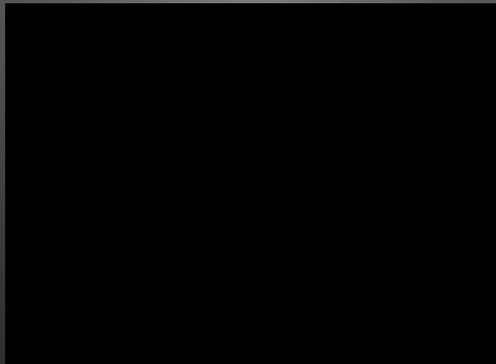
- Found Hope
- Made Significant Progress
- 80 students, 5 Full Time Speech Therapists

16

A video of my journey

17

My Journey



18



There are 3 experts.

The medical experts.
The families living with survivors.
And the survivors themselves.

You need all three legs for it to stand.

(Paraphrased from Dr. Audrey Holland)

Thank you for including me, a stroke survivor, as a speaker.

Next, what are the “take-aways” from my journey?

19

What can be learned? How can patient care improve?

My perspective as a patient.

My casual research online and
in conversations with stroke survivors
and their loved ones.

20

I talked with over 100 survivors and found:

The stories often told of **compromised care**
due to communication barriers.

They often shared they were **confused** about what
happened and next steps.

Surprisingly, *many* shared they were given a 6 month
recovery window...and **lost all hope** after that
point.

21

TAKE AWAYS

22

Take Away # 1 Psychosocial Issues Should Not be Ignored

- They affect motivation
- They affect well-being
- They affect the ability to cope and adapt
- Patient satisfaction increases when staff looks at the whole person - body, mind, spirit

23

Take Away #2 What Makes a Good Professional?

- Talks to the Patient - Looks them in the Eye (Rather than Talking to the Caregiver)
- Listens
- Offers Advice and Insight
- Teaches Patients About the Power of Neuroplasticity
- Offers Patients Resources for Education, Motivation, and Community Resources
- Doesn't Suggest Timelines That Take HOPE Away

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Take Away #3

- As Patient and Family Communication Improve so do Outcomes
- Effective Communication Increases Adherence to Meds, Appointments, and Follow Thru
- Communication is Critical to Patient Safety and Sense of Well-Being and Security as They Adapt to New Disabilities and Changes in Their Lives

25

According to the Joint Comission, 60-70% of patient harm in hospitals is associated with lack of effective **communication and skill set** when dealing with patients with aphasia.

26

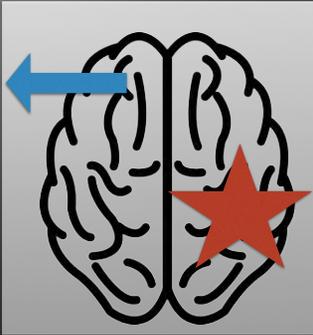
How to Improve Patient Communication:

From patient's perspectives

27

Show What You Mean

Where is it?
How big is it?
What will it affect?



28

Use **SHORT**
simple sentences.

Use gestures.

Emphasis **KEY**
Words



29

Write Down
Key Words or
Diagnosis



30

RESOURCES

34



I wanted to be a doctor
like my dad and brother.

I wanted to make a difference.

35

I couldn't be a doctor because my reading is challenging.
Abstract thought is hard.
Complex information is hard.

But I can still make a difference.

Over the past 22 years
I've met over 4,000 strokes survivors in person or online.

I asked questions. I learned.

I created many **resources**.

I'd like to share them with you.

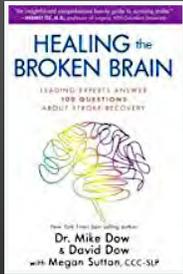


And hope you will share them
with your patients as they put the pieces
of their lives back together.

36

“An insightful and comprehensive how-to guide to surviving stroke.”

-Dr. Oz

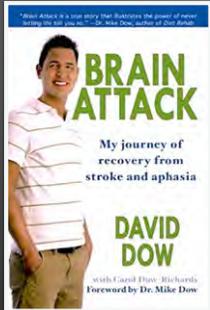


My brother and I interviewed experts with over 100 questions stroke survivors have.



Healing The Broken Brain :
Leading Experts Answer 100 Questions About Stroke Recovery

43



My story.
Tips about aphasia.
What is an MRI?
What is an Angiogram?
What is a Neurologist.

An Easy-Reader
For Patients or Children

Brain Attack: My Journey of Recovery

44



Speaking Engagements

Rehab Institute of Chicago

University of Michigan

Cleveland Clinic

American Heart and Stroke Association

American Speech Language Hearing Association

University of Toledo

Triangle Aphasia Project

45

Featured in..
Stroke Connection Magazine, People Magazine, Topics in Stroke Rehabilitation

46

Optimism
is the faith that
leads to achievement.

Nothing can be done
without hope and
confidence.

- Helen Keller

**Hope
Confidence**

Thank you for making a difference
in the lives of your patients.

They are counting on you for
guidance. For hope. For insight.

Please stop by my table for
information on resources for your
patients .

Or just stop by to say **hello**.

David Dow

48

There is no stop sign on the road to recovery.
