Allison’s Brain
by Robert McMechan with Allison Woyiwada

Brain Injury Association of Canada Annual Conference

Breakout Session “A”
September 24, 2014

Crowne Plaza Hotel
Gatineau, QC
Allison’s Brain

- Allison has been a lifelong musician and retired as public school music teacher in 2008 after teaching for thirty five years
- Bachelor of Music Degree, Brandon University
- Accompanist for Indian Residential School Glee Club and travelled in U.S. playing with “Canada’s Singing Indians” in the 1960’s
Hopewell School dedicated “Allison Woyiwada Wing” when Allison retired from teaching, and “Allison Woyiwada Music Award” is presented annually.
Allison’s Brain

• Performer and music director for Savoy Society of Ottawa for 20 years
• Recognized on many occasions for her contributions to arts, e.g. Whitton Award (1993); Arts Advisory Award for Innovative Programming (1997); Community Builder Award (2000); Capital Critics Circle Award as Best Director (2006-2007); Hopewell School Lifetime Achievement Award (2008)
Allison’s Brain

Allison played flute at a family wedding in the Valkyr Mountains near Revelstoke, B.C. in August 2011

Allison began having *olfactory hallucinations* at around this time.
Allison’s Brain

• Upon return to Ottawa, CT scans, MRI and angiogram, etc. revealed “giant” aneurysm arising from the middle cerebral artery

• 2003 International Study of Intracranial Aneurysms reports there is a 40% chance of a “giant” aneurysm rupturing within 5 years

• Rupture of a “giant” brain aneurysm likely to be catastrophic
Allison’s Brain

As aneurysm was partially thrombosed it was larger than shown. Actual size was the “size of a plum”.
Allison’s Brain

Dr. Howard Lesiuk and Dr. Amin Kassam proposed “clipping” the aneurysm:
Allison’s Brain

- Allison underwent a twelve hour operation at the Ottawa Heart Institute on May 28, 2012
- Surgeons used deep hypothermic circulatory arrest technique → body cooled to 16.5°C
- Allison put in state of “clinical death” for 30 minutes to optimize operating conditions
- Only 2nd operation of its kind in Ottawa
- Risk of stroke or death estimated as 10%-20%
Allison’s Brain

• Dr. Lesiuk says the surgery reminds him of “a successful military campaign” because of the extent of advance preparation and team work.
• Difficulty of surgery was a “9-10 out of 1-10”
• Dr. Lesiuk says Allison “went through as big an operation as anyone can go through”
• Dr. Lesiuk also says Allison “came as close to dying as anyone does without actually dying”
Allison’s Brain

- Allison was kept in a medically-induced coma for 10 days to allow seizure activity to abate.
- Beginning in the Intensive Care Unit there was classical music playing softly close to 24/7.
- Allison’s daughter Marya sang lullabies to her mother in Intensive Care.
- On June 8th for the first time we saw Allison struggle to hold up two fingers on request.
Allison’s Brain

We were told that “every square inch” of Allison was being monitored in ICU
Allison’s Brain

• Allison was moved from Intensive Care to Neuroscience Acute Care Unit on June 13th.
• Occupational Therapist’s Assessment on June 15th noted Allison could move her left hand and move her left toe slightly.
• No right side movement noted.
• By week four Allison was keeping time to music with left hand and mouthing lyrics.
Allison’s Brain

• Physiotherapist began helping Allison to sit up in a supported position in week four
• Speech therapist explained that “re-orienting” Allison was important, so she might re-gain an understanding of what she used to know
• Allison lacked “right side awareness”
• Tried 4 piece zebra puzzle unsuccessfully on June 22\textsuperscript{nd}, but always liked listening to music
Allison’s Brain

- Lotsa Helping Hands electronic platform was set up in late June → fantastic free resource
- Friends could schedule their own Hospital visits at times that were shown as available
- Allison often interacted with visitors over summer months, but has no recollections
- Began eating Hospital food in week 5 but had forgotten the niceties of eating with cutlery!
Allison’s Brain

• Allison moved out of Acute Care into the Neuroscience InPatient Unit in late June
• Allison was fitted with a helmet in late June because her skull had been left open after surgery to accommodate brain swelling
• Also in late June physiotherapist got Allison to take a few steps with a walker while supported by physiotherapist and assistant
Physiotherapist says Allison rammed her walker into everything she could as she was beginning to re-learn to walk at the Hospital
Allison’s Brain

• As Allison’s strength grew, she had to be restrained when no one was around, as she would take off her helmet, and often be found on the floor beside her bed or her wheelchair.

• Rehab doctor did an assessment on June 28th.

• Doctor’s notes say: “Draws a face when asked to draw the face of a clock. Recalls 0/3 objects. Ø insight into recent surgeries.”
Allison’s Brain

On June 30th Allison got her trach out and we were able to take her outside for the first time.
Allison’s Brain

- Speech therapist tried cognitive testing on July 6th, but Allison’s attention span was too limited.
- In a rare moment of lucidity, out-of-the-blue, Allison asked if I had been checking her email.
- This was cause for cautious optimism → Dr. Lesiuk explained that people recovering from brain injuries will typically settle over time “at their peaks rather than in their valleys.”
Allison’s Brain

• Allison next had several setbacks caused by infections / medication difficulties and in July returned to the Acute Care Unit

• Memory remained problematic and Allison could not recognize photos of our house

• Most days Allison knew her own name, but not the month or the year or my name
Allison’s Brain

• Allison moved back to Neuroscience InPatient Unit in week twelve
• Allison was speaking a lot by this time but we usually didn’t know what she was saying
• Marya began doing dictées with her mother and I did simple iPad exercises with her
• Marya also posted a daily events calendar in her mother’s room which we kept updated
Allison’s Brain

This is an early example of the dictées Marya did with her Mother
Allison’s Brain

• In week thirteen Allison used the phrase “It comes and goes” to describe her progress
• Allison has her first recollections of visits from friends that occurred during week thirteen
• Allison was weaned off all of her IV meds in week fourteen. Marya pushed her Mom in a wheelchair and set her in front of a piano in the Hospital that had some sheet music on it
Allison’s Brain
Allison’s Brain

• The CBC did an outstanding eight minute segment in advance of a Benefit Concert organized by Marya, that was held to raise funds for Allison’s rehabilitation expenses at Southminster Church in Ottawa on Sept. 23, 2012, that included this incredible story: http://www.cbc.ca/player/Radio/Local+Shows/Ontario/ID/2282127708/
Allison’s Brain

• By week fifteen Allison was walking on her own and fitted with an electronic bracelet as she’d been found wandering in the Civic Hospital.
• In week fifteen we received news that Allison was being admitted into the Acquired Brain Injury Care Stream, Rehabilitation Centre.
• In week sixteen Allison had surgery to replace her missing skull piece with titanium mesh.
Allison’s Brain

- Nurses’ notes from Civic Hospital Campus for June to September had many entries of this kind: “Not answering questions correctly or even appropriately.”; “Patient distracted easily.”; “Confused and disoriented, inappropriate speech.”; “Confused to place, year and reason for admission.”; “Often drifts to other subjects, confused when speaking”; “Patient verbalizing but presents with cognitive deficit.”; “Word salad persists.”
Allison’s Brain

• However, just before Allison was admitted to the Acquired Brain Injury Care Stream at the Rehabilitation Centre, Ottawa Hospital in September 2012, the Occupational Therapist at the Civic Campus noted this about Allison:

• “Patient continues to be pleasant, cooperative and motivated to participate in therapy.”

• Motivation was key ingredient going forward
Allison’s Brain

• Speech Language Assessment at Rehab Centre in week seventeen said Allison had:
• “severe aphasia affecting her ability to read, write, speak and understand language. Not oriented to person, place and time. Unaware of her communications breakdowns. Unable to point to common objects and to follow simple instructions.”
Allison’s Brain

• Occupational Therapy Assessment stated:
• “No formal testing completed because of severe communication difficulties. She has severe receptive and expressive aphasia which has a significant impact on her ability to understand and follow instructions given by therapists. Client does not seem to understand her communication difficulties affect her ability to communicate with others.”
Allison’s Brain
## Allison’s Brain

Allison began keeping a diary of daily activities with assistance from Rehab Centre staff. Here are her activities for September 24th and 25th:

### September 24th

- **0700**: Schedule Review
- **0800**: Breakfast
- **0900**: Physiotherapy
- **1000**: Speech Therapy
- **1100**: Speech/Social Skills
- **1200**: Lunch
- **1300**: Group Skills
- **1400**: OTY
- **1500**: Supper
- **1600**: OTY
- **1700**: OTY
- **1800**: Supper
- **1900**: OTY

### September 25th

- **0700**: Schedule Review
- **0800**: Breakfast
- **0900**: Physiotherapy
- **1000**: Speech Therapy
- **1100**: Speech/Social Skills
- **1200**: Lunch
- **1300**: OTY
- **1400**: OTY
- **1500**: Supper
- **1600**: OTY
- **1700**: OTY
- **1800**: Supper
- **1900**: OTY
Allison’s Brain

Allison made her first trip home for a few hours 111 days after her May 28th surgery
Allison’s Brain

• Report of Neuropsychology Assessment of Allison at Rehab Centre on Sept. 18\textsuperscript{th} stated:
  
• “Her speech would become incomprehensible with significant jargon.” “Formal ... testing deferred given the extent of her aphasia.”

• However, the Assessment added that Allison:
  
• “was cooperative and showed initiative for daily activities” → this was a critical factor
Allison’s Brain

• Allison worked continuously with speech therapists from Sept. 2012 to Dec. 2013
• Among other things, Allison spent 100’s of hours (and still does) working on an iPad using a 4-in-1 Language TherAppy program
• Allison found cognitive gains were evident when she worked hard, whereas if she stopped doing the exercises she slipped
Allison’s Brain

• In September 2012, Allison began sessions with Cheryl Jones, a music therapist with a specialization helping clients with brain trauma and neurodegenerative disorders.

• Cheryl’s extensive credentials are found on her website: http://conbriomusictherapy.com/

• Cheryl has contributed a research-based chapter to our book called Allison’s Brain.
Cheryl said Allison’s “library was intact” and music therapy aimed at “getting books out of her library”. Words are first put to music → melody withdrawn.
Allison’s Brain

- Speech and music share neurologically distinct and overlapping neurological networks.
- Melodic Intonation Therapy (MIT) supports recruiting right hemisphere for word retrieval.
- Music stimulates a *neuroplastic* response → brain can undergo a structural change.
- *Neuroplasticity* is from “experience-driven change” → not simply a recovery process.
Allison’s Brain

• *Neuroplasticity* depends on repetitive experience with variations and increasing complexity

• As Allison progressed, melodies created that increased cognitive demands on Allison

• Allison worked very hard and became increasingly fluent over time

• “Tip of the iceberg” → describes present understanding of use of music in therapy
Allison’s Brain

• After discharge from Rehab Centre in late October 2012 → continued to schedule “music visitors” using Lotsa Helping Hands
• Allison devoted several hours daily to various self-improvement exercises
• Regular physical exercise including personal fitness trainer at YMCA
• Setbacks were a common occurrence
Allison’s Brain

• Over time Allison recognized setbacks were temporary → followed by improvements
• Allison responded to setbacks by increasing her workload of improvement exercises
• It would be fair to say that Allison was “obsessed” with continuing her recovery
• During 2013-2014 Allison enjoyed a number of remarkable achievements
Allison’s Brain

Allison sang with the Ottawa Brahms Choir
Allison’s Brain

Allison staged a musical in Antigua

The Music Department of the Ministry of Education in collaboration with
The Education Officer, Principal, Staff and Students of the
Zone 1 Primary Schools
Cordially invite you to the premiere presentation of
“The Magic Book”, a Children’s Musical Theatre
Written and produced by Allison Woyiwada of Ottawa, Canada
on
Tuesday 15th April, 2014
5:00 p.m.
at
The Jennings Primary School Auditorium
Come and Be entertained!
Allison’s Brain

Directing part of “The Magic Book” cast
Allison’s Brain

Allison with leads from “The Magic Book”
Allison’s Brain

Allison hiked to top of Mount Obama in Antigua
Allison’s Brain

Allison also wrote the last chapter of *Allison’s Brain*, now available at www.woyiwadablogspot.ca and FriesenPress, etc.

Cover art by:
Jennifer Ettinger
www.ettinger.ca
Allison’s Brain

• Many factors have contributed to recovery
• Huge thanks go to The Ottawa Hospital doctors, nurses, therapists, social workers
• Huge thanks go to Allison’s amazing community of friends and supporters
• Huge thanks go to Cheryl Jones, http://www.conbriomusictherapy.com
• Huge thanks go to Allison’s family!!
Allison’s Brain

- A few of Allison’s personality traits seem to have played a large role in her recovery
- Positive attitude
- Good humour
- Stubbornness
- Strong motivation to recover
- Willingness to do a lot of hard work
- Never accepting defeat or giving up hope
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