Lewy Body Dementia
– *a personal narrative*

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October 2019

1984

A personal narrative

- July 2020, amidst the peak of Covid 19, I sat down to dinner with Mary

The Onset

- Saturday, July 18 , 2020
- Sat down to an ordinary dinner
- Mary asked, “Who are you? Do you work here? Are you staff?”
- “What kind of place is this?”
  - “Is this a nursing home? A jail?”

911?

- Sudden delirium
- Total dissociative event
  - Stroke?
    - Speech clear, no slurring, no hesitation in speaking
    - Pupils equal, reactive, accommodating
    - R = L grip, full ROM, Upper & Lower
    - Face symmetrical, no drooping, no drooling
    - Eyes followed six axes
    - No pain, no discomfort

I believed I needed to take her quickly to a hospital. This was a CNS emergency. I was certain it wasn't a CVA, at least not a life-threatening CVA, but could I be sure?

The World was at the peak of Covid-19

If I took her to emergency . . .

- She would have been admitted
  I would have been remanded to the waiting room, and then dismissed from the hospital premises (kicked out of the facility)

- Testing and referrals would have begun
  Standard blood and urine tests
  MRI, EEG
  Neurology, Psychiatry

- She wouldn't know anyone, or where she was

- When would I, or any of her family, ever be able to be with her?

What if I don't take her in?

Will I potentially be guilty of neglect?

Will being an experienced, if retired, paramedic weigh in my favor, or increase my guilt?

How dare I NOT take her in?

What are the risks to her? To me?

Her life is at stake. Among my relatives, my friends, I would end up a pariah, a disgrace, possibly a criminal.

I made a decision to bear the personal risk, believing that she wasn't "dying" – at least not emergently – and that I was the best person to care for her until we had "some" clue as to her condition

My Background

Career began in 1967, USN Hospital Corpsman, trained as USMC Field Medic Tech

Freedom House Ambulance – pioneer modern EMS with Nancy Caroline, MD and Peter Safar, MD 1970--1976

City of Pittsburgh EMS Paramedic Crew Chief & Training Officer (1976-1983)

University of Pittsburgh Health Sciences Center Liaison to the Center Emergency Medicine EMS Coordinator with Ron Stewart, MD (1978-1982)

McKeesport Hospital EMS Coordinator (1983-1986)

Reading Hospital Medical Center EMS Education Director (1986-1996)

University of New Mexico EMS Program Director (1996-2004)

Creighton University EMS Program Director (2004-2010)

My Background

At the UNM EMS Academy, assumed responsibility of the Taos County “Red River” Project

Model Community Health Practitioner Specialist developed in 1994 and modeled after the Alaskan CHP model

New Mexico DOH DEMS wanted to expand the project to additional communities

David Sklar, MD, Chair, Emergency Medicine, refused to expand the program unless independent outcomes/evaluation studies were conducted to assess the Red River Project

Mark Hauswald, MD, Andy Brainard, MD, and I were contracted under a NM DOH EMS grant to study the project

We filed a report and published a paper that ultimately “killed” the project and set Community Paramedicine back about 5 years

My Background

2007, Omaha, Nebraska

Denny Berens, NE DOH Rural Officer had a vision that there was no possible solution to medically underserved rural communities other than paraprofessionals, including a new “creature” – the Community Paramedic

Thus, began an new iteration, an international “reset”

Other agencies, other nations, were experimenting with various forms of expanded roles and skills for paramedics, but there was no template, no unified model

CHP Alaska, Navajo Health Aide/Practitioner Program; CHP Taos County Project & US Military Medic Specialist Programs (Army, Navy, USMC & Air Force): identified the most commonly used skill sets and recommended dismissal of rarely used and unused skills sets

Authored NAEMSE position papers and researched and authored reports on Critical Care Paramedics and Community Paramedics

Sitting at home, closely monitoring Mary's speech and movements, especially her balance.

1 R/O diagnosis – Post UTI Delirium

Alas, the hope for a quick and full recovery was not to be

And then, hopes for a recovery would be slowly and painfully dashed

Dementia

- Alzheimer's is #1
  - 10% of the general population
  - 73% are 75 years of age and older
  - 2/3 are female
  - Twice as prevalent in Black Americans
- Lewy Body Dementia
  - Relatively Rare - 2 to Alzheimer's
  - 3.5 cases per 100,000 population
  - Risk is twice as high in Males
  - Cases increase with age, especially late 70's

Alzheimer’s Pathology

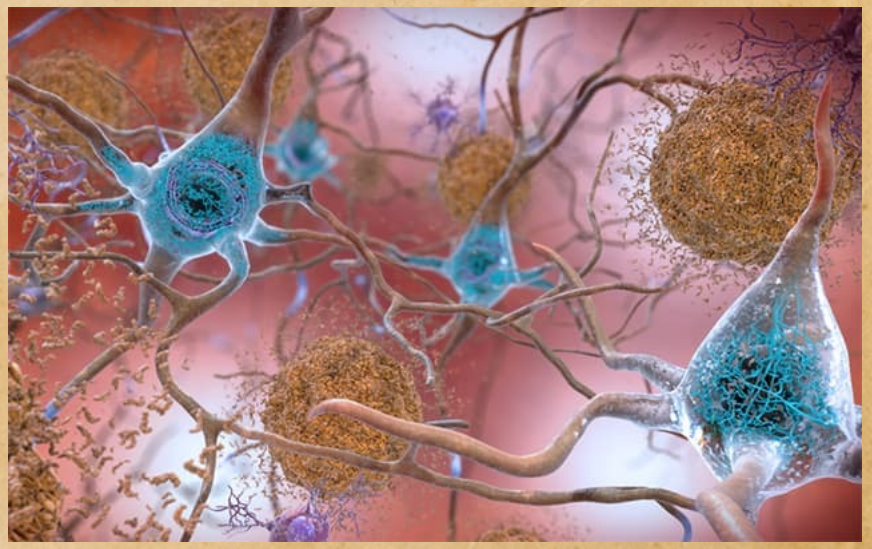
- Alzheimer's disease is a brain disorder that slowly destroys memory and thinking skills, and, eventually, the ability to carry out the simplest tasks. In most people with Alzheimer's, symptoms first appear later in life.
    - Alzheimer’s Association

Alzheimer’s Pathology

- In its early stages, memory loss is mild, but with late-stage Alzheimer's, individuals lose the ability to carry on a conversation and respond to their environment. On average, a person with Alzheimer's lives 4 to 8 years after diagnosis but can live as long as 20 years, depending on other factors.

Amyloid Plaques

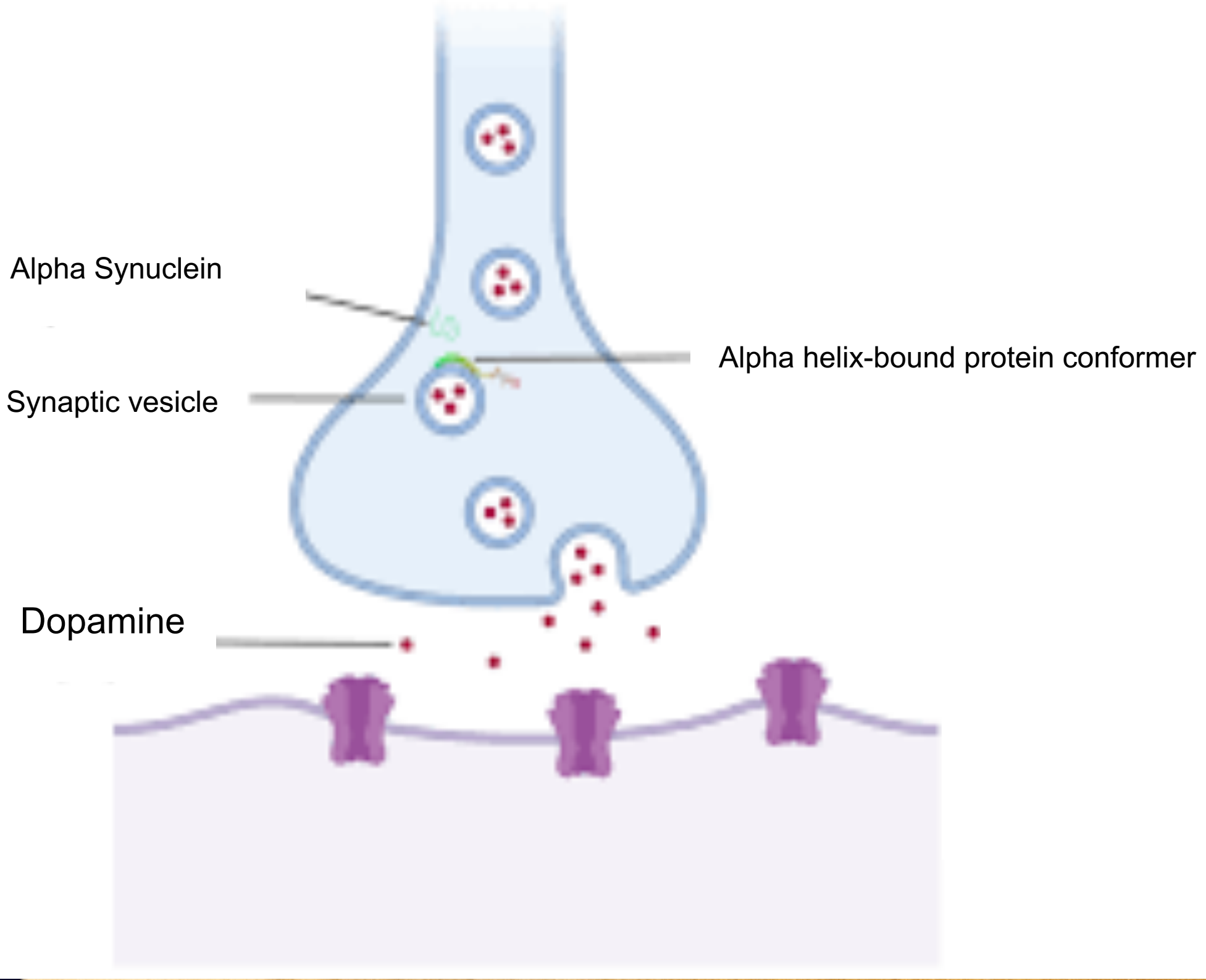
Amyloid plaques are aggregates of misfolded proteins that form in the spaces between nerve cells.



Lewy Body Dementia

- A Lewy body is composed of the protein alpha-synuclein associated with other proteins, such as ubiquitin, neurofilament protein, and alpha B crystallin

- Tau proteins may also be present, and Lewy bodies may occasionally be surrounded by neurofibrillary tangles.


Alpha Synuclein
Alpha helix-bound protein conformer
Synaptic vesicle
Dopamine

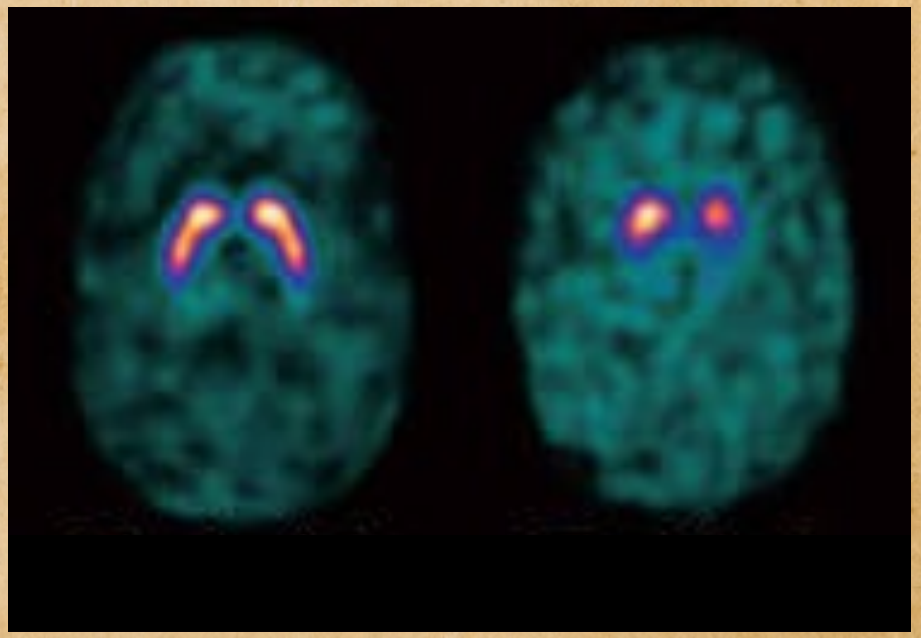
Held onto hope

MRI – normal

DaT Scan – rejected

NeuroPsych Assessment – rejected

Psychiatric Consult



The early weeks

- R/O Dx post UTI Delirium
- Sleep disturbance
- Polyuria
- Vivid Hallucinations – multiple people
- Pain in L hip – old fall
- Eyesight deteriorating rapidly

LBD Progresses

- August 3 Mary did not know who I was

- August 4 5:30 a.m., neighbor's dogs awaken him to alert him to something in the road
  - Mary went on a middle of the night walk out to an unlit dirt road wearing only her nightie
  - Door alarms installed

Side Notes

- August 7
  - Fell twice
  - Frequent Urination

- August 9
  - Wanted to discuss the reasons that “the young girl” didn’t want to stay with us
    - She just wants to pack her bags and head back home
  - I pointed out that it was 4 a.m.

Some Good Days

- August 12 Nothing Happened!
  - Good night's sleep, good meals, good PT
    - Per Mary

- August 12 Friction, Anger
  - Disappointment, frustration
  - Short temper
    - Bill

The intensity grows

- August 12th
  - Found in a hamper
    - 3 pairs of shoes, eyeglasses case and a hair brush
- Gravely concerned that I would be busted for drugs and alcohol
- Accused a neighbor of molestation, assault and rape

“Should we divorce?”

Called her niece and asked “ Can I come live with you?”

and then . . .

- August 17 , she thought we were homeless
  - She didn't want to stay in our house – it wasn't hers

- August 19 , 100% loss of contact with reality
  - Made nonsensical utterances
  - Began screaming for help
  - Walked on gravel out to main dirt road - barefoot

Another day, then another . . .

- August 23 , the drug use theme returned
- Didn’t know who I was
  - Fixated on a former unrequited love
- September 24 - “If you were my husband, don’t you think that I’d remember your face?”

October 31st

- Mary awakens not knowing who I am
  - She doesn't trust me
  - Calls others to confirm my identity
  - It doesn't do any good, she doesn't trust me
- There's so many people coming in here all the time. They all say that they are Bill Raynovich.
- We go through all the family photos, all the years together, all the memories . . . No.

October 31 continued

- I should have called the police
- Just Leave
- She dialed 911

- There's a stranger here. Yes, he threatened me. I don't see a weapon here. I don't know if he has one or not. Okay, thank you. I will.

October 31 close

- 911 response was well staged
  - Sheriff, Township Police, Fire Department & Paramedic & EMT approached in unison
- I showed them the communications with the General Practitioner MD and the MRI results
- About a 30 minute visit to assure that the home setting was safe and stable

Cataracts

- Upon returning home from the outpatient cataract surgery, Mary fell backwards and hit her head on the brick fireplace
  - Sounded like a coconut fell 20’ on concrete
  - 3 cm posterior occipital laceration
  - Needed stitches
- ED or Laser Center first?

Cataracts

- What do I do?
- Emergency? (Yes – she needs sutures)
- 911? (No, I'm 911)
- Destination?
  - Emergency? Head Laceration? How many hours in an ED waiting room? I won't be with her?
- I took her to the Laser Surgical Center
- The Emergency Physician went rabid on me for taking her to the Surgery Center before the ED

EEG / EP

- Evoked Potential Electroencephalogram
  - NREM1 (non-rapid eye movements, stage 1)
  - “Drowsy”
- Theta waves (9 Hz)
  - Non-specific, abnormal
  - Could be PD, could be metabolic (post UTI)

Early signs & symptoms

- 2018
  - Floppy foot
    - Hip Fracture
  - Finger twitches
    - Routine Anxiety, annoyance
  - Incipient forgetfullness
    - Medication compliance

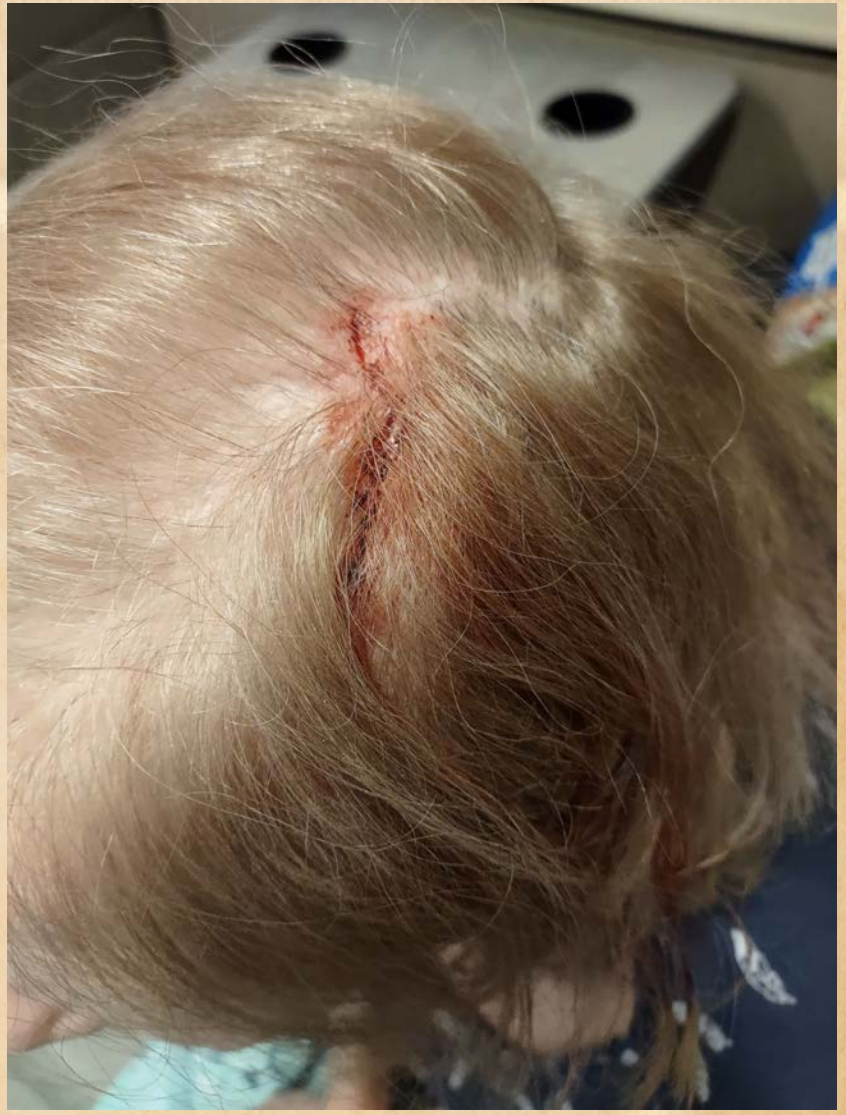
The “Trip”

- Mary hadn’t visited with family for years
  - Pets had aged and serially needed daily care
    - Sub-dermal fluid injections for renal failure
- Couldn’t (wouldn’t) fly

The “Trip”

The Injury

- Wednesday, April 13 2:30 a.m.
- “Mary fell & gashed back of head 6 inches
- Superficial
- Thursday, April 14 Arrived in NE about 6 p.m. Mary’s muscles were locked. 1 L DOPA



The Next Fall

- Friday, April 15 2:30 a.m.
- Mary fell face down, cut lip
- Taken to close hospital ED
- Transferred to Trauma I facility
  - Head Injury
  - Hand Injury (Fractured carpal)
  - LBD c PD

Palliative Care

- April 19 , Grand Rounds
  - “We’re discontinuing intensive care and recommending palliative care. A specialist will contact you later today or tomorrow to discuss options.”

Palliative Care

- April 20 Options were “comfort care only” or a PEG tube for feeding
- Transferred to hospice and “comfort care only”
- Comfort Care is morphine and a sedative, such as midazolam – only – No food, no water
- Mary “Passed” April 27th

Reflections . . .

- Paramedic training prepares the clinician well for emergency interventions
  - Immediate to 60-minute window
- Paramedic training doesn't (or didn't) prepare P students for chronic long-term care of patients with dementia
- The "patient" is sometimes not the "primary patient" for the community paramedic
  - The care provider – the family – of the dementia patient is often an obscure, occult patient
- This presentation is the most awkward of my career
  - I discovered that paramedics and paramedic students don't want to bother with this information . . . this, to me, distinguishes the CP from the P

Reflections . . .

- I am not naive about the CNS and Behavioral Emergencies education and training of Paramedics
- Nor am I naive about the clinical exposure and prevalence of Behavioral Disorders and Diseases among Emergency dispatches and patients
- However, I never appreciated the prevalence of dementia patients before my own family experience

Suggestions

Find your area Adult Daycare Facilities

Visit them for Hygiene, Odors, affect of the staff and residents
Costs? Certifications? Turnovers?

Support resources (for respite)

Listen, Affirmations, Empathy, Understanding

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- https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/dementia-with-lewy-bodies
- Alzheimer's Association Website
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