



A Journey Through Mis/Missed/ Diagnosis

By

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Learning Objectives

1. Participants will learn how a misdiagnosis can lead to a lifetime of low expectations and or even death.
2. Participants will be able to understand the importance of misdiagnoses and the importance of speaking up.
3. Participants will be able to recall and restate the examples given.
4. Participants will be able to compile examples of their own.
5. Participants will be able to recommend these examples to other OTs and or medical staff.

Background

- >30 year background specifically working with children identified as '**Emotionally & Behaviourally Disturbed**' (EBD)
- Venues, Prisons, Mental Health Centers, School districts, Locked facilities, hospitals.
- Born & Raised in Sahel region of the Saharan desert in Africa. English Language learner; first time into a school was at age 13. Multi lingual (5).
- Exposed to war, religious conflicts and repeated dictatorships.
- Wonderful home life; parents exposed all children to both sides of their backgrounds wholly!!!

A red speech bubble graphic with a white outline, containing the text 'Examples Mis/Missed Diagnoses'. The bubble has a tail pointing downwards and to the left.

Examples Mis/Missed Diagnoses

Abel

6th Grade

Labeled as '**Emotionally & Behaviorally Disturbed**' (EBD)

Sent to me with his file

He hummed when being spoken to or when any loud noise occurred

Lana

6ft 2 inch

Pushed
passed you

Spat

Identified
as EBD

Investigate

Saida

Functional
Behavior
Assessment

Appropriate
school age
level

Congenital
Arm
Discrepancy

Bullying and
fighting

Boston
Childrens
Hospital

Labeled
EBD

Investigate



Lifetime Prevalence of Mental Disorders in US Adolescents: Results from the National Comorbidity Study-Adolescent Supplement (NCS-A): LPMDUSA:NCS-AS

Soleimanpour, S., Geiestanger, S., Kaller, S. McCarter, V., & Brindis, C.D. (2010)

LPMDUSA:NC S-AS

- Subgroup of the National Institute of Mental Health (NIMH) National Advisory Mental Health Council, the NIMH established several research initiatives to address the lack of national statistics on mental health in children

Prevalence of MH DSM- Diagnoses

Anxiety disorders
were the most
common condition
(31.9%)



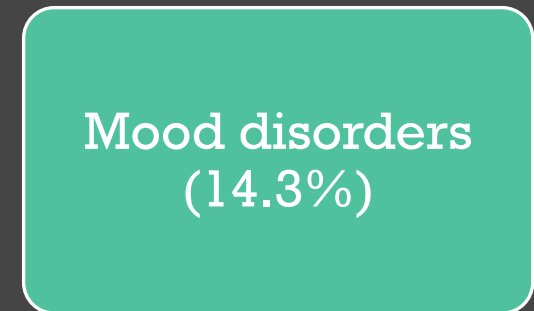
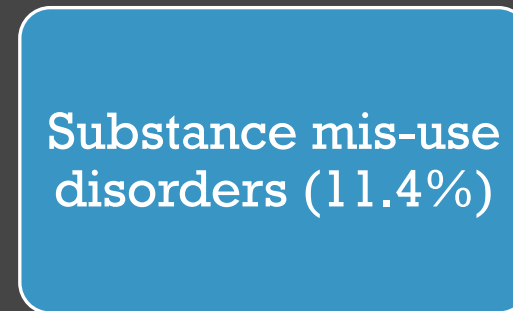
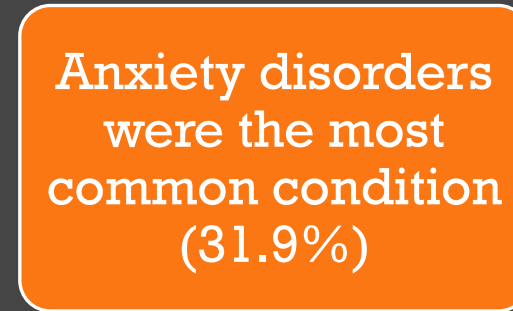
Behavior
disorders (19.1%)



Substance mis-use
disorders (11.4%)



Mood disorders
(14.3%)



Who?

Approximately one in every 4–5 youth in the U.S. meets criteria for a mental disorder with severe impairment across their lifetime.

Common mental disorders in adults first emerge in childhood and adolescence

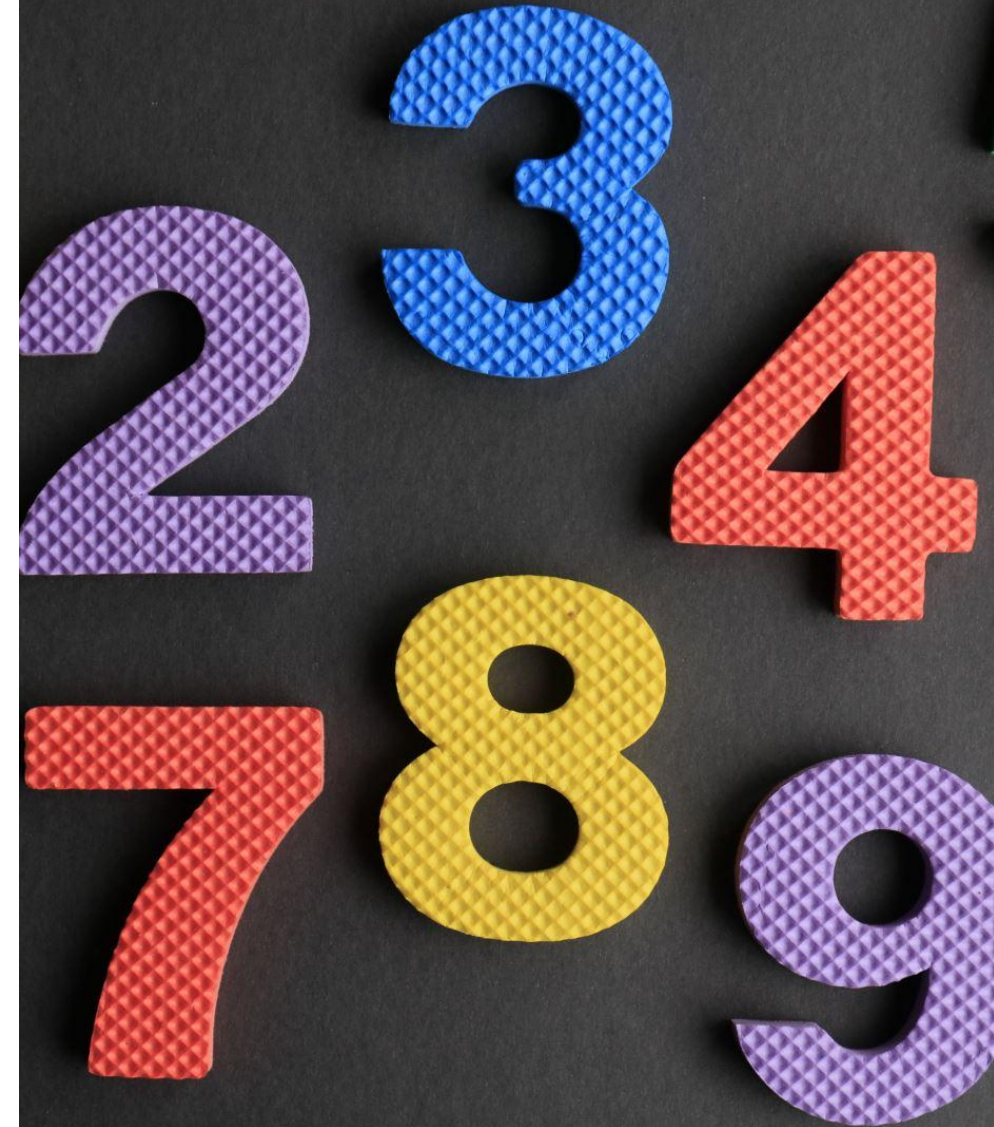
Socio-demographic characteristics LPMDUSA:NCS-AS

51.3% male and the mean age was 15.2 years,

36.2% youth aged 13–14 years

20.5% youth aged 15 16 and

22.3% youth aged 17–18 years.



School Mental Health Centers

(Ryan & Katsiyannis, 2009)

- Most common reasons for referrals to mental health services for new or returning clients were for:
 - ***academic performance**** (*label needs based*)
 - family conflicts
 - depression or
 - suicide ideation or attempt
 - peer relationships
 - anxiety or adjustment
 - anger management

Mental Health Centers

School health centers 'liked' by students because of confidentiality, free services, youth-friendly and convenient.



Psychosocial therapies:

cognitive behavior therapy,

psychoeducation

supported employment



These adjuncts all require pharmacologic treatment to be maximally effective.

Stigma: (Kranke, D., Floersch, L., Townsend, L., & Munson, M., 2009; Kataoka, S.h., Zhang, L., & Wells, K.B., 2010)
School/center based, hospital experience can accentuate stigma

Themes

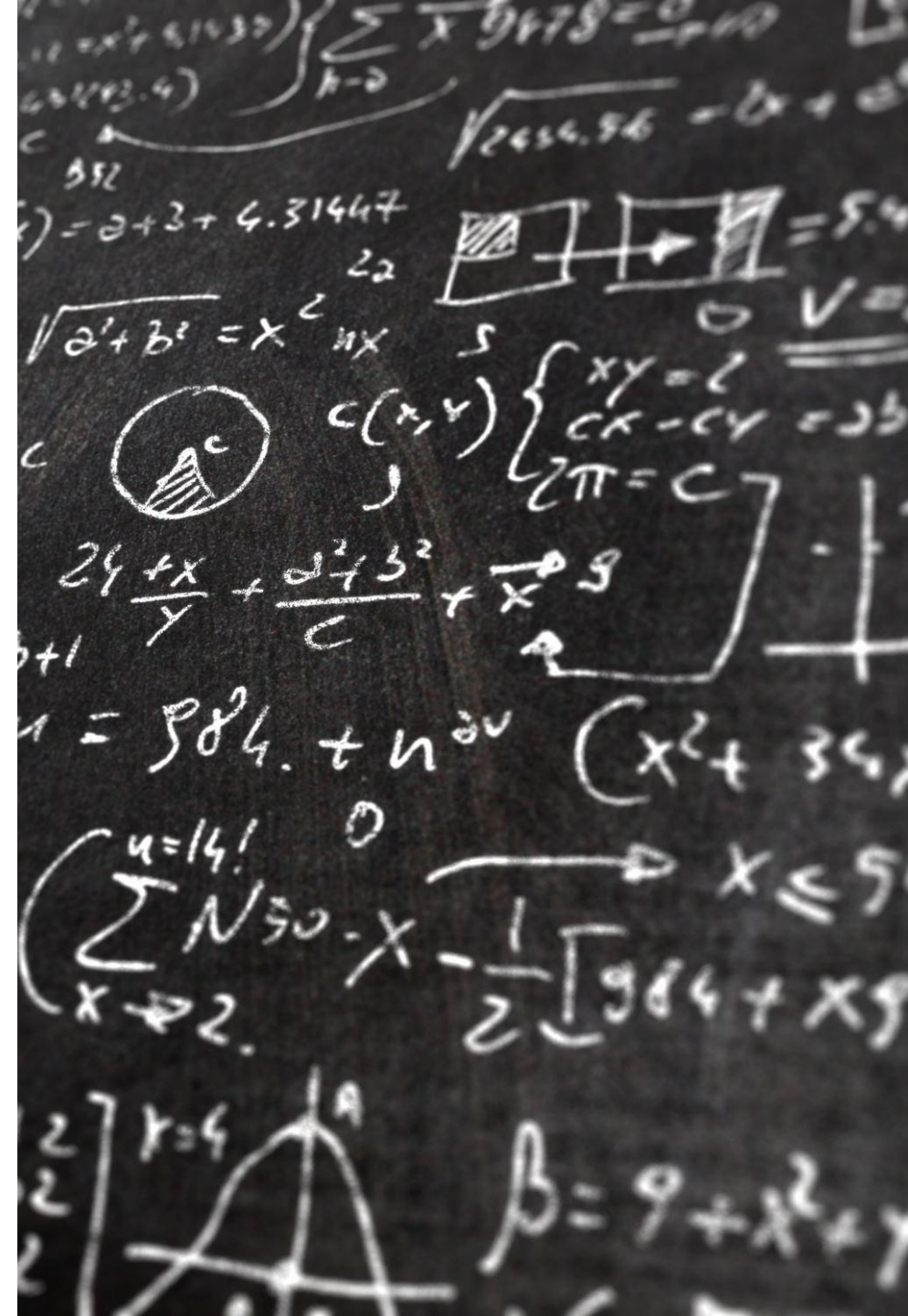
Secrecy

Shame

Limited social interaction

Perception of family members

Ethnicity and health insurance status affects access to MH services (80%)



Culture and its impact

- “Educational research has a very mixed history of impacting the quality of opportunities to learn for youth, **particularly youth who face persistent, intergenerational challenges due to their stigmatized status with regard to race, ethnicity, poverty, gender, and disability.** The challenges these youth face are complex in the context of various influences that are always ecologically situated. The challenges these youth face are institutional and structural, that is, systemic, and not limited to any singular cause” (Lee, 2008)

“What is happening here?”

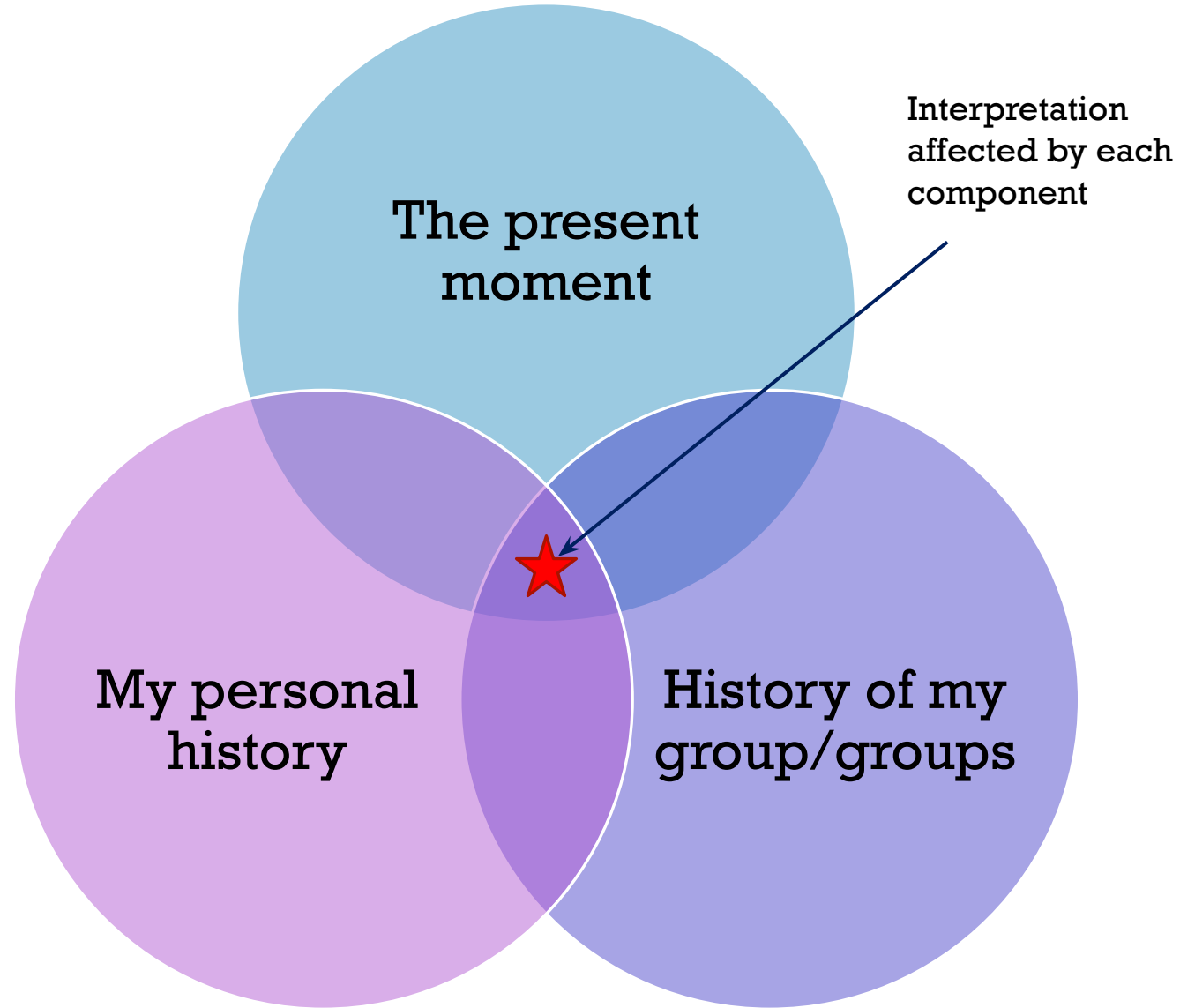
At any given moment a multitude of events occur.

The participant in that moment not only deals with the immediate and the simultaneous,

but also he/she has a unique experience of the events, as they are filtered through one’s own personal experiences and cultural view.

(Richardson, Anders, Tidwell, & Lloyd, 1991; Rogoff, 2005).





Affects of those with Power

- How we look at **difference** or **deviance** by bringing the cause out of the child and making visible the interactive quality of factors that reside ecologically is a step toward greater understanding.
- **It has been documented that teacher/physician held beliefs about their students/patients affect their performance** (Trent & Artiles, 1995).
- Knowing this leads one to point a lens toward the **manner in which we create and construct our environments doctors/teachers/OT/PT/counselors, hospitals/schools and systems**. How we do this can reinforce our beliefs about individuals that are **different** and those we see as the **same**.

What we Know

The combination of ethno-cultural and socio-psychological characteristics intersecting with learning/presenting characteristics of diverse individuals could be **misabeled as pathological if the norm is based on other ways of being.**



To be successful in practicing and supporting these individuals the approaches used must be a combination of multicultural and positive behavior **supports** (Utley et al., 2002) .



Acceptance & Membership

- Human interaction, socialization, and established relationships are crucial to the continued existence and performance of our society. We decide each day to accept or reject a person based on an assortment of individual traits (Hickox, 1999)
- Establishing positive human interaction, socialization, and relationships during childhood and adolescence are essential to healthy development. (cited in Bal & Turton 2007)

A red speech bubble graphic with a white outline, containing the text "My Journey". The bubble has a tail pointing downwards and to the left. The background features faint, curved lines in the top-left and bottom-right corners.

My Journey

Fast Forward



**Dec 2020 –deep
lower right
abdominal pain**



**First visit to the
hospital- UTI**



**Second visit – CT
showed
intussusception**



**Started to avoid
food and eating**



**Another visit to
hospital – low
heart rate 33**



**Medivacced to
Anchorage –
Anorexia**

I refused to leave as I was certain something else was wrong.

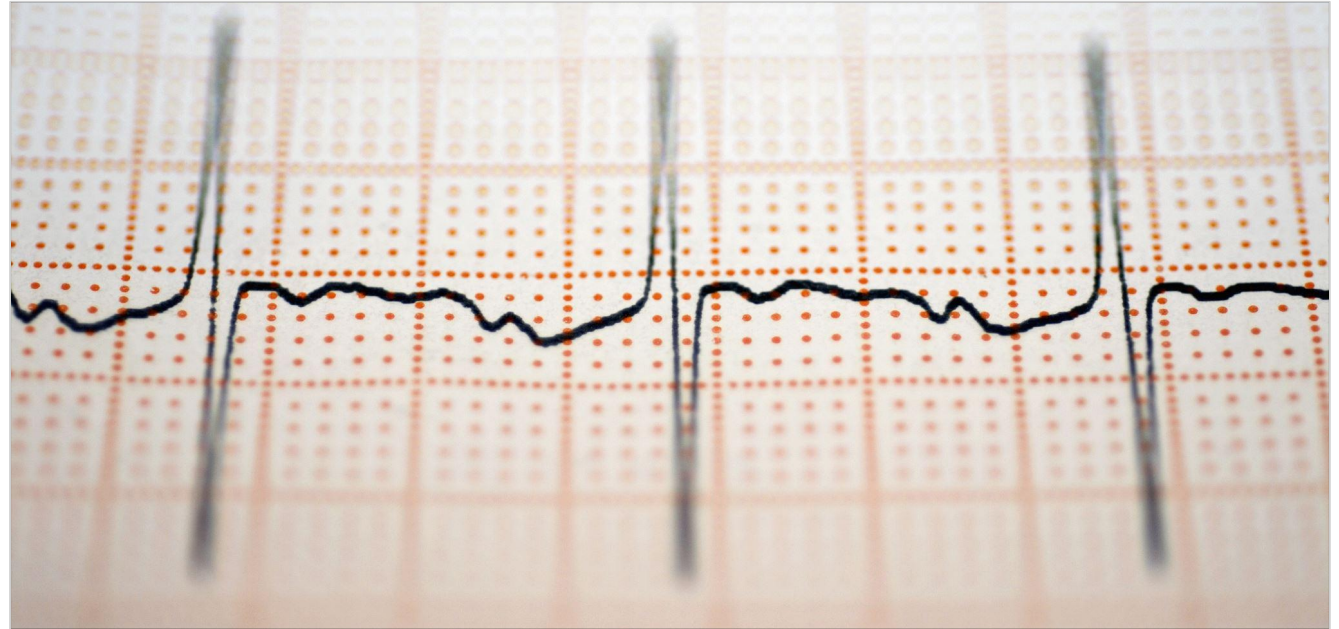
Social Worker was called to plan my exit.

Letter

Told Police would be called.

**I WAS VERY SCARED
AT THIS POINT!!!**

The Journey took (pt.1)



- Scheduled Echocardiogram showing low heart rate 13-23.
- Was sent to the ER halfway through the procedure
- Apparently I was having clear conversations with staff (I have no recollection at all)
- Woke up with a Cardiac pacemaker and Cardiac feeding tube I was fed being fed on Total Parenteral Nutrition (TPN)



Home & Warm

Daily Routine

- Feeding TPN 3X Day
- Feelings of feeling pacemaker switching on
- Pacemaker causing Sinus Atrial Arrhythmia
- Weekly change feeding tube dressing at doctor's office.
- No home visit Nurse in rural communities
- Continued to work

Tide coming
in!



Tidal wave

Found sitting in bath hours later crying incoherentLY

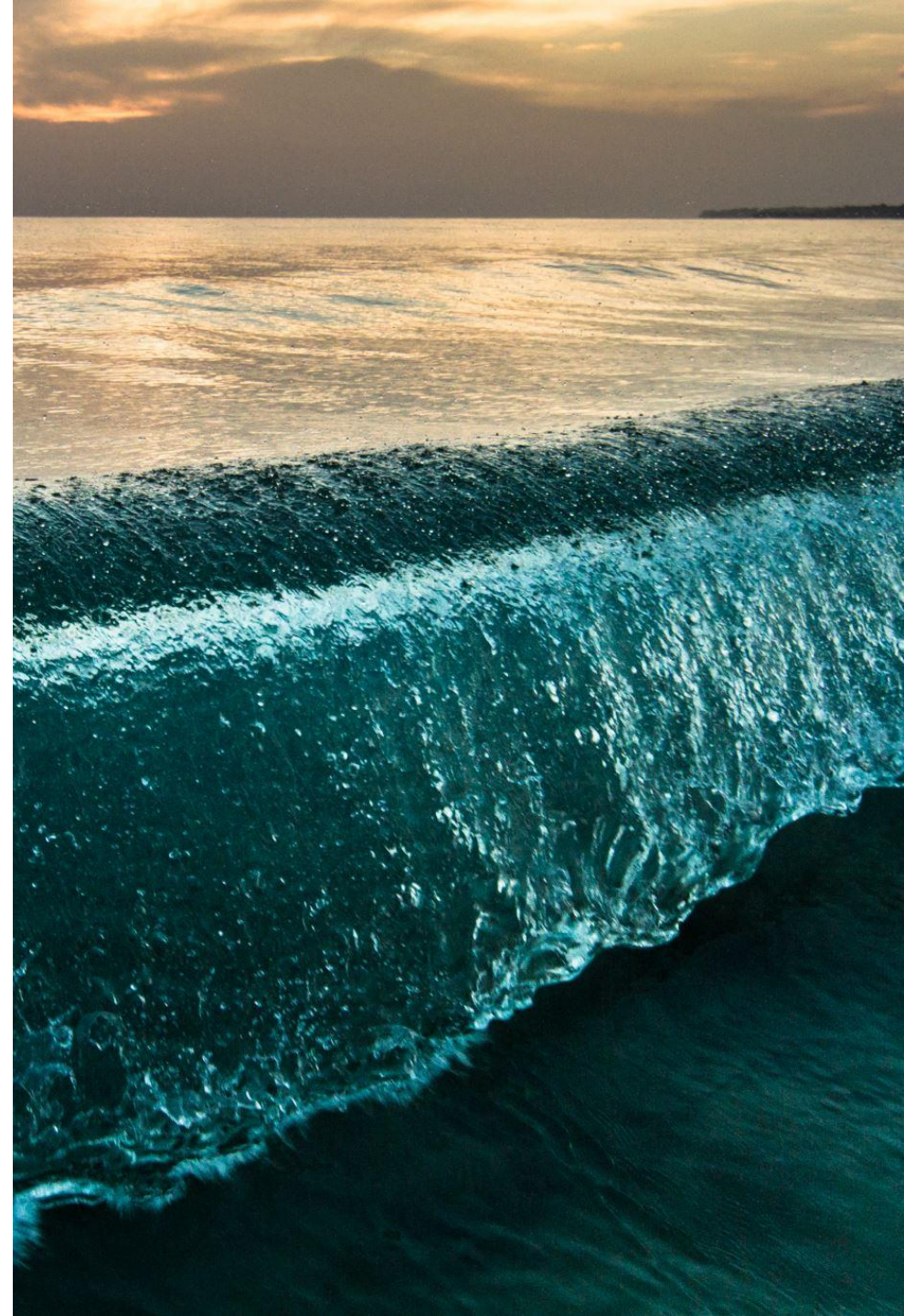
I had texted work and doctor

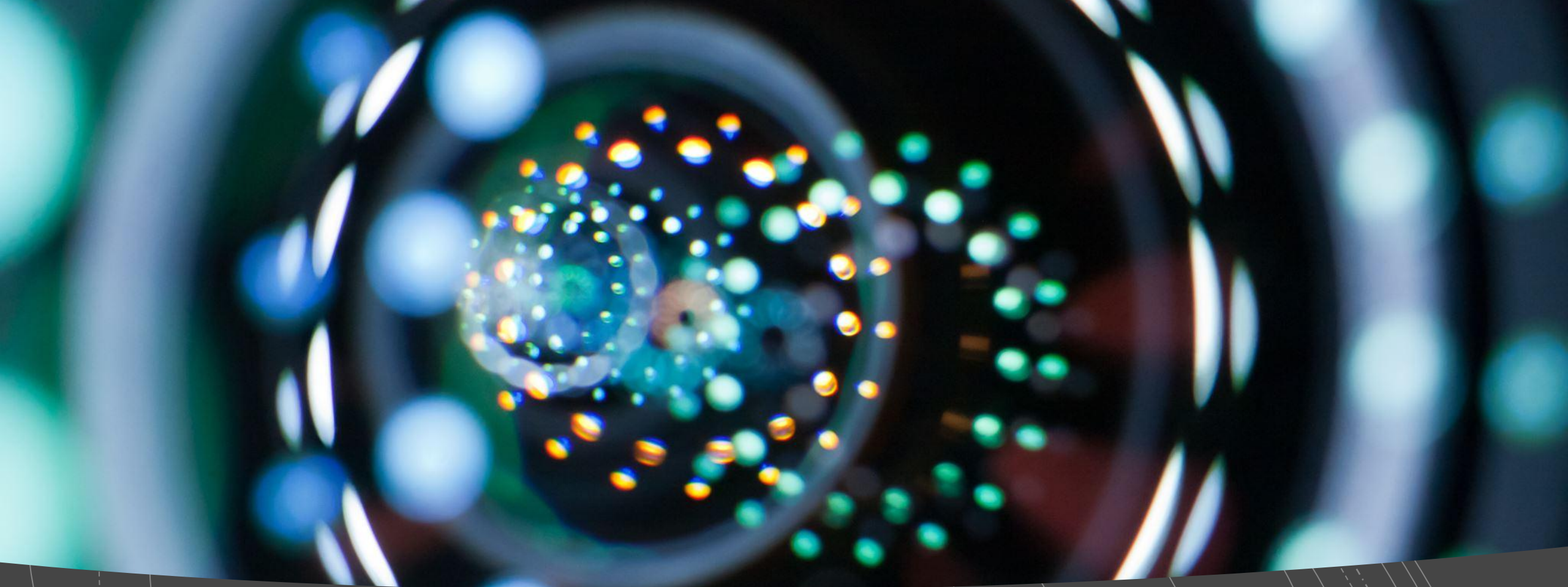
Put into bed (no memory but talking comprehensible*)

Sat up and stopped breathing *

Rushed to ER*

Medivacced to Anchorage*





Lights Out

- Coma
- Pneumonia
- Septacemia

By Chance



Magnetic Resonance Enterography (MRE)



Scheduled from July, performed November.



Fist time it had been done



Reveled abscesses in my back, abdominal and buttock muscles.



Specialist called in over zoom Ft. Bliss, Texas. He recommended immediate drainage or surgical removal by next day.



Was discharged within 3 days with oral antibiotics (3 types).

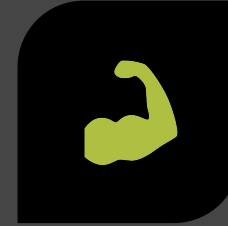


I was unable to walk at this stage.

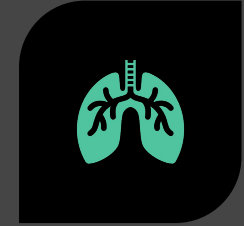
Airflight Three Frequent Flyer



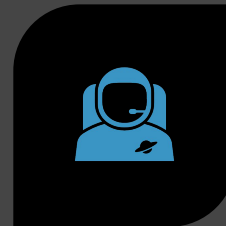
ABILITY TO WALK
DECREASED DESPITE
MULTITUDE OF ORAL
ANTIBIOTICS



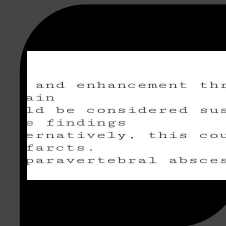
MY HIPS, PELVIS MAKING
LOUD KNOCKING,
CLANGING SOUNDS. WAS
GIVEN PELVIS BRACE.



STRUGGLING TO
BREATHE



TIME TO FLY BACK TO
ANCHORAGE AS
C-REACTIVE PROTEIN
(CRP) WAS 450. RANGE
0-3



PELVIS PARTS WERE
DEAD/NECROTIC AND
GANGRENOUS

Rock & a Hard Place



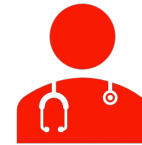
Scared



Ortho surgeons
denied to attempt
procedure.



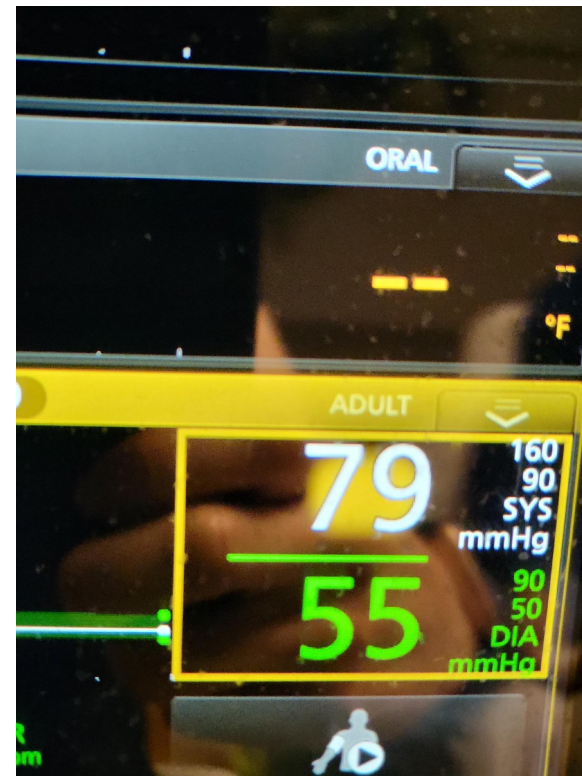
Too sick to get to
Seattle



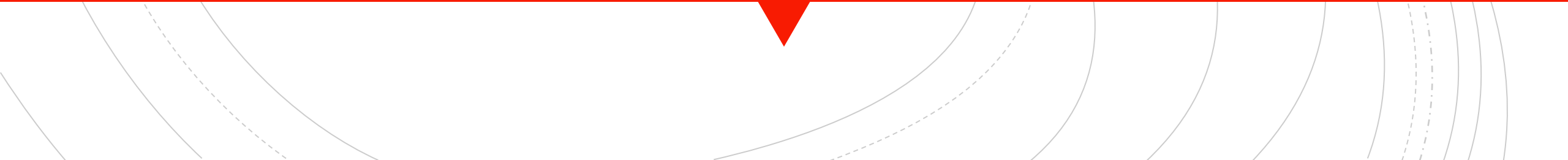
Thank you 'Trauma'
surgeon Thank
you!!!!!!



Cover ALL



“ALL THE SINGLE LADIES”

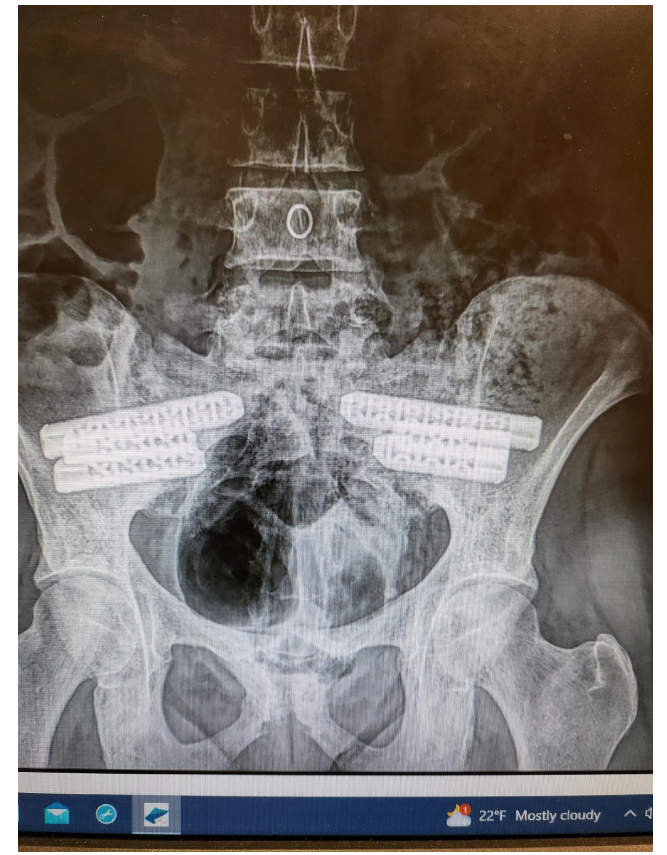
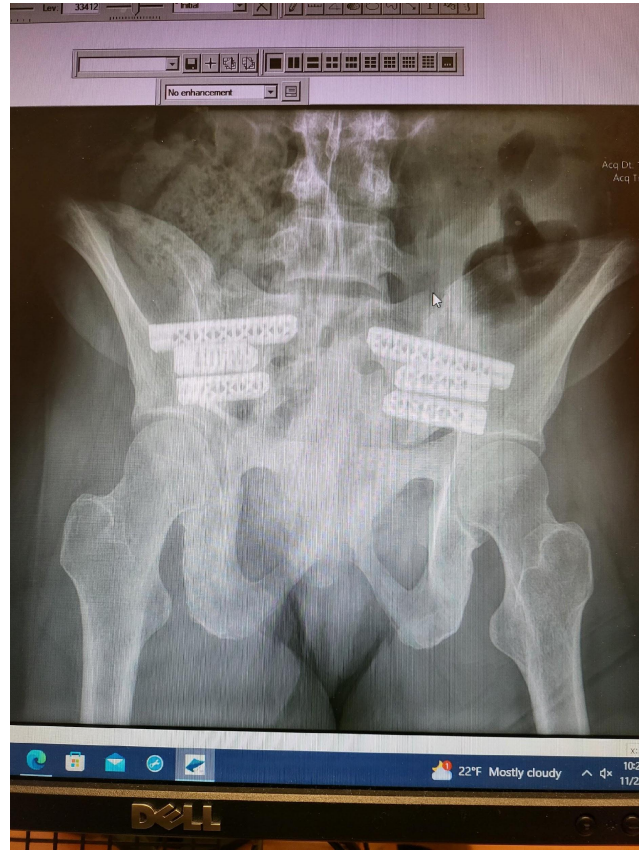




+16 weeks; 9 antibiotics; multiple organ failure

**Discharged
but.....**

- **From April 2023 - Until September 2023**
- **Tried OT**
- **Tried PT**
- **Clear I was struggling, clear they were struggling too.**
- **Trauma surgeon revisit: pelvis had not regenerated to connect where it had been cut apart or removed. I'd further broken my sacrum in addition in trying to heal.**
- **So new surgery and pelvic parts needed.**



Bionic Woman

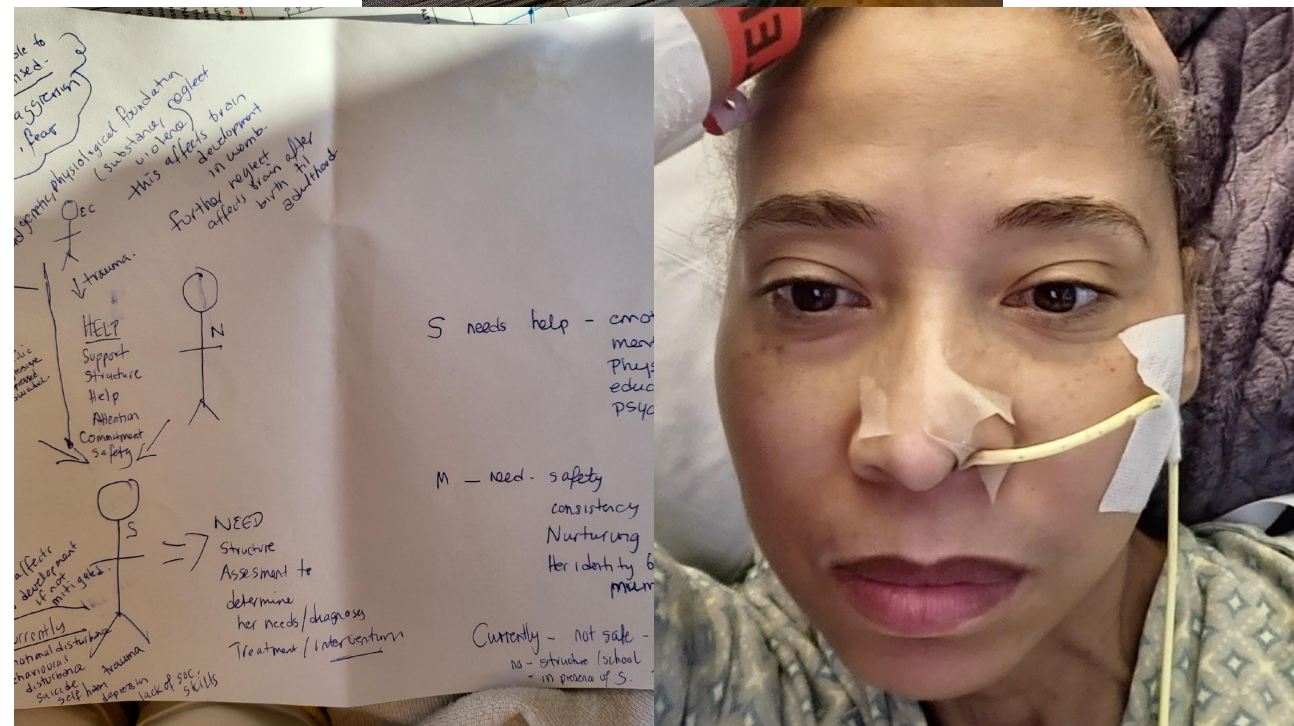
3D Printed Cobalt Pelvic parts ordered from Lower 48 and mailed up. Plus a whole new surgery.

Transition, Food & Journaling

For Pain Management

Understanding the triggers, routines and my body

Both types of eating tried Naso-Gastric tube; and actual food



able to
need.
system
Fear
genetic, physiological foundation
(Substance) in utero
This affects brain development
in womb.
Further neglect affects brain after birth
adulthood

↓ trauma
HELP
Support
Structure
Help
Attention
Commitment
safety

S needs help - emotional
Phys: educ
psyc

M - need - safety
consistency
Nurturing
Her identity
6 years

currently - not safe -
no - structure (school
- in presence of S.

affects development if not met
currently normal distribution
trauma
disturbance
suicide
self harm
depression
lack of skills

NEED
Structure
Assessment to determine her needs/diagnosis
Treatment / Intervention

A red speech bubble graphic with a white outline, containing the word "Rehabilitation" in white text. The bubble has a tail pointing downwards and to the left. The background features faint, curved lines in the top-left and bottom-right corners.

Rehabilitation



New Uniform & New Transport

A Walk in the Park



DJ-ying



I needed
everybody's
help...I REALLY
did!



Must Mentions

- **Trauma in history**
- **Chronic trauma leads to Post Traumatic Stress Disorder**
- **Chronic Pain**
- **The brain on trauma**
- **Children's minds on trauma**
- **The imprint of trauma**
- **Recovery pathways**
- **Body sensations rather than intense emotion is key to healing trauma.**

(Bessel van der Kolk, 2020; Levine, 1997)

What we see

- Feeling that have no physical cause
- Most human trauma is to do with love and loss
- Knowing one can be in full control of their life in all its visceral dimensions
- Communication gives us power to change ourselves and others by communicating
- We can change social conditions to create safe environments for ALL where we can thrive

(Van Der Kolk 2023) (The Collective Trauma- Hubl 2023)

The END

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 - QUESTIONS?