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## Educational Webinar

# Understanding and Managing Caregiver Trauma Associated with PANS PANDAS

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**inflamed brain  
alliance**

# Understanding and Managing Caregiver Trauma Associated with PANS/PANDAS

Sheilah M. Gauch, LICSW, M.Ed



# Goals for Today:

- Understand what trauma is
- Learn what is happening in your brain during a stress response
- Identify the barriers and obstacles that combine to create trauma
- Identify different ways to support

# What is trauma?

Trauma results from exposure to an incident or series of events that are emotionally disturbing or life-threatening with lasting adverse effects on the individual's functioning and mental, physical, social, emotional, and/or spiritual well-being.

- Trauma Informed Care Institute

# Create a pilot's checklist

- When a pilot takes off – they create a list of to do's and practice them so that in a crisis they can land the plane well.
- Consider making yourself a list to review at the start of each day
- Practice this list daily



**Anxiety is a physiological response to a primal survival mechanism**

**Fight**



**Freeze**

**Flight**

**When under stress we behave in predictably one of these ways.**

# POLYVAGAL THEORY CHART OF TRAUMA RESPONSE

The nervous system with a neuroception of threat:

## SHUT DOWN / COLLAPSE

*Immobility • Death-Feigning • Conservation of Energy*

Dissociation

Suicidal

Depression

Shame

Helplessness

Hopelessness / Trapped

Disappearing

**DORSAL VAGAL**

Confusion / Disorientation

*(LIFE THREAT)*

*Hypoarousal*

Going through the motions/checked out

Raised pain threshold/numbness

HYBRID OF SYMPATHETIC & DORSAL VAGAL

## FREEZE

"I CAN'T"

"I CAN"

Rage

Panic

Anger

Fear

Irritation

Anxiety

Frustration

Worry & Concern

**SYMPATHETIC**

*(DANGER)*

*Hyperarousal*

**FIGHT**

*Movement towards*

**FLIGHT**

*Movement away*

**ALERT**

*Orientation to Threat*

DEACTIVATION

The nervous system with a neuroception of safety:

## SOCIAL ENGAGEMENT

*Connection • Safety  
Oriented to the Environment*

Curiosity / Openness

Compassionate

Mindful / In the present

**VENTRAL VAGAL**

*(SAFETY)*

Calmness in connection

Settled

Groundedness

VVC is the beginning and end of stress response.  
When VVC is dominant, SNS and DVC are in transient blends which promote healthy physiological functioning.

## PARASYMPATHETIC NERVOUS SYSTEM

DORSAL VAGAL COMPLEX

### Increases

Fuel storage & insulin activity • Immobilization behavior (with fear)  
Endorphins that help numb and raise the pain threshold  
Conservation of metabolic resources

### Decreases

Heart Rate • Blood Pressure • Temperature • Muscle Tone  
Facial Expressions & Eye Contact • Depth of Breath • Social Behavior  
Attunement to Human Voice • Sexual Responses  
Immune Response

## SYMPATHETIC NERVOUS SYSTEM

### Increases

Blood Pressure • Heart Rate • Fuel Availability • Adrenaline  
Oxygen Circulation to Vital Organs • Blood Clotting • Pupil Size  
Dilation of Bronchi • Defensive Responses

### Decreases

Fuel Storage • Insulin Activity • Digestion • Salivation  
Relational Ability • Immune Response

## PARASYMPATHETIC NERVOUS SYSTEM

VENTRAL VAGAL COMPLEX

### Increases

Digestion • Intestinal Motility • Resistance to Infection  
Immune Response • Rest and Recuperation • Health & Vitality  
Circulation to non-vital organs (skin, extremities),  
Oxytocin (neuromodulator involved in social bonds that allows  
immobility without fear) • Ability to Relate and Connect  
Movement in eyes and head turning • Prosody in voice • Breath

### Decreases

Defensive Responses

ver 10.p

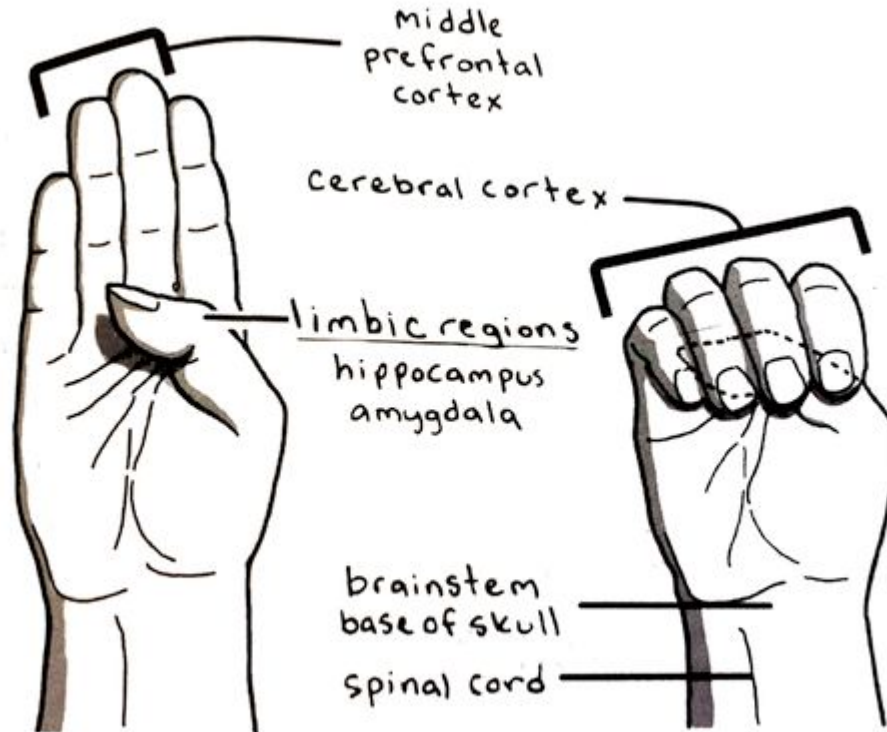


## Dr Dan Siegel and the Hand Model of the Brain





# Hand Model of the Brain



## Physical manifestations of the limbic system igniting:

- Racing heart rate
- Muscle tension
- Crying
- Difficulty breathing
- Headaches
- Nausea
- Working memory drops
- Unable to concentrate



# Dr Siegel and the Cortex



# Two pathways that lead to a stress response

- **Downstairs brain**

- In response to a trigger that happens BEFORE you can think
- “There is a lion in this room”



- **Upstairs brain**

- Happens from the thinking brain (worry thoughts)



# Our Amazing Evolution



## The Appropriate Use of Worry

**WORRY** → **PLAN** →

Not this:

**WORRY** → **PLAN** →



The diagram illustrates a feedback loop where the process of planning leads back to worrying. A blue arrow points from the word 'PLAN' to the right. Below this arrow, a curved blue arrow points back from the right towards the word 'WORRY'. Additionally, there are three curved blue arrows originating from the word 'WORRY' and pointing back towards itself, representing a self-reinforcing cycle of worry.

# The brain can flip it's lid.....









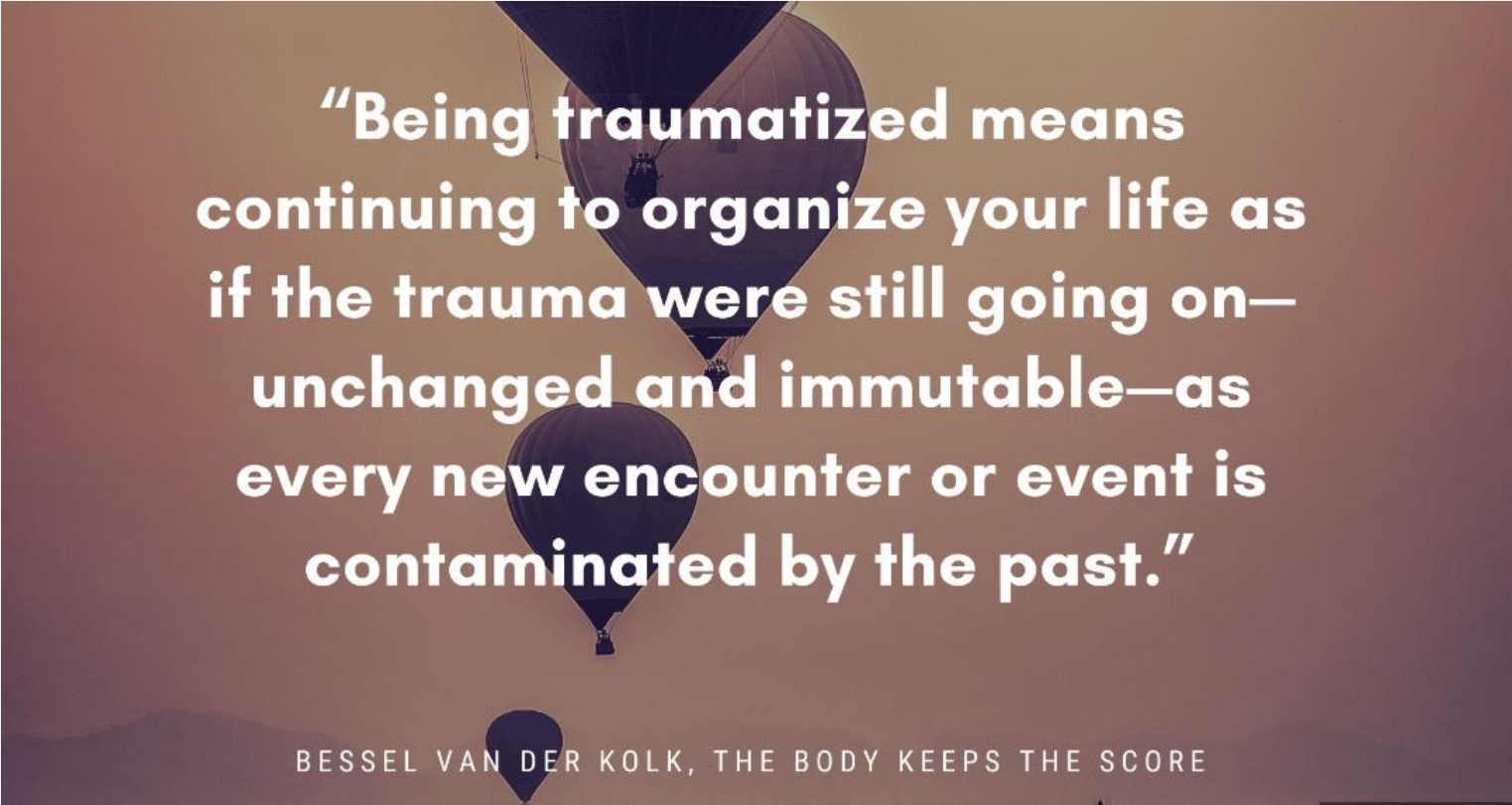
Anxiety is mostly  
about **AVOIDANCE**



*(and of  
course  
control...)*

# The Brain and the Body Remember



The background of the slide features a photograph of several hot air balloons floating in a hazy, orange-tinted sky. The balloons are dark in color, and their silhouettes are visible against the lighter sky. The quote is centered over this image in a large, white, sans-serif font.

**"Being traumatized means  
continuing to organize your life as  
if the trauma were still going on—  
unchanged and immutable—as  
every new encounter or event is  
contaminated by the past."**

BESSEL VAN DER KOLK, THE BODY KEEPS THE SCORE

# Trauma Causes Cognitive Distortions

- Erroneous thoughts and beliefs that lead an individual to perceive events in an inappropriate manner
- Sustained trauma can cause these to occur

Some common cognitive distortions:

- All or nothing thinking
- Catastrophizing
- Personalization
- Shoulds
- Mind reading

# Trauma means....

- You may feel like you are right back in the crisis place you have been in before
- This can make it really hard when our children start to heal
- We are always waiting for the other shoe to drop - the saw tooth recovery of this illness only compounds this
- We may not be able to acknowledge how far they have come



# This illness creates a complicated trauma response





# You may have your own trauma

- 61 percent of adults have had at least one adverse childhood experience (ACE)
- 16 percent have four or more types of ACEs.



# Mental Health Stigma





# History of how we view mothers and caregivers



# Lack of Access to Providers

- Provider availability
- Insurance barriers
- Limited options, long waits
- Lack of culturally appropriate and linguistically congruent care



# Socio-economic barriers

- *Does the family have insurance?*
- *Do they have a car to get to the hospital?*
- *Can they find treaters in-network?*
- *Can they afford medication?*



# Systemic Racism

- Distrust of medical community as a result of systemic racism (ect. eugenics, Tuskegee experiment)
- Lack of access/distrust of the mental health system

**You have to  
learn three  
new languages**

**...and be the  
casemanager  
for your  
child's case**

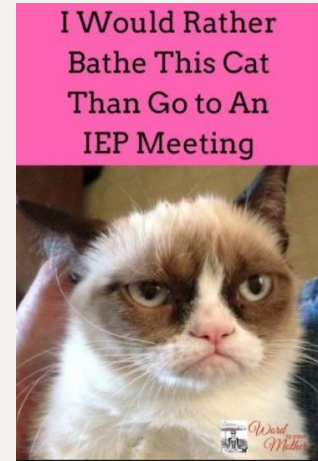
Mental Health  
System



Medical System



Special Education  
System





# Mental Health System



- Current system is totally overwhelmed
- Not intuitive as to how to access supports
- Crisis intervention challenging for caregivers to access
- Psychotropic medications can take a long time to work/are not always great fits
- Awareness of PANS/PANDAS is limited

# Medical System



- Generational view of doctors make is challenging to oppose them
- Many parents are used to doctors being the experts
  - Very few are knowledgeable about this illness
- Specialists are siloed and not consulting with one another
- Insurance creates barriers for practitioners to spend time with caregivers

# Special Education System

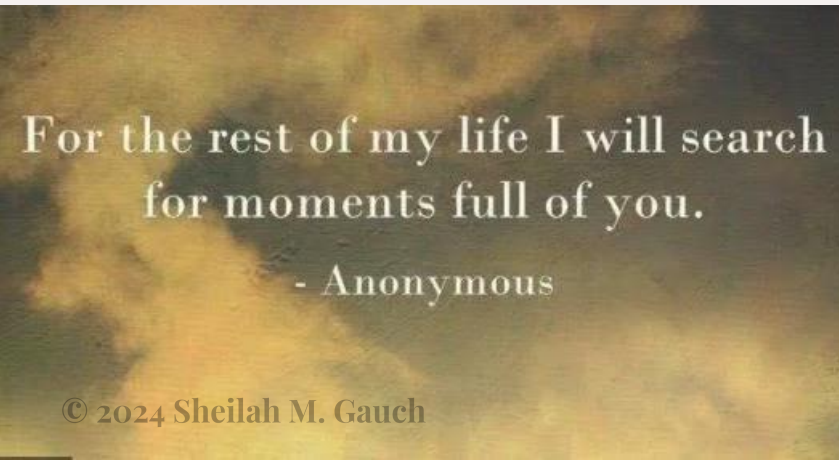
I Would Rather  
Bathe This Cat  
Than Go to An  
IEP Meeting



- Awareness of PANS/PANDAS is limited
- IEP meetings can be very overwhelming and confusing
- School attendance issues can be challenging for districts
- Schools are defacto mental health providers but they aren't set up to be



# Grief and Loss



# Impact to relationships

- You and your partner may have incongruent stress reactions
- You maybe parenting alone
- Presentation as mental illness means it comes with shame
- Your family and friends do not understand
- The prolonged nature of the illness makes it hard for others

## Intense separation anxiety

## Saw Tooth Recovery

- They are dependent on you in ways that are unique to PANS/PANDAS
- You may now be part of their OCD
- You take one step forward and then five steps back
- If your child was doing well, and has a flare, the stress reaction you may feel is intense
- We still don't understand how the brain heals

“Don’t get too happy, it might crash - be ready.”

“Child pushing you away but they really need you more.”

“Healthy optimism”

“Brutal facts of current reality.”

“It’s hard when you’re in it to be hopeful.”

“It’s scary to be hopeful.”



# The Symptoms

- Are like nothing you have ever encountered – they are not easily managed
- You feel like you are constantly negotiating
- Typical behavior management doesn't always work
- Everyone has an opinion how you “should” be managing

On going  
stress  
causes  
physical  
health to  
suffer

- There is research to indicate that the hormones that are sent out by the limbic system wreak havoc on the body physically – it leads to long term auto-immune issues and health dysfunction globally
- The brain learns a way of responding, it maps down this response
- Neurons that fire together wire together
- It leads people to feel perpetually unsafe in their world

“I’m not sick but I’m being held prisoner with someone who is sick.”

“I feel very responsible to keep child safe from themselves.”

“Did I do enough?”

“We cannot share with providers all that is happening because we are worried about repercussions”

“I can lose my rights to my child”

“Parents of young adults in crisis can feel totally powerless when they are not engaged. Institutions need better ways to judge when families can be supportive to treatment, rather than defaulting to treating patients in crisis as adults and parents as an afterthought.

“I feel completely lost, scared and overwhelmed most of the time - and truthfully feel providers didn't believe me how bad things were. “

# What can you do to help yourself?



“ If an organism is stuck in survival mode, its energies are focused on fighting off unseen enemies, which leaves no room for nurture, care or love. For us humans, it means as long as the mind is defending itself against invisible assaults, our closest bonds are threatened, along with our ability to imagine, play, learn and pay attention to other people’s needs”

– *Dr Bessel Van der Kolk, The Body Remembers*

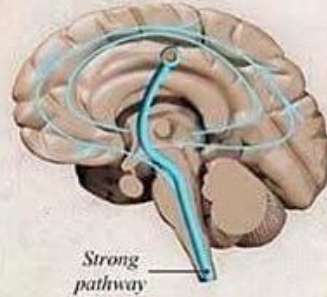
**Remember  
how  
important  
you are**



# Reprogram your brain

## Pathways

Neural pathways connect relatively distant areas of the brain or nervous system, each pathway is associated with a particular action or behavior.



Every time we think, feel or do something, we strengthen this pathway. Habits are well travelled pathways – our brain finds these things easy to do.

## Neuroplasticity



New thoughts and skills carve out new pathways.



Repetition and practice strengthen these pathways, forming new habits.



Old pathways get used less and weaken.

With repeated and direct attention towards a desired change, we all have the ability to rewire our brains.

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Shame  
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### DORSAL VAGAL

(LIFE THREAT)  
Hypoarousal

## FREEZE

HYBRID OF SYMPATHETIC & DORSAL VAGAL

"I CAN'T"

"I CAN"

Rage  
Anger  
Irritation  
Frustration

Panic  
Fear  
Anxiety  
Worry & Concern

### SYMPATHETIC

(DANGER)  
Hyperarousal

## FIGHT

Movement towards

## FLIGHT

Movement away

## ALERT

Orientation to Threat

DEACTIVATION

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(SAFETY)

VVC is the beginning and end of stress response.  
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### Decreases

Defensive Responses

ver 10.p



## **We stay out of shame and be kind to ourselves**

Shame is the intensely  
painful feeling that  
we are unworthy  
of love and belonging.

Brene Brown, PHD, LMSW

# Shame ➤ Pain ➤ Trauma

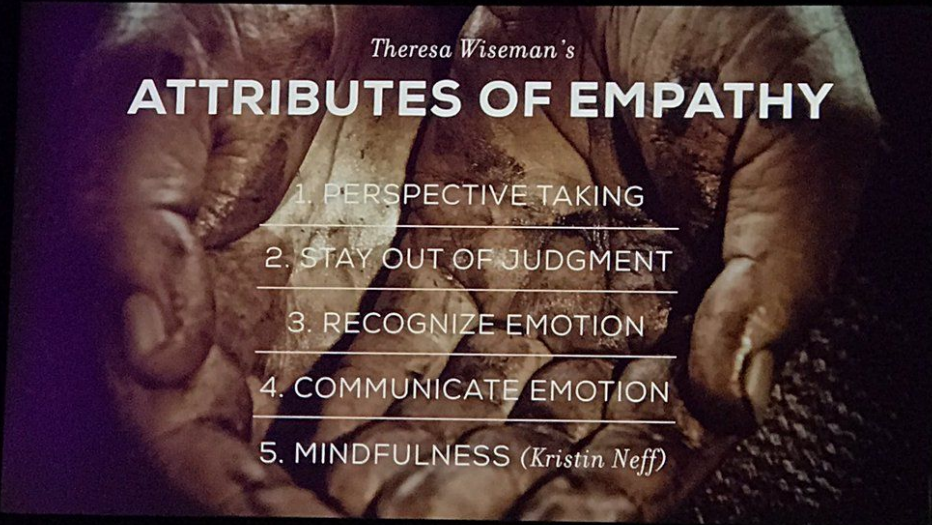
"Shame is so painful for children because it is inextricably linked to the fear of being unlovable . . . feeling unlovable is a threat to survival. It's trauma.

(Brene Brown, Daring Greatly pgs. 225-226)

# Practice:

Empathy and Acceptance (*for yourself*)





*Theresa Wiseman's*

## **ATTRIBUTES OF EMPATHY**

1. PERSPECTIVE TAKING
2. STAY OUT OF JUDGMENT
3. RECOGNIZE EMOTION
4. COMMUNICATE EMOTION
5. MINDFULNESS (*Kristin Neff*)

**The words  
we use  
with  
ourselves  
matter**



**Never in the  
history of calming  
down has anyone  
calmed down by  
being told to  
calm down.**

- I shouldn't be so scared
- So many people have it worse than I do
- If I just worked harder I could help them
- This is all my fault
-

# Identify your stress response

- This is really important because it will also determine how you move through treatment for your child (and for you..)

**Fight:** You may react quickly and want to move to “fix”

**Freeze:** You may struggle to move quickly

**Flight:** You may be prone to avoid and make excuses for symptoms/behavior

## Work hard to have a growth mindset

- People who have a growth mindset believe that even if they struggle with certain skills, their abilities aren't set in stone. They think that with work, their skills can improve over time.
- Do your best to stay in positive self-talk – use AND not BUT.....
  - My child is very sick AND I am doing my best to help them.
  - Things seem really bleak right now AND I will ask for help from others.

# Externalize the anxiety

- This is not who you are – this is the stress of your child being ill
- Give your stress response a name
- Acknowledge it to others



**Try not to  
accommodate  
the anxiety  
- step into  
discomfort -  
start to rewire  
our brains**

## **Anxiety Demands TWO Things:**

**Certainty:** “I have to know what’s going to happen next...and I want to control it!”

**Comfort:** “I want to feel safe and comfortable...or else I want out!”



# Acknowledge and face the grief and loss

- Journaling
- Write a trauma narrative
- Allow space and time to feel the pain



**On your  
list can be  
coping  
skills that  
fit you  
best...**

- Exercise
- Mediation
- Breathing
- Calling a friend
- Journaling
- Grounding techniques
  - What can you see, smell, taste, hear



**Stay off their roller coaster!!!**





# Remember: Q-TIP



## Find a support network

- Support Groups
- Professional Support
- Other PANS/PANDAS caregivers
- Friends who will tell you when you are in a stress response (the hit your knees moments)

I see your pain,  
and it's big.  
I also see your courage,  
and it's bigger.  
You can do hard things.

- Glennon Doyle