Trauma-Informed Care

XCENTER

Session 4: Survivor Perspective: How Trauma-Informed Care Can Support Individuals and Family Members

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Agenda

- Part 1: Overview of CPTSD
- Part 2: Tips for People Who Have Trauma
- Part 3: Tips for Advocacy

Introduction

- Working in digital strategy in healthcare
- Diagnosed with complex post-traumatic stress disorder (CPTSD) at the age of 51
  - Used a background in science writing to help me understand all the aspects of CPTSD and share my experience with others to offer support and education.
  - After learning about how CPTSD is linked with chronic medical problems, I wanted to help medical professionals understand the connection.
  - Advocating for widespread trauma-informed care because people with chronic illnesses and their caregivers often experience trauma as well, but it often goes unaddressed.

Part 1: Overview of CPTSD

Definitions

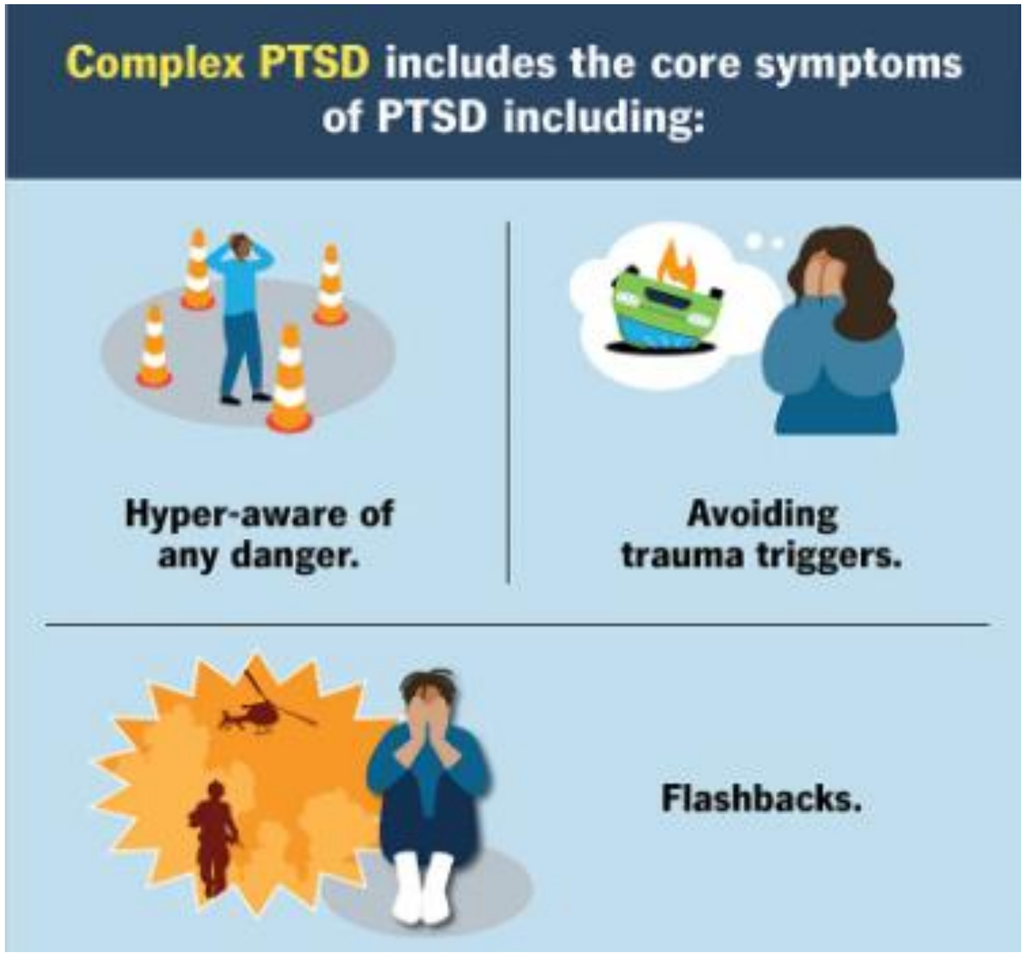
Post-Traumatic Stress Disorder (PTSD) is a mental condition that develops in reaction to physical injury or severe mental or emotional distress, such as military combat, assault, natural disaster, chronic illness, or other traumatic event.

Complex Post-Traumatic Stress Disorder (CPTSD) is the result of chronic, long-term trauma, such as childhood abuse or neglect, domestic violence, trafficking, or war.

The Difference between PTSD and CPTSD

- PTSD is the result of short-term trauma. Added to the DSM in 1980.
- CPSTD is the result of sustained, long-term trauma over the course of years.
  - Is on the ICD-11, but not in the current DSM.
  - Methods of diagnosis vary, but the Adverse Childhood Experience (ACE) test is a key indicator.
  - CPTSD is differentiated by additional characteristics, such as chronic medical problems, emotional dysregulation, a diminished sense of self, and relational issues.
  - Often misdiagnosed as borderline personality disorder or bipolar.
  - CPTSD and ADHD considered as a package deal, thought to be part of hypervigilance.

Symptoms of CPTSD



Infographic source: Cleveland Clinic

Aspects of CPTSD

- Emotional flashbacks
- Tyrannical inner critic
- Wounded inner child
- Social anxiety
- Low self-esteem
- Relationship difficulties
- Hypervigilance
- Hyperindependence
- Emotional dysregulation
- Frequent nightmares
- Sleep disturbances, low quality sleep
- “Highly sensitive person”
- Avoidance
- Toxic shame

Dissociation

"Dissociation is the essence of trauma. The overwhelming experience is split off and fragmented so that emotions, sounds, images, thoughts, and physical sensations related to the trauma take on a life of their own. The sensory fragments of memory intrude into the present, where they are literally relived. As long as trauma is not resolved, the stress hormones the body secretes to protect itself keep circulating, and the defensive movements and emotional responses keep getting played out."

—Bessel van der Kolk, *The Body Keeps Score*

Dissociation

- **Depersonalization-Derealization Disorder**
  - Depersonalization: feeling the self isn't real. Can also feel like you're observing yourself from an external point.
  - Derealization: feeling the world isn't real.

- Feeling spaced out, not tracking conversations/what's going on around them, shifts in behavior and character, retreating to inner worlds.

New Research about Traumatic Memories

A newly published paper demonstrates that traumatic memories are encoded differently. The study involved brain scans of 28 people with PTSD. Sad memories were shown to engage the hippocampus, the part of the brain that organizes and contextualizes memories. The hippocampus was not involved in recounting traumatic memories. The traumatic memories engage the posterior cingulate cortex (PCC), which is involved in internally directed thought like introspection or daydreaming. The researcher explained that it isn't in a state of memory, but a state of present experience. They're not experienced as memories but as fragments of prior events that take over the present moment.

- Neural patterns differentiate traumatic from sad autobiographical memories in PTSD, Ofer Perl, Daniella Schiller, et al. *Nature Neuroscience*, November 30, 2023

The 4 Fs

01 Fight

Combative
Angry
Controlling
Bullying
Narcissistic

02 Flight

Rushing or worrying
Busyholic/workaholic
ADHD
Anxious
Avoidance

03 Freeze

Isolation
Dissociation
Feeling overwhelmed
Social anxiety
Feeling stuck or shut down

04 Fawn

Loss of self
People-pleasing
Avoiding conflict
Parentified child
Unaware of own emotions

Hybrid Types

Fight-Fawn

Combines narcissism and codependence, “the charming bully.” Rarely takes any real responsibility for contributing to an interpersonal problem.

Flight-Freeze

Often stuck in a cycle of working to complete exhaustion, followed by collapse/shutdown.

Fight-Freeze

Passive narcissism, demanding that things go their way, but are not interested in human interaction. Tend to be quiet, limiting conversation.

Fawn-Freeze

History of being treated as a scapegoat, often not realizing they’re in abusive situations (or diminishing it). Have a tendency to constantly apologize.

Fawn-Flight

The super caregiver, always providing for everyone else’s needs. They often project their narcissism onto others, overburdening others with advice.

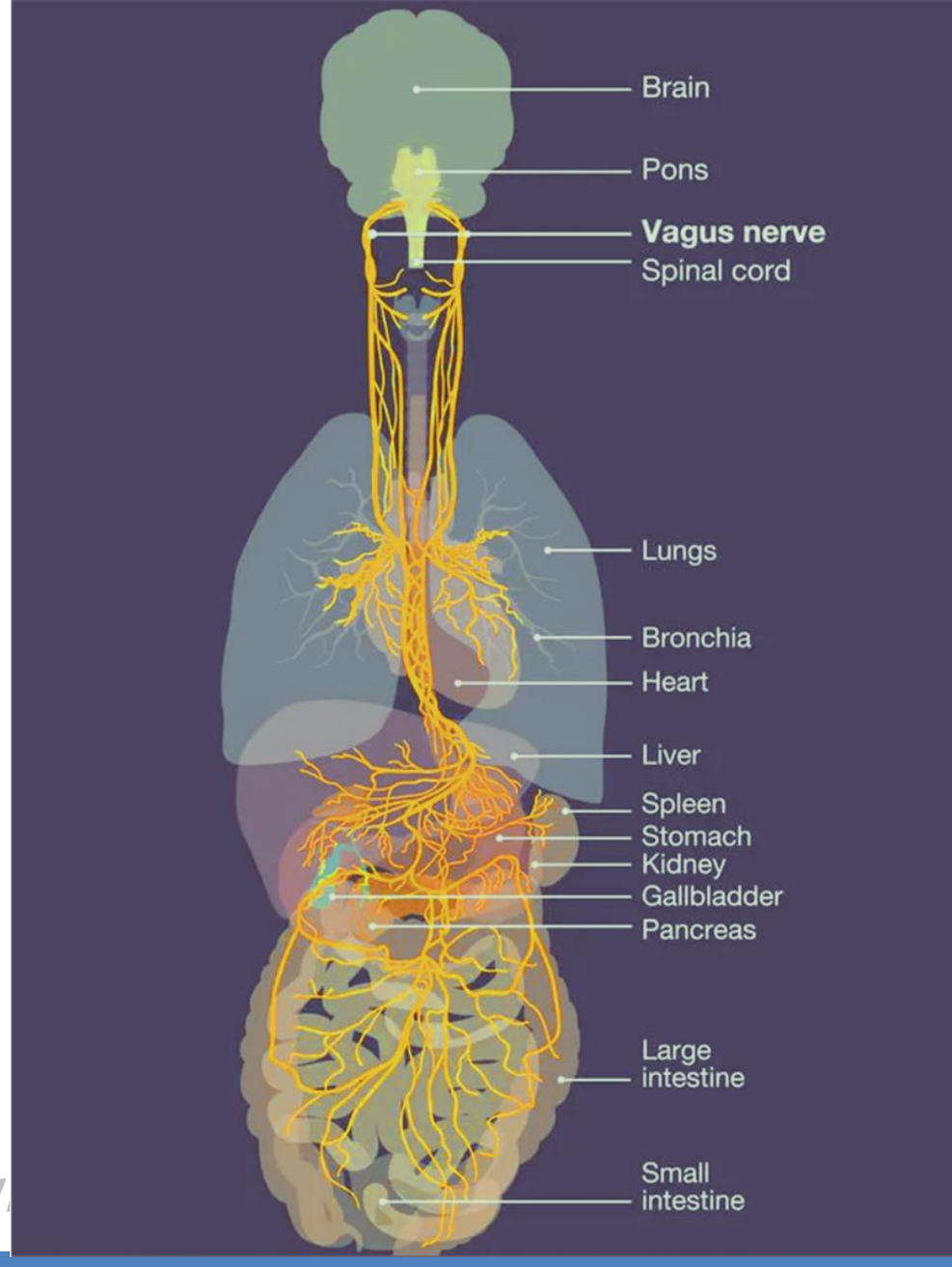
Fawn-Fight

A more aggressive version of Fawn-Flight. Overfocused on others, zealous caretaking; erupts when the one(s) they’re caring for balk at their help.

The Vagus Nerve

What Anxiety and Chronic Stress Do:

- Dry mouth
- Trouble breathing
- Changes in heart rate
- Temperature changes
- Slowed metabolism
- Digestive problems
- Stress hormones!



Autonomic Nervous System

Sympathetic Nervous System

System of Action

- Chaotic energy
- Mobilized to attack
- Driven to escape
- Anxious and angry

Parasympathetic Nervous System

Ventral Vagal

System of Connection

- Connect and communicate
- Go with the flow
- Engaged with life

Dorsal Vagal

System of Shutdown

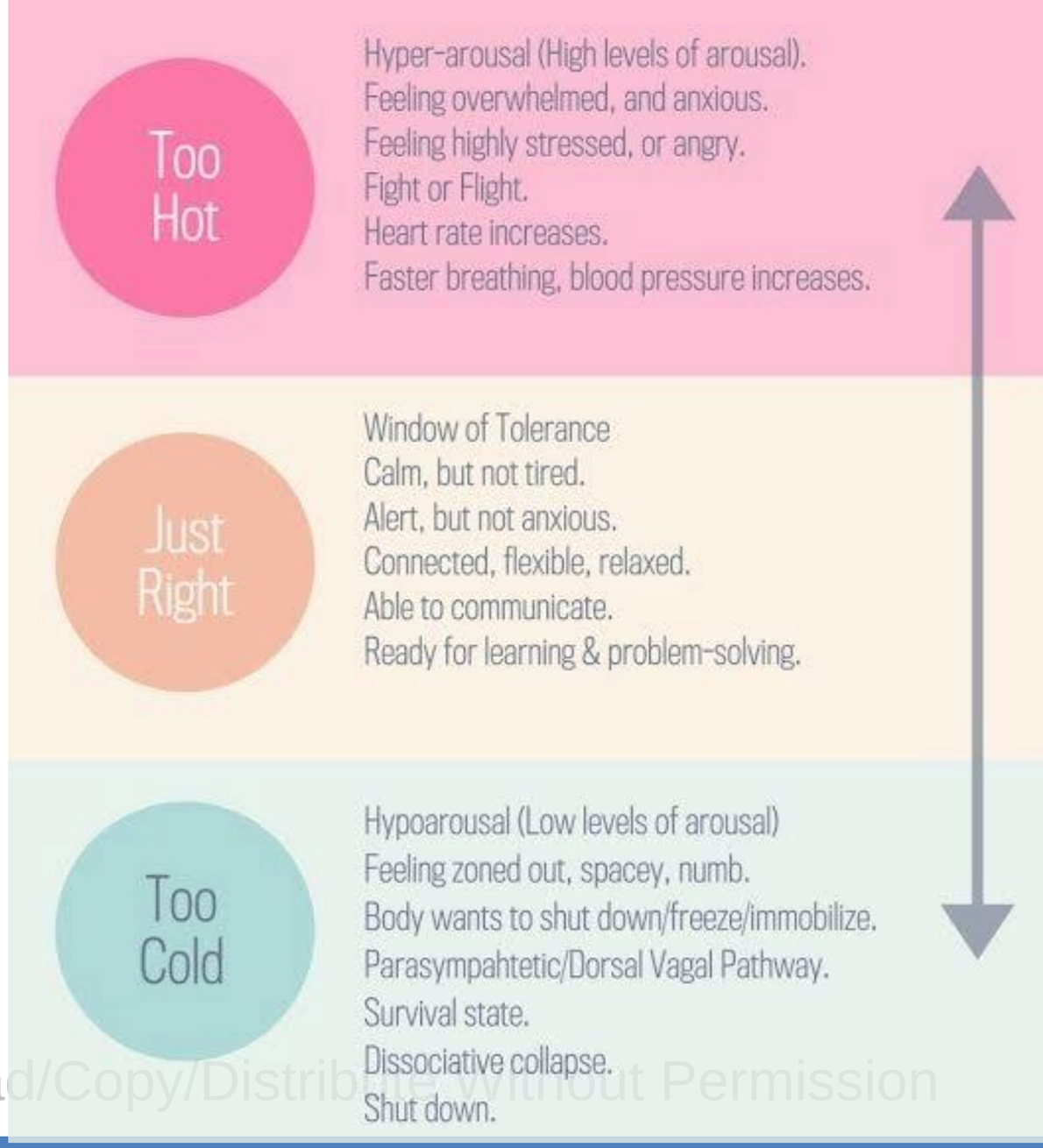
- Disconnected/ dissociation
- Drained of energy
- Just going through the motions

- Hypervigilance is part of neuroception: your internal surveillance system. To get a sense of neuroception, pay attention to what's happening inside your body: heartbeat, breathing rhythm, and tension in the muscles. It's noticing how you react to your environment as well.
- When in survival mode, the sympathetic system activates the 4Fs, and the hypothalamic-pituitary-adrenal (HPA) axis releases stress hormones.

"Our story, and how we think, feel, and act, begins with neuroception."

—Deb Dana, *Anchored*

Window of Tolerance



Connecting with the Present, Learning to Feel Safe

- **Grounding:** anchoring back to earth, feeling like you're back in your body
- **Orienting:** the process of regaining awareness of our surroundings
- **Resourcing:** a "toolkit" for getting out of a dissociated or "triggered" state—anything that shifts someone toward a sense of well-being, safety, or empowerment

Breaking the Cycle

The Cycle of Catastrophizing

Rumination—worry

Magnification—anxiety

Hopelessness

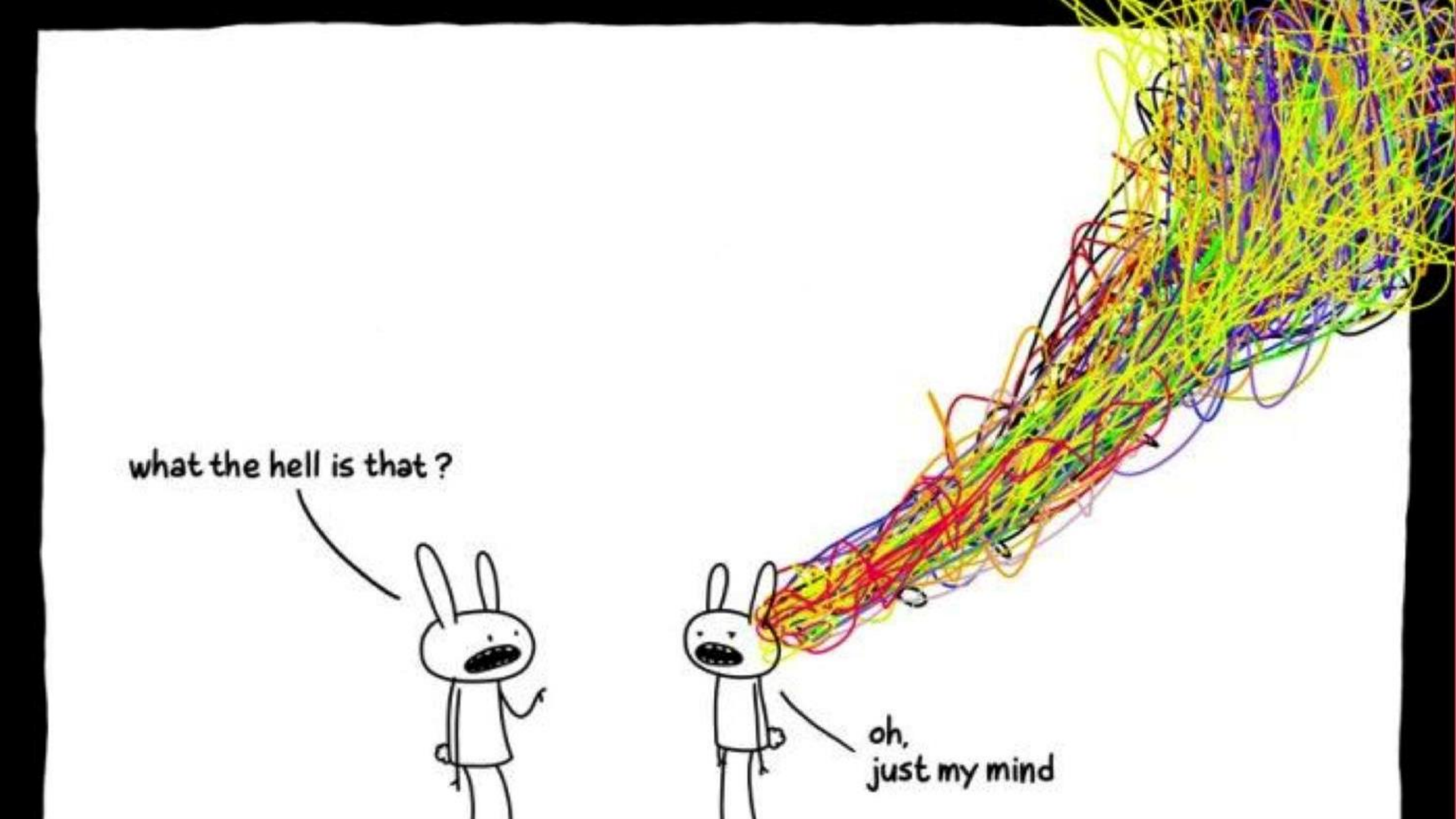
- **AIR Technique (awareness, interruption, replacement):** Change an unhelpful pattern in three steps. (a) *Awareness:* what is the pattern? What needs to change? Notice it in the moment—what is happening? Change in attitude—it's positive to recognize it. Over time, it rewires your brain to react more positively. (b) *Interruption:* Do something physical to break the problem. Disrupt the negativity. *Replacement:* What is your new pattern? Train your body—think ahead to solutions—stretch, meditate, enjoy some music or whatever helps. Redirect your focus to feel empowered. Try to start with one thing.
- **Outcome Independence:** Changing the level of success. Learning to be okay no matter how the situation changes. Don’t tie success to a set goal, be adaptable. Pace yourself, accept setbacks—don’t view them as a failure. It can use distractions—rather than focusing on symptoms and capacity, how many flowers did you see on your walk around the block? Did you listen to an interesting podcast? Was there a nice sunset?
- **Graded Exposure and Pacing:** Find your baseline and work up from there. Plan your increases. What is your safe zone? Don’t do more than you planned for. Adjust your increments as needed. What’s the right place under the threshold to be able to tolerate the activity?
- **Visualizing Success:** Strong correlation between actual and imagining, build up other neural pathways.

Source: Curable

“Where the attention goes, neural firing flows, and the neural connection grows.”

—Dr. Dan Siegel, Clinical Professor of Psychiatry at UCLA School of Medicine

Part 2: Tips for People Who have Trauma


what the hell is that ?
oh,
just my mind

Chronic Medical Problems Include:

- Angina pectoris
- Arthritis
- Asthma
- Autoimmune disorders
- Cardiovascular disorders
- ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome)
- Chronic pain
- Diabetes
- Endometriosis
- Fibroid tumors
- Fibromyalgia
- Gastritis
- Heart disease
- High blood pressure
- Irritable bowel syndrome
- Migraines
- Ulcers
- Tachycardia

Reproductive Issues

- There is a strong correlation between severe physical and sexual abuse and gynecological problems. The connection is also dose-related, meaning the chronic pain and symptoms correlate with the intensity of the abuse.
- ~79% of childhood sexual abuse survivors develop endometriosis and other pelvic problems.
- Women who experience chronic pelvic pain are more likely to use dissociation as a coping mechanism.
- Perimenopause is also harder for people living with CPTSD. Symptoms are more intense. Chronic stress can lead to imbalances of estrogen. As estrogen levels fluctuate and dip in perimenopause, anxiety can worsen. (Involvement of the HPA axis, already dysregulated in CPTSD, becomes more dysregulated during perimenopause.)

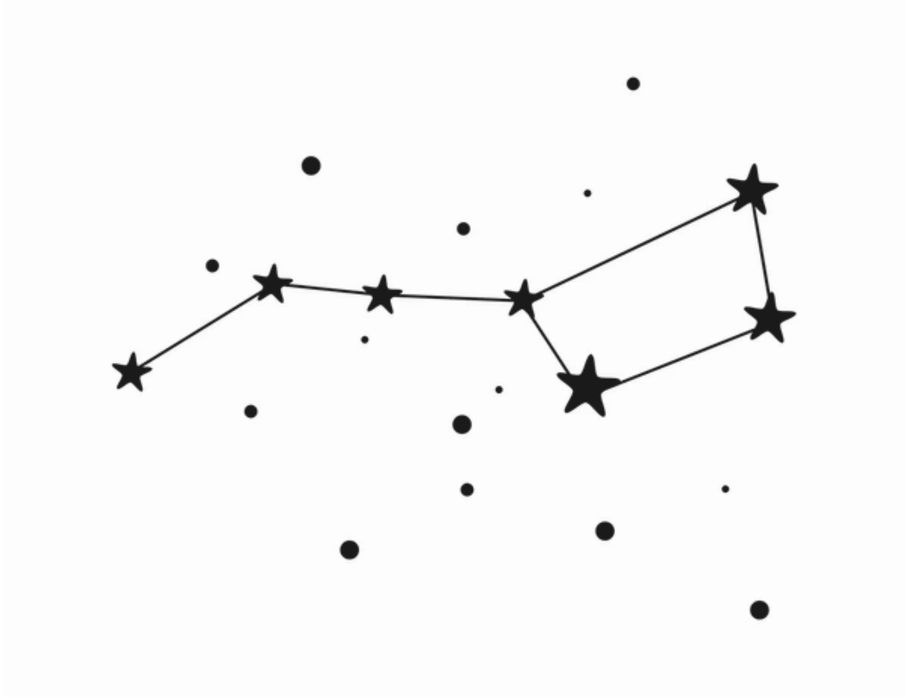
Symptoms of Dysautonomia

A general term for disorders that disrupt the autonomic nervous system. Dysautonomia can range from mild to severe. It can develop at any time in life, but average onset is between 50 and 60, and it affects more than 70 million people worldwide.

- Heart palpitations
- Fatigue
- Chest pain/discomfort
- Sexual dysfunction
- Frequent urination
- Clammy or pale skin
- Disrupted sleep
- Swings in body/skin temperature
- Mood swings and anxiety
- Exercise intolerance
- Sound or light sensitivity
- Vision problems
- Migraines or frequent headaches

Recommendations

- Take a holistic view of the person's medical history. A constellation of seemingly unrelated symptoms can form a picture of chronic stress and trauma.
- Encourage patients to keep track of symptoms and identify patterns.
- Bringing notes and questions to an appointment can fill in important context that may otherwise be forgotten.
- Show patience. Shut downs happen, and going nonverbal comes easily to people living with CPTSD.



Part 3: Tips for Advocacy

No Gatekeeping in Trauma

- From the perspective of the autonomic nervous system, there is no "big T" or "little t" trauma. The nervous system is stuck in functional freeze/survival mode, regardless of cause.
  - You may hear people say things like, "I didn't have it as bad as other people."
  - It's not always caused by physical abuse. Long-term, sustained emotional abuse can result in CPTSD as well.
  - Generational trauma can be passed on.

Promote Predictability and Consistency

- Expectations should be shared ahead of time.
- Set guardrails in the beginning.
- Provide a content warning when approaching difficult topics. It's okay if someone doesn't want to participate in discussions. Preverbal trauma may preclude people from being able to engage in difficult conversations.

Creating a Support System to Empower People Living with CPTSD

People with CPTSD have a harsh inner critic. Try to focus on building self-esteem to change the narrative that the inner critic produces. Changing that narrative is key in neuroplasticity and rewiring the brain to find a more positive outlook and get out of the trap of rumination/catastrophizing, etc.

- Lead with something positive before venturing into constructive criticism. Highlight the strengths of the situation/person as much as possible.
- Ask open-ended questions to help them think things through without the shadow of perceived judgment over them.
- Help people identify their strengths and build upon them. Once they start to gain confidence, it grows to other areas of their lives, and helps with skills like problem-solving.

Don’t Force Interaction

- People living in functional freeze rarely (if ever!) feel safe, calling them out for not participating can bring about feelings of shame. The inner critic *lives* for these moments.
- Allow them to gain trust.
- Check in and listen.

Glimmers

Glimmers: Glimmers are the opposite of triggers. They are small, positive moments that help break the cycle of chronic fear/anxiety and rewire the brain to focus on a healthier outlook. It establishes a habit that is more accessible than waiting for the big achievements. Note them whenever you can. Write them down and/or share them with a friend. Gather a group to share glimmers as often as you can.

Examples

- Feeling cozy and comfortable in bed
- A beautiful sunset while walking the dog
- Drinking a favorite cup of tea and having some time to yourself
- Sketching something that happens to turn out well
- Seeing a picture of something that moves you
- Watching a favorite film, show, or video

Anchors

- Identify and use things that are neutral or pleasing to the experience, to see, hear, touch, and that connect you with the present. Try to choose 3 things per room/space you're in. Consider writing them on a list to have when you need them. If possible, hide any objects that are triggering until you're able to deal with them. Physical anchors can be used as a source of comfort.

- **Resources:** A resource is anything that helps soothe and settle you. It provides a sense of goodness and is used to help anchor us in the here and now. A resource prevents downward spiraling thoughts, emotions, and memories that can impede our healing process. There are two types of resources: internal and external. How we experience our somatic self (our internal environment) will determine how well we can internally resource ourselves. For example, think of a child carrying a doll everywhere as a child, an external source of soothing. Over time, the external becomes internal. The key is whether or not you can tap into that "internal" quality without the external, i.e., the doll is no longer with you. Always resourcing can get in the way of healing. "Trying to breathe though it" can actually wind up causing suppression. Be cognizant of your current needs to be functional and living in your current situation.

- **Creating Capacity:** An essential step in the healing process, so that old trauma can be released and you develop the ability to be more regulated and resilient.

Identifying Resources

1. Write down as many resources as you can.
2. Are they internal or external?
3. Can you remember a time when you used a resource to help you calm down and be more alert?
4. Did it help, or maybe did you feel like it may have kept you from fully processing something at the time that was uncomfortable, but maybe actually needed to be felt?
5. What resources did you have as a child?

Essential Reading

1. *Complex PTSD: From Surviving to Thriving*, Pete Walker
2. *Coping with Trauma-Related Dissociation: Skills Training for Patients and Therapists*, Suzette Boon and Kathy Steele
3. *Healing the Fragmented Selves of Trauma Survivors*, Janina Fisher
4. *No Bad Parts: Internal Family Systems*, Richard Schwartz
5. *The Body Keeps Score*, Bessel van der Kolk
6. *Trauma and Recovery*, Judith Lewis Herman
7. *Anchored: How to Befriend Your Nervous System Using Polyvagal Theory*, Deb Dana
8. *The Myth of Normal*, Gabor Maté

Thank You

For more information and educational resources please visit

https://www.healthadvocatex.org/