

Patient Name: _____

DOB: _____

MR #: _____

UW Health
(University of Wisconsin Hospitals and Clinics Authority)
AUTHORIZATION FOR VERBAL
COMMUNICATION AND/OR TO LEAVE VOICE
MAIL MESSAGES

Index to Auth – Communication

This does not authorize release of copies of medical records – Use form UWH1280490-DT
Authorization for Disclosure of Protected Health Information
Fax: (608) 662-4444

1. Patient Information:

Name – Last, First, MI (Maiden or former name)			
Street Address	City	State	Zip
Medical Record Number (only if known)	Birthdate	Phone Number	

2. Information to be Disclosed: Verbal communication only re: patient's care – This form is not to be used for production of medical records. If requesting written use Authorization for Disclosure of Protected Health Information (UWH1280490-DT).

3a.

VERBAL COMMUNICATION BETWEEN:

☐ **All UW Health providers/locations or specify below**

Checking UW Health includes University Hospital, American Family Children's Hospital, UW East Madison Hospital, and UWH Urgent Care, Specialty Care, and Primary Care locations within Wisconsin.

_____, **and:** _____
(list name of UW Health healthcare facility or specific healthcare provider /staff member) (to whom your confidential information may be disclosed.)

AND/OR

3b.

Leave voice mail for the patient at the following phone number(s): _____
_____ (voice mail includes any information, unless limited below):
Limit voice mail only to information specified: _____
(see back of form for notice regarding voice mail messages)

4. Purpose of Communication: Continued care, unless specified: _____

5. This authorization will expire in one year from signature unless otherwise indicated below:

☐ Until revoked in writing / indefinite

☐ Other specific expiration date: ____/____/____ (mm/dd/yyyy)

(If this authorization is for a minor and signed by a parent or legal guardian the expiration date cannot surpass their 18th birthday.)

****PLEASE SEE NEXT PAGE FOR FURTHER INFORMATION****

In accordance with the conditions listed above and on the next page of this form, I authorize the use and/or disclosure of my medical information. This authorization includes disclosure of information regarding substance use disorder, psychiatric consults and mental illness, developmental disabilities, genetic testing, AIDS or AIDS-related illness, sexually transmitted infection, and/or HIV test results, unless I limit the disclosure to exclude the following: _____

Signature of Patient/Representative: _____ Today's Date: ____/____/____

If signed by person other than the patient, print name and state relationship and authority to do so. (See next page for information about signatures)

Print Name: _____ Relationship: _____

Patient is:	☐ Minor	☐ Incompetent/Incapacitated	☐ Spouse/Domestic Partner of Deceased
Legal Authority:	☐ Legal Guardian	☐ Parent of Minor	☐ Next of Kin
	☐ Health Care Agent		☐ Other: _____
	☐ Personal Representative		

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Print Name: _____ Relationship: _____

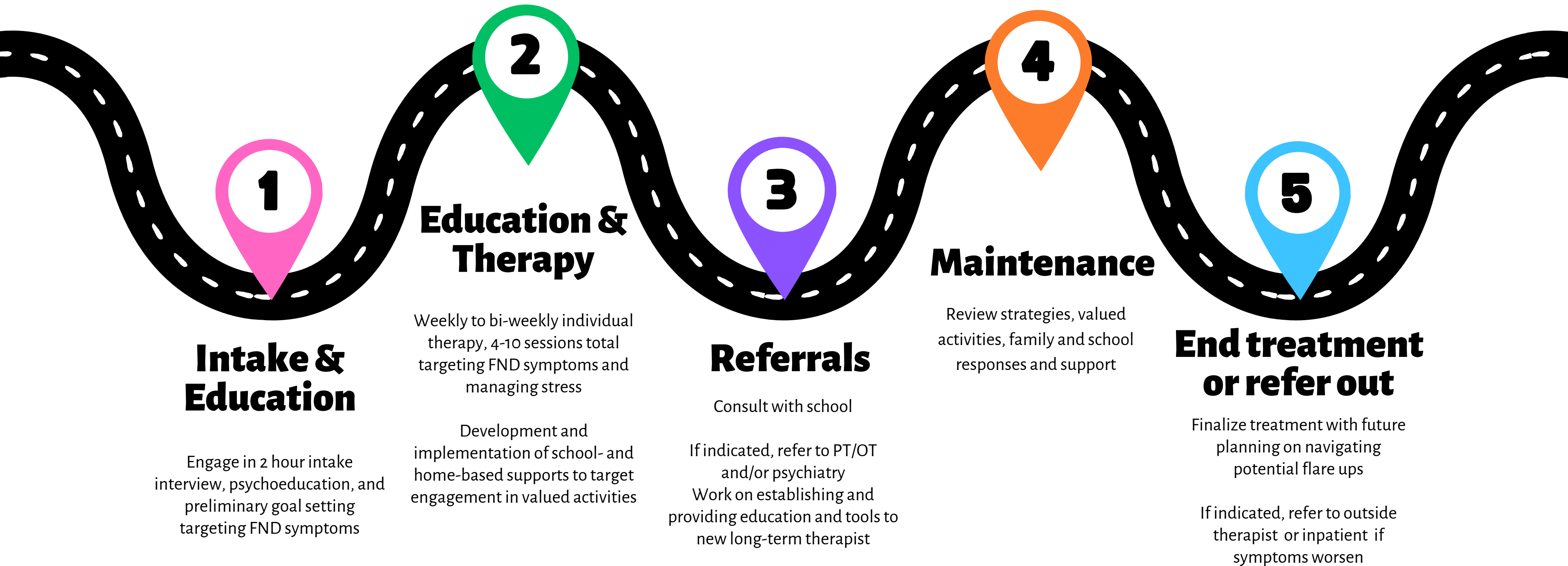
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PEDIATRIC FND CLINIC: ROADMAP FOR TREATMENT

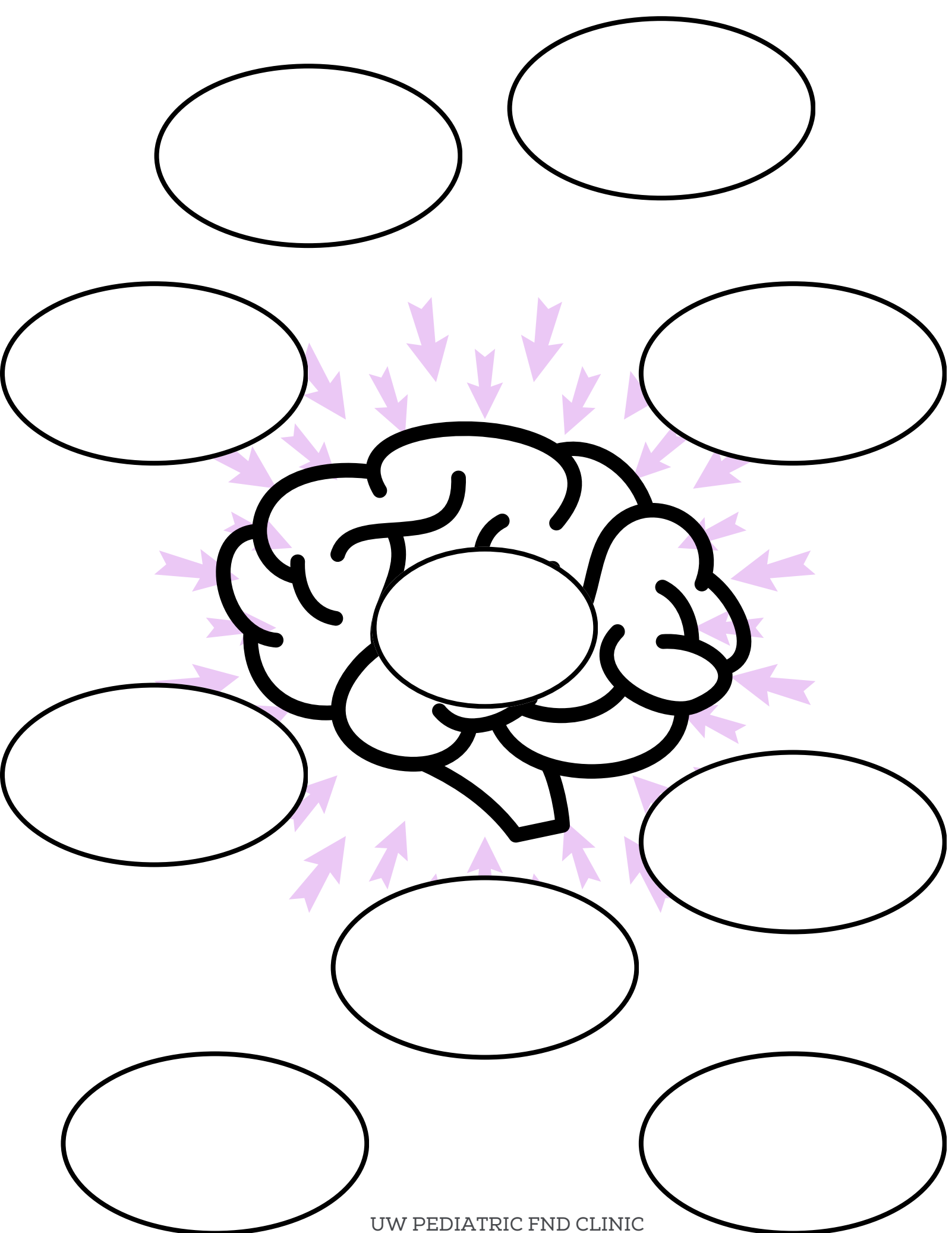


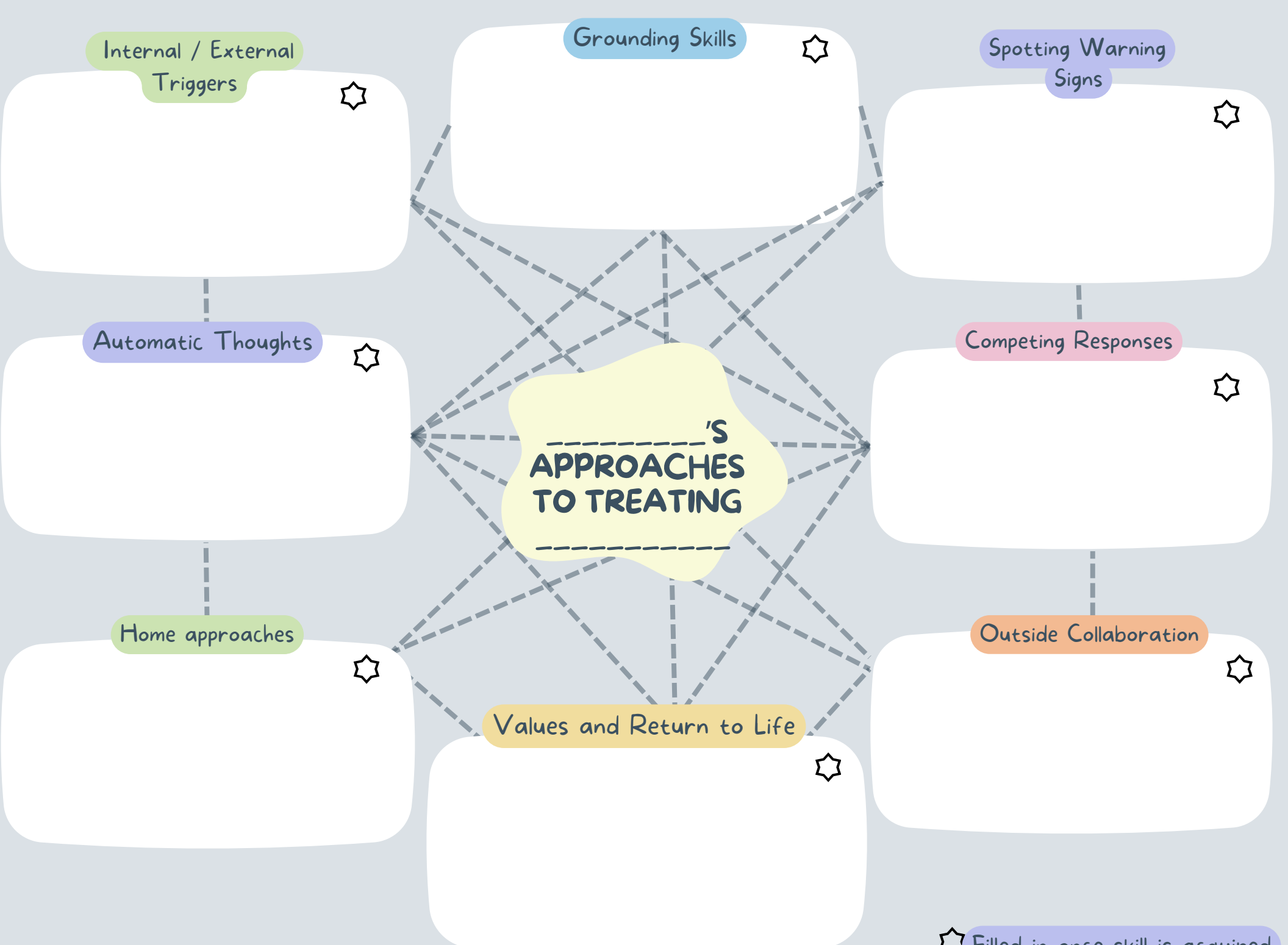
Department of Psychiatry
UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH

UWHealth



Pediatric FND Clinic
Aisha Rosh, PhD, NCSP
Clinical Psychologist





Internal / External
Triggers

Grounding Skills

Spotting Warning
Signs

Competing Responses

Outside Collaboration

Values and Return to Life

Home approaches

Automatic Thoughts

---S
APPROACHES
TO TREATING

★ Filled in once skill is acquired

SECTION A: BEFORE YOU BEGIN

Thank you for being here. You have found this workbook, likely because you and/or someone who loves you have hope of you feeling better and living free from Functional Neurological Disorder (FND). You are not alone. FND is the second most common diagnosis in neurology clinics after headaches. It has become more common since The Pandemic and Lockdown, especially in adolescents and older adults. **The GOOD news is that the brain can be rewired.**¹ People do get better.² This workbook can help.

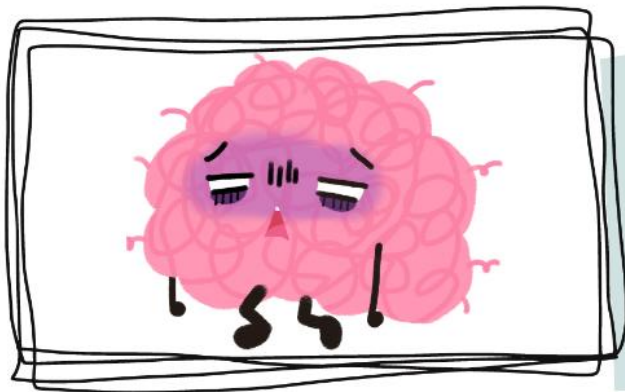
A.1 Let us start with some definitions...

Functional Neurological Disorder:

Functional Neurological Disorder (FND) is a common and treatable medical condition.

According to Dr. Jon Stone & the FND Society, FND is a problem with the functioning of the nervous system. That means that the brain and body are not sending and receiving signals well. The result is unwanted and uncontrollable symptoms that can get worse over time without treatment. With treatment, FND symptoms can decrease or even stop.

FND symptoms are real and not your fault. There are physical changes within your nervous system and brain that have led to your FND symptoms.^{3 4} Often, FND symptoms begin when there is “nervous system overload” and the brain and body cannot process any more information. The brain and body deal with this by releasing the extra energy through physical movements, called FND symptoms. Each type of symptom comes with changes in key areas of the brain and nervous system. Those key areas **can be rewired** with the exercises in this workbook. The goal of this workbook is to help you reduce your symptoms and reengage in life with a richer understanding of how to care for your nervous system.



Common symptoms are:

- Uncontrolled movements in your legs, arms, hands or face
- Brain fog, memory changes, episodes of confusion and disorientation
- Episodes that can look like epilepsy
- Changes in the way you talk
- Pain, numbness or weakness in certain parts of your body

¹ Porto, P., Oliveria L., Mari J., et al. Does Cognitive Behavioral Therapy Change the Brain? A Systematic Review of Neuroimaging in Anxiety Disorders. *The Journal of Neuropsychiatry and Clinical Neurosciences* 21:2, 114-125 (2009).

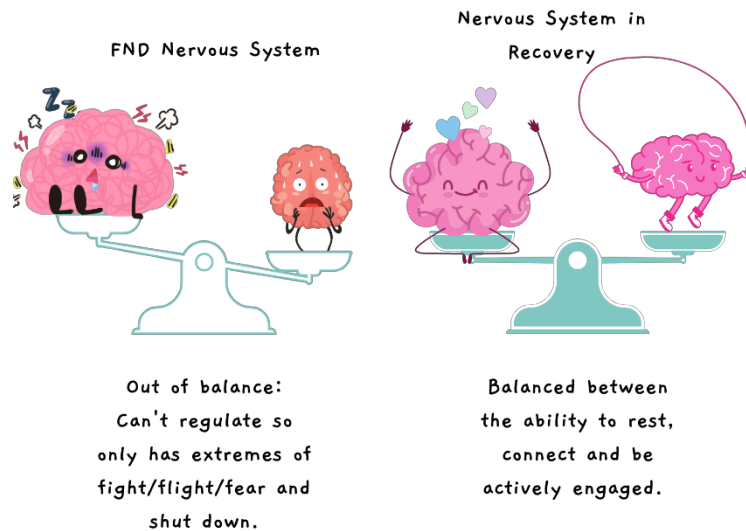
² Vassilopoulos, A., Mohammad, S., Dure, L. et al. Treatment Approaches for Functional Neurological Disorders in Children. *Curr Treat Options Neurol* 24, 77–97 (2022). <https://doi.org/10.1007/s11940-022-00708-5>

³ Roelofs, J.J., Teodoro, T. & Edwards, M.J. Neuroimaging in Functional Movement Disorders. *Curr Neural Neurosci Rep* 19, 12 (2019). <https://doi.org/10.1007/s11910-019-0926-y>

⁴ Perez D., Nicholson T., Asadi-Pooya, A. et al. Neuroimaging in Functional Neurological Disorder: State of the Field and Research Agenda, *NeuroImage: Clinical*, Volume 30, 2021, 102623, ISSN 2213-1582, <https://doi.org/10.1016/j.nicl.2021.102623>.

SECTION E: WAYS TO REWIRE (W2R)

W2R #1: Balance Your Nervous System



If you feel a warning sign, your nervous system is upset and telling your body to have a fight/flight response. The human body is all about balance and has a built-in way to counteract and calm down the fight/flight response. The fight/flight response is balanced by resting and connecting with others. Right now, your rest and connect response needs strengthening so it can be strong enough to balance your fight/flight response. The fastest way to strengthen the rest and connect side of the equation, is to do Vagus Nerve Workouts! Remember, we recommend practicing the exercises below, multiple times a day for one week, before moving to Ways to Rewire #2.

Goal: A strong Vagus Nerve

Vagus Nerve Workout #1: “Wait to Exhale”

Our favorite is to “Wait to Exhale” on in the Appendix on page 27. There are lots of other exercises you can learn, including the following two:

Vagus Nerve Workout #2: Draw out your breath

On paper draw any shape and then, breathe mindfully as you trace your finger along its sides. Find an example shape in the Appendix on page 28.

On the next page, you will find additional Vagus Nerve Workouts you may like to try!

WAY TO REWIRE #1

VAGUS NERVE STRENGTHENING

SING LOUDLY



HUG FOR 20 SECONDS



SPLASH COLD WATER ON YOUR FACE



MASSAGE



MEDITATE



OMEGA 3 FOODS



GARGLE



YOGA



ICE MASSAGE



CHANT



MOVEMENT



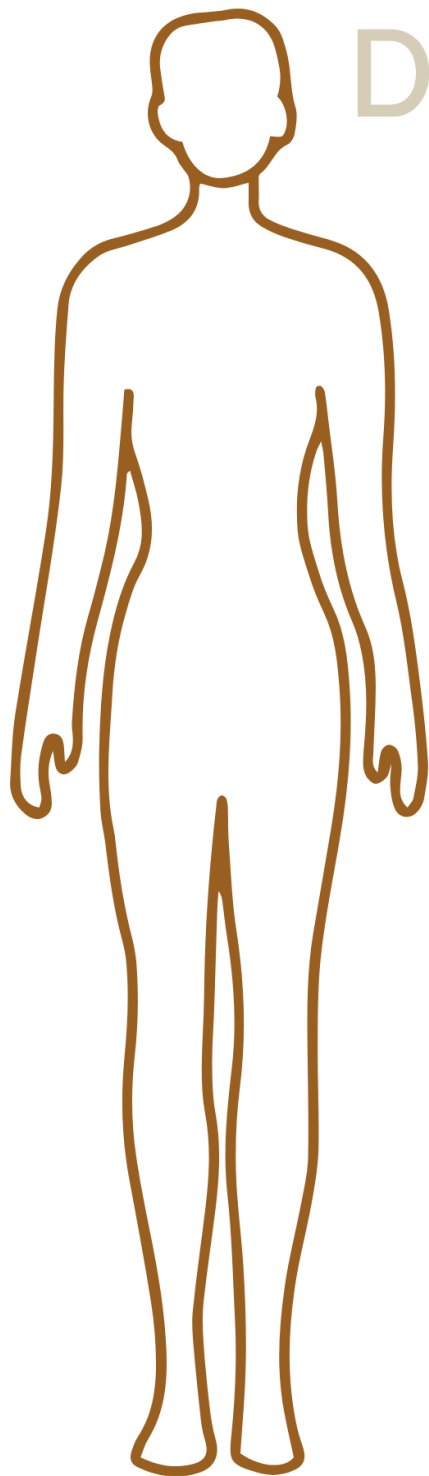
BREATHE



Vagus Nerve
Workout #2 –
Trace Your Breath!



Together, number each symptom and sensation in the order that they occur. This helps you track the FND in your body and will help you and your FND Support Team to determine what techniques you can use next time to calm your nervous system.



Draw what you felt before it happened

these are your warning signs



Mixed up



Tight



Pain



Far away or flipped

(My own sensation)

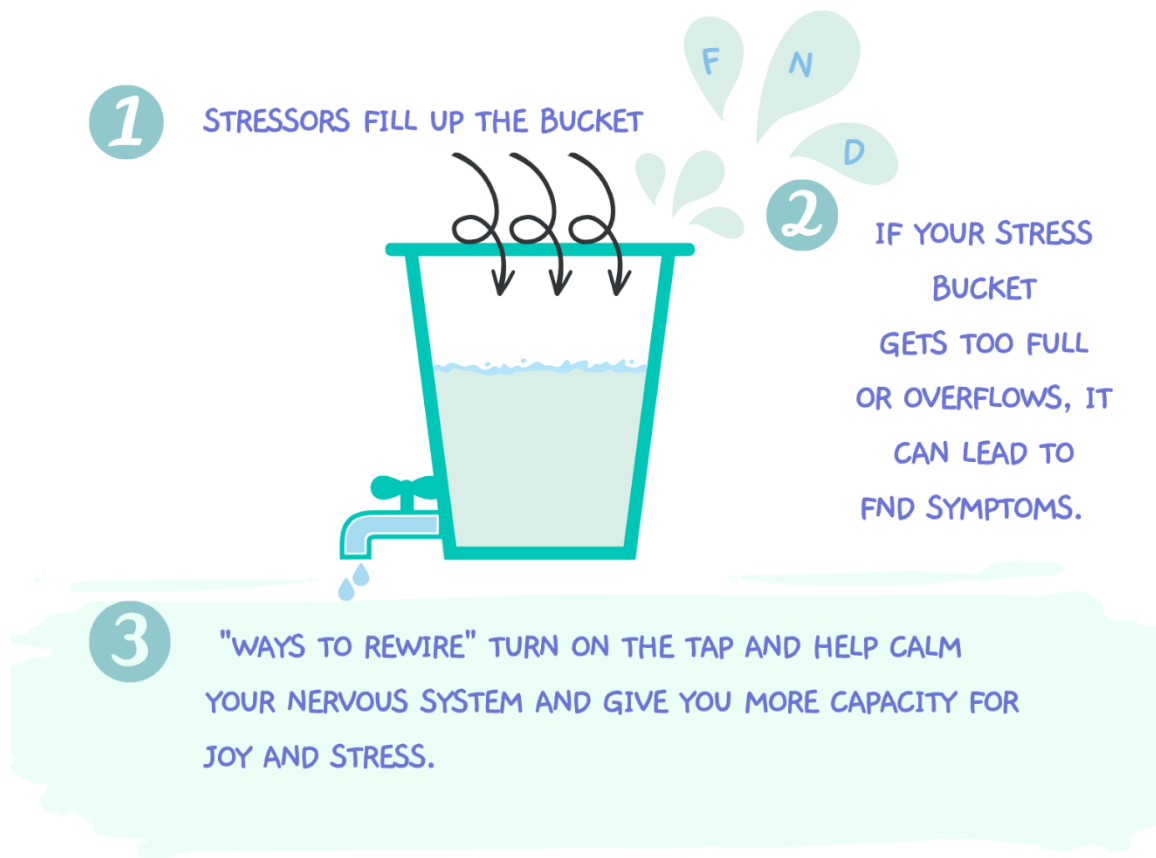
(My own sensation)

SECTION B – THE RESET PROTOCOL

B.1 What is it?

The Reset Protocol is a gentle and research-based (brain science!) series of exercises to complete over a weekend to reset your nervous system and prepare yourself for the work of rewiring. This calms your nervous system, turns on the tap and offloads stored up stress in your body. Imagine your body is a big bucket, filled with stress:

THINK OF YOUR NERVOUS SYSTEM AS A BUCKET O' STRESS



Starting FND treatment will take energy you may not have yet. To make room for this work in your bucket, turn on the tap. Rest your nervous system with [The Reset Protocol](#).

B.2 When should I use it?

Now: The Reset Protocol is a must, no matter how long you have had FND or what treatments you have already tried. For most people’s schedules, the best time to start the Reset Protocol is on a Friday evening. They’d then do the exercises all of Saturday and up until Sunday night. You can choose any 2-3 days that you are able to devote to the protocol. “The Reset Protocol” sounds very official and medical, because it works, but it is also a simple kindness after the hard journey that brought you here.

Later: You can always come back to the Reset Protocol when you need it. The more you do it, the stronger the neural pathways get.⁵ If you have a flare up, do the reset protocol again.

B.3 Why does it work?

The Reset protocol helps reduce symptoms and relieves “nervous system overload”. People with FND have had changes to their brain which make their nervous system more sensitive to sensory inputs. Things you can see, hear, touch, smell, taste and sensations within your body can more easily bombard a nervous system affected by FND.

B.4 What should happen after the Reset Protocol?

After completing the Reset Protocol, you may already be feeling better and having fewer symptoms. To continue this trend, bring some of what you learned during the reset protocol into your every day routine . In other words, you need to practice radical self-care when your nervous system is in crisis. DAILY. That means: breathe, drink lots of water, eat regularly, do not skip meals and get enough sleep. Learn more in [Way to Rewire #3](#). You can also use some of these Emergency grounding techniques when a warning sign or symptom occurs (Learn your warning signs in section D):

Daily Practice

	DAY 1	DAY 2	DAY 3
Calming Skill #1	☐	☐	☐
Target Symptom	☐	☐	☐
Ways it helped	☐	☐	☐

THE RESET PROTOCOL

Fun, Gentle and Backed by Brain Science

DAYS 1 & 2
SELF TALK SCRIPT:
YOU ARE SAFE.
I AM LISTENING NOW. THIS IS OUR
TIME TO REST AND RESET.



DAY 3 SELF TALK SCRIPT:
THANK YOU. I HEAR YOU AND I
PROMISE TO TAKE CARE OF YOU, SO
YOU DON'T HAVE TO SHOUT.
I'M IN CHARGE, YOU CAN WORK.

CIRCLE AT LEAST 3 TO COMPLETE EACH DAY FOR 3 DAYS



"Body Scan Meditation"
find on Youtube



Get and give a massage

10

Use a Tens machine on
a comfortable vibration
level on your back, legs
and arms.



Dance to music
in the living room
with one or
more of your FND
support team

Switch from very cold
to hot during a shower



Buy a baby hospital brush
to brush your skin gently



Lay under a weighted
blanket, breathe in
aromatherapy while listening
to relaxing music.

Journal for 30 minutes
each day.



Sit, nap, walk in nature

Pssst...the most important part of this is the self-talk....

Daily Practice

DAY 1 DAY 2 DAY 3

Calming Skill #1

Target Symptom

Ways it helped



DAY 1 DAY 2 DAY 3

Calming Skill #2

Target Symptom

Ways it helped



DAY 1 DAY 2 DAY 3

Calming Skill #3

Target Symptom

Ways it helped



Taming _____

_____ is your over-protective bodyguard.
It has zero chill. Let's write down how you're going to
set some boundaries

What FND Says (The Glitch)

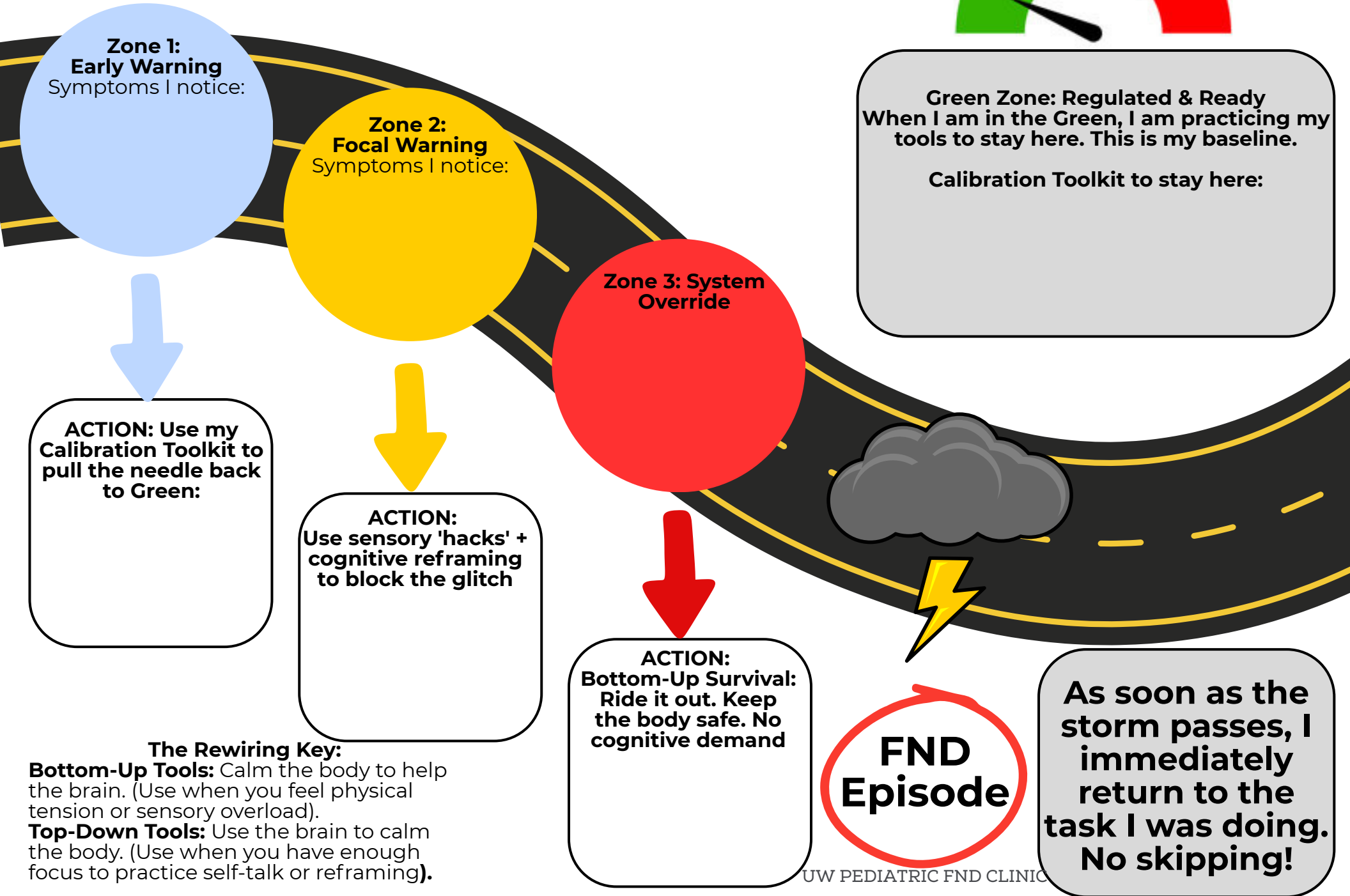
e.g., "Your legs are shaking, you
need to stay in bed today!"

What I Say Back (The Boundary)

e.g., "Thanks for looking out
for me, but I am safe. I'm
going to school anyway"

My Physical Override Hacks:

FND Calibration Roadmap



My Calibration Toolkit:

Cheat Sheet

A quick guide to keeping my nervous system in the Green

Green Zone: Regulated & Ready



- Daily Maintenance: 8+ hours of sleep, eating breakfast, daily movement.
- Sensory: Weighted blanket, calm music playlist, petting my dog/cat.
- Connection: Checking in with my "Cool Captain" (Parent/ Teacher).
- Mindset: "I am in control of my nervous system."

Zone 1: Early Warning



- Paced breathing: 4 in, hold, 6 out
- Find the rainbow in the room
- 5-4-3-2-1 Grounding: Name 5 things I see, 4 I feel, 3 I hear, 2 I smell, 1 I taste.
- The "Reset": A quick lap around the room or shoulder rolls. Self-
- Talk: "My heart is just working hard. I am safe. I can turn the dial back."

Zone 2: Sensory Hacks



- Temperature: Hold an ice cube or splash cold water on my face.
- Taste: Bite a lemon, eat a sour candy, or chew strong mint gum.
- Scent: Smell peppermint oil or a strong candle.
- Tactile: Use a hairbrush or textured fidget on my skin.

Zone 3: System Override



- Tremor: "Clasp & Resist" (Press palms together hard for 10 seconds).
- Weakness: "Shift & Stomp" (Shift weight, squeeze leg, stomp hard).
- Episode/Dissociation: "Grip & Describe" (Push heels into floor, describe an object out loud).
- The Anchor: "My body is resetting. I am safe. I will return to _____ immediately."

My Top 3 Go-To Tools:

1. _____ 2. _____ 3. _____

The Cool Captain Protocol

Supporting your teen through
an FND episode



When turbulence hits, the pilot
doesn't panic. They stay calm
and fly the plane.
Be the Cool Captain for your teen

Pause And Breathe

Take a deep breath.
Keep your face and
voice completely
neutral

1

Validate & Reassure

Keep it brief! "I see FND
is acting up. You're safe.
Take your time, use
your tools, and I'll be
right over here

2

Give Space

Walk away. Do not
hover, stare, or ask
questions. Let their
brain realize there is no
emergency

3

Keep Expectations Stable

Do not let FND excuse
them from chores
or school. Reward effort
and function, not the
symptoms

4

Functional Disability Inventory

Child and Adolescent Form

When people are sick or not feeling well it is sometimes difficult for them to do their regular activities. In the past two weeks, would you have had **any physical trouble or difficulty doing these activities?**

	<u>No Trouble</u>	<u>A Little Trouble</u>	<u>Some Trouble</u>	<u>A Lot of Trouble</u>	<u>Impossible</u>
1. Walking to the bathroom.	0	1	2	3	4
2. Walking up stairs.	0	1	2	3	4
3. Doing something with a friend. (For example, playing a game.)	0	1	2	3	4
4. Doing chores at home.	0	1	2	3	4
5. Eating regular meals.	0	1	2	3	4
6. Being up all day without a nap or rest.	0	1	2	3	4
7. Riding the school bus or traveling in the car.	0	1	2	3	4

Remember, you are being asked about difficulty due to physical health.

8. Being at school all day.	0	1	2	3	4
9. Doing the activities in gym class (or playing sports).	0	1	2	3	4
10. Reading or doing homework.	0	1	2	3	4
11. Watching TV.	0	1	2	3	4
12. Walking the length of a football field.	0	1	2	3	4
13. Running the length of a football field.	0	1	2	3	4
14. Going shopping.	0	1	2	3	4
15. Getting to sleep at night and staying asleep.	0	1	2	3	4

Functional Disability Inventory

Parent Form

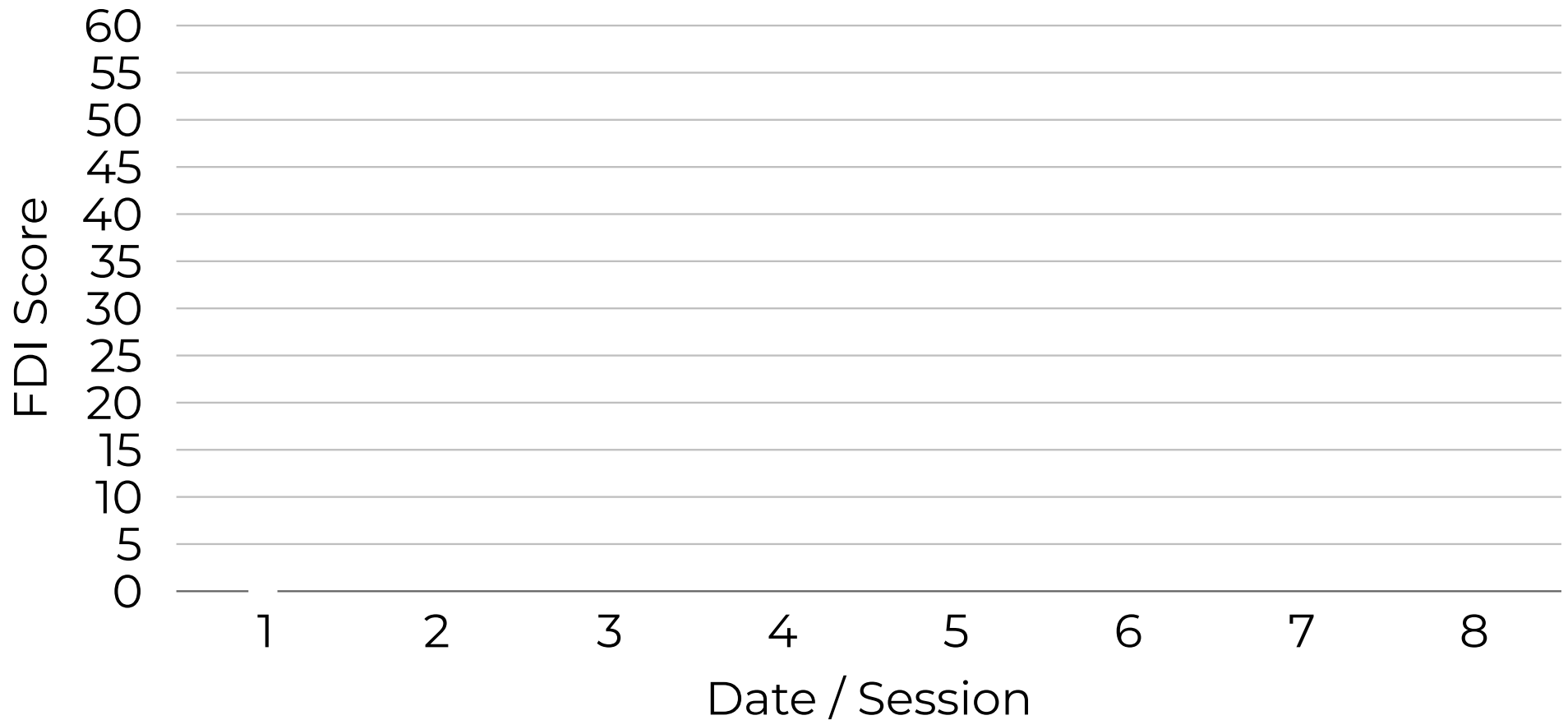
When people are sick or not feeling well it is sometimes difficult for them to do their regular activities. In the past two weeks, would your child have had **any physical trouble or difficulty doing these activities?**

	<u>No Trouble</u>	<u>A Little Trouble</u>	<u>Some Trouble</u>	<u>A Lot of Trouble</u>	<u>Impossible</u>
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5. Eating regular meals.	0	1	2	3	4
6. Being up all day without a nap or rest.	0	1	2	3	4
7. Riding the school bus or traveling in the car.	0	1	2	3	4
<i>Remember, you are being asked about difficulty due to physical health.</i>					
8. Being at school all day.	0	1	2	3	4
9. Doing the activities in gym class (or playing sports).	0	1	2	3	4
10. Reading or doing homework.	0	1	2	3	4
11. Watching TV.	0	1	2	3	4
12. Walking the length of a football field.	0	1	2	3	4
13. Running the length of a football field.	0	1	2	3	4
14. Going shopping.	0	1	2	3	4
15. Getting to sleep at night and staying asleep.	0	1	2	3	4

Functional Ability Tracking:

My Road to Recovery

Recovery is the expansion of your life, not just the absence of symptoms



0–12: Minimal Disability
13–20: Mild Disability
21–30: Moderate Disability
31+: Severe Disability

My Level-Up Log: Functional Wins

"What is a 'Win'?" A win is not the absence of symptoms. A win is completing a task while using your tools. Even if you felt a "rumble" or a "glitch," if you used your tools and returned to your task, that is a 100% successful Win

Date	The Valued Task (what I was doing)	Tool Used? (yes/no)	Did I return to the task?	The Win (how I felt after)

My Functional Levels

- **Level 1:** I completed the task with FND along for the ride.
- **Level 2:** I completed the task + used my tools.
- **Level 3:** I completed the task + used my tools + returned to the task immediately after a glitch.

Color in one star for every Level 3 win you have this week!



Pattern Recognition Log

A "glitch" rarely happens in a vacuum. By identifying the patterns that precede your symptoms, you can move from reacting to a glitch to preventing one. Use this log to observe the context of your day. Over time, you will begin to see recurring themes—certain environments, emotional states, or physical demands that act as "glitch triggers."

Date	Context (Environment, Social, Mental, Physical)	Pre-Glitch Sensation	Tool Utilized	Outcome

Themes I noticed:

GOAL TRACKER

NAME: _____

GOAL #1: _____

USE THE TRACKING FORM BELOW TO TRACK YOUR PROGRESS.

DATE / SESSION #	1-10 RATING OF PROGRESS TOWARD GOAL (1 = NO PROGRESS; 10 = MET GOAL)	WHAT I TRIED

NOTES

GOAL TRACKER

NAME: _____

GOAL #2 : _____

USE THE TRACKING FORM BELOW TO TRACK YOUR PROGRESS.

DATE / SESSION #	1-10 RATING OF PROGRESS TOWARD GOAL (1 = NO PROGRESS; 10 = MET GOAL)	WHAT I TRIED

NOTES

GOAL TRACKER

NAME: _____

GOAL #3 : _____

USE THE TRACKING FORM BELOW TO TRACK YOUR PROGRESS.

DATE / SESSION #	1-10 RATING OF PROGRESS TOWARD GOAL (1 = NO PROGRESS; 10 = MET GOAL)	WHAT I TRIED

NOTES

Class is Back in Session

How school can support FND recovery



Discussion topics for schools and families

- FND is the second most common reason for visiting a neurology office, after headache. It is common and treatable.
- Can you schedule a parent/school meeting to discuss the FND Response Plan?
- Can a 504 plan help the student have scheduled daily coping time?
- What are the school nurse and counselor's recommendations to help the student stay in school and cope with physical sensations and overwhelming thoughts?



Classroom friendly coping skills

- 4-7-8 Breathing
- Draw a shape on paper and trace it with your finger as you breath in for one side, out for the next, in for one side, out for the next.



We recommend in person school for kids with FND. Progress and recovery happen when we face challenges with the support of their community.

- FND Society

Sharing resources with your school



- FND Response Plan
- Classroom friendly coping skills
- FND Hope Website

D.3 Nervous System Calming Techniques

When a warning sign happens, it's time to practice a healthy response. Practicing healthy responses will rewire your brain. The more you practice, the stronger the healthy, NEW, neural pathway becomes. The stronger the pathway becomes, the easier it gets to use. Review the Classroom Friendly Calming Tips below and circle which you will use. Prepare your backpack or purse with the things you will need to help you use these calming techniques when you are away from home.

CLASSROOM FRIENDLY CALMING TIPS for your nervous system



Temperature:

Cold will slow your heart rate.
Drink ice cold water. Rub
an ice cube on your wrist.



Aromatherapy:

Carry a scent you like
with you and inhale
when needed.

Engage all of your senses
with the 54321 Exercise.
It will bring you out of
your head and into the
present moment.

Opposite Action:

Do something intentional
with the affected body part.
Press a shaking hand, swing
a jerking arm.



Paced Breathing:

Inhale for 4, Hold for 7,
Exhale for 8.



Step away from what
you're doing or into the
hallway for 5-10 minutes,
with permission.



Progressive muscle relaxation:

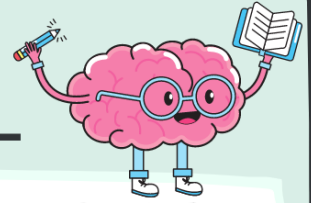
Start with the top of your
body from head, shoulders,
knees and toes. Tighten each
muscle for 5 seconds and then
release.



Suck on sour candy.



FND RESPONSE PLAN



NAME/DOB: _____

I, _____, HAVE BEEN DIAGNOSED WITH FUNCTIONAL NEUROLOGICAL DISORDER, BY MY HEALTH CARE PROVIDER. SYMPTOMS CAN HAPPEN THROUGHOUT THE DAY OR IN EPISODES. EPISODES ARE SIMILAR TO PANIC ATTACKS, **ARE NOT MEDICAL EMERGENCIES** AND GET BETTER WHEN RESPONDED TO CORRECTLY.

FOR ME, FND LOOKS LIKE:

MY WARNING SIGNS

WHAT TO DO DURING

- ☐ REMAIN CALM.
- ☐ SPEAK POSITIVELY ABOUT ME OR BETTER YET, NOT AT ALL. I CAN HEAR YOU AND ATTENTION MAKES IT WORSE.
- ☐ HELP ME SAFELY TO THE GROUND.
- ☐ COVER HARD SURFACES NEAR ME.
- ☐ SAY "YOU ARE HAVING AN FND EPISODE. YOU ARE SAFE. YOU HAVE THE TOOLS TO GET THROUGH IT. I AM HERE WHEN YOU ARE READY." THEN GIVE ME PRIVACY AND SPACE.

WHAT TO DO IF AN EPISODE IS ABOUT TO HAPPEN

- ☐ GIVE ME A REASSURING NONVERBAL SIGNAL THAT I KNOW MEANS, "I'M HERE. YOU ARE GOING TO BE OKAY."
- ☐ REMIND ME TO USE A COPING SKILL TO REGULATE MY NERVOUS SYSTEM.
- ☐ _____

WHAT TO DO AFTER

REINVOLVE ME/RETURN ME TO CLASS.

PRAISE ME ONE-ON-ONE FOR COPING THROUGH MY SYMPTOMS.

PLEASE WAIT UNTIL THE END OF THE DAY TO CONTACT MY GUARDIAN USING THEIR PREFERRED METHOD.

WHAT NOT TO DO

- ☐ DO NOT CALL AN AMBULANCE UNLESS INJURED. (PLEASE CHECK BASED ON INDIVIDUAL NEED.)
- DO NOT REMOVE ME FROM SCHOOL.
- DO NOT BEHAVE FRANTICALLY.
- DO NOT TIME THE EPISODES. UNLIKE EPILEPSY, THE CARE DOES NOT CHANGE AFTER 5 MINUTES.



Provider Signature: _____

Date: _____

Provider Name: _____

Provider Contact: _____

Mental Health Provider Letter for FND

Patient Name:

DOB:

Dear Mental Health Provider,

The above patient is followed by the UW Pediatric Functional Neurological Disorder (FND) Clinic. They have been diagnosed with a Functional Neurological Symptom Disorder (FND). FND is the new name for Conversion Disorder or somatizing overwhelming feelings and stress. We would like you to work with them as their mental health provider. This child will continue to be our patient in the neurology clinic. We would like you to consider us as a member of your team.

This patient's FND manifests in the following symptoms during times of extreme or suppressed stress:

Like panic attacks, the frequency of these episodes can go down and even remit for years. Your expertise in brain rewiring (through DBT, CBT, Mindfulness or Somatic work) is what is needed to help this patient begin to:

- Reintegrate their mind-body connection
- Connect sensations in their body with needs that can be met
- Feel self-agency and the ability to change their brain, thinking, behavior and experience of life, stress, and relationships
- Reinforce cognitive skills like reframing "symptoms" to "sensations" and communications from the body to the mind/Self
- De-catastrophize "symptoms" and sensations (Bodies are funny, bodies are neat. They can feel uncomfortable at times, and I am still safe, okay and I can still cope)
- Utilize coping skills: breathing, grounding, body work, boundary work, mindfulness, increasing distress tolerance
- Validate, affirm, and support that is human to need and necessary to have boundaries

We want to reassure you that this patient has been assessed by a pediatric neurologist and does NOT have epilepsy. If they have an episode in your session, please do not call emergency services. Calling emergency services can lead to the patient being unnecessarily treated with antiepileptic medications that can compromise their breathing. These medications will NOT stop their symptoms. Further, the heightened stress that comes with medics and an ER visit tend to prolong the episode, which reinforces FND wiring.

Sincerely,

UW Pediatric FND Clinic

Letter is from the evidence-based Reset + Rewire Workbook by Watson, Carey (2023)

School Letter to Support FND

Patient Name:

DOB:

Dear Educators,

Your student is followed by The Pediatric Functional Neurological Disorders (FND) Clinic and has been determined to have a Functional Neurologic Disorder by their neurologist. They experience episodes that are similar to panic attacks. What you need to know to support this student:

- FND episodes are not emergencies, do not call 911 or remove the student from class. The more normalcy you provide the faster episodes will resolve
- This person is not doing this on purpose
- FND is common AND treatable. This student is actively working on getting better

How to handle an FND episode:

1. Remain calm
2. Redirect the class's attention by saying, "This student just needs some time to work through this. Let's give them space to do that while we continue with our lesson. They will rejoin us when they can."
3. Re-involve the student as soon as possible
4. No need to time the episode. Unlike Epilepsy, no extra action needs to be taken after 5 minutes or more.

Expectations:

Gym: This student is cleared to participate in gym class.

Class: The student may have a perceived inability to participate fully in class at times. The proper response is, "I'm sorry your FND is causing you trouble right now. Is this a good time to use a coping skill? That way, you can re-center before getting back to your work."

Accommodations and Assistive Devices are generally discouraged. We STRONGLY oppose Homebound status for these students as it will exacerbate their symptoms and prolong their debility. Your collaboration and adherence to this plan is vital to the success of this child's treatment. I am available to schedule a virtual meeting with school representatives to help you keep this child in school.

Many thanks,

UW Pediatric FND Clinic

Letter is from the evidence-based Reset + Rewire Workbook by Watson, Carey (2023)

Letter for your Occupational Therapist (OT) (if you are referred to one):

Patient Name/DOB:

Dear Provider,

The above patient has been referred to OT for help in their FND Recovery. FND is short for Functional Neurological Disorder. It used to be called conversion disorder or pseudoseizures. OTs were the first to treat FND after the first world war when it was called "Shell Shock." You are a key part of this patient's FND support and treatment team.

Their condition is not dangerous. If they have episodes during sessions, please use the FND Response Plan given to you by the patient's family.

The following guidance was compiled by pediatric OTs with expertise in treating FND and part of the Reset + Rewire Workbook by Watson, Carey (2023):

Occupational Therapy's role in treating FND

1. Educate on coping and self-management strategies to help with symptom management and better understanding of possible triggers for symptoms
2. Promote independent completion of ADLs
3. Develop plans and strategies to return to preferred activities (IADL), such as: band, sports, clubs, schoolwork, etc.
4. Address how sensory impairments impact symptoms and overall functioning in ADL/IADL. Retrain the body and brain connection to elicit automatic responses.
5. Address sleep and its impact on overall functioning
6. Treat using a Biopsychosocial approach being aware of each predisposing, precipitating and perpetuating factors which could cause or perpetuate a patient's symptoms (1)
 - a. Biological: illness, disease, history or functional symptoms, etc.
 - b. Psychological: personality traits, Poor attachment/coping style, emotional disorder, etc.
 - c. Social: Adverse life events/stressors, childhood neglect, difficult interpersonal relationships, financial difficulties/deprivation, etc.
7. Help determine modifications to activities to improve independence and safety with ADL/IADL (limit DME use, but it is important to note when its use is appropriate)
8. Collaborate with other disciplines for treatment plan and d/c planning

OT Assessment and Treatment

It is not the role of the treating team to focus on what they do not have, rather focusing on positive signs and potentially reversible nature of the disorder focusing on mechanism (problem with software and not hardware problem)

- Develop goals with help from the patient to focus on during therapy and for home exercise programs - Meet the patient where they are and work with them to take the first step forward (Patient lead, therapist guided therapy)
- Let the patient know what to expect with therapy and discuss how you plan to help the patient progress functionally

- UE Assessment tests: hold arms out and assess for UE drifting of affected limb, Tremor entrainment testing - LE Assessment tests: Hoover's test, assessment of twitches or positional deformities

Things to Ask or Discuss during Eval or Treatment

- Ask about symptoms (fatigue, pain, sleep, memory symptoms that are volunteered or observed): when did they start, what makes them worse, what helps subside them, what strategies have they attempted? - What activities are they avoiding? What are they anxious about? What are their stressors/events that perpetuate these symptoms?
- What DME or aides are they currently using?
- Only provide DME if completely necessary. The goal is to decrease dependence on DME o Decrease use of Aids, but openly discuss the risk of falling and importance of safety
- Educate caregivers on importance of independent ADL/IADL completion and restoring normal relationships (vs hovering, disabling, not believing in symptoms/diagnosis)
- Possibly using the UEFI (Upper Extremity Functional Index) or LEFI (Lower Extremity Functional Index) to get a patient's/caregiver's perceived level of impairment (good to have to initiate education and get patient/caregiver on the same page)

Utilize the Sensory Preference Checklist for further assessment/clarity

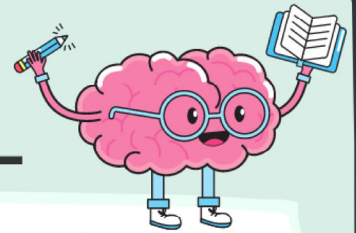
- Helps develop a sensory based treatment vs completing desensitization or environmental modifications without fully understanding the individual
- These strategies positively impact attention, emotional regulation and coping techniques to enhance normal movement
- Sensory activities: environment changes during IADL/ADL completion (light, sound, visual distraction, smells, what is touching them), desensitization, vestibular work on t-ball, in hand manipulation with varied textures or sized items, etc.

Many thanks for your collaboration in caring for this patient.

Sincerely,

UW Pediatric FND Clinic

FND RESPONSE PLAN



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Date: _____

Provider Name: _____

Provider Contact: _____