# RESET & REWIRE THE FND WORKBOOK

#### FOR KIDS & TEENS



Developed by:

Katie Carey, BSN, RN Meagan Watson, MPH

In affiliation with:

The FND Society – Pediatric Special Interest Group FND Hope US Texas Children's Hospital Reset & Rewire: The FND Workbook for Kids & Teens. Copyright © 2023 by Katie Carey and Meagan Watson

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## **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 that you will feel better and live free from Functional Neurological Disorder (FND). You are not alone. FND is the second most common diagnosis in neurology clinics after headaches. It has happened more since the Pandemic and Lockdown, especially in adolescents and older adults. The GOOD news is that the brain can be rewired.<sup>1</sup> People can get better.<sup>2</sup> 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.<sup>3 4</sup> 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

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<sup>&</sup>lt;sup>1</sup>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).

<sup>&</sup>lt;sup>2</sup> 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

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

<sup>&</sup>lt;sup>4</sup> 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.

#### A.2 How to use this workbook...

We made this workbook for a very specific purpose - to be a resource for you and your FND Support Team after you get the FND diagnosis. However, this is not the only resource available. Our goals are to help you reduce your symptoms, increase your confidence in your ability to cope with flare ups and assist you in getting the support you need from your care team. The exercises in this workbook will be helpful whether your symptoms have just started or have been around for a while. Bottom line – you are in control of how fast you rewire your brain to reduce or stop your FND symptoms. We recommend spending at least 45 minutes on rewiring a day, following these steps:

✓ STEP 1: You've already completed Step 1 by reading Section A, hooray! Now you know more about what is happening to you and you know that YOU have the power to feel better. You're prepared to start Step 2!

#### □ STEP 2: Ready your Nervous System with "The Reset Protocol."

Complete The Reset Protocol <u>during the first weekend after receiving this workbook</u>. Ideally, you will start this on a Friday evening and continue it until Sunday night. This can reduce symptoms right away and will help prepare your nervous system for the work of rewiring.

STEP 3: Prepare your team and your symptom toolbox. (Complete Sections C & D).
 Assembling your FND Support Team: Learn who can help you rewire. Be sure to give them each a copy of the "FND Response Plan" and the letters and materials in "The Care Coordination Packet." <sup>5</sup>

Symptom Toolbox: This section will teach you emergency grounding techniques, that are preapproved for the classroom and out in public. Use these when you experience warning signs. Learn why the "FND Response Plan" works. Discuss and share it with the support team you've built.

#### □ STEP 4: Rewire in Section D - Ways to Rewire.

Let the healing begin! This is where you get to "choose your own adventure." You can work through the exercises in order or skip around based on what your brain and body are telling you they need. These exercises can be revisited whenever you need them. We recommend practicing each "Way to Rewire" exercise at least three times per day for one week. If you have a Brain Rewiring Expert (page 8), bring this workbook with you to appointments and practice together!

#### ...Are you ready to start rewiring your brain?

I,\_\_\_\_\_, am committed to rewiring my brain and communicating my needs to my FND Support Team. I understand that no one else can rewire my brain to reduce my FND symptoms but me.

Signature: \_\_\_\_\_

Date:

<sup>5</sup> Kozlowska K, Chudleigh C, Savage B, Hawkes C, Scher S, Nunn KP. Evidence-Based Mind-Body Interventions for Children and Adolescents with Functional Neurological Disorder. Harv Rev Psychiatry. 2023 Mar-Apr 01;31(2):60-82. doi: 10.1097/HRP.00000000000358. PMID: 36884038; PMCID: PMC9997641.

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## **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. Your body has been through A LOT to get here. You deserve and need a break. Imagine your body is a big bucket, filled with stress. The Reset Protocol calms your nervous system and opens the bucket's tap to release the stress stored up in your body:

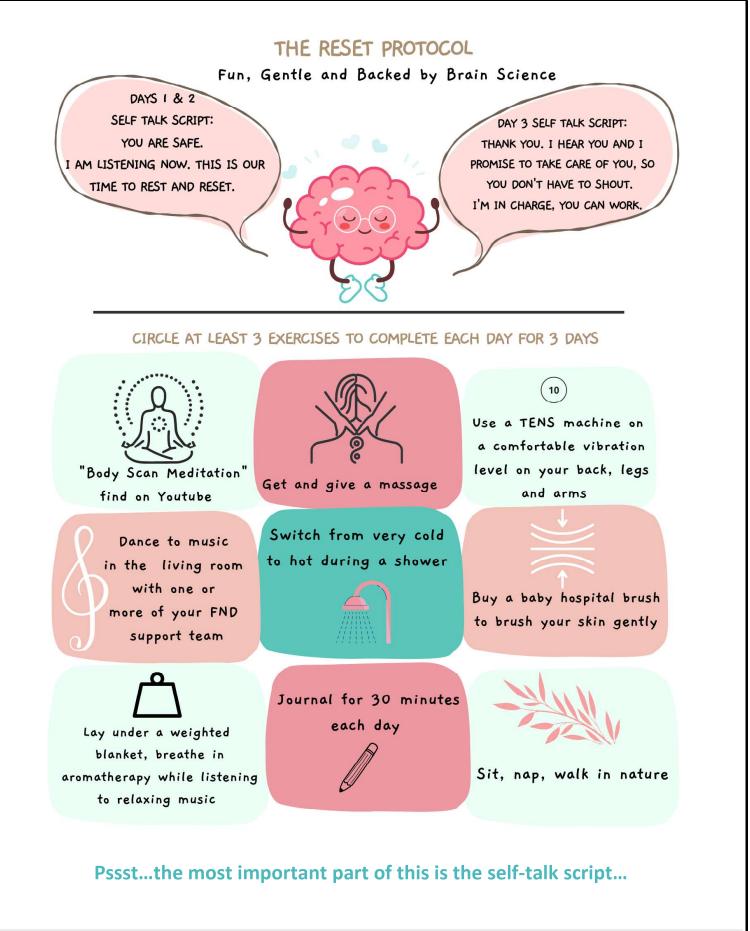
# THINK OF YOUR NERVOUS SYSTEM AS A





YOUR NERVOUS SYSTEM AND GIVE YOU MORE CAPACITY FOR JOY AND 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 <u>The Reset Protocol.</u>



#### **B.2** When should I use the Reset Protocol?

Now: The Reset Protocol is a must, <u>no matter how long you have had FND or what treatments you have already</u> <u>tried.</u> For most people's schedules, the best time to start the Reset Protocol is on a Friday evening. Speak the first script out loud to yourself and then do the exercises throughout the weekend until Sunday night. Once you get to Sunday night, speak and repeat the second script to yourself. If weekends don't work, 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.<sup>6</sup> 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.<sup>7</sup> Things you can see, hear, touch, smell, taste, and the sensations within your body can more easily flood 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 everyday routine. In other words, you need to practice self-care ESPECIALLY 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	0		
Ways it helped	•		

 <sup>&</sup>lt;sup>6</sup> Ranford J, MacLean J, Alluri PR, Comeau O, Godena E, LaFrance WC Jr, Hunt A, Stephen CD, Perez DL. Sensory Processing Difficulties in Functional Neurological Disorder: A Possible Predisposing Vulnerability? Psychosomatics. 2020 Jul-Aug;61(4):343-352. doi: 10.1016/j.psym.2020.02.003.
 <sup>7</sup> Perez, D., Nicholson T., Asadi-Pooya A. 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 C – Assembling Your Team**

Now that you have done the Reset Protocol, it is time to take the next steps in your FND recovery. The Reset Protocol "warms up" the brain to get it ready for brain rewiring. So, what do we mean by Brain Rewiring?

## **C.1** Brain Rewiring

The most basic definition for brain rewiring is: using thinking and behavior exercises to build better brain pathways which communicate without FND symptoms.

In FND, the brain is not communicating well with itself. The brain (neural) pathways that messages travel along may be overloaded, like in a traffic jam. There are also pathways connected to the wrong destination,

like the ones that connect your brain's emotion center and movement center. Unfortunately, scientific technology (like brain scans) is not advanced enough to figure out why this happens.

What we **DO** know is that we can reduce the FND symptoms by making and strengthening new neural pathways and "overriding" the ones that lead to FND symptoms. You do this with brain rewiring exercises: new thinking skills and body calming techniques. This is possible thanks to something called neuroplasticity which allows your brain to learn and change. *You* 



know that *your* brain can be rewired because its wiring was altered to create FND symptoms! Now, you're going to learn how to create new pathways in your brain to reduce or eliminate those symptoms.

## C.2 Who are Brain Rewiring Experts (BREs)?

Brain Rewiring Experts (BREs) are medical or mental health professionals, like psychologists, counselors, physical therapists (PT)<sup>8</sup> or occupational therapists (OT). You can start the brain rewiring process on your own by using this workbook. However, we recommend you assemble an FND Support team, which includes loved ones and Brain Rewiring Experts (BRE). Bring this workbook to your BRE (therapy/counseling) appointments and between those appointments, practice the "Ways to Rewire" starting in Section D.

#### Which Brain Rewiring Experts should you work with?

Follow your doctor's recommendations. We recommend always working with a mental health professional (therapist). A physical or occupational therapist might be helpful too, depending on which FND symptoms you have. They have brain rewiring expertise that helps FND. Depending on where you live though, you may not have access to all of these resources. We wish that was different, but that doesn't mean that you can't benefit from what these experts have learned. We have included their top tips for FND in this workbook. For guidance on the treatment path for FND, refer to the Appendix for a roadmap!

<sup>8</sup> Yu-Na Kim, Nicola Gray, Anna Jones, Stephen Scher, Kasia Kozlowska, The Role of Physiotherapy in the Management of Functional Neurological Disorder in Children and Adolescents, Seminars in Pediatric Neurology, Volume 41, 2022, 100947, ISSN 1071-9091, https://doi.org/10.1016/j.spen.2021.100947.

#### C.3 FND Support Team

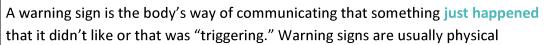
This workbook is for you AND your FND Support Team. Your team could include your parents/guardians, siblings, friends, your school nurse, teachers, doctors and brain rewiring experts. The Appendix at the end of this workbook includes a FND Support Team sheet and letters for you to share with each member of your team. The letters lay out how they can use their expertise to help you, even if they have never heard of FND.

## **SECTION D: SYMPTOM TOOLBOX**

## **D.1** Warning Signs

Knowing an FND symptom is about to start is extremely important for two reasons:<sup>9</sup>

- 1. You can stop the symptom before it starts.
- 2. You can begin to understand what your body is trying to tell you.



sensations in the body that come before FND symptoms. Listening to your warning signs can help you and your Brain Rewiring Expert better understand how to cope with triggers in the future. Learning how to cope is what allows your brain to have more time to choose a different, more effective pathway. On the new healthy pathway, overload is released in a helpful way, instead

of through FND symptoms.

When you feel a warning sign, know that you are okay - that you are in control of your brain and that you can listen and respond to your body's needs.

# **D.2** Common warning signs that you may experience

Where	What happens
Voice	Shaky, high-pitched, quiet, slur, slowed down, different
Eyes	Far away, dilated, pinpoint pupils, closed, darting
Arms and Hands	Shaking, tremoring, stiff, unable to move, contorted
Legs	Shaking, tremoring, stiff, unable to move, contorted

Work with someone on your FND Support Team who has seen your FND symptoms and ask them to circle what happens on the chart above. Have them do this while you draw what YOU have *felt* on the diagram below. Then, compare what your support has seen and what you have experienced. Together you will get a fuller picture of what signs come first and can give you enough warning to slow down the "FND train" and move to a new neural path.

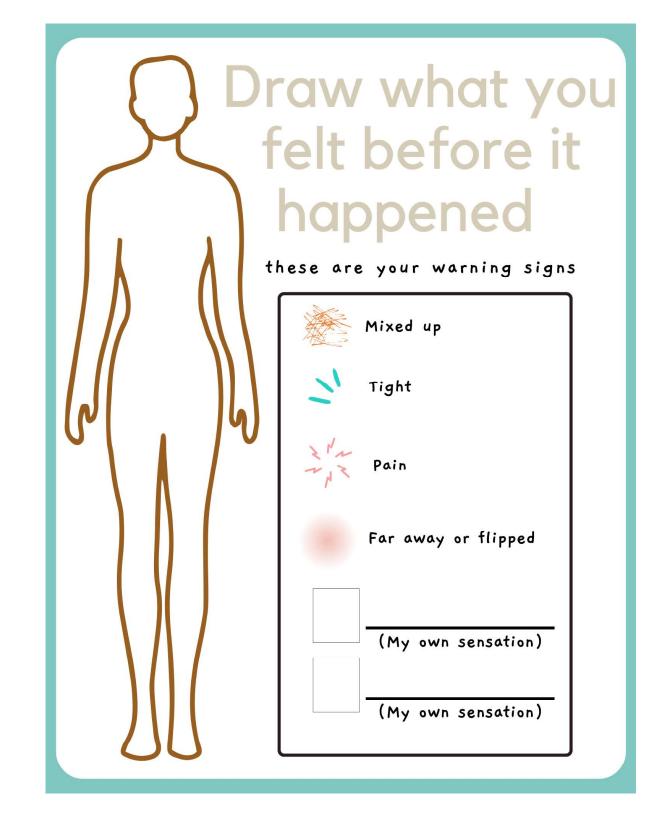
<sup>9</sup> Fobian AD, Szaflarski JP. Retraining and Control Therapy (ReACT) is a bottom-up, body-oriented intervention. Seizure. 2021 Nov;92:236-237. doi: 10.1016/j.seizure.2021.09.015. Epub 2021 Sep 27. PMID: 34619526.





Image credit: Averiel Hossley

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After you have both done your activity and shared with each other, see if you can figure out what signs happen first, second, third, etc. 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 and interrupt the FND cycle.

#### **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 is to use. Review the Classroom Friendly Calming Tips below and circle the ones that you will use early in your healing. Add the things you'll need to use these calming techniques to your backpack or purse so that you'll have them when you're 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 Method. (see Appendix) It will bring you out of your head and into the present moment.

Paced Breathing:

Try either Belly Breathing,

Box Breathing, or "Wait to

Exhale" (see Appendix)

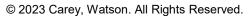
Progressive muscle relaxation: Start with the top of your body from head, shoulders, knees and toes. Tighten each

muscle for 5 seconds and then release. Opposite Action: Do something intentional with the affected body part. Press a shaking hand, swing a jerking arm.

After getting permission, step away from what you're doing or into the hallway for 5-10 minutes.







### D.4 Thinking Skills - What to think when warning signs happen

Thoughts help rewire our brains, too. When a warning sign occurs, remain calm and practice saying:

I am going to be okay.

#### I don't have to have FND symptoms, I am in control.

When people first start treatment, feeling certain warning signs can spark overwhelming thoughts like, "Oh no! It's happening again. I'm going to have FND symptoms, and everyone will see and I won't get better, and..." This is common. Talk back to this thought. Practice interrupting those thoughts by thinking or saying out loud:

"I know what this is. My body is telling me I need to calm my nervous system. I don't have to have FND now."

Sometimes, FND symptoms can't be stopped. If that is the case, you and your support team members will want to know how best to respond. Discuss the recommendations below with your support team members.

How a support person can help (During Warning Signs) -Reduce the sensory inputs: turn off noise, guide others out of the room (if at home), lower lights -Use a secret nonverbal signal that you know means "I'm with you. You are going to be okay." -Model the "Wait to Exhale" breath (see Appendix) -Remind you to use a coping skill

## **D.5 FND Response Plan and Why It Works**

An FND Response Plan, backed by brain science and proven to help others with FND, is on the next page. Fill in the blanks to make it meet your needs and hang it up on your fridge. Then, give a copy to each member of your FND support team to make sure everyone is on the same page. See page 11.

It helps to always carry it with you in case someone who doesn't know you have FND calls your local emergency line.

# 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 MORE LIKELY TO OCCUR WITH NERVOUS SYSTEM OVERWHELM, \*\*ARE NOT MEDICAL EMERGENCIES\*\* AND CAN GET BETTER WHEN RESPONDED TO CORRECTLY.

FOR ME, FND LOOKS LIKE:

MY WARNING SIGNS

#### WHAT TO DO IF AN EPISODE IS ABOUT TO HAPPEN

	GIVE ME A REASSURING NONVERBAL SIGNAL	
WHAT TO DO DURING	THAT I KNOW MEANS, "I'M HERE. YOU ARE GOING TO BE OKAY."	
REMAIN CALM. SPEAK POSITIVELY ABOUT ME OR BETTER YET, NOT AT ALL. I CAN HEAR	REMIND ME TO USE A COPING SKILL TO REGULATE     MY NERVOUS SYSTEM.	
YOU AND ATTENTION MAKES IT WORSE.	WHAT TO DO AFTER	
THE GROUND.	REINVOLVE ME/RETURN ME TO CLASS.	
COVER HARD SURFACES NEAR ME.	PRAISE ME ONE-ON-ONE FOR COPING THROUGH MY SYMPTOMS.	
SAY "YOU ARE HAVING AN FND EPISODE. YOU ARE SAFE. YOU HAVE THE TOOLS TO GET THROUGH IT. I AM	PLEASE WAIT UNTIL THE END OF THE DAY TO CONTACT MY GUARDIAN USING THEIR PREFERRED METHOD.	
HERE WHEN YOU ARE READY." THEN GIVE ME PRIVACY AND SPACE.	WHAT NOT TO DO	
	DO NOT CALL AN AMBULANCE UNLESS INJURED. (PLEASE CHECK BASED ON INDIVIDUAL NEED.) DO NOT REMOVE ME FROM SCHOOL.	
FND 🐝 HOPE	do not Behave frantically. <u>Do not time the episodes. Unlike epilepsy, the care</u> <u>DOES not change after 5 minutes</u> .	
Provider Signature:	Date:	
Provider Name:	Provider Contact:	

#### How does the FND Response Plan work?

This response does not reinforce FND-creating pathways and DOES communicate support.<sup>10</sup>

We know this because we have applied 2020 research from the Yale School of Medicine Child Study Center in our own FND clinics and have seen it work. Yale's research has shown the potential for parents and FND Support Team members to help your brain wiring by responding using the recommended phrases below.

"You are having an FND episode. You are safe" ... this communicates Acceptance of where you are.

"You have the tools to work through it. I will give you the space you need to do that." ...this conveys your Confidence in your ability to do hard things.

"I'm here when you're ready" ... reassures you that they will be Supportive when you need them.

#### Acceptance + Confidence = Support. <sup>11</sup>

This plan supports YOU and not FND. A support person accidently makes FND wiring stronger when they:<sup>12</sup> (What NOT to do)

- Behave frantically
- Call 911 (emergency services number)
- Use this time to give attention or affection
- Go to the Emergency Room

#### Recap

School Friendly Calming Tips are the emergency "Ways to Rewire" we recommend you use these during warning signs and FND symptoms. There are many other "Ways to Rewire" that, when practiced daily, will help build healthier neural pathways.

In the next section, you will learn and practice one "Way to Rewire" daily, every week for ten weeks. We recommend you do this with your Brain Rewiring Expert (BRE). Practicing brain rewiring exercises - even if just for two minutes - strengthens the new neural pathways so that they become strong and automatic. Any time you interrupt or stop using unhealthy pathways that lead to FND symptoms, they will get weaker, make them less automatic, and decrease your FND symptoms.

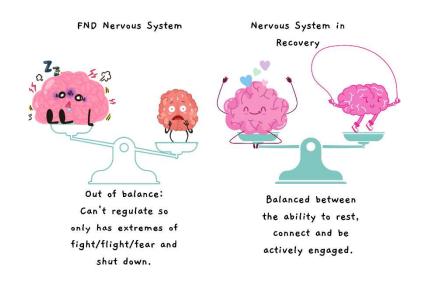
<sup>10</sup> Lebowitz E, Marin C, Martino A, et al. Parent-Based Treatment as Efficacious as Cognitive-Behavioral Therapy for Childhood Anxiety: A Randomized Noninferiority Study of Supportive Parenting for Anxious Childhood Emotions, Journal of the American Academy of Child & Adolescent Psychiatry, Volume 59, Issue 3, 2020, Pages 362-372, ISSN 0890-8567, https://doi.org/10.1016/j.jaac.2019.02.014.

<sup>&</sup>lt;sup>11</sup> Lebowitz E, Martin C, Martino A, *et al.* Parent-Based Treatment as Efficacious as Cognitive-Behavioral Therapy for Childhood Anxiety: A Randomized Noninferiority Study of Supportive Parenting for Anxious Childhood Emotions, Journal of the American Academy of Child & Adolescent Psychiatry, Volume 59, Issue 3, 2020, Pages 362-372, ISSN 0890-8567, https://doi.org/10.1016/j.jaac.2019.02.014.

<sup>12</sup> Zilcha-Mano, S., Shimshoni, Y., Silverman, W. K., & Lebowitz, E. R. (2020). Parent-child agreement on family accommodation differentially predicts outcomes of child-based and parent-based Child anxiety treatment. Journal of Clinical Child & Adolescent Psychology, 50(3), 427–439. https://doi.org/10.1080/15374416.2020.1756300

## **SECTION E: 10 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!<sup>13</sup> The Vagus Nerve is the largest nerve in your body, and it connects your brain to every single organ you have got! When you exercise the Vagus Nerve, it can send relaxation and balance to your body more easily. 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 "Wait to Exhale" in the Appendix on page 32. There are lots of other exercises you can learn, including the following:

#### 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 31.

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

<sup>&</sup>lt;sup>13</sup> Noble, L.J., Souza, R.R. & McIntyre, C.K. Vagus nerve stimulation as a tool for enhancing extinction in exposure-based therapies. *Psychopharmacology* **236**, 355–367 (2019). https://doi.org/10.1007/s00213-018-4994-5

## WAY TO REWIRE #1 STRENGTHEN YOUR VAGUS NERVE



## W2R #2: Thank you, Body

The purpose of this Way to Rewire is to help remind your body that it works and can release built up tension and negative energy it has stored, anytime, not only through an FND symptom. Practicing being grateful for your body will help you take back control of it.<sup>14</sup>

Goal: Become friends with your body again!

First, **THANK** your body for getting you through difficult times. Affirm to your body that you are aware of how hard it has worked. Some of this will be familiar to you, from The Reset Protocol. That's because these exercises are more effective (help reduce your FND symptoms faster) when you practice them several times.

1) Begin by saying out loud:

"Thank you, Body, for helping me survive and for getting my attention so that you didn't have to continue struggling. You are tired, part of you is overwhelmed. I'm listening now. I am in charge, and I will care for you."

2) Show your body you mean what you say by speaking in a language it understands: Movement will help release the stored-up stress your body has been carrying for you:

Note: Vigorous exercise is likely NOT what your body needs right now. Go gently and return to competitive sports slowly with the help of your OT/PT or other BRE.<sup>16</sup>

Body Part	How to Release					
Forehead	Scrunch your eyebrows and then soften them.					
Jaw	Open your mouth against the resistance of your thumb, then shift your jaw left and					
	right against resistance. Open wide as you can without resistance and blow air					
	through your lips (horse lips).					
Shoulders	Drop and roll your shoulders away from your ears.					
Chest	Place your hand on your chest applying light pressure and breathe deeply.					
Stomach	Sway your arms back and forth to release tension in your abs.					
Hands	Close into a fist and squeeze tightly, then release and spread your fingers wide. Shake					
	them out. Let them fall relaxed at your side.					
Booty	Notice and release any clenching.					
Muscles	Notice and relax big muscle groups. Rub them with tiger balm or mentholated cream.					
Any	Watch this hypnosis video when experiencing pain					
	anywhere in the <u>body</u> . <sup>15</sup>					

## CHECK IN TIME: On Ways to Rewire #1 & #2

After practicing Ways to Rewire #1 and #2 for two weeks, choose which ideas are your favorite. Write down your favorites on the Check In Time document in Appendix on page 36.

<sup>&</sup>lt;sup>14</sup> Kyeong S, Kim J, Kim DJ, Kim HE, Kim JJ. Effects of gratitude meditation on neural network functional connectivity and brain-heart coupling. Sci Rep. 2017 Jul 11;7(1):5058. doi: 10.1038/s41598-017-05520-9. PMID: 28698643; PMCID: PMC5506019.

<sup>&</sup>lt;sup>15</sup> Coogle J, Coogle B, Quezada J. Hypnosis in the Treatment of Pediatric Functional Neurological Disorder: The Magic Glove Technique. Pediatr Neurol. 2021 Dec;125:20-25. doi: 10.1016/j.pediatrneurol.2021.08.011. Epub 2021 Sep 4. PMID: 34624606.

<sup>&</sup>lt;sup>16</sup> Standard of Care: Functional Neurologic Disorder. Brigham and Women's Hospital Department of Rehabilitation Services.

## W2R #3: Self-Care Routine

As a child, your guardians work to provide you stability and care. Now as an adolescent, you are responsible for learning your boundaries and limits, and taking action to prevent your body from feeling bad. When your nervous system is close to "system overload," and lacks daily self-care or helpful coping mechanisms, FND symptoms become the only way to release the energy. FND forces your body to pause and rest. Instead of letting FND control when you pause and rest, YOU get to choose, using a regular self-care routine.

Goal: Create a daily self-care routine.

Self-care is what you deserve and need to give yourself. Everyone deserves and needs self-care to feel their best and perform at their highest level. Sometimes we don't think we deserve care or self-care unless we are sick, exhausted, or injured. This is SO FALSE. You are worthy of great care, but what is self-care? Self-care includes actions that meet your basic human needs, like: sleep, healthy food, water, rest, and companionship. Every day, for the next week, practice these basics to self-care. This week we want to raise your awareness and encourage you do these with intention:

- 1. Do not skip meals. Eat three meals and one or two snacks a day at roughly the same time every day. Each meal should include at least one fat and one protein. See where you can add vegetables to one meal or more meals/snacks each day.
- 2. Exercise regularly. Try these short, simple but effective exercises:
  - a. Stretching or Yoga
  - b. Take a 15-30 minute walk.
  - c. Throw a ball around with a friend.
- 3. Drink more water:
  - But how much? Divide your weight, in pounds, by two. This is the amount, in ounces (OZ), that you need each day to keep your brain and body happy.
  - b. Without this much water, you will likely experience headaches, dizziness and reduced distress tolerance.
- 4. Schedule time to see friends in person, not virtually via Facetime or instant messaging.
- 5. Create a bedtime ritual.
  - a. Try to go to bed around the same time each night.
  - b. Stop screen time (no TV, phones, or computers) at least 1 hour before bed.
  - c. Play soothing music/sounds to help you fall asleep.

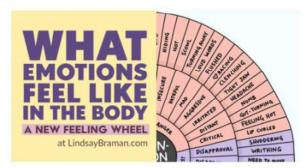


## W2R #4: Speak Your Body's Language

In Way to Rewire #2, we learned how to communicate with our bodies to learn when it was telling us something. In this Way to Rewire, we are going to learn how to connect emotion with that body sensation.

**Goal:** Learn to label the emotion tied to your body's sensations (non-judgmentally).

Visit LindsayBraman.com or use the QR code below to download the Emotion-Sensation wheel. Once this is complete, follow the activity below.





Scan Me!

Sensation in the body is your body's way of communicating something you need. Look at the outer most ring of the Emotion-Sensation wheel below to find the sensations you have experienced during warning signs or even just in your day to day. Each sensation is color-coded to link up with the emotion your body might be urging you to notice and pay attention to. Are your numb hands telling you that a part of you is feeling unwanted or embarrassed?

#### How to deal with a difficult body sensation-emotion pairing:

All bodies communicate good and bad emotions. There are times when we feel uncomfortable, and it is not an FND symptom, but a feeling in your gut. Try getting curious about that gut feeling. For example:

#### "Hi stomach, I'm listening. Are you telling me anything new? If not, I'd like to focus on the present moment instead."

This is a great exercise to do with a Brain Rewiring Expert.<sup>17</sup> It is a kind, curious approach to your body that allows your feelings to exist and then drift away. When we ignore feelings, they grow larger and more unmanageable. When we are afraid of them and treat them as signs of illness, we can increase the FND cycle and, in turn, make the symptom more intense.

<sup>&</sup>lt;sup>17</sup> Benbadis S, Ledford R, Sawchuk T, Dworetzky B. A broader perspective: Functional symptoms beyond Neurology. Epilepsy Behav Rep. 2021 Nov 25;18:100506. doi: 10.1016/j.ebr.2021.100506. PMID: 35198949; PMCID: PMC8850744.

## W2R #5: Triggers

So far, we've learned how to identify a warning sign and how to connect an emotion to it. In Triggers, you will learn what actions, statements, or sensory input triggers the emotion in you that leads to your warning signs, and eventually your FND Symptom (if you can't stop it first!).

Goal: Learn some of your triggers.

#### A trigger is something that happens, which leads to a sensation in your body.

In the past that sensation made you either want to react or shut down. Now, instead, try to think back to WHAT led to that sensation (ex: bright lights, loud noise) or WHERE those sensations happen most often (ex: school). Then, connect those WHATs and WHEREs to WHICH feeling/emotion you are experiencing.

Try this exercise as an example: Alex's heart starts racing a week before a big test coming up at school.

WHAT was Alex's warning sign?

WHAT is causing Alex's warning sign?

**WHERE** is Alex's warning sign showing up in their body?

**WHERE** is Alex when their warning sign happens?

**WHICH** emotion is connected to Alex's warning sign? Alex is feeling...

## What triggered me?

01. I felt excluded.

- 02. I felt powerless
- 03. I felt unheard.
- 04. I felt scolded.
- 05. I felt judged.
- 06. I felt blamed.
- 07. I felt disrespected.
- 08. I felt a lack of affection.
- 09. I felt uncared for.
- 10. I felt lanak
- 10. I felt lonely.
  - 11. I felt ignored.
- 12. I felt like I couldn't be honest. 12. I felt controlled.
- 13. I felt like the bad guy.
  14. I felt forgotten.
  15. I felt unsafe.
  04. I felt unloved.
  05. I felt like that was unfair.
  06. I felt frustrated.
  07. I felt disconnected.
  08. I felt trapped.
  09. I felt a lack of passion.
  10. I felt like I couldn't speak up.
  11. I felt manipulated.
  12. I felt controlled.

The Gottman Institute

WHICH Reset Protocol exercise(s) can Alex use to help prevent their FND Symptom from starting?

#### **Reflect on your triggers:**

Now, using Alex's example as a guide, can you identify actions, statements or environments that have triggered your FND symptoms in the past? Go to page 35 in the Appendix. See if you can fill out the table there with your own examples!

## W2R #6: Boundries

Let's face it, life is unpredictable, and we are constantly faced with stressful situations. Many of them are out of our control, but there are equally as many within our control (even though it may not feel like it). While it may seem very difficult (because it is!), your reactions to these stressful situations are within your control. On the flip side, how others react to you and those same stressful situations is within <u>their</u> control.

Goal: Determine when triggers are in or out of your control.

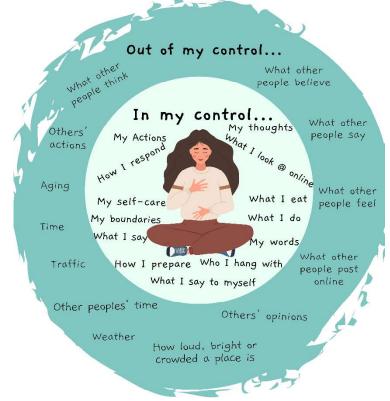
Often, individuals with FND feel responsible for others' emotions and take on the stress of others' negative emotions. We are NOT suggesting that you stop caring about others, but we are recommending you practice pausing and asking yourself:

"Is this emotion/reaction/situation in or out of my control?"

Or

#### "Is this emotion/reaction my responsibility or someone else's responsibility?"

Now, pausing to determine if something is within or outside your control, especially in a stressful situation, is very difficult. We <u>do not</u> expect you to master this skill overnight. However, the act of pausing begins to rewire the automatic reactions or responses your body is trained to do. Therefore, we have provided a guide to help get started.



#### No Triggers?

What happens if I don't have any triggers or cannot identify all my triggers? That is okay! There are many cases where the trigger is buried so deep that it takes the help of a Brain Rewiring Expert to figure it out.

## W2R #7: Reframe Your Thoughts

Many people with FND report that they have given up or lost something they love prior to receiving their diagnosis. This makes sense because a change in routine or future goals, or a loss of something or someone you love is likely unpredictable. Unpredictability can make us feel unsafe. Feeling unsafe can make us worry or have thoughts that may be untrue.

You may also have been worried about having your FND symptoms in front of other people. Part of you has this worry, and that part of you is valid. This thought is one you can acknowledge without letting it rule you and your choices. Challenging your thoughts is a helpful technique to make sure your brain is telling you the truth and puts you in control of whether to engage with your thoughts. Below are some ways to begin challenging your thoughts.

Circle two or three of the thought pairs in the following table that apply to you. For the next week, practice replacing the thought in the left column with the thought in the right column. If you have a specific thought you would like to replace that isn't included in this list, add it below!

Goal: Learn to challenge negative thoughts that can lead to your FND symptoms.

Challenge Y	our Thoughts
When thinking this	Try this instead
l never do anything right.	That isn't true. I do get things right.
feel like doing 'x' so   should go do it right now.	I can take time to process my thoughts without reacting first.
I have no control over my reactions.	I can learn to control how I react.
My emotions are who I am.	My emotions are my brain processing info.
Everything will end badly.	What if things work out?
All I do is mess up.	What would my friends tell me?
eBlessi	ingManifesting

Write down a thought that comes to mind before an FND symptom:

Now, see if you can replace or challenge that thought with another:

When you have this distressing thought, acknowledge it without judgment. Then respond to it assertively using your new reframed thought.

## W2R #8: Mindfulness

Mindfulness helps control your amygdala (emotion center) of the brain, an area of the brain which is overactive or "hijacked" in FND.<sup>18</sup> Meditation, mindfulness and listening to podcasts about these subjects can also help improve your Interoception, which is the brain science word we use for "ability for your brain to communicate well with your body." This is one of the major areas impaired by FND. When you did the Reset Protocol, earlier in your recovery, you were gently reconnecting your mind and body with the scripts and the exercises you chose.

Goal: Add mindfulness to your daily self-care routine.



Listen to "Radio Headspace" Podcast each morning while you brush your teeth. After school, watch one of these videos and allow it to guide you through meditation. Helpful Online Meditations: https://www.youtube.com/watch?v=DWOHcGF1Tmc https://www.youtube.com/watch?v=70j3xyu70Gw https://www.youtube.com/watch?v=wf5K3pP2IUQ

## **CHECK IN: On Ways to Rewire #3-8**

After practicing Ways to Rewire #3 through #8 for six weeks, choose which ideas are your favorite and add them to your Check In Time document in the Appendix on page 36.

18 Baslet G, Ehlert A, Oser M, et al. Mindfulness-based therapy for psychogenic nonepileptic seizures. Epilepsy Behav. 2020 Feb;103(Pt A):106534. doi: 10.1016/j.yebeh.2019.106534.

## W2R #9: Communicate with Others

Connection with yourself and others can be affected by how you communicate your needs. Right now, your FND symptoms are the primary communication tools your body is using when it becomes overwhelmed or can't meet a need.

Goal: Begin to communicate your needs before FND does.

We often think of FND as a way for the body to communicate a need that isn't being met or when a boundary has been crossed but doing so in a very unhelpful way. For example, most people don't enjoy being yelled at (we certainly don't!). One way to get away from the yelling is to go to another room. By leaving the room where the yelling is happening, you meet the need of not hearing the yelling. But what happens when there isn't another room to go to? Or you can't define exactly what the need is?

If you're unable to define exactly what the need is, sometimes it involves your values being compromised. Values are the ideas or concepts that your boundaries are protecting. When a boundary is crossed, something you value (that means a lot to you, like trust) is under fire. The exercises below will help you define your values and practice how to communicate when someone or something is crossing your boundaries.

#### Personal Values Assessment

- This is best done with your Brain Rewiring Expert. If you do not have a BRE yet, try journaling answers to the following questions:
  - What qualities are important to have in a friend? Why?
  - What are a few goals I have for myself this year? In the next 3 years?
  - What are some of my core beliefs? (ex: honesty vs. lying)

#### Role Playing (yes, we know...it can be awkward...)

- This is best done with your Brain Rewiring Expert or someone who you trust. This should be done IN-PERSON so you can see the other person's body language and practice looking them in the eye. Try role playing the following situations:
  - Someone tells you to keep a secret and you don't feel comfortable with it.
  - Someone asks you to post something mean about someone else on social media.
  - Your teacher or family member is rushing you to complete an assignment that you need more time on.

#### **Relationship Mapping**

To create a relationship map, draw a circle with your name in the center. Then, draw a larger circle around that first circle and write the names of the people closest to you inside it. Then, draw another circle around that circle and write the names of more distant friends. Continue this process until you have defined who your closest friends are and those who you may want to stay further away from. Then ask – why are some people in the closer vs. farther circles?

#### **Movie & Book Characters**

- Think about your favorite books, movies or TV show. Who are your favorite characters? Then, ask yourself why? What kinds of relationships and choices do they make that make them your favorite?

## W2R #10: Connection

No one can do this alone. Whether someone has FND or not, human beings are social creatures and need to feel connected and supported by others. Social connection and helping others has been shown to improve our health. Like most animals (even some plants and insects!), we are built to connect and help one another. Mammals even have a special part of their nervous system that is soothed by social interactions, others' facial expressions, and tone of voice. The ventral vagal system calms our fight/flight response when we see a reassuring smile from a support person.<sup>19</sup>

**Goal:** Reset your first impressions of others and your environment.

Seeking connection is hard, especially after COVID-19 when we were instructed to limit interaction for our own safety. While we are technologically more "connected" than we have ever been because of social media, we are unable to connect using all our senses. Much of human communication is based on body language through non-verbal signals. Social media reduces our ability to identify these non-verbal cues, which then can make it hard to interpret them in real life, away from the screen. Fun fact: stress can change our ability to correctly communicate what we are feeling through non-verbal signals. When you're feeling stressed, you're more likely to misread others' body language as negative. Often people with FND pay more attention to negative body language and threats in their environment because they always feel "on alert."

Notice if you are jumping to conclusions about what others are thinking and feeling. Ask yourself, "Am I mind reading right now?" Mind-reading gets in the way of truly connecting with others. We humans have a unique part of our nervous system that is all about connecting and relating to others.

To practice connecting with others, you need to be with others **in-person!** Instead of using social media or texting to connect, try the recommendations below. During these activities, as best you can, be aware of your eye contact and other non-verbal signals. Try smiling at the other person, we bet they will smile back (3).

- 1. Going on a walk with a friend or family member with your phone on silent.
- 2. Grab a deck of playing cards and teach/learn a new card game. Suggestions: Go Fish, Crazy 8s, Slap, Spades, Spoons, Rummy
- 3. Play a board game!
- 4. Invite a friend to do arts and crafts with you.

## **CHECK IN: On Ways to Rewire #9-10**

After practicing Ways to Rewire #9 & 10 for two weeks, choose which ideas are your favorite and add them to your Check In Time document in Appendix on page 36.

<sup>&</sup>lt;sup>19</sup> Porges, S. W. (2021). Cardiac vagal tone: A neurophysiological mechanism that evolved in mammals to dampen threat reactions and promote sociality. *World Psychiatry*, 20(2), 296–298. https://doi.org/10.1002/wps.20871

## **CONCLUSION:**

Congratulations! You completed the FND Workbook: Ways to Rewire. We hope this has been helpful!

So..., what's next?

To keep the progress going, we recommend the following:

- 1. Remember to provide Care Coordination Letters to each member of your FND Support Team.
- 2. Continue using the skills you have learned in this workbook every day.
- 3. If you have a FND symptom flare up, do the Reset Protocol again!
- 4. Continue working with your Brain Rewiring Expert, referencing the skills you learned in this workbook as often as you can.
- 5. If the exercises in this workbook were not enough or did not work for you specifically, other resources are available online through the following organizations:



@ www.fndhope.org



@ www.fndsociety.org



@ www.neurosymptoms.org

For questions about content in this workbook, please email: fndintegration@gmail.com

## **GLOSSARY**

Brain Rewiring Expert (BRE): A behavioral health/mental health professional, therapist, or counselor.

**Coping Mechanism:** A strategy to overcome or deal with a life problem, person, or situation.

**Functional Neurological Disorder (FND):** Neurological symptoms such as weakness, movements, fatigue, seizures that result from incorrect sensory processing in the brain. Other terms used include: conversion disorder and psychogenic symptoms (ex: psychogenic non-epileptic seizures/PNES).

**Neuroplasticity:** The ability for the brain to form and reorganize connections in the brain, especially in response to learning, experience, or injury. Neuroplasticity is responsible for how we learned to walk or talk. We weren't born walking or talking, we had to learn how - just like you weren't born with FND. FND developed over time, which means with the help of brain rewiring exercises, you can train your brain to not cause FND symptoms.

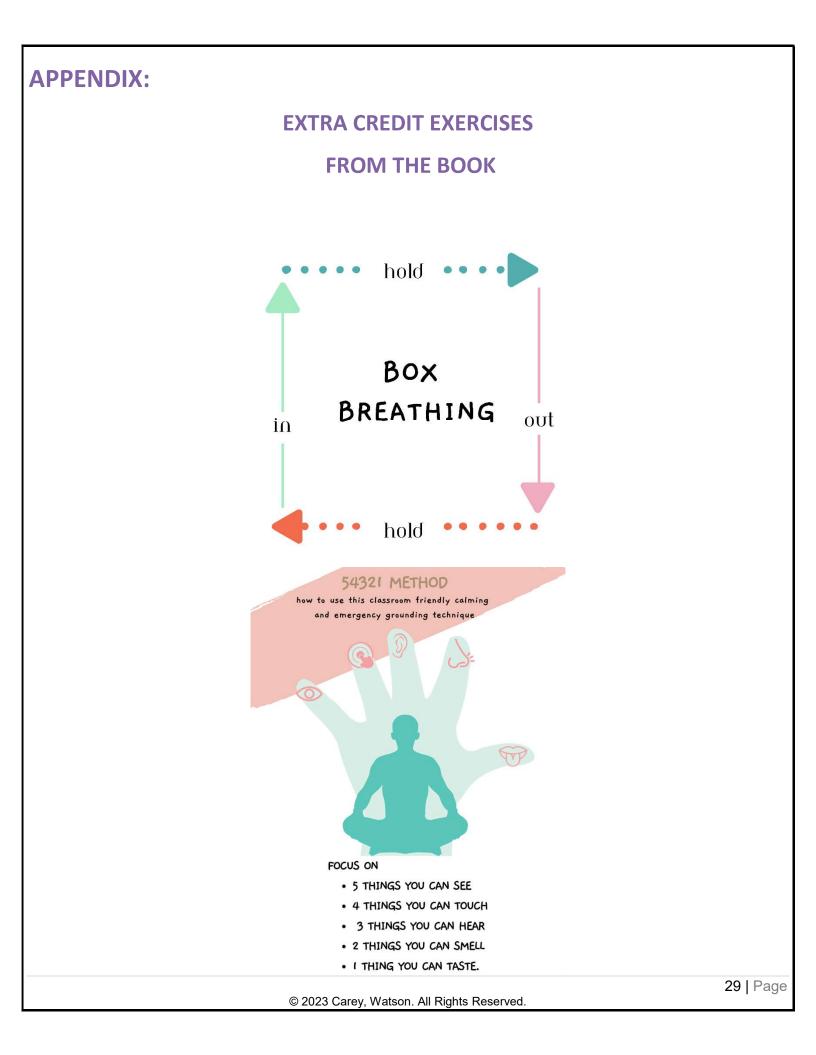
**Non-Epileptic Seizure (NES):** A symptom of FND that can involve full body shaking, loss of time awareness, awareness, or consciousness (ex: black out).

**Overriding:** Replacing or overruling something; "taking over."

**TENS Machine:** A TENS (Transcutaneous Electrical Nerve Stimulation) machine is an inexpensive device that uses electric current to stimulate nerves for therapeutic purposes. It can help to reduce pain and tremors and to induce relaxation. Consult your doctor before buying or using a TENS. It should not be used by people with implanted medical devices such as pacemakers or by people who have damaged skin, epilepsy, or deep vein thrombosis. Pregnant patients should use a TENS with care and only after consulting a doctor.

**Vagus nerve:** One of the many nerves that controls the heart, lungs, digestion and other organs in the chest and abdomen. The vagus nerve is one of the most important nerves in the body and is responsible for regulating heart rate, blood pressure, sweating, and even speaking.

Yale School of Medicine Child Study Center: to learn more, visit: Child Study Center < Child Study Center (yale.edu)





## **Other Techniques for Warning Signs & FND Symptoms**

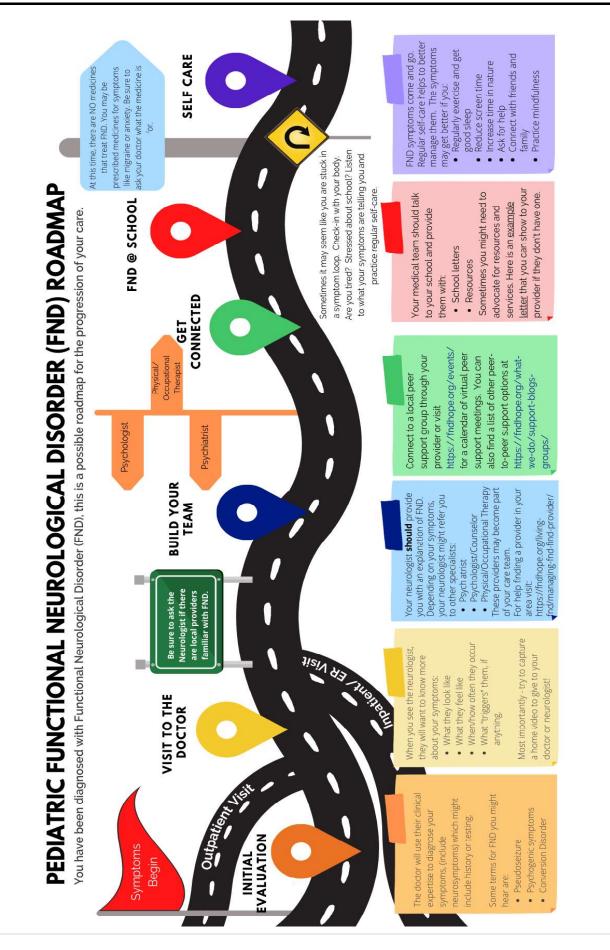
Action	Why it Works
Weighted blanket or vest	Can reduce tremors, shaking, convulsions, and panic.
Sour candy	Sour candy will shock all your neurons into focusing on your mouth.
Focus on an object	Keep a seashell, stone, or piece of driftwood with you. If it is small enough to fit in the palm of your hand, you can focus your sense of touch and sight on it during warning signs. This "grounds" you with your sense of touch.
Get into nature	Nature is calming for the nervous system and can take you outside of yourself and into the present moment.
Walk outside with a friend	Walking outside with a friend engages every sense, including the all- important sense of connection. Doing so will nurture your connection in a way that Facetime, texts and phone calls cannot.

Daily Prac	ti	ce	,
	DAY 1	DAY 2	DAY 3

Calming Skill #1		
Target Symptom		
Ways it helped	0	

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

Calming Skill #3		
Target Symptom		
Ways it helped		



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Trigger Table f					
WHAT is a possible Warning Sign? (ex: butterflies in stomach)	WHAT led to Warning Sign? (Alternative question: WHEN does the Warning Sign normally happen?)	WHERE is the Warning Sign felt in your body?	WHERE are you when your Warning Sign is felt? (most often)	WHICH emotion could be tied to this Warning Sign?	WHICH Reset Protocol exercise/calming technique will you use?
			tson. All Rights Reserve		<b>33  </b> Page

CHECK IN TIME:	
On Ways to Rewire #1-2	Skills I will keep:
CHECK IN TIME:	
On Ways to Rewire #3-8	Skills I will keep:
CHECK IN TIME: On Ways to Rewire #9-10	Skills I will keep:
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AN ADULT AT SCHOOL/WORK WHO I CAN REACH OUT TO WHEN I NEED HELP REGULATING	
MY NERVOUS SYSTEM IS:	
(CIRCLE ONE) WEEKLY/BIWEEKLY FOR A MINIMUM OF 8 WEEKS. OCCUPATIONAL THERAPISTS (OT) ARE ALSO A BRAIN REWIRING EXPERTS. THEY HELP ME REGAIN FUNCTION AND ABILITY.	
MY PRIMARY CARE PROVIDER HAS SENT REFERRAL FOR ME FOR:	
I WILL SEE MY OT/PT WEEKLY/MONTHLY. MY NEUROLOGIST IS: I HAVE REGULAR	
FOLLOW UP APPOINTMENTS WITH THEM EVERY 6 MONTHS/12 MONTHS/OTHER.	
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# Back to School Pack & Care Coordination Letters

These letters were reviewed for and by members of the following professions:

- School Nursing
- Mental Health
- Primary Care Provider
- Occupational Therapy
- Physical Therapy

## **Back to School Pack**

Patient Name: DOB:

Dear School Nurse and Educator,

Your student is followed by \_\_\_\_\_\_ and has been determined to have a Functional Neurologic Disorder by their neurologist. They experience episodes that are like 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. Emergency Medical Services and Emergency Centers make episodes worse.
- This person is not doing this on purpose.
- FND is common AND treatable. This student can improve with treatment actively working on a treatment FND response plan.

#### How to handle an FND episode:

- 1. Center yourself and 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: 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. If you have concerns, I am available to schedule a virtual meeting with school representatives to help you keep this child in school.

Sincerely,

Neurologist Signature: \_\_\_\_\_

Best way to contact for school meeting: \_\_\_\_\_

# **Class is Back in Session**

How school can support FND recovery



- 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?



- 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

# 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

SPEAK POSITIVELY ABOUT ME OR BETTER YET, NOT AT ALL. I CAN HEAR YOU AND ATTENTION MAKES IT WORSE.

─ SAY "YOU ARE HAVING AN FND EPISODE. YOU ARE SAFE. YOU HAVE

GIVE ME PRIVACY AND SPACE.

FND HOPE

THE TOOLS TO GET THROUGH IT. I AM HERE WHEN YOU ARE READY." THEN

REMAIN CALM.

HELP ME SAFELY TO

COVER HARD SURFACES

THE GROUND.

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 INTURED
DO NOT CALL AN AMDULANCE UNLESS INUKED.
DO NOT CALL AN AMBULANCE UNLESS INJURED. (PLEASE CHECK BASED ON INDIVIDUAL NEED.)
<ul> <li>DO NOT REMOVE ME FROM SCHOOL.</li> </ul>
. DO NOT BEHAVE FRANTICALLY

Date:

DO NOT TIME THE EPISODES. UNLIKE EPILEPSY, THE CARE DOES NOT CHANGE AFTER 5 MINUTES.

Provider Signature:

Provider Name:

Provider Contact:

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## **Brain Rewiring Expert (Counselor/Therapist):**

Patient Name/ DOB:

Today's Date:

Dear Mental Health Provider,

The above patient is followed in our clinic: \_\_\_\_\_\_\_\_. They have been diagnosed with a Functional Neurological Symptom Disorder (FND) by a pediatric neurologist. FND is the new name for Conversion Disorder or somatizing overwhelming catastrophized sensation 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 members of <u>your</u> team. You are the Brain Rewiring Expert.

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

The frequency of these episodes can go down and even remit for years. Your expertise in brain rewiring (through DBT, CBT, Mindfulness, EMDR, IFS, ACT, 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.
- Reinforce cognitive skills like reframing "symptoms" to "sensations" and communications from the body.
- 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.

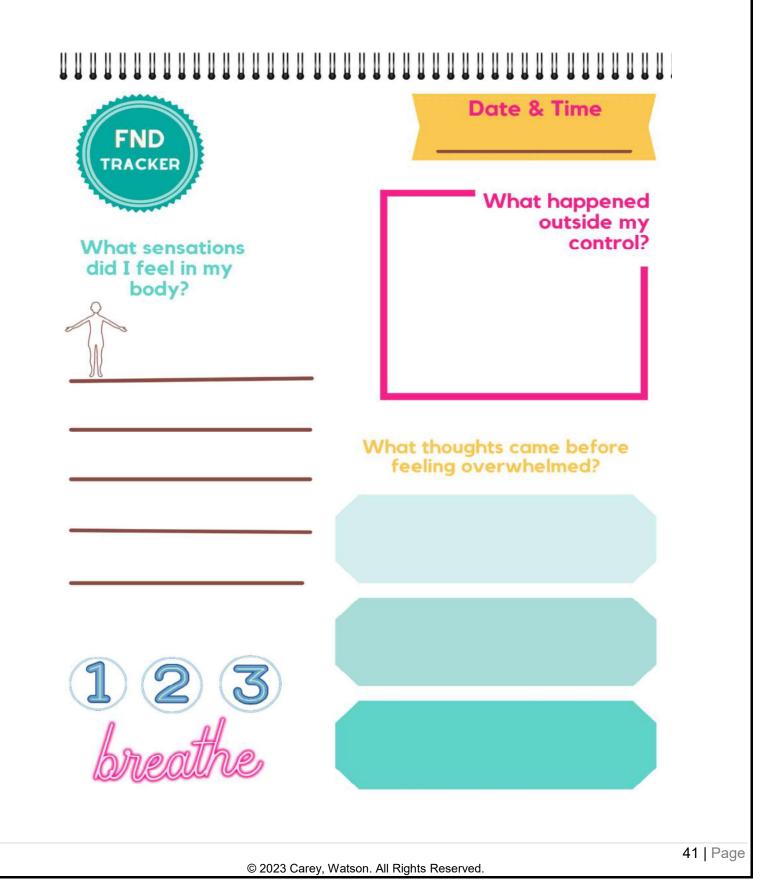
We want to reassure you that this patient has been assessed by a pediatric neurologist and does NOT have epilepsy. If they have an episode in your session, please do not call emergency services. Calling emergency services can lead to the patient being unnecessarily treated with antiepileptic medications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

Sincerely,

Neurologist Signature: \_\_\_\_\_\_ Printed name/contact:

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## **\*\*Bonus therapy resource for the START of treatment with a Brain Rewiring Expert\*\***



#### Letter for your Primary Care Provider (PCP):

Patient Name/DOB:

Dear Provider,

Our mutual patient was assessed by a pediatric neurologist in our clinic and was diagnosed with Functional Neurological Disorder. This is a new name for a common and long misunderstood issue, where physical symptoms result from malfunctioning neural pathways. Children do get better and a unified approach from their care team is key. Please use this new terminology (rather than pseudoseizure, conversion disorder, psychosomatic illness, etc.). Encourage families to reflect on new symptoms (sensations) as signs of unmet needs from the body/nervous system for rest, connection, food/water. Assistive devices, homebound status and referrals for new symptoms are discouraged and should be approached with cautious reflection as they can feed anxiety and exacerbate symptoms.

This patient's FND manifests in the following symptoms:

The family have been given an FND Response Plan, a workbook, school letters and a list of mental health providers (Brain Rewiring Experts) in the community to work the program with them.

Their FND Response Plan has been given to their school (as opposed to Seizure Action Plan) is as follows:

- 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.

#### How to handle an episode:

Remain calm. Say to the child: "You are having an FND episode. You are safe. You have the tools to get through it. I will give you the space you need, and I will be here when you are ready." Redirect others' attention by saying, "They just need some time to work through this. They will rejoin us when they can." Do not face or watch the child. Re-involve them after.

School Issues:

Homebound is NOT recommended. Isolation worsens this condition. Maintaining normalcy improves outcomes. Gym: This student is cleared to participate in gym.

Many thanks,		
Neurologist Signature: _		
Printed name/contact: _		

## Letter for your Physical Therapist (PT) (if you are referred to one):

Patient Name/DOB:

Dear Physical Therapy Provider,

The patient listed above has been referred to PT for help in their FND Recovery. FND is short for Functional Neurological Disorder. This common disorder used to be called conversion disorder. This new name reflects our improved understanding of the impaired brain networks that result in motor, sensory and cognitive symptoms, for example:

- Weakness or paralysis
- Abnormal movement, such as tremors or difficulty walking
- Loss of balance
- Non-epileptic dissociative attacks or convulsions
- Episode of unresponsiveness

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. Your expertise in helping children rewire their brains through exercises and exposures is needed. Here are ways you can help:<sup>20</sup>

Symptom	Movement Strategy
Perception Integration Issues	Wiggle boards, trampolines, walking on soft surfaces that more require more adaptation and adjustment to maintain posture and movement. Limit "hands on" treatment. <sup>21</sup>
Leg Weakness	Create weaning plan from assistive devices (if used). Early weight bearing. Utilize distraction aids (walk with an object in hand, like a soft toy).
Gait Abnormality	Redirect attention with music or focal point. Change speeds of walking (may first worsen gait). Walk to a rhythm. Walk with exaggerated movements intentionally.
Functional jerking movements	As these are occasional, work on identifying warning signs and then redirecting attention away or initiating an opposite action (similar to CBIT).

More guidance is available through Brigham and Women's Standard of Care: Functional Neurologic Disorder Guide.

Sincerely,

Referring provider signature: \_\_\_\_\_

Printed Name/Contact: \_\_\_\_\_

<sup>20</sup> Standard of Care: Functional Neurologic Disorder.2019. Brigham and Women's Hospital Department of Rehabilitation Services.

<sup>21</sup> Weissbach, A., Moyé, J., Takacs, A., Verrel, J., Chwolka, F., Friedrich, J., Paulus, T., Zittel, S., Bäumer, T., Frings, C., Pastötter, B., Beste, C., & Münchau, A. (2023). Perception-Action Integration Is Altered in Functional Movement Disorders. *Movement disorders : official journal of the Movement Disorder Society*, 10.1002/mds.29458. Advance online publication. https://doi.org/10.1002/mds.29458