Agenda

Topics Covered

- Nervous System Regulation Tips
- Supportive phrases
- Reset Protocol
- Workbook
- School and Care coordination
Ways a loved one can help:

1. Learn about FND (hooray! You just did that! Well done.)
2. Learn how to model nervous system regulation
3. Acceptance + Confidence = Support
4. Do the Reset Protocol Together
5. Do the workbook with them: (Help identifying warning signs, model/join them for nervous system regulation techniques when you see a warning sign. Learn and practice the FND Response Plan)
6. Provide School and other providers with letters

Find on Amazon, by searching "FND Workbook"
Nervous System regulation

First self-regulate

- You are deserving of care and recognition for how hard you have fought for your child
- We see you
- Modeling self-regulation helps your child map new pathways in their nervous system
- Model out loud the self-talk you hope they will begin to have around their body and nervous system
Regulation Techniques

The techniques you choose will depend on what your child’s nervous system needs.

- Cultivate the opposite, if the nervous system is activated, choose soothing exercises
- If shutting down, choose activating exercises

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

Suck on sour candy.

Opposite Action:
Do something intentional with the affected body part.
Press a shaking hand, swing a jerking arm, breathe deeply when you have the urge to tic cough.

Engage all of your senses with the 5-4-3-2-1 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.

Aromatherapy:
Carry a scent you like with you and inhale when needed.
Fastest way to soothe: Vagus Nerve

- Gargle
- Hum
- Sing Loudly
- Blow Bubbles
Help Identify Warning Signs
**SYMPATHETIC**

- Vagal Nerve Inhibited
- Dilates Pupils
- Inhibits Salivation
- Increases Heart Rate
- Bronchial Dilation
- Inhibits Digestion
- Secretes Epinephrine & Norepinephrine
- Stimulates Glucose Release
- Inhibits Intestine Activity
- Relaxes Bladder
- Ejaculation
- Peripheral Vasconstriction

**PARASYMPATHETIC**

- Vagal Nerve Activity
- Constricts Pupils
- Stimulates Salivation
- Decreases Heart Rate
- Bronchial Constriction
- Stimulates Digestion
- Stimulates Gallbladder
- Stimulates Intestine Activity
- Contracts Bladder
- Vaginal Lubrication
- Erection
- Peripheral Vasodilation

**KNOWN AS YOUR FIGHT OR FLIGHT RESPONSE**

**KNOWN AS YOUR REST & DIGEST RESPONSE**
Script

How to show support
Support = Acceptance + Confidence

**SUPPORT = ACCEPTANCE + CONFIDENCE**

When we voice both our acceptance of our child for where they are now AND our confidence in their ability to get through a difficult challenge, we are being supportive.

We accept our children when we recognize:

1) They struggle with anxiety
2) Anxiety causes them distress
3) No one chooses to have anxiety

We convey confidence in our children when we tell them that we believe they can do hard things.

<table>
<thead>
<tr>
<th>Are these statements supportive?</th>
<th>Acceptance</th>
<th>Confidence</th>
<th>Supportive</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know anxiety makes situations like these really tough, but I believe you can cope.</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>I see how worried you are, if you don’t want to do X, you don’t have to.</td>
<td>✓</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>I’m here, don’t worry, I got this.</td>
<td>✓</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Stop obsessing. You got this!</td>
<td>No</td>
<td>✓</td>
<td>No</td>
</tr>
<tr>
<td>Give me a break! Just do it!</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>
Coregulation

First self-regulate
- Reset Protocol Together
- Shiny Eyes
- Remove nonessential to-dos right now
- Pause and breathe before committing, better yet, ask for more time
- Identify things that fill your cup. Find ways to incorporate them

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 EXERCISES TO COMPLETE EACH DAY FOR 3 DAYS

- "Body Scan Meditation" find on Youtube
- Get and give a massage
- 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
- Use a TENS machine on a comfortable vibration level on your back, legs and arms
- Buy a baby hospital brush to brush your skin gently
Form your Squad

- Identify your support team
- Assign roles

AN ADULT I LIVE WITH OR AM CLOSE TO WHO CAN HELP ME WITH MY REWIRING WORK IS: ____________________.

A FRIEND WHO I CAN TELL ABOUT MY FND SYMPTOMS AND CAN HELP ME WITH MY REWIRING WORK IS: ________________________.

AN ADULT AT SCHOOL/WORK WHO I CAN REACH OUT TO WHEN I NEED HELP REGULATING MY NERVOUS SYSTEM IS: ________________________.

MY PRIMARY CARE PROVIDER HAS SENT REFERRAL FOR ME FOR:

☐ OT  ☐ PT

OCCUPATIONAL THERAPISTS (OT) AND PHYSICAL THERAPISTS (PT) ARE BRAIN REWIRING EXPERTS. THEY HELP ME REGAIN FUNCTION AND ABILITY. I WILL SEE MY OT/PT WEEKLY/MONTHLY. I WILL WORK WITH THEM ON HOW MANY SESSIONS WE WILL NEED.

MY OTHER BRAIN REWIRING EXPERT KNOWS ABOUT PSYCHOLOGY. THEIR NAME IS: ________________________.
Who are Brain Rewiring Experts?

01 Occupational Therapy
Sensory integration
Warning Signs
Coping Skills

02 Physical Therapy
Maximizing function
Reintegrating body & brain, areas of brain
Building better pathways

03 Neurology
Diagnosis and monitoring new symptoms to ensure all diagnoses are addressed

04 Mental Health
Nervous system regulation
Support for loss of function, adjustment to life with illness
Make a plan

Care Coordination

- Create an FND Response Plan
- Edit Letters to fit your needs and share with your care team
- If you are missing key people from your care team, I'll show you how to find them!
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. This form must be reviewed, completed and signed by a provider in order to be valid.

FOR ME, FND LOOKS LIKE:

MY WARNING SIGNS

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 DURING

☐ Remain calm.

WHAT TO DO AFTER
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 AFTER

REINVOLVE ME/RETURN ME TO CLASS.

praie 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 AUTOMATICALLY.

(Reasons to call later are injury or can be added by your doctor to a separate letter).

☐ 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:
Care Coordination Pack

Letters written by FND experts in each field:

- School Nursing
- Occupational Therapy
- Physical Therapy
- Primary Care
- Mental Health
Steps to take to coordinate with school

01 School Letter Draft
Show your doctor the school letter, ask if there is anything they would add. Gain a signature. Share with school nurse.

02 Request a meeting
Consider a virtual meeting with your child's main teacher, school nurse and counselor. Your doctor may be able to attend or share an additional letter. What services can the school provide and what do they need from you/doctors to qualify?

03 Suggested 504
- 75% reduction in take home work
- Scheduled regulation time in safe classroom or office

04 Understand the school's push/pull factors
Be open to their feedback and concerns.
How to find providers
How do I access BREs?

**Occupational Therapist**
Need a referral from PCP or Neurologist

**Physical Therapist**
Need a referral from PCP or Neurologist

**Mental Health Therapist**
Do not need a referral
Find a Mental Health Therapist

How to Control Your Emotions
Are You Feeling Overwhelmed?

Find a Therapist

Therapists
houston

Houston, Texas
Online Therapy Platforms

**BetterHelp**
- towers per session
- 20% first month with code word Forbes

**TalkSpace**
- Accepts Insurance
- $80 off with code SPACE80

**Charlie Health IOP**
- Need a referral
- Insurance accepted

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*Forbes*
Tool Kit

Learn 10 ways to rewire plus gain a CLEAR PLAN for flare ups and treatment.

RESET & REWIRE THE FND WORKBOOK
FOR KIDS & TEENS

By: Katie Carey, BSN, RN & Meagan Watson, MPH

Illustrated & Self-Paced

Includes School & Care Coordination Packs
Support expanding access to care

Special Price today on Amazon Ebook
Be a part of improving FND Care!
1) 15% of all proceeds go to:
   • FND Hope
   • Pediatric special interest group of FND Society: outreach to providers to educate them on FND evidence-based care

2) 30% to Supporting providers starting/sustaining FND clinics

3) 5% to creating an adult version of this book