

FND

Resources

Caregiver



Presented by Katie Carey, BSN, RN





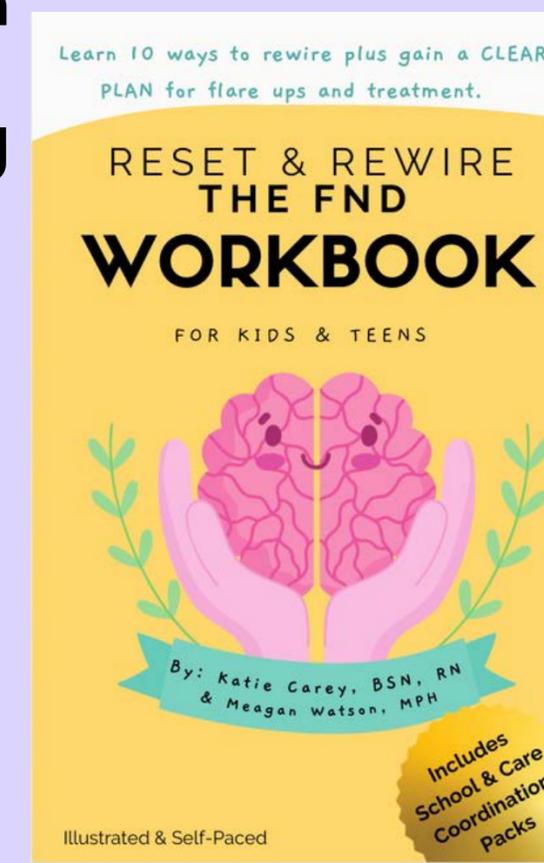
Agenda

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

CLASSROOM FRIENDLY CALMING TIPS

for your nervous system



Temperature:

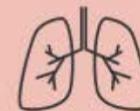
Cold will slow your heart rate.
Drink ice cold water. Rub
an ice cube on your wrist.



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.



Paced Breathing:

Try either Belly Breathing,
Box Breathing, or "Wait to
Exhale" (see Appendix)



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



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.

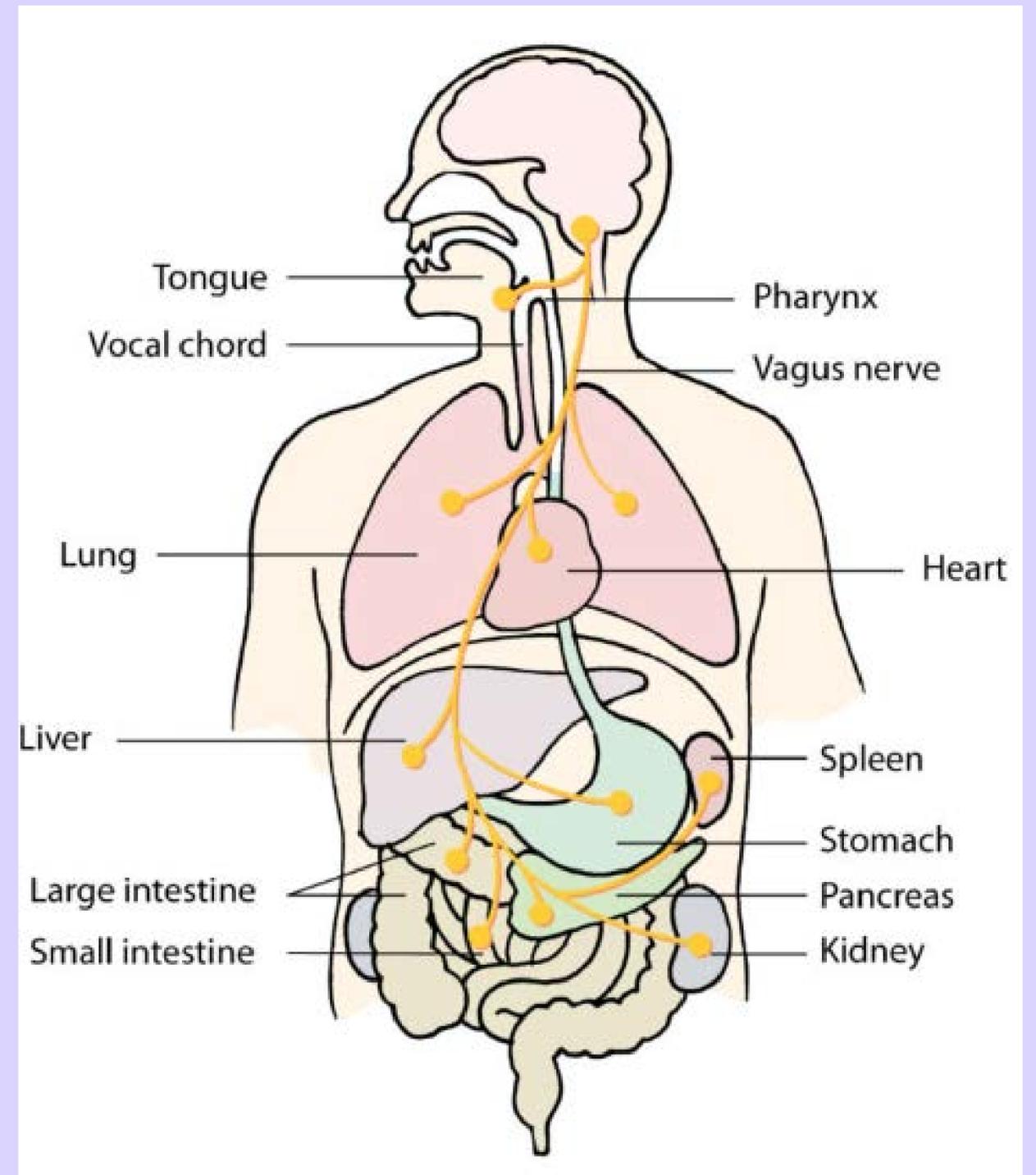


Aromatherapy:

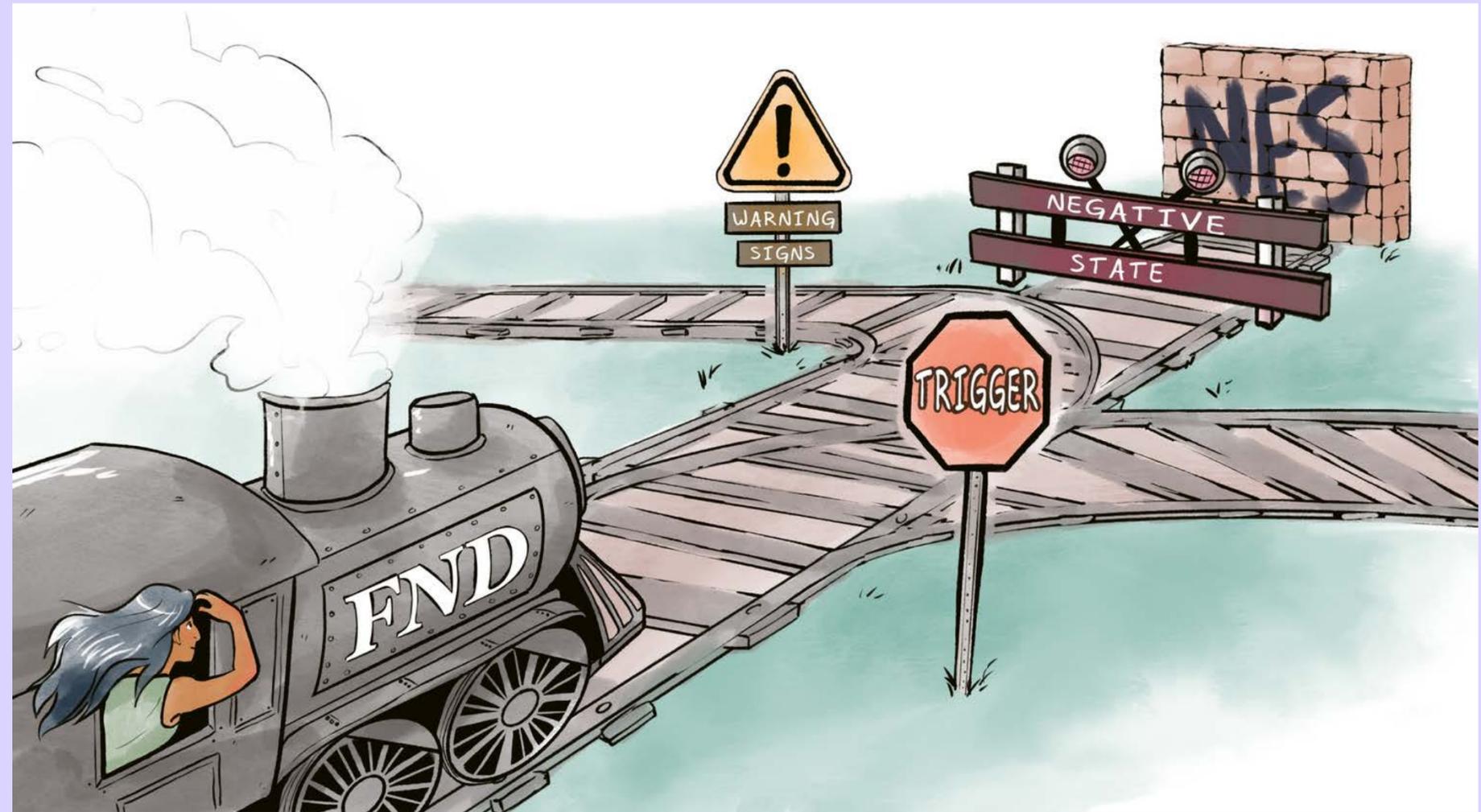
Carry a scent you
like with you and
inhale when
needed.

Fastest way to soothe: Vagus Nerve

- Gargle
- Hum
- Sing Loudly
- Blow Bubbles



Help Identify Warning Signs



SYMPATHETIC

Nervous System Controls

Vagal Nerve Inhibited
Dilates Pupils

Inhibits Salivation

Increases Heart Rate

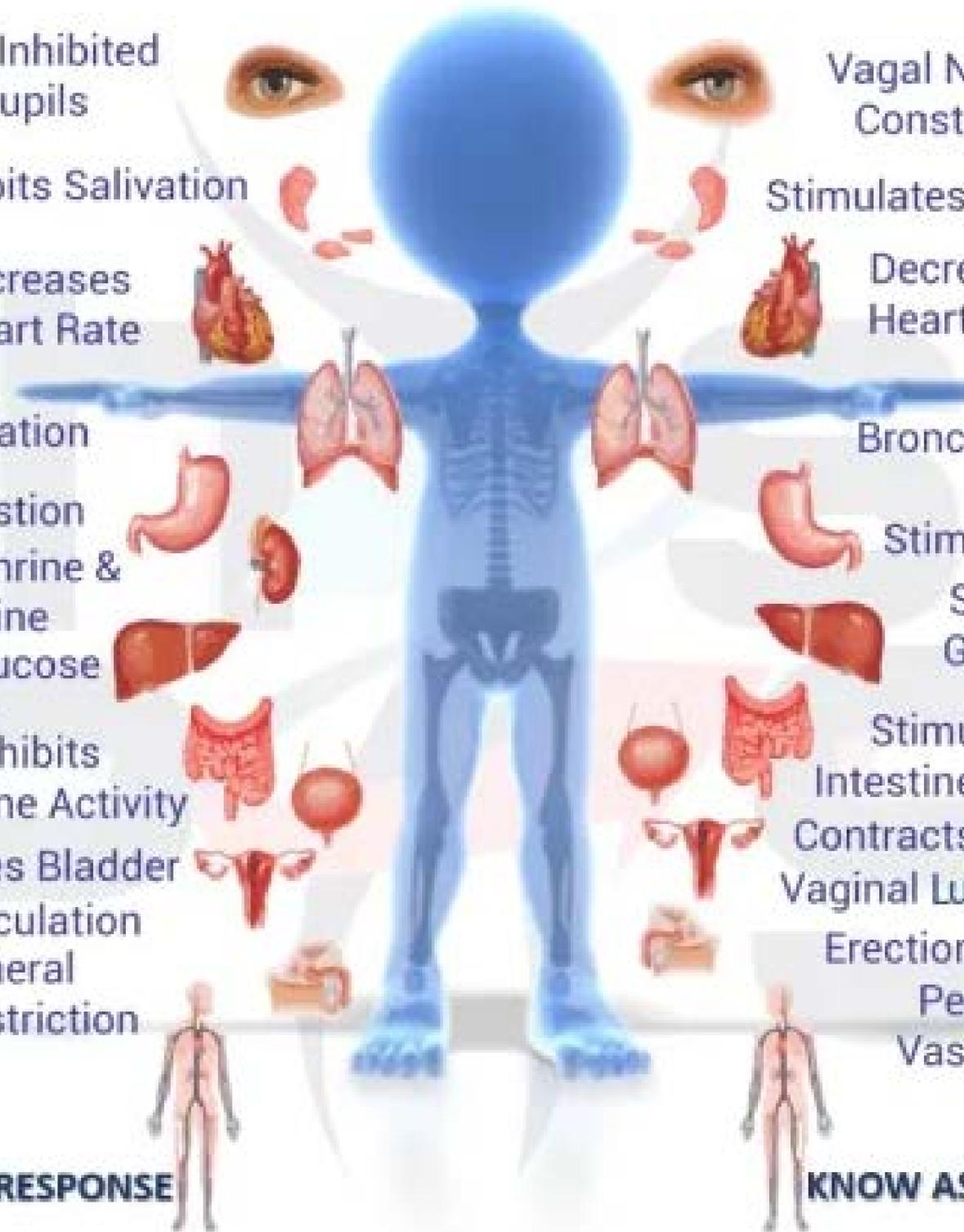
Bronchial Dilation

Inhibits Digestion
Secretes Epinephrine &
Norepinephrine
Stimulates Glucose
Release

Inhibits Intestine Activity

Relaxes Bladder
Ejaculation

Peripheral Vasoconstriction



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

Nervous System Controls

PARASYMPATHETIC

KNOW AS YOUR FIGHT OR FLIGHT RESPONSE

KNOW 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.**

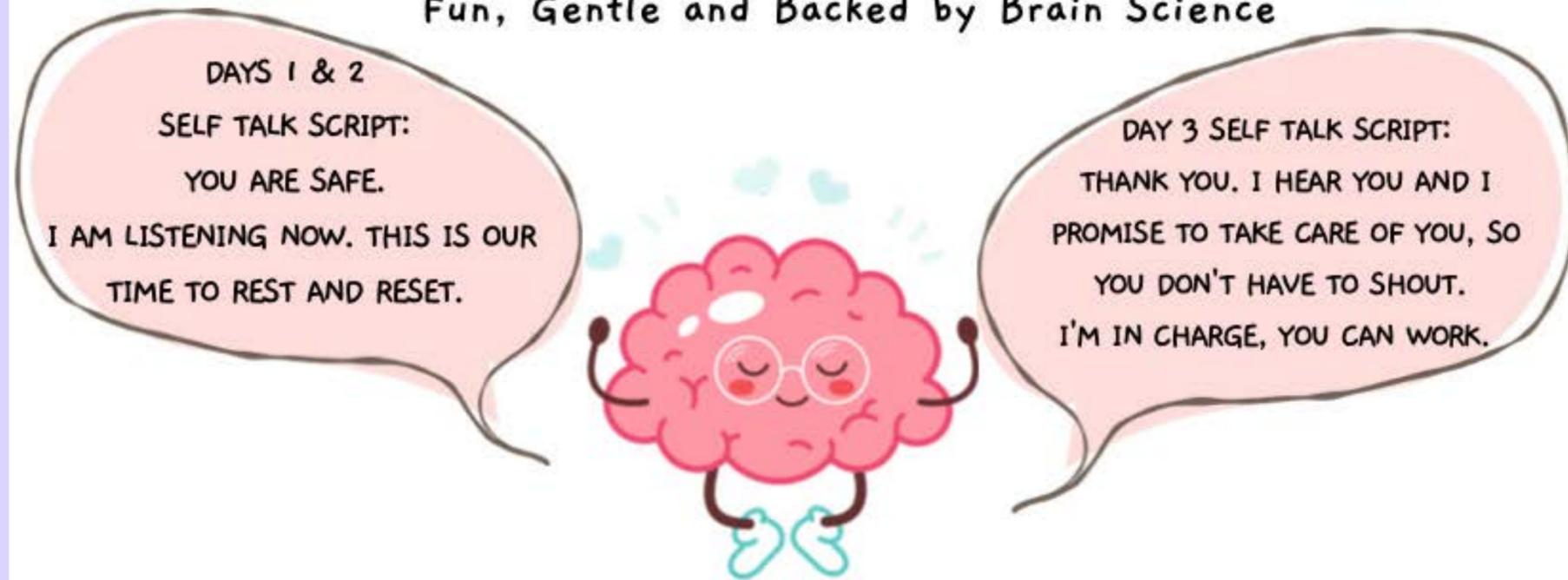
Are these statements supportive?	Acceptance	Confidence	Supportive
I know anxiety makes situations like these really tough, but I believe you can cope.	✓	✓	✓
I see how worried you are, if you don't want to do X, you don't have to.	✓	No	No
I'm here, don't worry, I got this.	✓	No	No
Stop obsessing. You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

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



CIRCLE AT LEAST 3 EXERCISES 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

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

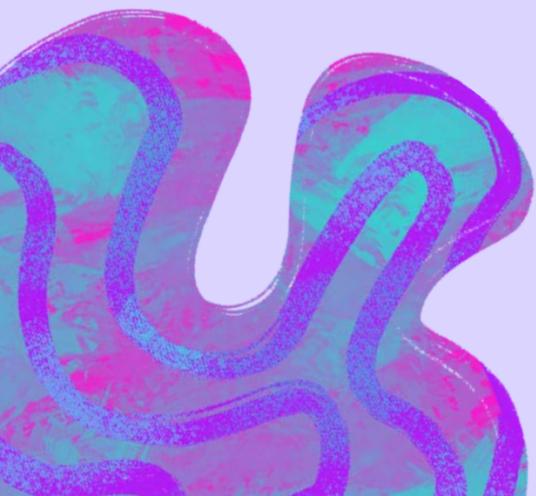
Neurology

Diagnosis and
monitoring new
symptoms to ensure all
dianoses are addressed

04

Mental Health

Nervous system
regulation
Support for loss of
function, adjustment to
life with illness

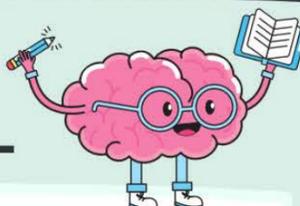


Make a plan

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.

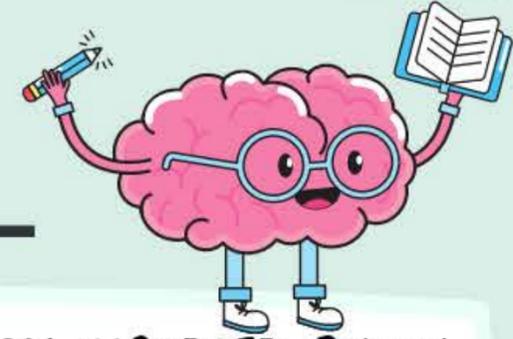
FOR ME, FND LOOKS LIKE:

MY WARNING SIGNS	WHAT TO DO IF AN EPISODE IS ABOUT TO HAPPEN
<div style="border: 1px solid black; height: 60px; width: 100%;"></div>	<ul style="list-style-type: none"><input type="checkbox"/> GIVE ME A REASSURING NONVERBAL SIGNAL THAT I KNOW MEANS, "I'M HERE. YOU ARE GOING TO BE OKAY."<input type="checkbox"/> REMIND ME TO USE A COPING SKILL TO REGULATE MY NERVOUS SYSTEM.<input type="checkbox"/> _____
WHAT TO DO DURING	WHAT TO DO AFTER
<ul style="list-style-type: none"><input type="checkbox"/> REMAIN CALM.<input type="checkbox"/> SPEAK POSITIVELY ABOUT ME OR BETTER YET, NOT AT ALL. I CAN HEAR YOU AND ATTENTION MAKES IT WORSE.<input type="checkbox"/> HELP ME SAFELY TO THE GROUND.<input type="checkbox"/> COVER HARD SURFACES NEAR ME.<input type="checkbox"/> 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.	<div style="border: 1px solid black; padding: 5px;"><p>REINVOLVE ME/RETURN ME TO CLASS.</p><p>PRAISE ME ONE-ON-ONE FOR COPING THROUGH MY SYMPTOMS.</p><p>PLEASE WAIT UNTIL THE END OF THE DAY TO CONTACT MY GUARDIAN USING THEIR PREFERRED METHOD.</p></div> <div style="border: 2px solid black; padding: 5px;"><h3>WHAT NOT TO DO</h3><ul style="list-style-type: none"><input type="checkbox"/> DO NOT CALL AN AMBULANCE AUTOMATICALLY. (REASONS TO CALL LATER ARE INJURY OR CAN BE ADDED BY YOUR DOCTOR TO A SEPARATE LETTER).<ul style="list-style-type: none">• DO NOT REMOVE ME FROM SCHOOL.• DO NOT BEHAVE FRANTICALLY.• <u>DO NOT TIME THE EPISODES. UNLIKE EPILEPSY, THE CARE DOES NOT CHANGE AFTER 5 MINUTES.</u></div>

Provider Signature: _____ Date: _____

Provider Name: _____ Provider Contact: _____

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.

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 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.
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Provider Signature:

Provider Name:

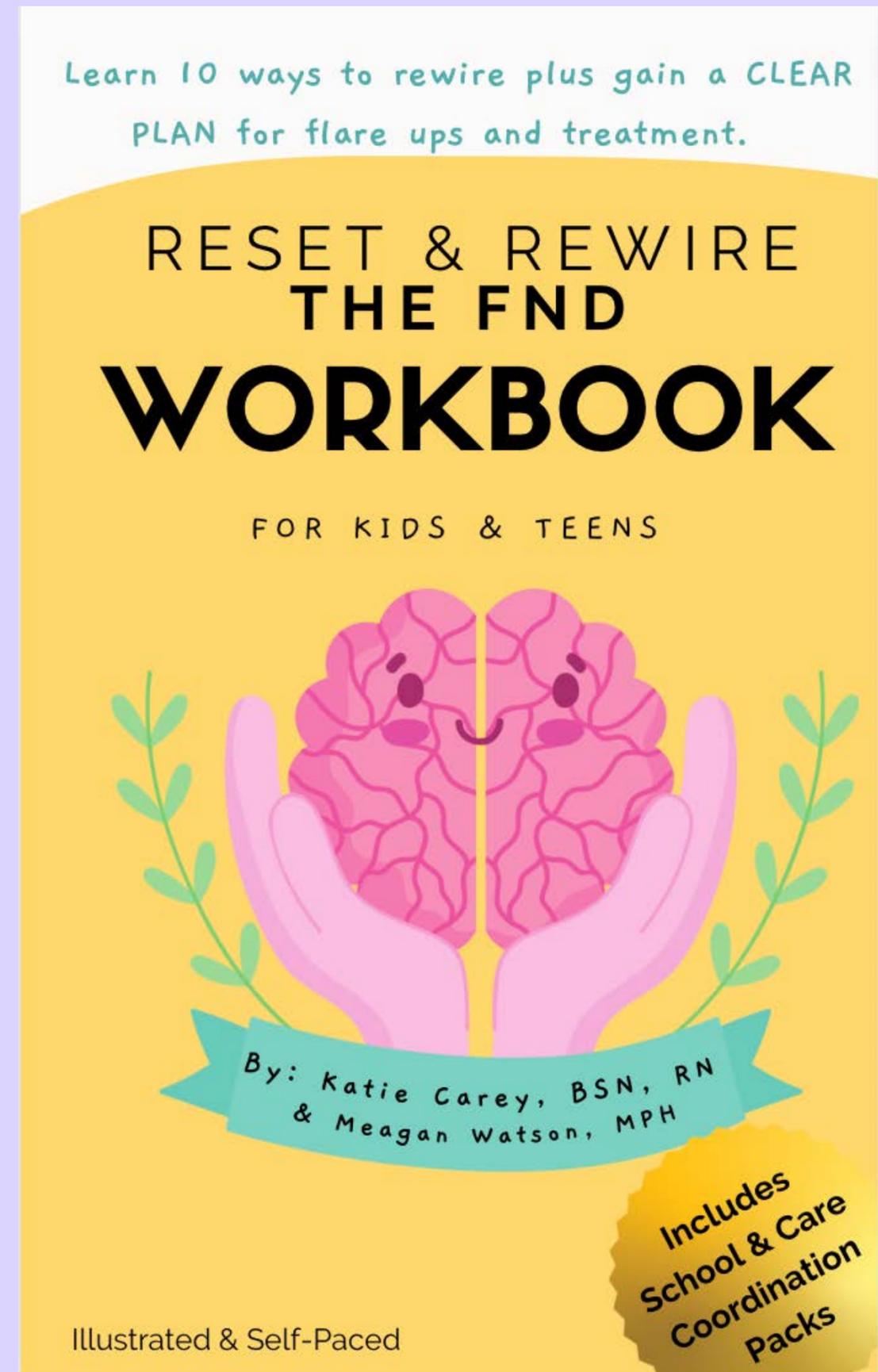
Date:

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

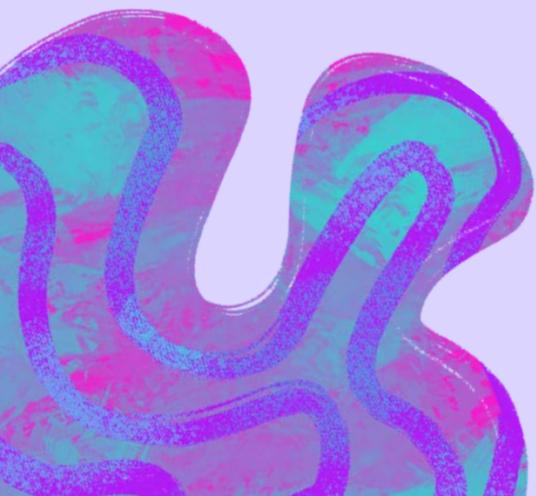
Suggested 504

- 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

Psychology Today

Find a Therapist ▾

Get Help ▾

Magazine ▾

Today ▾

🌐 US



How to ~~Control~~ Your Emotions

Are You Feeling Overwhelmed?

Find a Therapist

✓ Verified by Psychology Today

Therapists ▾

houston



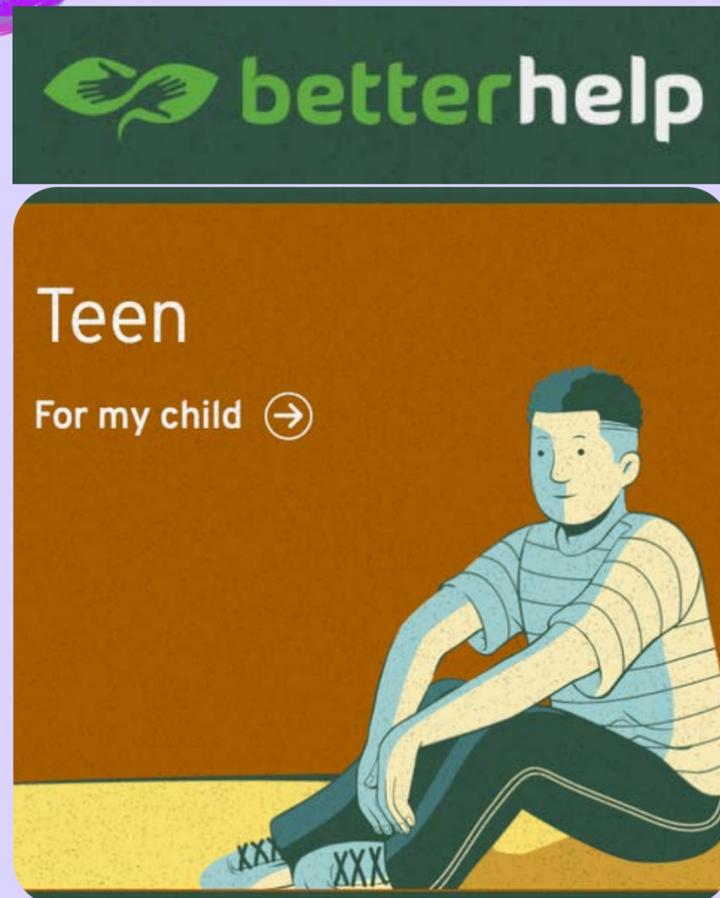
Houston, Texas

Professionals

Sign Up and Get Listed

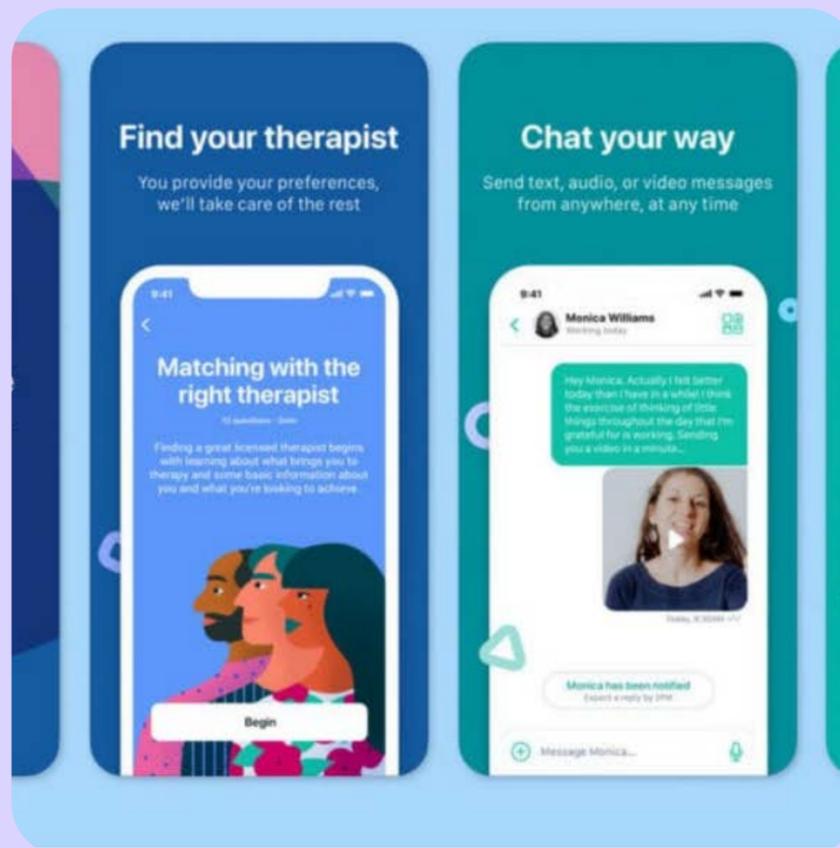
Login

Online Therapy Platforms



BetterHelp

\$60-90 per session
20% first month with code
word Forbes



TalkSpace

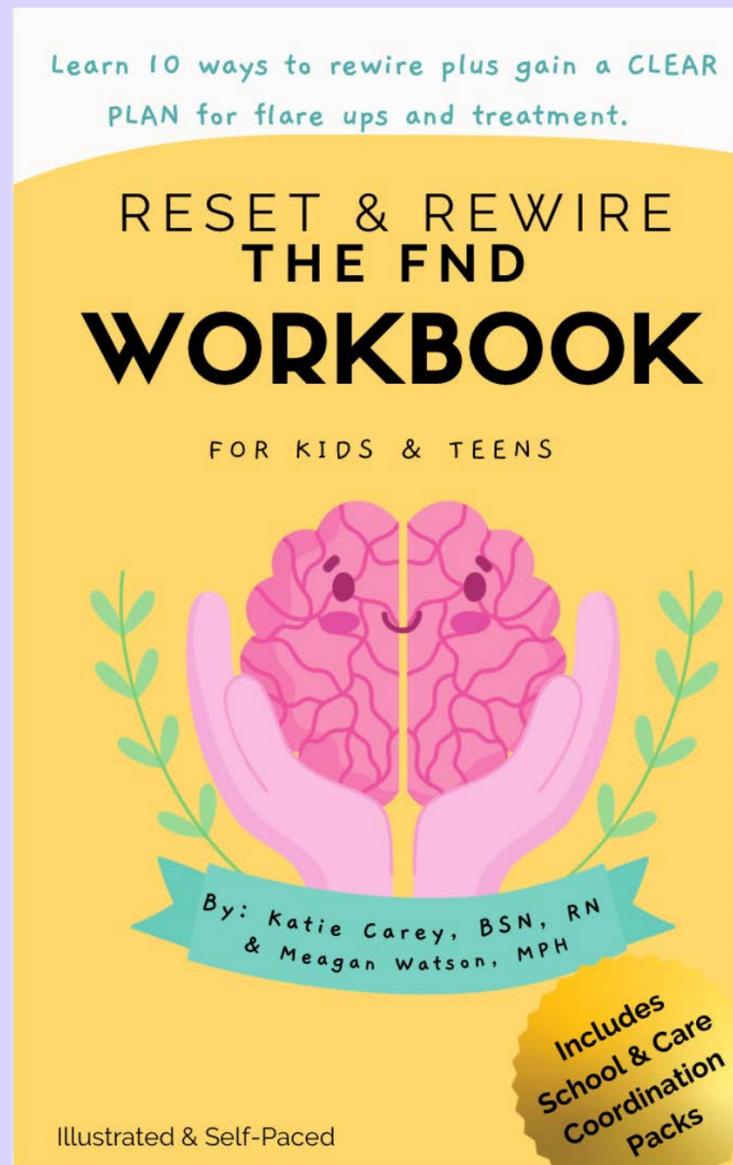
Accepts Insurance
\$80 off with code
SPACE80



Charlie Health IOP

Need a referral
Insurance accepted

Tool Kit



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

