



# MANAGING COMMON SYMPTOMS OF PANDAS/PANS

PANS TREATMENT GUIDELINES PART 1

PSYCHIATRIC AND BEHAVIORAL INTERVENTIONS

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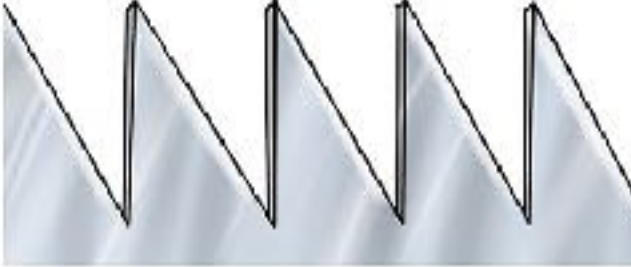


Figure 3. Molly's free writing. She was asked to write but did so with great reluctance.

I went to the car and  
and took books for a  
walk in the  
water

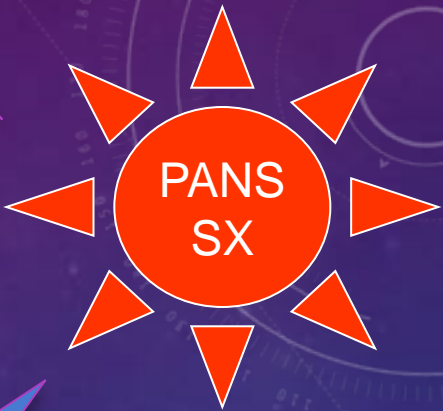


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# PANS TREATMENT

Psychotherapies  
Psychiatric medications

Infection, Inflammation

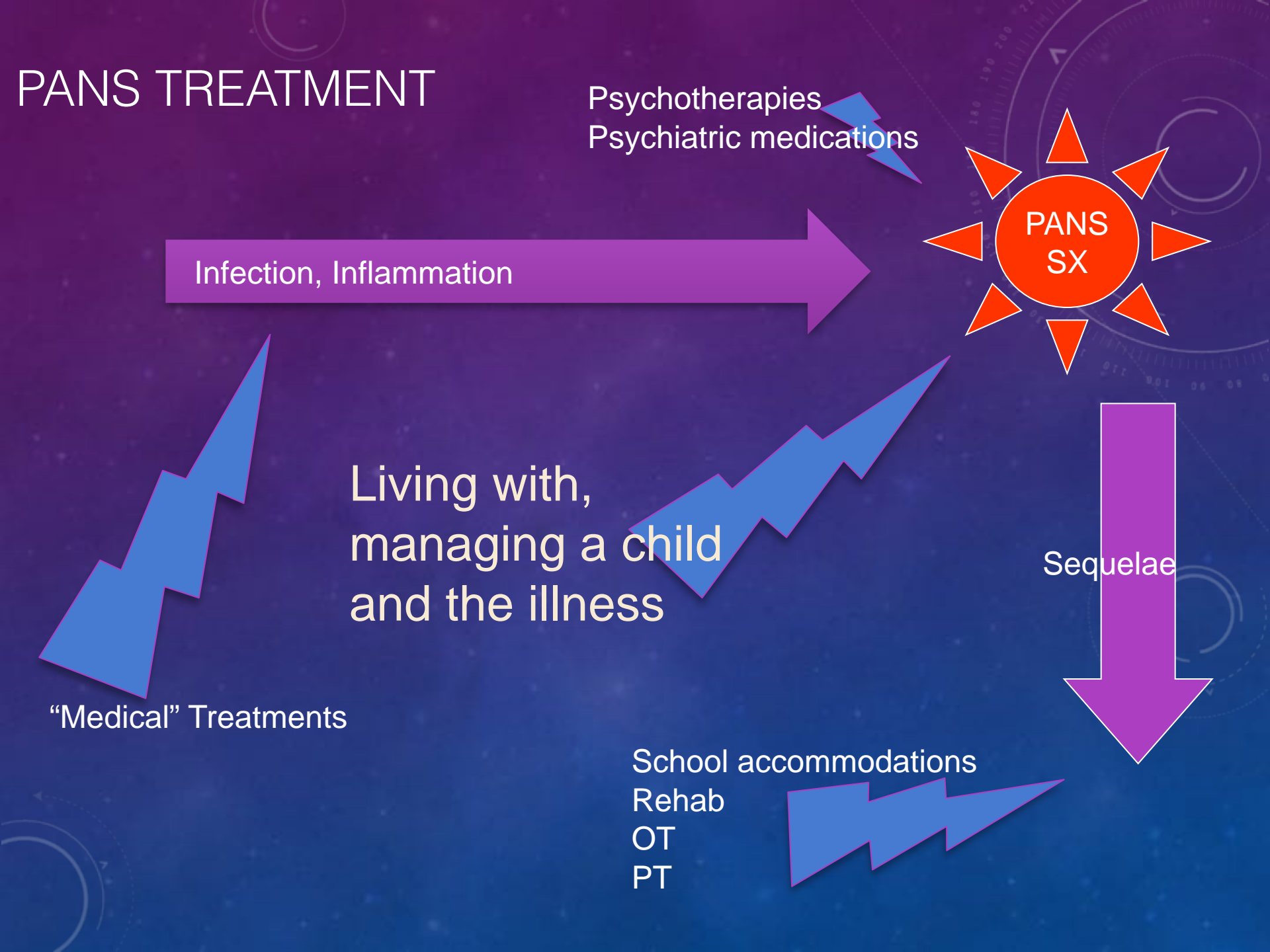


Living with,  
managing a child  
and the illness

Sequelae

"Medical" Treatments

School accommodations  
Rehab  
OT  
PT

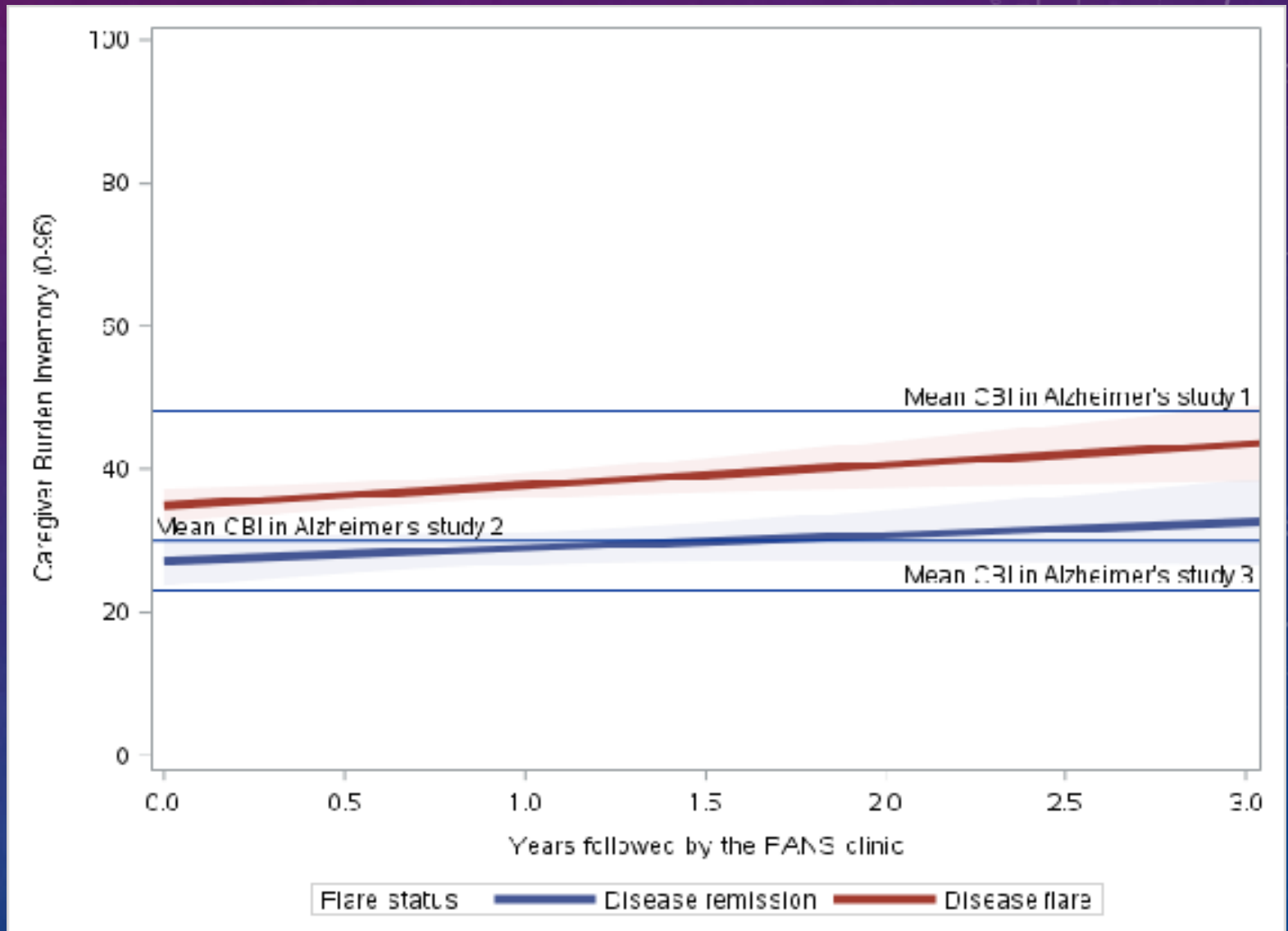




- Caregiver Burden is high
- Uncharted treatment path
- Many professionals unaware of PANS
- Many appointments
- Parental leave
- Patient at home
- Patient separation anxiety
- Sleep disruption
- Difficult to manage behavior
- Social isolation
- Rest of family neglect



# CAREGIVER BURDEN LIKE ALZHEIMERS' FAMILIES



Medical  
Care for  
Child

Self Care

Safety

Educate  
Self about  
PANS

Family  
Duties

Be case  
manager

Interface  
with School



Reasonable  
Expectation  
s

Simplify  
Life

Learn as  
much as  
possible

Seek  
Support

Care for  
Self

Expect  
some  
Setbacks



# GETTING TREATMENT

- Find a doctor
  - Size up the doctor: Do you say PANS or PANDAS?
  - Educate professionals
- Gather data
  - Time-line of infections, treatments and results (consult pediatrician)
  - Create a binder/electronic file of time-line, lab and evaluation reports
- Coordinate care among health care providers
  - Share lab
  - Schedule phone appointments, joint meetings





EVALUATE CHILD'S CAPACITY TO FUNCTION NOW:

IS IT REALISTIC TO EXPECT CHILD TO:

- Eat?
- Go to sleep now?
- Sleep alone?
- Stop compulsions?
- Stop crying?
- Stop being violent?
- Go to school?
- Get up early in the morning if he/she has not slept?
- Sit still in class?
- Concentrate?
- Do homework?
- Be quiet?
- Be away from home?



# CHILDREN WITH PANS MELT DOWN

- Anxious protest
- Anxious avoidance
- Compulsions thwarted
- Mood
- Rage
- Sensory discomfort
- Sleep disturbance
- Fatigue, pain
- Trouble thinking things through, planning
- School stress

# “RAGE ATTACKS:” DEFENSIVE AGGRESSION

- Attacks may come without warning
  - Uncharacteristic aggression
  - Biting
  - Kicking, hitting
  - Threatening language/ shocking

- Precipitants:

- Threatening stimuli: real or perceived
- Hunger
- Thirst
- Pain
- Sensory overload
- Frustration
- Change in routine
- Psychotic thinking
- Irritability

- Marked sympathetic output

- Minimal cortical input

- Theories:

- Inflammatory cytokines
- Basal ganglia stimulates medial hypothalamus or the periaqueductal gray (like sham rage)



# EXTERNALIZE THE PROBLEM: THE PROBLEM IS PANS, NOT YOUR CHILD

- Name the problem
- Draw a picture of the problem
- Don't punish PANS behaviors



- Is explosive behavior due to...
  - Bad Children?
  - Bad Parenting? NO!!!
- Parent and Child
  - Characteristics
  - Capacities
  - Deficits
  - Behaviors
  - Their interactions



# PANS CAN LEAVE CHILDREN WITH COPING DEFECITS:

- Low flexibility
- Low adaptability
- Low frustration tolerance
- Low problem solving
  
- All needed to
  - adapt
  - environmental changes and demands,
  - internalize standards of conduct
  
- Increased demands for compliance without these coping abilities cause frustration and emotional arousal



# WHWHAT SKILLS ARE MISSING?

- Executive function
  - Working memory
  - Organization
  - Shifting cognitive sets
- Language processing skills
  - Understanding others
  - Expressing one's self
  - Forming verbal models in one's mind
  - Labeling feelings
- Emotion regulation skills (Put aside emotion to accomplish a goal v. cognitive incapacitation)
- Cognitive flexibility (routines, transitions, black and white thinking)
- Social Skills

# HOW CAN ADULTS BE VULNERABLE?

- Parent executive function issues
  - Setting priorities
  - Black and white thinking
  - Rigid definitions of correct parenting
  - Planning
  - Emotional difficulties

# QUESTIONS TO ASK ONESELF...

- Is this a trainable moment?
- Is it imperative that my demand be met?
- Can we drop this demand?
- Can we figure out a workable solution?



# TRY:

- Empathy
- Validate
- Define the problem
- Brainstorm a solution
  - Never mind
  - We must
  - Lets problem-solve





# 911: HOSPITALIZE?

- Home
  - Difficult to maintain safety
  - Difficult to administer treatments
  - Exhausting
  - You know what is happening to the child
  - You are in control of what is happening to the child
- 911: how to call, what to say
- ED: call me to talk to personnel there
- Talking to doctors



## AVOID PSYCHIATRIC HOSPITALIZATION UNLESS:



- A medical-psych unit is available
- Available family resources cannot assure safety
- Severe food/drink restriction, but does not meet criteria for pediatric hospitalization
- Severe psychiatric symptoms when not in flare
  - Can contain dangerous behaviors
  - Usually rely on medications, to which PANS patients generally respond poorly
  - Ill equipped to diagnose, treat infections, immune conditions
  - Separation from family required

## AVOID PEDIATRIC HOSPITALIZATION UNLESS:



- Life-saving treatment cannot be given otherwise (eg. plasmapheresis)
- Advantages
  - Can allow parents to stay 24/7
  - Can deliver medical treatments
- Disadvantages:
  - Not designed for/comfortable with combative, emotionally labile children
  - Many noises, sensory stimuli and sleep interruptions
  - Not set up to contain dangerous behaviors
  - Medical admission criteria usually not met?

# HELPING CHILDREN COPE WITH TREATMENTS

- Environmental
  - Parent presence
  - Music
  - Electronic distractions
- Behavioral interventions
  - Desensitization, rewards
- Psychopharmacological interventions
  - Antihistamines
  - Benzodiazepines
  - Clonidine
- Appropriate pain control



# PANS PSYCHOPHARMACOLOGY BASICS

- Basis for Recommendations:
- Research has not established the most effective symptomatic treatments
- PANS Patients Do Not Respond as Expected
- PANS Patients May Only Tolerate LOW Doses of Psychotropics
  - PANS patients are more likely to exhibit
    - Agitation
    - Dystonia
    - Catatonia
- PANS Symptoms are episodic:
- Review medication frequently
- Pain may cause Behavioral Problems:
- PANS patients experience headache, abdominal pain and musculoskeletal pain.



# FACILITATE PATIENT GETTING DIAGNOSTIC AND TREATMENT PROCEDURES

- Benzodiazepine Issues
  - Sedation
  - Memory issues
  - Paradoxical reaction
  - Dependence
- Other
  - Diphenhydramine
  - Clonidine
  - Propranolol
  - Atypical antipsychotics
- Benzodiazepines Help
  - Anxiety
  - Catatonia
  - Mania
  - Psychosis
  - Sleep

# FOOD RESTRICTION

- Why?
  - Fear of vomiting
  - Smell
  - Texture
  - Contamination fears
  - Swallowing difficulty
  - Body image concerns
- Focus on calories in
- May require hospitalization
- Occupational therapy
- Dietary consultation
- Swallowing study



# OCD MANAGEMENT

- Medication:
  - SSRI's: pts. prone to side effects
  - Possibly more helpful for "left-over symptoms" than in acute phase
- CBT:
  - Small study supports effectiveness of CBT with family
  - Caretakers:
    - Refrain from accommodation
    - Externalize and label symptoms
    - Contain "spread" of symptoms



# STRATEGIES TO DEAL WITH RAGE

- Punishment does not work
- Distraction can be powerful
- Minimize risk factors: sleep, hunger, abrupt transitions
- Must set limits on violence
- Use 911 prn
- Pharmacological
  - Benzodiazepines
  - Gabapentin?
  - Antipsychotics
- Treat the underlying infection, inflammation



# SEPARATION ANXIETY

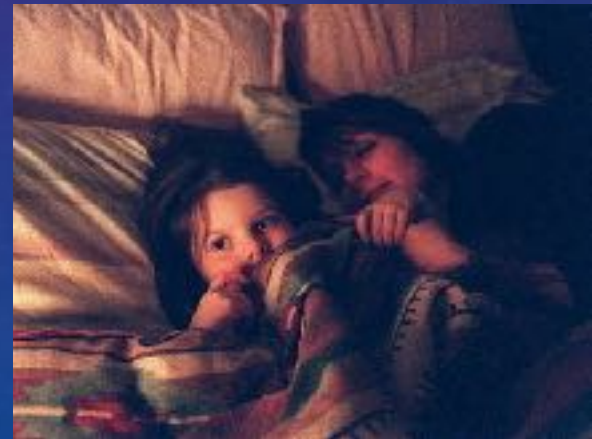


- Symptoms may be short-lived:
  - Maybe do not fight it
  - Go back to room, school as soon as tolerated
- Parents need breaks
  - Encourage parent to help find additional attachment figures
- Cognitive Behavioral Therapy:
  - Label as PANS symptom
  - Help child address probability/severity of feared event
  - Stepwise, practice separations: time/distance (Parent in hallway, library, car, on a walk...)
  - Praise, rewards
- “Safe place in school” to which may retreat



# SLEEP DISTURBANCE: A FUNCTION OF:

- Separation anxiety
- Enuresis
- Insomnia
- Night terrors
- Temperature dysregulation
- REM sleep disorder
  
- Strategies:
  - Proximity
  - Melatonin
  - Diphenhydramine
  - Benzodiazepine
  - Trazodone



# PAIN

- Muscle/joint pain
- Headaches
- Stomach aches
  
- Anti-inflammatories
- ? Dietary changes
- Gabapentin
- Low dose naltrexone
- Physical therapy



# FATIGUE: POOR PHYSICAL AND COGNITIVE STAMINA

- Reduce school load
  - Fewer classes
  - Accept work done by bedtime as adequate
  - Selected problems
  - Permission to excuse self from class t
  - Place to rest
- PE Accommodations
  - Adaptive
  - Excused



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# SCHOOL ACCOMMODATIONS

- Most children miss some school
- Difficult to plan for needs with an illness with a fluctuating course
- Cognitive symptoms may be significant and trail other sx in resolution
  - Concentration
  - Memory
  - Processing speed
  - Math and reading difficulties
  - “Brain fog”
- Tell school specifically how they can help:
  - Specific
  - Detail
- Be assertive



HYPERACTIVITY, INATTENTION,



- ADHD accommodations:
  - Preferential seating
  - Extended time on tests
  - Resource class for executive function help
- Permission to take breaks, “errand” breaks
  - Without interrupting class
  - Without asking for permission



# HANDWRITING DIFFICULTIES

- Occupational therapy
- Photocopy enlarge assignment pages for larger writing area
- Write on large grid paper
- Note taker
- Scribe in class
- Scribe for dictation
- Proctor/scribe for tests
- Assistive technology
  - Keyboard
  - Computer
  - Audio-recording



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# SLOW PROCESSING

- Cut down assignment number
- Cut down assignment length
- Extra time for tests, in-class assignments
- Give directions in written form, orally, and provide on school homework website



## Math Difficulties

- Calculation difficulties common
- Tape chart with times table, etc. to desk
- Allow electronic calculator
  
- Psycho-educational testing
- Neuropsychological testing



# SCHOOL: EXPOSURE TO INFECTION?

- Strep notification
- Strep letter
- Hand washing education
- Prophylactic antibiotics?



# PSYCHOTHERAPIES OF PANS

- CBT with family involvement has support
- Can work with parents even when patient is not available
- Other therapies derive from guidelines for specific symptoms



# FOCI OF OUR PANS PARENT SKILLS GROUP THERAPY

Mindfulness

Parents of kids with chronic illnesses

Acceptance and Commitment Therapy tools

Post-Traumatic Stress Disorder

Distress Tolerance

Chain Analysis/Emotion Regulation

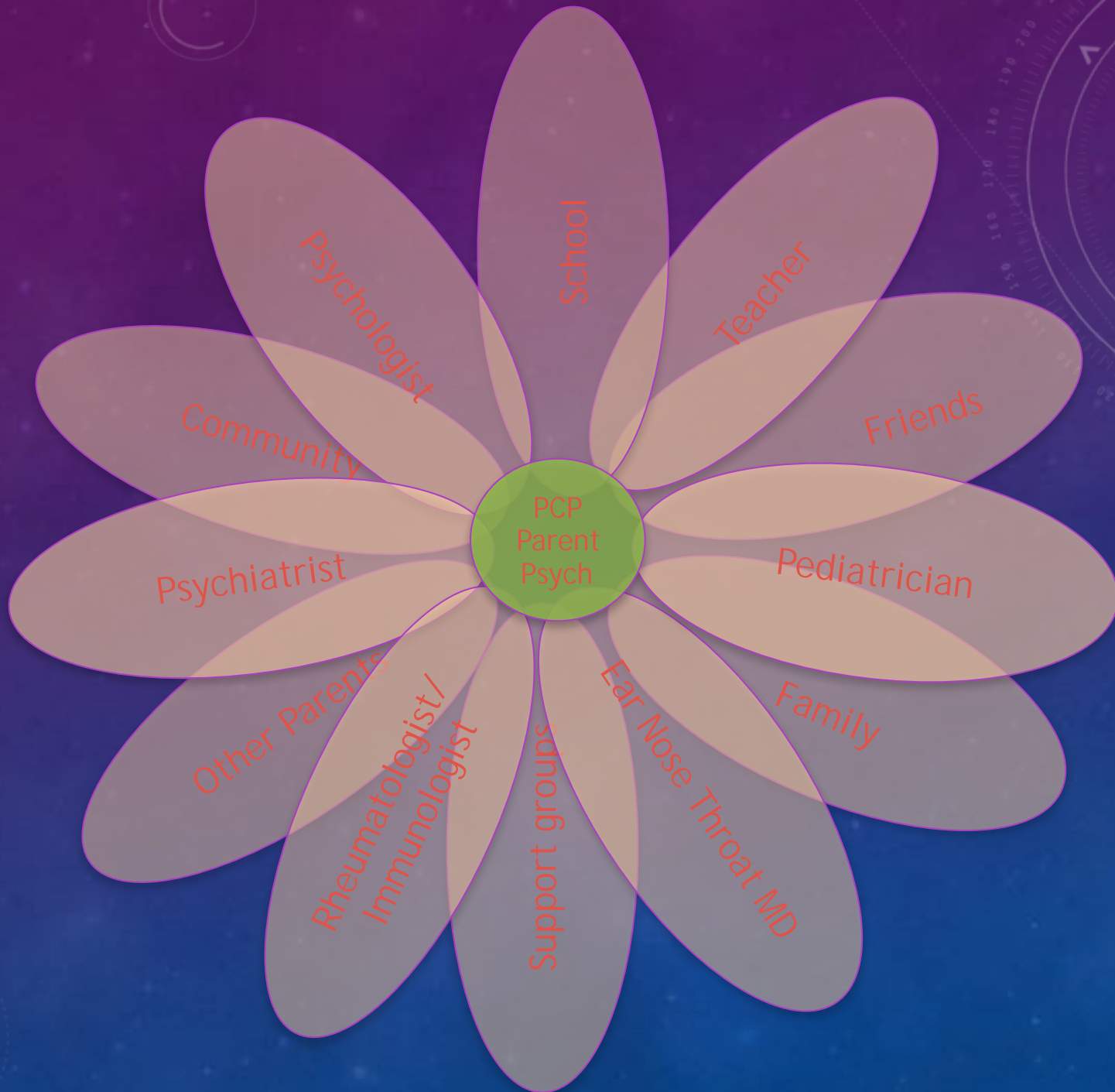
Radical Acceptance

Cognitive Skills

Collaborative Problem Solving

Impact of chronic illness on siblings and other family members





PCP  
Parent  
Psych

School

Teacher

Friends

Pediatrician

Family

Ear Nose Throat MD

Support groups

Rheumatologist/  
Immunologist

Other Parents

Psychiatrist

Community

Psychologist