Supporting Families Through The Use of CPAP

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Why wearing a CPAP is hard

- Newness of CPAP and a change
- Difficult to see immediate benefits
- Sensory components
Sensory Processing

- Overview: sensory processing is our ability to take information in from the outside world as well as our internal sensations, organize it, identify it, and produce a functional response. This system helps us understand information about a situation, might determine how we feel, and might help us produce a response.
  - Some people have high thresholds for input (need more!)
  - Some have low thresholds for input (need less!)
General Sensory Strategies for Challenging Situations

- Isolate sensory experiences to avoid overwhelm
- Provide foreshadowing of what is going to happen, what it might feel like, and identify a tool that could help
- Create a list of "before, during, after" sensory-based tools that help a child feel ready, calm, and regulated to have ready for use.
  - If a child can feel as regulated as possible going into the attempts of CPAP usage, they may be at a better place for success.
Strategies to Help with Sensory Difficulties

- **Touch:** the feeling of a mask on the face, the pressure it puts on the skin, nose, jaw, mouth; the sensation of air blowing into the face, humidity and moisture on the skin
  - Slow exposure while awake, placing mask while asleep, mask pads/cushions, trials with mask without flow (tube disconnected), adjusting the temperature and humidity levels

- **Noise:** the sound of the airflow, possible squeaking with leaks
  - Background noise/soft music playing, white noise machines, ensuring proper mask style and fit, tubing placement in bed to avoid disconnection, chin strap
Strategies to Overcome Sensory Difficulties

- **Vision:** vision may be occluded with use of the mask; possible air into eyes
  - Ensuring best mask fit, best mask style (nasal vs full face mask)
- **Smell:** Plastic or breath odor
  - Oral care before using and when waking to use bathroom, Chap Stick
- **Position:** discomfort with laying down with these added sensory components
  - Begin trials sitting up, in favorite chairs or spots in the house, snuggled with a parent, pair with preferred distraction activity
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Graduated Exposure

- Environment
- Routine
- Equipment
- Duration
- Body Placement
What does this look like?

Mask (without tubing or straps or machine)
- Place on hand for a brief time (10 seconds)
- Move from hand, to forearm, elbow, shoulder, ear, cheek, nose (10 seconds)

Mask with Straps
- Start at 10 seconds and work up to 30 seconds

Mask with Straps and Tubing
- Start at 30 seconds and work up to 1 minute

Introduce CPAP Machine (off and not connected)
- Turn on Machine (not connected)
- Connect Machine
- Increase Duration from minutes to hours
- Shift to bedtime routine
- Remove prior to falling asleep

Adapted from Gregory Young, PhD, LABA, BCBA work at Franciscan’s Childrens in Boston MS
Dr. Young created and recommended an outpatient protocol to a down syndrome group and the protocol is based in behavioral strategies.
Positive Reinforcement

Behavior: Hold CPAP Mask In Hand for 10 Seconds
Favorable Consequence: Receives a High Five and 5 minutes of Ipad
Behavior More Likely to Occur: May be more likely to want to do this again to get more Ipad time
Real life and family considerations

- Start exposure while awake
- Pair with favorable activity, set timer, celebrate small victories
- Focus on positives benefits of use, feeling better, healthier, more energy.
- Point out positive outcomes “you used your CPAP last night and look like you have so much energy—let’s go to the park” Make it meaningful to the individual
- Use of social story with pictures
- Praise success, downplay struggles
- Optimize sleep hygiene
- Find a mentor who uses CPAP

https://adscresources.advocatehealth.com/assets/1/13/Going_to_Get_My_Sleep_Mask.p
Expectation setting

- Set realistic expectations
  - Don’t expect perfection initially
- Be positive
  - Caregiver attitudes can affect ability to tolerate
- Practice consistently
  - Try an introduction method and continue for a period of time before changing approach
- Be willing to pause and reintroduce
  - It OK to say this is not working NOW....try again in the future with new outlook, maturity, and expectations
Remember

- Some individuals will be able to tolerate CPAP. Some will benefit from tips today. Some will not be able to tolerate CPAP when initially presented and we recognize that all of these scenarios exist.

- Families may have tried all the ideas today. Also, what you are doing is enough and if the information given today does not serve you, we give permission to set it aside.

- Find the positive successes and celebrate those along the way.
Questions


