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Supporting Families Through The Use of CPAP



Why wearing a CPAP is hard

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

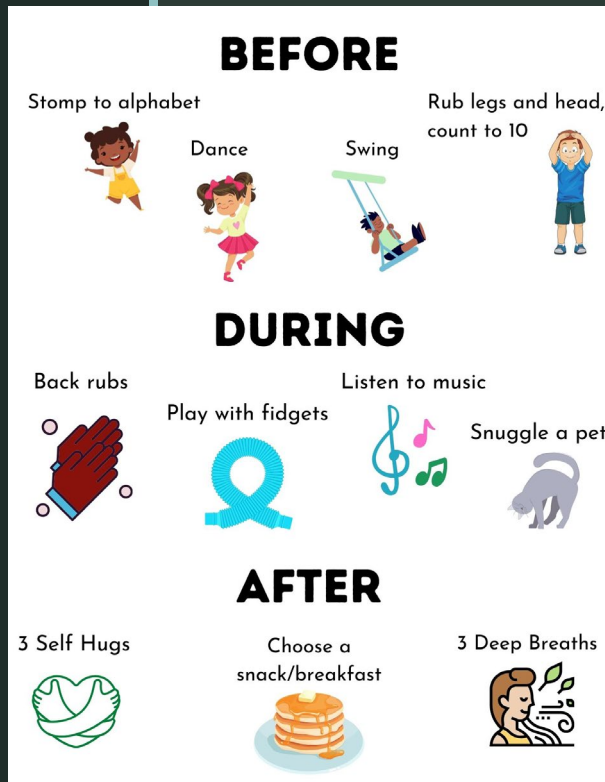


Sensory Processing

- 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

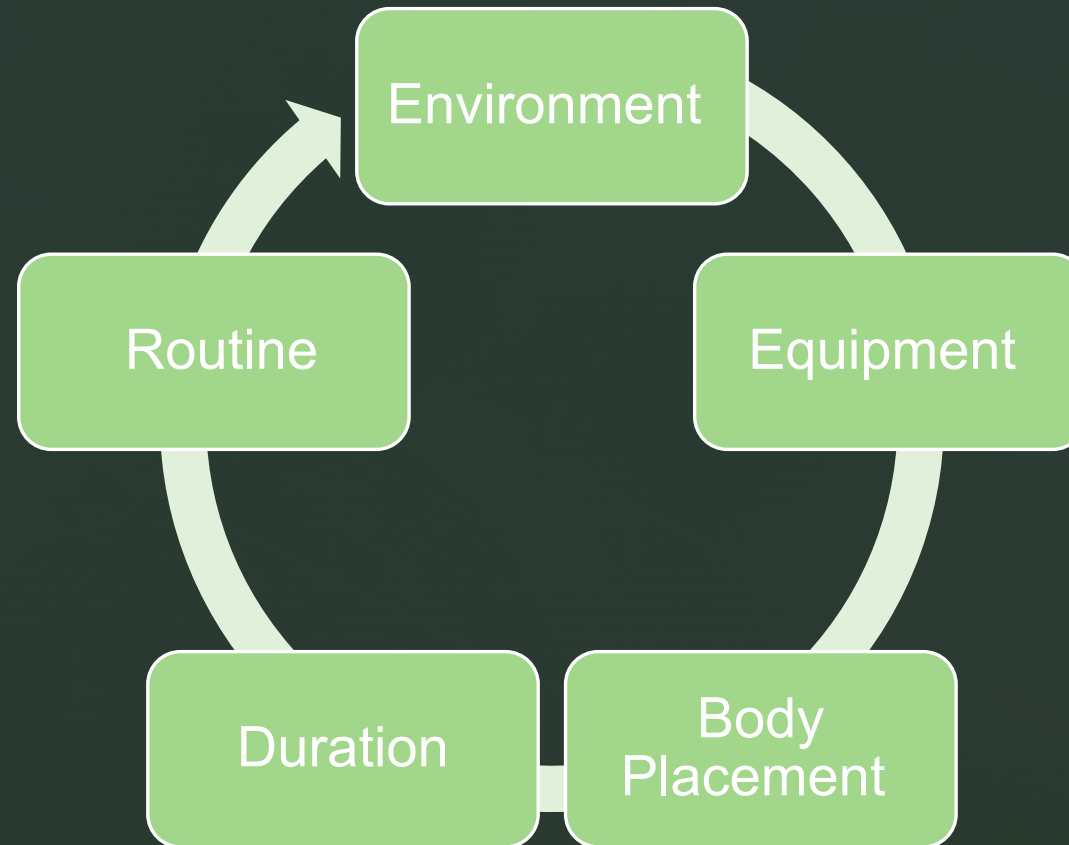
- Vision: vision may be occluded with use of the mask; possible air into eyes
 - Ensuring best mask fit, best mask style (nasal vs full face mask)
- Smell: Plastic or breath odor
 - Oral care before using and when waking to use bathroom, Chap Stick
- Position: discomfort with laying down with these added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

Behavior Based Strategies

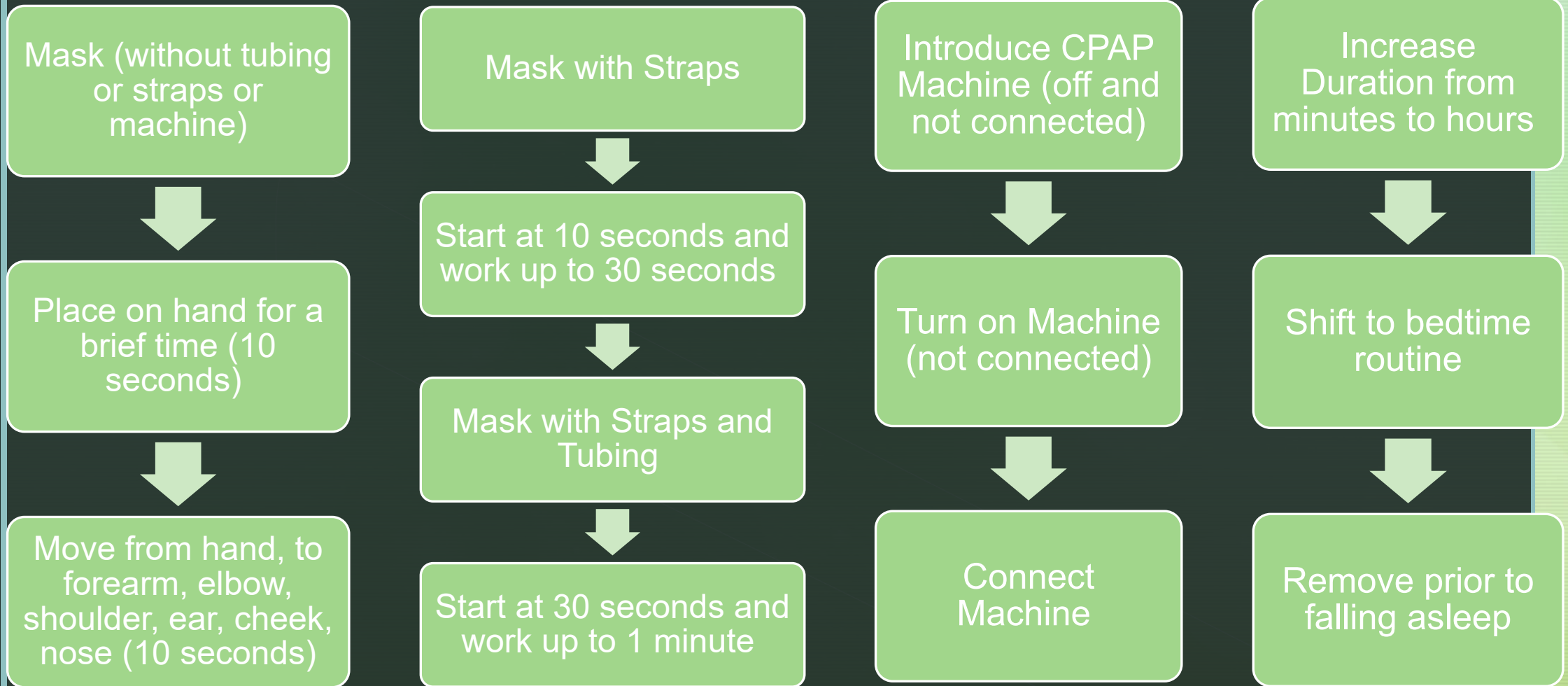
Graduated
Exposure

Positive
Reinforcement

Graduated Exposure



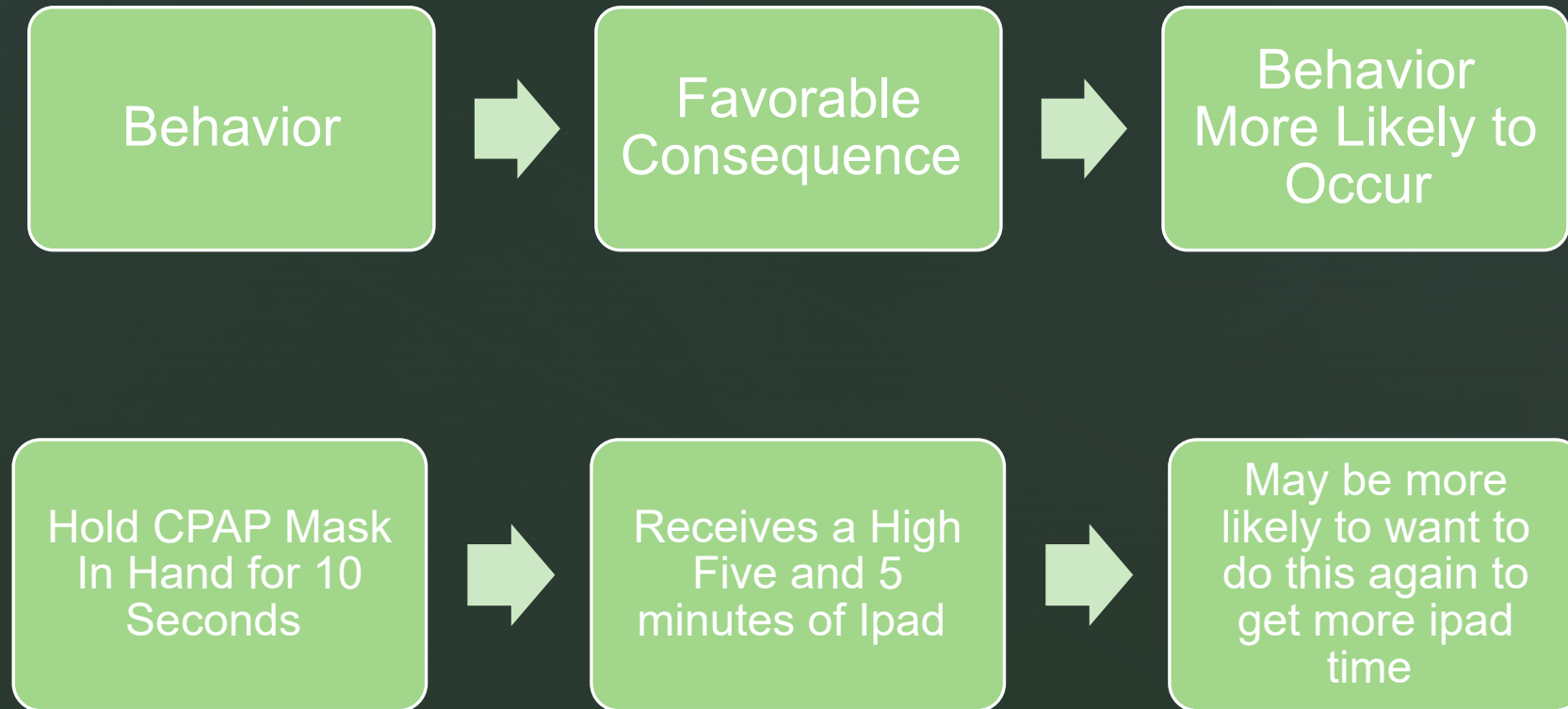
What does this look like?



Adapted from Gregory Young, PhD, LABA, BCBA work at Franciscan's Childrens in Boston MS

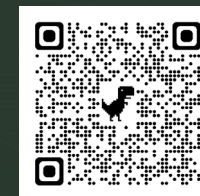
Dr. Young created and recommended an outpatient protocol to a down syndrome group and the protocol is based in behavioral strategies

Positive Reinforcement



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-lets 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



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

- Bruni, M., Cameron, D., Dua, S. & Noy, S. (2010) Reported Sensory Processing of Children with Down Syndrome, Physical & Occupational Therapy In Pediatrics, 30:4, 280-293, DOI: [10.3109/01942638.2010.486962](https://doi.org/10.3109/01942638.2010.486962)
- Chernyak Y. Improving CPAP adherence for obstructive sleep apnea:a practical application primer on CPAP desensitization. MedEdPORTAL.2020;16:10963. https://doi.org/10.15766/mep_2374-8265.10963.
- Isralowitz EB, Sideris J, Stein Duker LI, Baranek GT, Cermak SA. Comparing sensory processing in children with Down syndrome to a mental age matched sample of children with autism, other developmental disabilities, and typically developing children. Res Dev Disabil. 2023 Mar;134:104421. doi: 10.1016/j.ridd.2022.104421. Epub 2023 Jan 11. PMID: 36638671.
- Patel, L. (2023, April 27). Improving Tolerance to Device Wearing (hearing aids, glasses, CPAP masks). (#153) *Down Syndrome Center Podcast*. <https://downsyndromecenter.libsyn.com/153-improving-tolerance-to-device-wearing-hearing-aids-glasses-cpap-masks>
- Slifer, K. J., Tunney, M. A., & Paasch, V. (2018). Behavioral intervention for positive airway pressure (CPAP/BPAP) desensitization. *Sleep in Children with Neurodevelopmental Disabilities*, 373–382. https://doi.org/10.1007/978-3-319-98414-8_34
- Xanthopoulos, M. S., et al. Caregiver experiences helping children with Down syndrome use positive airway pressure to treat obstructive sleep apnea. *Sleep Medicine*, Volume 107, 2023, Pages 179-186, ISSN 1389-9457, <https://doi.org/10.1016/j.sleep.2023.04.022>. <https://www.sciencedirect.com/science/article/pii/S1389945723001521>