

red overview

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with advice and input from:
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The RED device procedure and recovery may be a daunting process, but our panel of caregivers has helped to demystify and prepare your family for the “big one.” In this overview, we will walk you through the steps to take before the surgery, the best post-operative tips, and how to conquer the recovery process at home. We will give you tips and tricks for optimal hygiene, nutrition, and comfort. Are you ready? Yes, you will be!

The Rigid External Device (RED) may be a necessary surgical intervention that your child requires. It is a staged process, involving one surgery to attach the device, wearing it for a defined period while turning the device, followed by a waiting period while wearing the device, and then a removal surgery.

The goal of the RED is to improve air flow through the airway, realign the jaws on a vertical and horizontal plane, and reset the position of teeth for better dentition and mouth closure. The surgery improves your child’s ability to breathe, chew, and continue to grow into their bodies.

BEFORE

Our expert parent panel suggests preparing for the surgery

early given its invasive nature and lengthy recovery time.

We suggest the first thing to start with is developing daily practice with meditation, prayer, or a soothing ritual. Proactively calming the mind will prevent surgical trauma and assist in healing. Plus, taking care of your mental health is important for the entirety of your life, but is especially important for this milestone surgery.

A good place to start -- for both you and your child -- may be **downloading a meditation app**. Easy and accessible, the [Calm App](#), [Headspace](#), and [Balance](#) are all good ones that are great for beginners. Keeping your mind right during the easy and the tough times is so critical for a smooth recovery. If meditation is not your thing, make sure you are taking time each day to check in with your child. One therapist recommends a daily question, “What was the rose of your day, and what was the thorn?” This sets up a clear time each day for children to feel safe and talk, and over time they will come to recognize this ritual as a safe place to share feelings.

Other techniques to practice include grounding techniques like counting things in the exam room, singing, or smelling a favorite essential oil (lavender and peppermint are calming) as ways to stay in the moment. Prefer to talk it out? Help your child shift their mindset by encouraging them to consider what benefits this surgery will provide for them.



Image credit:
KLS Martin

Focus on the benefits rather than the costs of the surgery, to make a positive difference in the process. It is important to remember that the RED and midface advancement surgery is not all about looks. The removal of the trach, the ability to sleep without a CPAP machine, and the ability for the facial bones to grow are huge motivators to celebrate with your kid, too.

EMPOWERING YOUR CHILD TO MAKE THE BEST DECISION AROUND THE TIMING OF THE PROCEDURE IS KEY, TOO.

Allow them to feel and describe what is best for their bodies. Whenever possible, trust them and their judgment, and allow them to make decisions on the course of treatment. “Either/Or” questions are great options here. For example, “We need to do the surgery either the week of July 1 or July 21. Which do you prefer?” or “We can start the IV when you arrive or we can first use some numbing cream, but you will need to be there 30 minutes earlier. Which way would you like to do it?” These simple choices give your child a sense of control at the moment and also build their proficiency in being their own care manager.

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red overview, continued

REVIEW THE PROCEDURE AND THE ACTIVITIES AROUND YOUR RECOVERY WITH YOUR MEDICAL TEAM IN ADVANCE

Viewing before, during, and after X-Ray imaging and photographs of other patients can help your child and family understand how the road ahead will look. A tip that nearly all panel members agreed upon was: do some rehearsals! Practice with the WaterPik, start using mouthwash (make sure you check with your team what brand/flavor they will want you to use), take a nap with a neck pillows, try out recipes for a soft food diet, and simulate suture cleaning on dolls or siblings, to familiarize your child with the recovery process. The transition from post-operation to recovery will go smoother when there is less resistance to the newness and the variety of products involved.

HARNESS THE SUPPORT OF FAMILY AND FRIENDS

Involve your entire family, especially brothers and sisters, in the preparation for the surgery, too. Bring them to appointments when possible to see the device on dolls or skull models. Youtube videos are another useful tool that you can watch with family and friends. In general, the more siblings and friends know, the less fearful they are. The more practiced they are with the products you'll use, the more help they will be in the recovery

period, giving them a way to contribute and feel appreciated. Educate them on the benefits of the surgery as well, so they can remind your child that they are undergoing this procedure for a good reason. Hearing this encouragement from a friend or sibling will go even further than words from parents and providers! One of our SuperSibs shared with their sibling that she would look like a celebrity after it was all done. Kids know how to relate to other kids, so enlist their help and make sure to recognize their efforts.

GO TO THE SALON

Go to the salon. Another huge tip that many parents shared with us in preparation for the surgery was to cut their child's hair before heading into the hospital. One parent expert shared that she joined in the fun and shaved her head for the procedure, too. Certainly, that is not required, but finding humor and camaraderie in difficult situations can definitely help bolster your child's resilience. Talking about how much and when to cut their hair is another one of those times your child can make a decision all on their own that you can support.

SURGERY DAY AND PICU RECOVERY PERIOD

Contact the Child Life department in your hospital before you go in for the surgery. Child Life can assist in the pre-op area with distracting games, a reassuring presence, and the mindfulness techniques you practiced in the months leading up to the surgery. They can also provide iPads, emotional support animals, musical instruments and more throughout your stay.

Assure your child that they are safe and their pain will be managed by the medical professionals. Share with your child that they may spend some time in the PICU after the surgery. Shine a positive light on the hospital and medical team. Kids take cues from you. If you show confidence, they will too! Let them know you researched this hospital and the team and you chose them for their skills and because they are the best team to do this surgery.



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red overview, continued

In the days following the surgery, parents should look out for unusual swelling and bruising and complaints of intense pain from your child. Keep a notebook of questions and notes for the doctors when they visit the room. Record the responses with a voice message app on your phone so you can review them later, and share them with others, if needed. You may be tired and stressed, so don't rely on your memory alone.

Additionally, our parents strongly suggest that your child take their first shower post-op at the hospital with the help of nursing staff. They highly encourage practicing wound care and oral cleansing with medical professionals, too, before leaving.

CAREGIVERS, TAKE CARE OF YOURSELF!

Caregiver self-care will result in better care for your child. Bring top-quality instant coffee, or your favorite tea bags, healthy snacks, and phone numbers of experienced CCA friends to call and chat with. Bring fun books to read, or line up movies and shows to watch on your favorite streaming service that will



keep your mind light and bright. All of these things will help you weather the storm with ease and grace.

AT HOME RECOVERY

Let's be honest, the panel agreed: the recovery after the RED device is a long one. It takes a village to get through to the other side. Recruit siblings, extended family, and friends to help you and your family out. Your village can help with meals for your family, TV show suggestions, or keep your kiddo engaged by playing quiet games together or exchanging small gifts.

Caregivers will have to turn the distractors each day for a period of time, and then the RED is worn without turning for an additional four to six weeks. The panel reassured everyone that the turning was manageable. Often one caregiver is designated as the turn-manager, as they are emotionally and physically able to complete the task with as little "drama" as possible. If you are the caregiver, do not act squeamishly or be overly apologetic during turns. Be patient and take a few deep breaths together, but stay strong, knowing this is the right treatment at the right time.

Keep your child comfortable with contouring neck pillow, and ice packs for their eyes and face. Choose shapes that will cradle the face well. [CranioRehab](#) has some good ones that comfortably wrap around the head.

A unanimous tip from the panel was to prepare yourself for the secretions that will ooze from the sutures, mouth, and nose. It surprised all of our panel members, so they wanted you to mentally get ready for a lot of bodily fluids. Cleaning the sutures and skin can be painful, but is necessary. Find a positive way to entertain your child perhaps with an iPad or music to help improve their mood while this activity takes place. Triple-antibiotic ointment, cotton swabs, mouth rinses, and lots and lots of button up shirts are your tools through this process. Don't be surprised or shocked at the amount of oral and nasal secretions you see daily. Of course, contact your medical team if color and consistency changes to rule out infections and complications, but know in advance you will deal with secretions. If your child is sensitive or self-conscious about these secretions, prepare them in advance as well. Have some strategies in mind for coping with them in public. Maybe you wear bandanas, maybe you keep wipes and a small mirror at their desk, but make sure they understand they are not "gross," and they are normal. Their hygiene is another area where they can be empowered to practice self-care.

Finally, we've put together a list of products to consider having on hand for preparation and recovery.

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PRODUCTS THAT OUR CAREGIVER EXPERTS FOUND USEFUL

HYGIENE & COMFORT

- [Water Pik](#)
- [Oral Swabs](#)
- [Biotene Mouthwash](#)
- [Cepacol Mouthwash](#)
- [Diluted Hydrogen Peroxide Rinse](#)
 - (¼ tsp to 6 oz of water to rinse in mouth and spit)
- [Neck Pillow](#)
- [Cetaphil Face Wipes](#)
- [Ice Packs](#)
- [Eye Mask Ice Pack](#)
- [Squeeze Bottle for Liquids](#) (and Liquid Diet)
- [Long Handled Kids Spoon](#)
- [Small Bowls for Purees](#)
- [Large Oral Syringes for Cleaning & Eating](#)
- [Cloth for Oral and Nasal Secretions](#)
- [Bottle Brushes](#) (to clean squeeze bottles)
- [Bottle Caddy](#) (Rubbermaid)
- [Food Grade Squeeze Bottle](#)
- [Pillow Cases](#)
- [Q-Tips](#)
- [Antibiotic Ointment](#)
- [Washable Mattress Pads](#)
- [Hair Detangling Spray](#)
 - to reduce tugging and pulling on hair

NUTRITION

- [Yogurt/smoothie pouches](#)
- [NUUN Electrolyte Tablets](#)
- [Gatorade Energy Gels](#)
- [Ensure](#)
- [Boost water supplement](#)
- [Travel blender to use in the hospital](#)
- [Squeeze bottles with angled squirt-straws for eating and drinking](#)
- [More Bottles for Eating and Drinking](#)

CLOTHING

- [Button-Up Shirts](#)
- [Tank tops](#)
- [Wide V-neck T-shirts](#)
- [Zip Up Hoodies](#)
- [Button up Pajama Set](#)

CONCLUSION

We hope this overview provides you with suggestions to help you and your family weather the RED device and midface advancement surgery. Please reach out to us at contactcca@ccakids.com if you have questions, or would like to be paired with a caregiver mentor who has experienced this surgery first-hand.



CHECK OUT THE PANEL DISCUSSION VIDEO ON OUR YOUTUBE PAGE:

