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Surviving Rigid External Distraction

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by Lia Burton

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Getting a paper cut, stubbing a toe, getting shampoo in your eyes—how painful life can be! And don't you just hate it when people complain about how one of these things is "oh my gosh, the worst thing everrrrrr!!!"

You know that, as someone with a craniofacial syndrome, you could easily one-up them with your last surgery, but even if you tried, they just wouldn't understand—especially if you've already experienced Rigid External Distraction (RED). While RED is definitely not the epitome of human suffering, I'd often rather not think about it.

While the traditional mid-face advancement involves moving the mid-face forward all at once in a single operation, RED involves moving the mid-face forward gradually by turning screws that are part of the physical RED system. The screws are turned once or twice a day for however long the surgeon prescribes, thus moving the mid-face forward and allowing the resulting bone gaps to heal gradually.

RED is often preferred to the traditional method as results typically last longer and bone grafts are not necessary to hold the advancement in place. After the screw-turning period, the RED is left on for a few weeks as a retention device while the bone continues to heal. Once things are stable, it is removed in a relatively minor surgery.

Like many of you reading this, I was born with a craniofacial syndrome (Pfeiffer's) and was predestined to have lots of surgeries and constant unwanted attention in public. But in general, I was a pretty happy kid. Surgery and getting stared at everywhere was just part of everyday life.

Fast forward several years and several surgeries and it was time for a mid-face advancement.

Even in 2001, RED was still relatively new and controversial in the craniofacial community. One of my surgeons firmly believed in preserving the traditional all-in-one surgery and disliked the idea of RED, so I was horrified when a new surgeon said I would need to go through the distraction process soon. However, I would only need the less-obtrusive internal distractors instead of RED. But after a rough two weeks of complications with the internal distractors requiring extra surgery, I had the RED installed after all.

We spent a month living at a Ronald McDonald House from the time they installed the internal distractors to when we stopped turning the screws on the RED.

Once things were stable, I got to go home to finish out the retention period. Most of the pain involved with RED comes from the stress put on the muscles lying across the mid-face that are being stretched as the screws are turned, so by that point, since I was no longer turning the screws, the pain was minimal and RED became

more of a nuisance than anything else. A few weeks later, I was on a plane back to Sacramento to have it removed.

No surgery is ever fun, but these surgeries were particularly tough. It was a big pain (both literally and figuratively), but with lots of medicine and support, it was tolerable. Now that I'm on the other side, I can say that everything was definitely worth it.

Since then, I've been able to breathe through my nose (a once-impossible task), talk more clearly, and not have to worry about injuring my eyes as much. It certainly was not the last surgery I would have, but it yielded some of the most significant benefits. And as an extra bonus, the teasing and staring I was so used to started to subside.

Let me emphasize again that the change in appearance was only a bonus. While you probably will look more "normal," don't expect to love your new face right away. First of all, change always takes getting used. Second, you'll still be slightly swollen even a few months afterwards, so give it time. Third, it is common to "over-correct" the degree of mid-face advancement since doctors expect that your lower jaw will continue to grow while your mid-face remains static. So embrace your new overbite and know that it is probably not permanent.

Most important, remember that the purpose of RED is to get you breathing normally with protection for those beautiful eyes, so it's worth claiming victory when those two goals are accomplished.

Since RED, I've had several more surgeries, gotten a license to drive, earned the right to vote, finished my first year of college and enjoyed all kinds of other fun stuff. I also put up a website devoted to this topic. I've been very blessed to only have to go through it once, but I know some of you have had it multiple times, and I am humbled by how much you guys have had to endure.

The truth is, no one looks forward to RED, and with all the hype about it on the Internet and in newsletters like these, it's easy to get stressed out about this procedure and not know what to believe. On the one hand, you've read the brochures saying that this procedure is easy, virtually pain-free and minimally invasive. But then on the other hand, you have probably also heard the rare horror story of the surgery-gone-wrong that is enough to terrify any patient or parent.

My main advice is just to relax and give it over to God. In the end, what will happen will happen and you *will* get through it. I have never met a craniofacial kid who wasn't filled to the brim with endurance. You've been through tough surgeries before, and you can definitely get through this too.

If you want more reassurance, talk to other people who have already gone through RED. I am no more qualified to write this article than anyone else who has ever gone through it, and no two people have ever had the same experience with RED. I'm sure some people do not agree with my point of view in this article, so it might help to get multiple perspectives. But when it comes down to it, don't think too hard. Do something fun the day before the surgery and pig out on your favorite crunchy foods. Then just take every day after that one at a time.

I am nearing the maximum word-count, but I have so much more I would love to share with you guys. Everything from food suggestions to RED fashion pointers to basic tips can be found on my website: <http://REDSurvival.tripod.com>, so I really hope you'll come by for a visit!

And if you ever want to ask questions, chat, or need to vent about something, drop me a note at Lmburton@usc.edu. I love hearing from you all! Stay strong and best wishes for all those going through RED.

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12 Tips for a Better RED Experience

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1. **Don't plan on going to school while wearing the RED.** A select few have done it, but it wasn't even a question for me. Take my advice: Stay home and focus on recovering. You have enough to deal with already.
2. **Interrogate your surgeon.** There is no such thing as a stupid question when it comes to your health, so ask away. If you don't understand something, you have every right to stay in that office until you do. And if anything doesn't seem right during any part of this whole process, speak up and don't back down until your concerns are resolved.
3. By the same token, **if you need something, just ask.** This applies to any point in the process, but especially while you're in the hospital. More pain medicine, something to drink, more blankets, another pillow, a new Mercedes, whatever it is you want, just let the nurses know.
4. **Grab a handful of wide-tip syringes before leaving the hospital.** They are the answer to getting liquid into a mouth that can't seal closed.
5. **Invest in a small blender** and harness the power to puree virtually any food product. You should also load up on Ensure (or your protein drink of choice). Make sure to allocate a good portion of the day to eating and getting those recovery calories.
6. **Keep disinfectant on hand** at all times and very gently clean the pin sites (where the halo of the RED is attached to the head) regularly. You do *not* want an infection. Ask your surgeon if you have more questions about how to protect the pin sites.
7. **Get a new wardrobe.** You will need to shop for button-down shirts and wide-neck tank tops that will comfortably go over the rather cumbersome RED. As stylish as they are, turtlenecks simply do not complement the RED.
8. **Keep a chart of all your meds** and plan out when you will take each pill. Then use pocket-size alarm clock to keep you on schedule. You won't want to accidentally miss pills or let the pain get out of hand by delaying the pain meds. Along with pill-planning, you need to decide when you will turn the screws and stick to the same time(s) each day. Try to keep things as consistent as possible.
9. **Experiment with pillows** of all different sizes and shapes. Sleeping is not super comfortable, since you can't move around much and have to stay on your back. Some people have found success with neck pillows; I used a small home-made pillow that fit between the back ends of the halo. In addition, you will need to keep lots of pillows under your entire back to keep your head elevated for at least the first week or so to help with the swelling.

10. **Make your own heating/cooling pack** with raw lentil beans in the soft comfy sock of your choice. This is smaller and lighter than the average hot/cold pack and much easier (and safer) to use with the RED on.
11. **Demand fan mail.** Make sure friends and family know what's going on and let them know you would appreciate letters of encouragement (or large wads of cash) while you recover.
12. **Get a hold of every funny movie you've ever wanted to see.** Reading's a challenge with a bar in front of your eyes, contact sports aren't an option, and you certainly don't want to sit thinking about how much you hate the RED, so keep your mind as busy as possible.