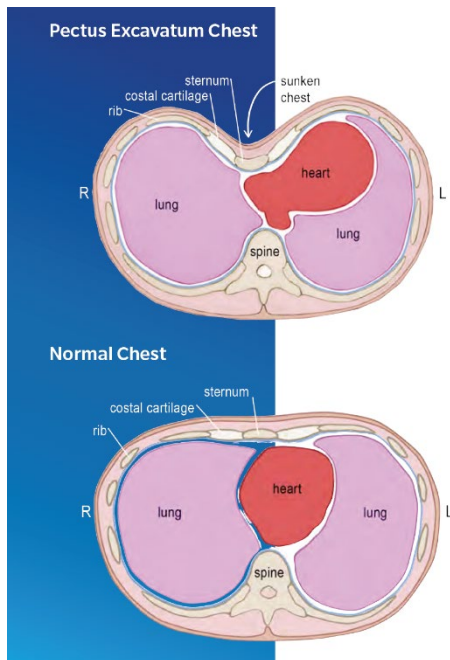


## The Discomfort behind Teens Recovering from Pectus Excavatum Surgery

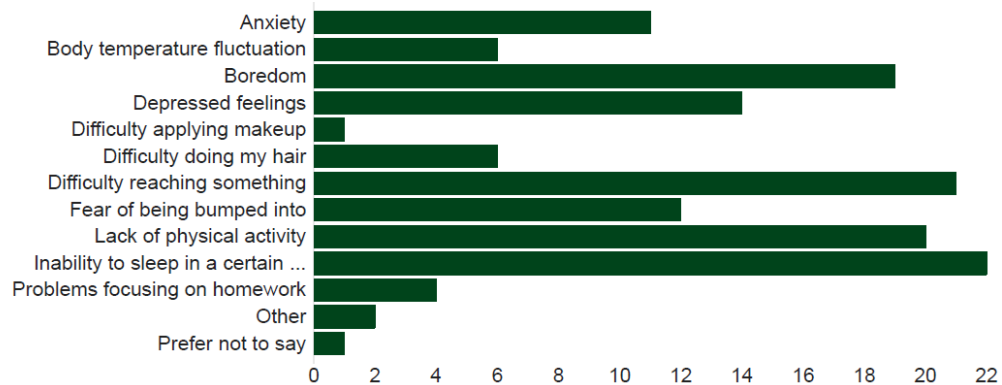
*Tessa Wheeler*

Over the past two years, I have seen two of my three brothers go through the NUSS procedure to treat Pectus Excavatum. According to Cincinnati Children's Hospital and Zimmerbiomet, this deformity occurs once in every three hundred to four hundred births, making it one of the most common chest wall deformities in existence. Pectus Excavatum patients can choose between the NUSS procedure or Ravitch procedure; both of which require about a three-month recovery period. Although surgery is more commonly performed for health reasons, it can also be for purely cosmetic motivation as well.



Pectus Excavatum is a “congenital chest deformity caused by abnormal growth of the cartilage that holds the ribs to the breastbone” (Zimmerbiomet). As a person with Pectus Excavatum ages, their condition usually causes health problems and affects a person's quality of life. The indented chest creates pressure on internal organs – such as the lungs and heart – which can cause difficulty breathing and restrict vital organ functions. After the surgery, patients undergo a recovery period which requires both mental and physical healing. They are advised to sleep sitting up, lift no more than five pounds, and avoid any waist bending or twisting. Breathing exercises are also vital to a healthy recovery and should be performed in the morning and evening.

Aside from a difficult physical recovery, major surgeries also challenge many patients on a mental and emotional level. Pectus Excavatum surgery is usually performed while a person is still developing during their teen years, so many patients choose to have the procedure during the summer months when it won't interrupt school. Although it may prevent most from missing classes, there is a significant trade-off. Teens in recovery are forced to sit and watch from the sidelines while friends are out swimming, playing pickup sports games, taking day-long trips to the mall, or camping. Even daily tasks become difficult and often require assistance. Twenty of thirty-four people in an online survey claimed they felt a lack of physical activity during their recovery. Nineteen of the thirty-four participants also expressed having difficulty reaching something during the process.



The survey also stated that 59% of participants would rate sleeping arrangements as the first or second most difficult task during recovery. Similarly, twenty-two of the thirty-four also experienced an inability to sleep in a certain position. Sleeping flat on your back, belly, or side, can lead to a higher chance of the bars accidentally shifting. Therefore, doctors recommend sleeping in a comfortable recliner or purchasing a wedge pillow to provide more support behind the patient’s lower back. The patients don’t need to sleep sitting straight up but should rest at a slight incline to alleviate pressure on their sore chest. Some businesses, such as Avana Comfort, an innovative orthopedic support company, provide an array of different pillow shapes and sizes to fit nearly every setup. Their products run anywhere from \$60 to \$275 and use bamboo-based materials for easy cleaning. Some former patients also recommended sleeping on bean bags or propping pillows in certain areas. One person recollected their recovery setup, telling any future patients to prepare “an inclines pillow situation [...] I had a big bean bag that I was able to put under me with some pillows to support my lower back.” They stated the “set up allowed me to sleep well while also being high enough to easily get up and out of bed.”

The recovery period for Pectus patients is usually a long, challenging, and uncomfortable one. However, the community surrounding parents and patients is abundant with information and assistance. When asked what tip one might give to someone in a similar position, a former Pectus patient said, “Remember why you chose to have surgery because your life is so much better now.” A parent-to-parent tip stated, “Every child reacts to the surgery differently and has a different level of pain tolerance.” An expert physical trainer who works with recovering patients at Cincinnati Children’s Hospital, Lauren Niehaus, said the care team’s “goal is to limit the things we know will be harmful but promote the things that will help them [patients] heal.”

Niehaus also suggested patients explore meditative and mindful exercises. Since she and her team “actually don’t teach them [patients] any exercises to make them stronger for the first twelve weeks,” it is important to keep a positive outlook. Although “we control a lot of pain in our head,” says Niehaus, it can be a lot easier to improve if “you can get your mind into the right place.” Some hospitals, such as Roswell Park, have started integrating art, music therapy, and animal therapy as recovery tools for patients. Khurshid Guru worked closely with Roswell Park Comprehensive Cancer Center to bring an art gallery into the facility. Many patients find it difficult to take their mind off the pain, emotional stress, and physical disabilities after treatments. Roswell Park found a way to integrate a peaceful space for their patients to release some of that burden. Chris Eberle, a woman in the middle of chemotherapy,

radiation, and immunotherapy recalls her visit to the space as a relaxing coping mechanism. She said, “It was peace. It was quiet. It was instant stress relief, sitting on a bench and staring at a work of art.” The gallery provided many long-term hospital-stays a place of serene disconnect from the patients’ current treatments and maladies.



Considering the effect of a temporary getaway, Pectus Excavatum patients might also be interested to hear about in-transition housing. One former patient looks back on their surgery, saying, “it was just a small bump in the road and you can get through it.” Considering the recovery process as a temporary situation may help relieve some anxiety behind one’s situation and keep a hopeful eye towards the future. Similarly, one might take inspiration from programs offered to teens transitioning out of the foster care system. The Tom Roy Youth Guidance Home “offers older adolescents training and support to successfully transition into adulthood and, in many cases, exit successfully out of child protective services, youth court or correctional services” (Youth Homes). They focus on helping teens work towards a GED, employment opportunities, and advocate for personal responsibility. The Tom Roy Youth Guidance Home provides access to community services, therapy, health care, and recreation to ease the teen through transitory life periods. Although the program does not necessarily focus on teens who have gone through surgery, the foundation examines important social, emotional, and forward-thinking goals for teens who are unsure of their future. It also points out the importance of routines and independence for developing young adults. Similar tactics might help someone going through a temporary health problem such as Pectus Excavatum patients.

Moreover, temporary furniture may also be an appealing route for families with recovering teens. During her interview, Niehaus mentioned how “a lot of people don’t have means to a recliner, just because they can’t afford one or borrow one from someone.” While some families have the capabilities to provide a new recliner for their child’s recovery, other households may struggle to find a comfortable and affordable alternative. Shigeru Ban, a Japanese and Pritzker Prize-winning architect, worked closely with volunteers to address a similar problem during the disaster relief efforts in Okayama Prefecture, Japan. Ban created “a modular system of partitions using recycled paper tubes,

cardboard panels and fabric to create areas that can be curtained off for privacy” (Block). Photos of the space show modular rooms for each person, equipped with a bed and sheet partitions.



While Pectus Excavatum patients may find comfort being home after a hospital visit, they also require a lot of assistance from parents or a caretaker. Privacy may be lost during these interactions, making the teen feeling uncomfortable or vulnerable. It could be interesting to consider how one can encourage private space for patients amidst the much needed helping hands surrounding them.

Overall, a major surgery such as Pectus Excavatum challenge teens on both mental and physical levels. Since the surgery is usually performed on a person during their teen years, it is interesting to consider the many different factors which play into a speedy and comfortable recovery. This time period could be an important piece of the teen’s development as they are already beginning to transition from adolescence into adulthood while facing a major health hurdle. After evaluating the many pain points patients face during recovery, it is crucial to consider which areas can be improved and tweaked to be more comfortable. One would assume a recovery could go faster and smoother if carefully planned around the patients’ emotional and physical comfort.