

Congenital Heart Disease Patient Stories regarding Telehealth Care

These stories are a compilation of stories of Congenital Heart Disease (CHD) patients that could reflect situations seen across the United States in any setting. These stories are in no way intended to mirror any specific story or life of any one person with CHD.



PEDIATRIC PATIENT STORY

Taylor, Age 4

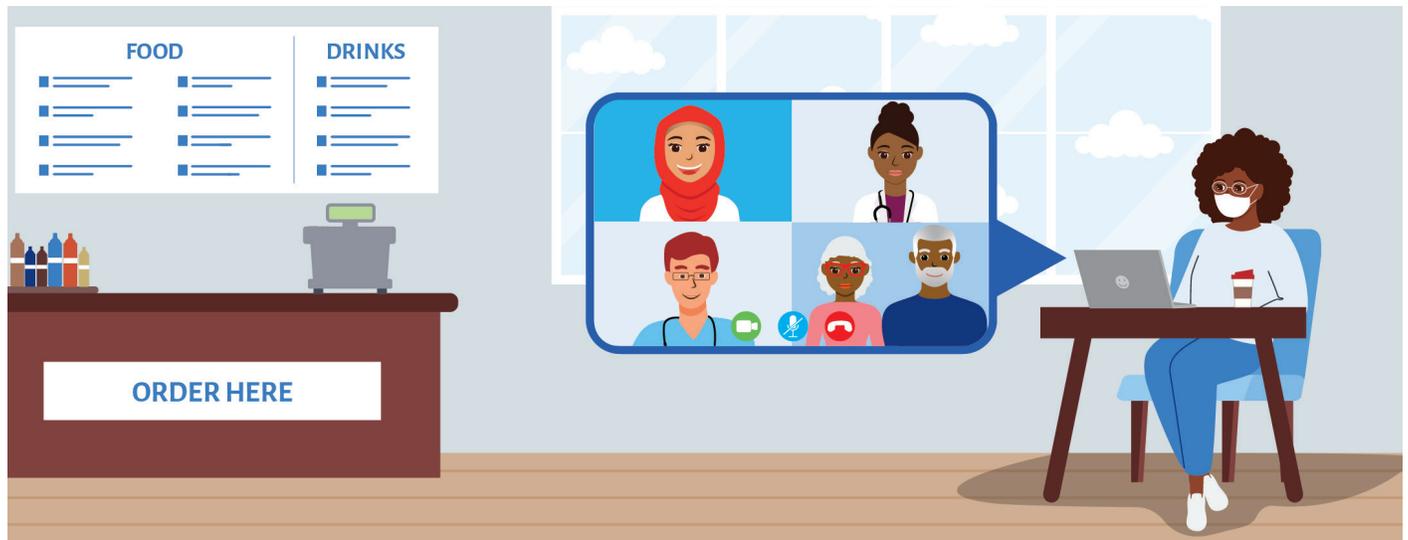
During the COVID-19 pandemic, telemedicine has been a lifeline to the parents of 4-year-old Taylor who was born with a complex congenital heart defect. Taylor is energetic and loves to play outside with friends. With Taylor's diagnosis of coarctation of the aorta, his parents always make sure that family and friends are healthy and they go to great lengths to minimize germ exposure. Concerns about getting sick have grown significantly during the pandemic. Taylor and his parents are very anxious about simply leaving the house and meeting other people during the pandemic. Yet, Taylor continues to require specialized cardiology care like monitoring blood pressure and frequent medication adjustments with the cardiac nurse. Telehealth visits are a great relief because they provide the opportunity to talk with a clinical expert and ask even the smallest question in their chosen environment. Telehealth gives Taylor's parents the ability to receive critical information about their son's care promptly without having to add risk of exposure. For example, questions about behavior, growth and development and mild symptom checks are all addressed through telehealth. As he is preparing for pre-school, Taylor has begun experiencing shortness of breath, so an in-person visit was rapidly scheduled. After confirming that Taylor's heart is healthy, the cardiology team invited a social worker and psychologist to join remotely and introduce some mindfulness exercises into Taylor's daily routine while the family is at the clinic. Taylor's parents feel supported between their in-person visits and are more easily able to access specialized experts through the use of telehealth.



TEENAGER PATIENT STORY

Morgan, Age 15

Morgan is an active teenager who was born with a complex congenital heart defect that required multiple surgeries during childhood. Right before the pandemic, Morgan had a new pacemaker placed during open heart surgery. Throughout the pandemic, Morgan has had visits with her cardiologist in-person every 6-months to monitor how well her new pacemaker is working. With parental supervision, Morgan has also been able to schedule a telehealth visit to ask questions and provide feedback about her pacemaker. Now that school is returning in-person, Morgan is concerned about the risk of getting COVID-19 and how that might affect her complex heart disease. Morgan also has questions about how her new pacemaker will impact her normal teenage activities like gym class and her role as an outfielder on the sports team. Thanks to telehealth, a virtual interdisciplinary case conference is scheduled that includes Morgan, her primary care pediatrician, CHD specialists, school nurse, and both her parents, who are separated. Meeting with everyone together ensures that all questions are answered. The decisions made during this meeting will be documented in a shared plan of care that will be updated as necessary. Morgan will continue in-office visits regularly, but having the between-visit support, and the ability to speak with everyone on her care team is very comforting for Morgan and her parents.



ADULT PATIENT STORY

Sasha, Age 28

Sasha was born with transposition of the great arteries and had an arterial switch procedure. Sasha lives and works in a very rural area. Internet connectivity can be very unreliable and frequently unavailable for days following a storm or severe weather. Sasha only needs to schedule a visit with a congenital cardiologist once per year but it involves taking a full day off work and traveling to the university medical center located 85 miles away. Sasha has questions about COVID-19 vaccination and its impact on someone with congenital heart disease. Sasha's parents, who live out of the state, are concerned too. COVID-19 information is abundant on social media, in the local and national news but the family does not know which information to trust. Sasha recently got engaged and is planning a wedding. Sasha wants to talk with a congenital cardiologist to discuss her reproductive health, possible restrictions on becoming pregnant, and vaccination-related questions, but the office is only open for critical care due to the pandemic. Sasha wants to include her parents as a part of the discussion, and a telehealth visit is the answer that allows everyone to be a part of the call. Sasha does not have an internet connection at home due to a recent outage, but she is able to participate in the meeting using the Wi-Fi service of a local restaurant in her town. Telehealth allows Sasha, Sasha's parents, her partner, and the clinical providers to discuss questions and important care management issues in between Sasha's scheduled yearly exams.

The telehealth fact sheet is an output of the Congenital Health Public Health Consortium (CHPHC); it was supported by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS). The contents of the fact sheet are solely the responsibility of the CHPHC and do not necessarily represent the official views of, nor an endorsement by the member organizations of the CHPHC, CDC/HHS, or the U.S. Government.