Transition: Preparing for your Future

Transition is a process - a series of steps involved in preparing to move from pediatric healthcare providers and beginning treatment with a team of adult healthcare providers. Since Phoenix Children’s Hospital has both a pediatric team and an adult Cystic Fibrosis team, some of our staff overlaps between the two programs. In addition, we have only one site for CF outpatient clinics in Phoenix (unless you are eligible for CRS), which also means transition needs to be clearly discussed and planned with the patients and families.

Helping individuals prepare for independence and adulthood is the goal for transition. We have a responsibility to help you get ready to take charge of your health as an adult. Transition is to be gradual and should occur over many years.

Reaching adulthood means taking charge of many areas in your life, such as deciding where you want to live, where you want to go to college, or what kind of work you want to do. This is the exciting part of transition when you can make more of your own decisions and take on more responsibility. However, since Cystic Fibrosis requires daily attention, there are additional tasks involved in planning for your future. It is important to know that you, your family and your healthcare team all share the responsibility for making your transition as smooth as possible. We will work together to get you ready one step at a time.

If you ever have questions about the transition process or CF care in general, please contact the Cystic Fibrosis Clinic at Phoenix Children’s Hospital at (602) 933-0985.

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The Cystic Fibrosis Foundation (CFF) is a leader in the efforts to advance and promote specialized care that improves and extends the lives of people with Cystic Fibrosis. Not one advance in therapeutics has occurred without the support and facilitation from the Cystic Fibrosis Foundation. Thanks in large part to the care provided by the CF Foundation’s Care Center Network, the median predicted age of survival for people with CF is in the late-30s and is increasing. To ensure this continues, the Foundation provides its accredited care centers with up-to-date care guidelines based on the latest research.

Care or practice guidelines recommend treatment based on published reports of clinical trials that look at safety, effectiveness and potential benefit. Care guidelines are established by the CFF. They bring together committees of subject-matter experts which include doctors, nurses, respiratory therapists, dietitians and CF families, to write guidelines on each topic. If there is not enough published information, expert opinion of the best care is documented and used.

As the lifespan of people with CF expands, and science improves therapeutic avenues, these guidelines are readdressed to ascertain what evidence based practices are used in the care of patients and families with Cystic Fibrosis. Committees remain active and continue to readdress and update the guidelines on a frequent basis. In all chronic illnesses the CFF guidelines are considered the gold standard of advancement of a chronic illness pathway.

Understand, these guidelines are both evidence based and the most current relevant information for the care of our families and patients. Please inquire at Clinic visits what the guidelines are, and how they can be implemented in your lives.

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Respiratory viruses that cause colds and influenza (flu) spread through coughing and sneezing. They cause illness when they touch your eyes, nose, or mouth. The flu usually causes mild illness, but young children and people with certain health conditions like CF are at higher risk of serious complications.

To reduce the chances of getting a cold or flu:

- Wash your hands frequently and avoid touching your nose, eyes and mouth.
- Try to keep babies and young children away from people who have cold and flu symptoms.
- Get your flu shot each year to help protect yourself.

Generally, flu shots for your child are available through your child’s doctor. For more information on flu shots for adults and other family members, or to locate a flu shot clinic visit www.cir.org or call:

Source: PCH Infection Control

‘Tis the (Cold & Flu) Season

- and Spotting the Difference

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In the Spotlight

My name is Weatherly. I am a 37-year-old Cystic Fibrosis patient here at Phoenix Children’s Hospital and I am also a volunteer on the Cystic Fibrosis Family Advisory Council (FAC). I wanted to make a difference in the life of others with CF and by joining the FAC I am able to have a voice for other CF adult patients.

I always knew something was different about me, being misdiagnosed all my life with either bronchitis or pneumonia, and I’ve always had pancreatic problems. The misdiagnoses can be viewed in two different ways: One, I was lucky enough to go through childhood without knowing I had CF. I played sports throughout junior high and high school. After graduation I joined the Air Force and got married. Two months after my husband and I were married, I was diagnosed with CF at the age of 20. All of this may not have been an option including my military service, which I knew I was born to do, if I was diagnosed earlier in life. The second perspective is the “what if”. Would my long-term health be better or would my life expectancy be longer if I had the right medicine? Now, I can only manage my life as it is and get the most out of every day.

After I was diagnosed with CF my life went through some major changes. I was in the later part of my first enlistment in the US Air Force when I was honorably discharged because I had a terminal genetic disease that made me unfit for military service. The US military does not cover any genetic defects, so no medical benefits were awarded. I lost my career and was told I was dying at the age of 20; it was overwhelming to say the least. I’ve since gone back to school to get my Associates Degree in Architectural Computer Aided Drafting from Glendale Community College and transferred to ASU’s Architecture program. I worked as an architectural project manager until 2009. At that time I had a tough year. After five admissions into the hospital, for no less than a week at a time, the architectural firm graciously relieved me of my position.

My life now focuses on my home and health. My husband of more than 16 years, my partner in this journey who I love more than words can describe, is my focus. We have two horses that we don’t ride enough, two dogs that I love more than I can express and we are currently building our dream home. I designed the house while my husband, father-in-law, father and I are working tirelessly to complete.

It wasn’t until I moved to Phoenix that I realized the reality and the commitment that CF takes. The staff at this Clinic is my backbone and my support group. There are days when I don’t know where else to turn, but they always seem to have the answer. There’s not a day goes by that I don’t realize that I have this disease for a reason. I know I can handle it. This is my life, and it’s a good life.
Clinic News

The Cystic Fibrosis Clinic at Phoenix Children’s Hospital is proud to announce our newest team member, Katie Whitley, who serves as our newest adult CF nurse program coordinator. Following is an introductory letter from Katie.

I grew up in Prescott and went to nursing school there. After graduation I moved to Phoenix and started working at Banner Good Samaritan on the Pulmonary floor and eventually got my BSN from ASU. I have an amazing husband named Matt and we have been married four years. We have a Boston Terrier named Olive and a French bulldog named Macy who are both incredibly spoiled!

I have been working with CF patients since I started at Good Sam. In the last few years I have become very interested in the CF patient population after joining the Clinic’s CF Quality Improvement Committee and working on several projects to help bridge the inpatient and outpatient worlds and improve the inpatient care at Good Sam. I am very excited to be the new adult CF nurse program coordinator and hope that I can continue working on some of these projects and more in this position. We have an amazing CF team at the Phoenix Children’s Hospital CF Center and I could not be more proud to be a part of it.

Please let me know if I can ever assist in any way.

Sincerely,

Katie Whitley
kwhitley@phoenixchildrens.com

Helpful Websites

The Emily Center at Phoenix Children’s Hospital
www.phoenixchildrens.org/health-information/the-emily-center

Cystic Fibrosis Foundation
www.cff.org

Cystic Fibrosis Foundation, Arizona Chapter
www.cff.org/chapters/arizona/

Upcoming Events

March
25 • CF Support Group

April
22 • CF Support Group
27 • Great Strides benefiting the Cystic Fibrosis Foundation

May
27 • CF Support Group