

One Step at a Time

A day in the life of cystic fibrosis
patient Colleen Crowley





photography by David Colwell , text by Gary Logan

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Living with cystic fibrosis – a chronic disease that attacks the lungs and digestive system – can feel like a constant uphill battle. For 10-year-old Colleen Crowley of Frederick, Md., the fight means rigorous self-treatments at home each day and, every three months, a visit to Hopkins Children's CF clinic.





Another day at the CF Clinic Above left, Colleen checks in with her dad, Patrick Crowley, who takes on the tedious task of updating his daughter's paperwork. Colleen, an energetic fourth-grader, likes seeing her friends at the CF Clinic but hates to miss school.

Colleen and her dad meet with the clinic's research coordinator, Carolyn Chapman, who updates them on clinical trials available to CF patients. There is no cure for CF – the median age of survival is 36.5 years – but thanks to research, new drug treatments are allowing patients like Colleen to live healthier and longer lives that include careers, marriage and families of their own.

Left, physical therapist Holly Loosen uses a tissue to work with Colleen on a breathing exercise to keep her lungs clear. In CF patients, the thin layer of mucus that helps keep the lungs free of germs becomes very thick and difficult to move, clogging the airways and triggering infections. "See your breath?" says Loosen. "That's it, take a deep breath, then pause and huff. Perfect. Do that for 15 minutes, four to six times a day."

After asking Colleen a litany of questions about her appetite, breathing and summer activities,

pulmonologist Peter Mogayzel swabs her throat for any signs of bacteria that may be colonizing in her lungs. For CF patients, battling chronic lung infections is their biggest battle. Reflecting, Colleen's dad says she's "a sweet kid and a hard worker" who loves Irish dancing and swimming. Because CF inhibits patients' growth, too, dietitian Erin Davis is also on Colleen's list of people to see. Two waffles for breakfast, spaghetti and chocolate milk for lunch, chicken and a hot dog for dinner, Colleen reports. "You're doing a good job," Davis replies, "but we need to look for places where you can add something more."



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when Colleen was five.”
– Patrick Crowley



Back home: Colleen does her breathing drills while wearing an oscillating vest to unclog mucus from her lungs. Through her own diligence and support from her dad; her mom, Molly; and her sisters, Kelly (standing) and Bridgett, Colleen's lungs have remained free of infections. Colleen and her family have also become well-educated about the emotional impact of CF: "We had our 'Why me?' talk when Colleen was 5," says her dad. ■



