



## **PERSONAL EXPERIENCE**

### **CF & EXERCISE: PERSONAL PERSPECTIVES**

#### **Introduction by Julie Desch, MD**

*As an exercise “addict” myself, I enjoyed reading how two other adults with CF have incorporated exercise as a permanent and prominent part of their health maintenance regimen. Besides the obvious beneficial aspects of exercise to physical health, there is an underlying extra benefit that exercise provides to both Jake and Eliza, as well as anyone else with CF who makes exercise important - through regular exercise, we are actually in control of aspects of our bodies. This is a subtle benefit, but it is incredibly important when living with a disease like CF. With that sense of control, that knowing that we are doing everything we can to optimize our health, including being as active as we can, we live as well and as long as we can NOW. If a cure or control of CF is around the corner, we are ready. And if not, well, we had a great time while we were here.*

#### **Eliza, age 31, Pennsylvania, USA**

To many, CF is one of the few diseases that makes it embarrassing to love exercise. I feel guilty that so many of my fellows can't lift weights, climb stairs, or jog. Some are attached to machines that make it difficult, some have secondary conditions that preclude it, and some are simply too out of breath.

When I changed clinics a few years ago, I felt I was moving from a place where they were trying to keep me as healthy as possible until I died to a place where they were trying to keep me as healthy as possible until a cure or true control was found. It was a huge shift in my brain about my care - and a big part of it was exercise.

Exercise is the one thing my doctor says he would prescribe if he could prescribe nothing else. Ever since I came to my current clinic, they have pushed me to use exercise as a tool like the Vest (which I do 30 minutes twice a day). So I swim, work out on machines, and lift weights. I also enjoy yoga and Tai Chi. When I am not at the gym, I like walking and hiking. I don't do any of these things particularly gracefully or fast, but I enjoy them.

Another problem is that it is hard to feel excited about exercising when you feel great one day and then you are flat on your back in the hospital the next. What's the point? The point is that I feel good when I exercise. I am less scared. I eat better. I sleep better. I recover from sinus surgery faster. Sometimes I can't get out of bed, much less pull on a swimsuit, but when I go back, I return to full-strength faster. I am happier.

I am on disability in the United States. If I need to be on disability, aren't I too sick to swim a mile? The answer, of course, is no. Disability is a judgment about my ability to hold down a full-time job. I am unpredictable in my day-to-day health. I can't get a full-time job



every time I have a good day, but on the days I can swim a mile, shouldn't I get in the pool and do it?

I have grieved enough over those I lost to CF that it seems criminal that despite the mucus and a little bronchiectasis and occasional hemoptysis, my lungs are pretty ordinary. However, I also have a long list of ailments, from my sinuses to my belly (with surgeries to match), including CF arthritis, asthma, depression, panic attacks, fibromyalgia, costochondritis, and urinary incontinence.

So, these are my answers--there is no earthly reason to feel embarrassed about working out, and it is good for people with CF. It's a boring reason to get on the treadmill, I know, but here is the exciting part: I believe there is a minority of CF adults who, like me, started in this world with low expectations of life and its length, who are now running a race in which they may outrun CF.

### **Jake, age 27, Melbourne, Australia**

Since the age of 4, I participated in basketball, football and other athletics both competitively and non-competitively. As a result, I have always loved sports and I am thankful that my parents encouraged my participation. While my doctor did not recommend sports, he did encourage exercising.

As I became older, I added new activities. I started working out at the gym at age 17 and I continued exercising throughout my university studies. Ten years later, I still enjoy working out. I cycle instead of drive, enjoy occasional walks, and swim. In addition, I use the flutter physio device 2 to 4 days per week and I take Creon forte and insulin. I have not found any barriers to exercising except I sometimes cough. CF barely affects my activity levels. My lung functions are in the 95-110% range. I spent a week in the hospital when I was diagnosed with CF related diabetes, but this was my hospital stay. Whether this is related to my exercising or my genetic mutation, I do not know and I may never know. Still, I like exercising not just for the physical benefits but also the mental and social benefits. Because I look healthy and fit, people do not realize I have CF. Honestly, I



like not having to tell people I have CF and this motivates me to continue my exercise routine. Plus, I am eternally thankful for the role that exercise plays in keeping me mentally and physically fit.

Here is my exercise routine:

Sunday – Ride bike to gym (10-15 mins) then weightlifting for 45 minutes

Monday – Swim laps in the pool for an hour

Tuesday – Ride bike to gym (10-15 mins) then weightlifting for 45 minutes

Wednesday – Spend up to an hour walking or riding my bike

Thursday- Ride bike to gym (10-15 mins) then weightlifting for 45 minutes

Friday – Spend up to an hour running or walking

Saturday – Swim or spend an hour in the gym, half weightlifting and half cardio

I think my passion for sports and fitness combined with my adherence to treatment is helping to give me the best chance of living a productive life. My interest in public health prompted me to earn a degree in Health Sciences and a Diploma in Recreation.

*Jake works in the Sport & Recreation field in Melbourne, Victoria, Australia. He enjoys genetics, reading, politics, movies, share markets and travel. He has travelled overseas twice by himself and is a member of Cystic Fibrosis Victoria.*

*Julie Desch is a 45 year-old retired physician with CF. She is the founder of New Day Wellness, a non-profit organization, through which she provides wellness coaching to those with CF and other serious medical problems. Dr. Desch is a passionate exercise advocate and writes a wellness column for CF Roundtable, a quarterly publication of USACFA. She can be reached at [julie@newdaywell.org](mailto:julie@newdaywell.org).*

*Eliza Callard was born, raised, and still lives in the Germantown section of Philadelphia. She graduated from Skidmore College in Saratoga Springs, NY. She is a fiction writer. Her hobbies include laughing, reading, and swimming, learning Spanish. She lives with her partner and their three cats.*

