

THE DISEASE OF OBESITY: THE PATIENT PERSPECTIVE

Making informed decisions about your health is the first step to recovery

The conversation around obesity is complex

42% Americans suffer from the disease of obesity.

1 in 5 children in America are diagnosed with the disease.

64% are never diagnosed with the disease.

Start by talking with your healthcare professional

STEP ONE: Awareness
THE PATIENT IS NOT TO BLAME

Understanding that obesity cannot be effectively treated through self control is the first step in breaking the failure, shame, and blame cycle and moving towards a lasting solution.

STEP TWO: Recognition
OBESITY IS A COMPLEX DISEASE

Recognizing obesity as a complex chronic disease involving an interrelationship between physiology, genetics, socio-economic status, and psychology is essential to optimal health outcomes.

STEP THREE: Action
TREATMENTS ARE MORE EFFECTIVE

Obesity science has evolved, scientists and doctors are developing treatments to tackle the obesity epidemic and bring a higher quality of life to those affected.

What action can I take now?

Learn the Facts

Being informed about your disease will empower your recovery.

Seek Support

Speak openly with your doctor about your disease and treatment.

Resources

Talk with a healthcare professional about available tools and resources.

Learn more from the research.

Learn how one patient addressed her disease through engaging in a Patient-centered Outcomes Research Institute (PCORI) study. (next page)

PCORI-funded Study:
Comparing Three Types of Weight Loss Surgery

PCORI-funded Study:
Testing a Health Coaching Program to Help Patients with Obesity Lose Weight



National Alliance
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Driving Health, Equity and Value

A PATIENT TESTIMONIAL

“I was overweight by the time I was five years old”



A lifelong search for answers finally led to a comprehensive plan to treat the disease of obesity as the chronic illness that it is

Ava Zebrick, Patient Experience & Engagement Coordinator, Ochsner Medical Center

Family Dynamics

Genetic predisposition for diabetes and obesity come from both sides of my family. At one point one of my aunts weighed as much as 500 pounds. I was overweight by age five. I weighed 200 pounds my freshman year of college. My parents, who were “normal weight” and worked in healthcare, feared for my health and happiness. I felt that I was disappointing and hurting the people who love me. Nobody was as vicious to me, as I was to myself.

Young Adult Traumas

Obesity is complex and so are its consequences and comorbidities. I was trapped in a cycle of failure, shame, and blame. I had clinical depression, hypertension, high cholesterol, prediabetes, and polycystic ovarian syndrome. Even with interventions I could lose some weight for some period, but I would regain and then gain more. I continued to gain weight through college. I went to work as a paralegal and years of trial preparation was stressful and crushing. My mental and physical health deteriorated further. My weight increased to 300 pounds.

I was facing possible weight-related knee surgery at age 25. That was my rock bottom, realizing that as miserable and sick as I had been, it was going to get worse. I decided on metabolic vertical sleeve surgery where two-thirds of my stomach was removed. The procedure reduces intake of food and alters appetite and satiety. Surgery was not covered by my health insurance and so I went into significant medical debt. However, I lost 150 pounds. My energy and lifestyle changed. Two years after surgery, my appetite returned with a vengeance, compounded by the stress of graduate school. I regained 50 pounds. I turned to anti-obesity medications, also for which I did not have insurance coverage.

I strongly believe that if my doctors knew and understood the disease of obesity, I would never have gotten to 300 pounds. Doctors often tell patients, “You’re obese and it’s important for your health that you lose weight. Your BMI should be under 30. You should eat this and not that. You should move more.” It’s like telling a person with depression, “You look sad and depressed. You should be happy and do things to be happy. The next time I see you, you should be 10% happier.” That is not treatment.

Cascading Health Plan Failures

I was trapped in endless cycles of a complex disease and no insurance support. At first, I was on my father’s health insurance, which offered bariatric surgery to employees only. I could have switched to my husband’s insurance, but his policy did not cover spouses. It was later amended to cover spouses but still does not cover dependent children (under the age of 26). It covers only one surgery per lifetime (and excludes revisions), and no anti-obesity medications. My law firm’s policy excluded any obesity treatment “regardless of medical necessity.” I will never forget that phrasing.

Finally Coming Home

After my metabolic surgery, I attended an obesity patient advocacy convention. I began to learn the science of obesity, and an expert stated that the patients who were the most successful in the long run are the ones who make health their job (dietitians, personal trainers, etc.). I took that as a prescription. I returned to school for my master’s degree in healthcare management. A supportive attorney at my law firm introduced me to a childhood obesity researcher at Pennington Biomedical Research Center in Baton Rouge. The researcher referred me to Dr. Katzmarzyk and PCORI and PROPEL.

My life dramatically changed. I learned further how obesity is a disease that can be treated by a combination of lifestyle management, mental health support, medication, and surgery. The key component, though, is having the support of specialists who understand the disease and its relapsing nature.

For the first time in my life, I felt like I was home, supported, and surrounded by people with answers.

My Passion of Passions

I began work as a patient partner for PROPEL, scripting screening phone calls to guide how coaches talk with patients, the language they use, and the sensitivity they show. No more shaming and blaming.

Obesity is a disease. Just like with any disease, we need evidenced-based treatment, whole-person-health, and providers trained in the right language and the spectrum of treatment options. With obesity, like cancer, each situation is different.

Resources:

Novo Nordisk Rethink Obesity®
PCORI PROPEL Study
PCORI Obesity Surgery study
The New Science of Obesity, National Alliance Video
STOP Mental Health, Obesity, and Racial Disparities
STOP Mental Health Fact Sheet
Link Between Obesity and Mental Health
Parity Infographic
Greater Philadelphia Business Coalition on Health: Prescription Weight Loss Therapies



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