

# **Obesity Journey SURVEY** REPORT

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#### **OBESITY JOURNEY SURVEY REPORT**

Obesity is a multi-factorial chronic disease that can affect individuals in myriad ways. Each person has a unique experience, but there are common threads that stitch the stories together. Shame, stigma, and judgement are frequent occurrences, and many face a constant battle against hunger, appetite, genetics, and the food environment to find a weight loss method that finally works.

In Canada, about 63% of the population is living with obesity (27%) or overweight (36%).<sup>1</sup> Despite it being so common, there are countless myths and misunderstandings surrounding the disease, including what it means to live with obesity, what causes obesity, and how to lose weight and keep it off. In this report, we invited those who have lived experience with this disease to explain the day-to-day reality of obesity.

From August 2023 to January 2024, we conducted a survey in English and French, open internationally to individuals who were 18 years of age or older who live with obesity. We had 1,487 individuals take the survey, 1,050 of whom completed it. Most of our respondents were female (95%) and from Canada (62%), the United Kingdom (27%), or the United States (10%).

# **The Patient Journey**

The obesity journey often begins before conception, with the complex genetics and epigenetics passed down through the generations. During our time as zygotes and fetuses, what our mothers eat, which medications they take, their emotional states, the environment they live in, and many other factors can all influence our likelihood of developing obesity. The way we are born (vaginal birth or caesarian section) and what we eat (breastmilk or formula) as infants can affect our microbiomes and influence our future weight. As we grow up, there are so many aspects of life that can contribute to obesity, including family environment, trauma, mental health conditions, and social determinants of health (e.g., economic class, education, etc.).

Many people experience obesity beginning from a very young age, and others find that certain events, such as puberty, college, pregnancy, starting a new job, relationships, etc., can lead to weight gain. More than half (55%) of our survey respondents had excess weight before the age of 20 years.



## **Causes and Contributors**

From a medical perspective, weight is genetically, biologically, socially, and culturally derived. Several factors can affect weight, such as metabolic conditions, thyroid function, physical disabilities and injuries, medication side effects, eating disorders, trauma, grief, social standing, anxiety and depression, pregnancy, aging, lipedema, lymphedema, genetics, social isolation, and the microbiome.

Ultimately, obesity is caused by an intake of calories that is higher than the calories an individual burns. However, the reasons why a person is unable to maintain this typical balance are complex and include numerous influences. Sometimes, a person eats more calories than they need due to a lack of nutrition education, or because they eat too many highly processed foods, which are often more affordable, or because they lack access to appropriate food. In other cases, a person might have a greater appetite than others due to certain diseases, medication side effects, mental health issues, eating disorders, stress, and a variety of genetic influences. Some people also experience a decrease in the calories they burn, such as when an injury or disease causes a person to be sedentary, or when a hormonal condition decreases metabolism. On top of these factors, an individual might experience weight gain that isn't fat gain, such as diseases and medications that cause fluid retention. People living with obesity often have several of these factors woven into the fabric of their lives.

Whether a result of genetics, learned behaviour, or a combination of the two, obesity tends to run in families. Of our respondents, 77% said that they had family members who experienced overweight/obesity.

#### **BMI: The Flawed Path to Diagnosis**

While the general definition of obesity is having too much adipose tissue (fat), deciding on exactly where the cutoff between healthy bodyfat and obesity lies is complex. For the past few decades, physicians have primarily relied on the body mass index, or BMI, a simple mathematical equation that looks at the relationship between an individual's height and weight. While BMI can be an important tool for looking at trends in weight across large groups of people, it isn't as

useful for determining whether an individual has too much bodyfat.

BMI is unable to account for an individual's age, sex, lean mass, weight distribution, ethnicity, and many other factors that affect both how much fat an individual has and how much their body needs for ideal health.

Most people know they are living with obesity without needing a doctor's diagnosis. Children and teens often calculate their BMI in school, sometimes in front of their peers, and internet calculators make it easy for anyone with a measuring tape and scale to find out their BMI. For those whose BMIs are higher, it is usually clear without any need for measurements. Obesity is a disease that everyone else can see and, inappropriately, they use this information to make judgements about a person's health.



# **Moving Past BMI**

Modern experts understand that the relationship between a person's weight and height alone isn't enough information to understand if they have obesity. Instead, they look at how a person's weight affects their health, function, and quality of life. They might use other tools, such as taking waist measurements, which can indicate where on a person's body they are storing excess fat, as accumulation in some areas (e.g., abdomen) increases health risks more than others (e.g., thighs). In addition, they will consider other risks, including whether the individual has a metabolic condition (e.g., diabetes).

This is important, as many with obesity want to be seen holistically. Sadly, lots of people have experience with healthcare professionals who take one look at the BMI written in their chart and make assumptions about their health without considering the bigger picture.

## **Experiences With Healthcare**

In our survey, 19% of respondents did not seek help from any healthcare professionals to manage their obesity. However, 64% did seek help from a general practitioner, 39% went to a registered dietitian, 28% went to a nutritionist, 22% to a mental health practitioner, 21% to a personal trainer, and 17% to a surgeon.

We asked respondents how their doctors diagnosed them with obesity and 42% said that their doctor outright told them or diagnosed them with obesity. However, 35% said their doctor only mentioned obesity in passing or in relation to another condition, and 23% said their doctor never even mentioned it.

One of the big issues of living with obesity is that people, including doctors, can be judgemental. Several respondents' physicians made assumptions about their lifestyles, such as that they ate too much junk food or were inactive. While most doctors mention obesity in neutral terms, some people experience mistreatment from their physicians. This is what some people living with obesity experience from their physicians:

"Didn't overtly mention it, but said I "should probably go back to being anorexic, haha."

"She was harassing me to lose weight. I was chided and scorned."

"She told me I would end up in a white casket."

"Looks at me like I am not a valuable person and just fat."

"I asked for help doc said don't be stupid you know what not to eat go home and don't eat it. So I never went back."

"Constantly mentioned weight as a cause for every medical issue."

However, some doctors are more considerate:

"I suffer from an eating disorder, so my doctor knows about it and doesn't refer to my weight so as not to cause me psychological distress."

"I've also been anorexic and bulimic, and now I'm overweight, so we talked about it but not in terms of weight loss."

Since the family doctor is the first stop for most Canadians looking for healthcare, we wanted to know what management options physicians offered their patients who were living with obesity. We asked respondents whether their physician had spoken to them about medications or surgery to treat obesity. 24% said that their physician didn't offer them any treatment support at all for their obesity, 25% said they only spoke about diet or lifestyle changes, 15% said their doctor spoke to them about both medications and surgery, and 10% said their doctor spoke to them about medications and/or surgery, but only after the patient brought it up. For 11% of respondents, their physician only spoke about medications, and for 5% only surgery. 6% of respondents were sent to a specialist to learn about these options.

#### PAGE | 5

#### OBESITY JOURNEY SURVEY REPORT

People living with obesity can also face difficulties getting treatment for other health issues. We asked survey respondents if obesity had affected their healthcare in other areas (e.g., being told to lose weight instead of reviewing other treatments for different conditions, not having access to certain medical procedures because of weight, having a different process of care due to weight, etc.). 54% said that their weight had affected their treatment, 13% were not sure if it had, and 33% said their weight did not influence how they were treated.

"Medical doctors blame obesity for almost any medical condition. They should ask themselves this first: "If they weren't obese, how would I treat/diagnose this.""

"I have PCOS [polycystic ovary syndrome], genetic diabetes type 2, mental health issues, and I get told to diet. No one has taken the time to "treat" me as a whole person."

"Many in the medical profession are the worst for misunderstanding obesity and discriminating against patients even though there are medical studies that show that many assumptions are untrue. It has taken me 25+ years to find a doctor to truly help me."

"Access to well-informed health/allied health professionals is a barrier to support to lose and maintain weight loss. Access to Bariatric Surgery in Saskatchewan is very limited. Disappointing!"

"I have noticed that my medical care has gone from never being treated except to be told to lose weight, to never speaking of my weight as a cause of anything. I'm not an idiot. It's frustrating in both extremes."



# **Managing Obesity**

Most people living with obesity spend tons of money, time, and effort trying a variety of different diets, programs, devices, exercise programs, exercise equipment, supplements, and various products to find something that finally works. Those who seek help from healthcare experts might also be offered behavioural therapy, other diets, medications, or surgery.

Since obesity is a chronic disease, management is an ongoing, lifelong effort that involves weight loss as well as other methods of improving health. Accessing healthcare for obesity can be challenging. Many patients are ashamed or embarrassed of their weight or of the fact that they need help. There are so many messages about how easy it is to lose weight that people might feel as if they should be able to cure themselves on their own. In addition, physicians can be affected by biases the way everyone else can, and might not offer much support or education. When healthcare providers raise the issue of obesity in a sensitive and collaborative manner, they can help create an ideal management plan.

Due to the health concerns associated with obesity, most people focus on trying to lose weight. Our respondents' reasons for wanting to lose weight most often were health-based, such as for overall health (76%), to be more physically fit (46%), and to reduce or eliminate chronic pain (37%). Some other common reasons that people wrote in were to be there for their kids, to be able to get a surgery, or to improve their mobility.

#### **Diet and Nutrition**

Most people living with obesity begin their treatment journey by changing the way they eat. It's common to go at it alone, but some will use the advice of their physician or a dietitian to guide them. There are countless diets and eating styles that promise weight loss, but they all depend on one thing: creating a calorie deficit that they claim is easy to follow.

While 6% of respondents had never tried to change their eating habits to lose weight, the majority had. The most common methods included calorie counting (73%), WeightWatchers\*/WW\* (57%), and low carb diets such as keto or Atkins\* (40%). However, it can be incredibly difficult to maintain many of these dietary changes in the long term while living in a community or culture that has nuances related to eating. Respondents considered their greatest difficulties dieting to be gaining weight back over time (54%), finding the diet difficult to stick to (52%), and the time and effort involved in eating this new way (39%).



Overall, dietary changes are the simplest treatment option for weight loss and can lead to great success for some individuals. However, most will try diet after diet, either new ones or repeating ones that were successful in the past, each time hoping that this diet will finally work long-term. But the research shows that diet is rarely enough to cause lasting weight loss.

> In addition, just focusing on diet can cause an individual to ignore any underlying causes that might need to be addressed to fully treat obesity and avoid gaining weight back. Severely restrictive fad diets tend to work in the very short term (e.g., a couple of weeks) but often lead to rebound weight gain.

Research shows that small, lasting changes to diet and activity level are most effective for weight loss. In our survey, when asked what was most effective for weight loss, techniques such as these were helpful for many.

The problem with dietary changes is that they often become extremely difficult over time. The body fights back against weight loss by initiating hormonal changes that work to rev up appetite and thoughts about food, making it more

#### PAGE | 7

and more difficult to continue eating at a deficit. Many people living with obesity mention "food noise", a term referring to the round-the-clock thoughts about food that many deal with. Dieting in this state is incredibly difficult, as it is a never-ending effort to stay on track.

Imagine if there were a medication that could potentially reduce your risk of future illness and pain, but you needed to take a pill every five minutes. Most people would consider that extremely difficult and would look for a different medication that is easier to take. When a treatment is too difficult for the majority of people to maintain, we call the treatment a failure. But for obesity, we blame the patient when they are unable to stick with a diet that involves constantly thinking about what you can and cannot eat, incessant hunger, continuously calculating calories or carbs, and having to turn down food at social gatherings and cultural events.

These issues can compound during stressful times in life, as it can be especially difficult to worry about exactly how many calories are in each meal when you are cramming for exams, when you are packing your house to move across the country, when your newborn is waking you up all night, when you are making funeral arrangements for a loved one, when you are in constant pain, and so forth.

All of this is before considering the many side effects of dieting, such as fatigue, irritability, changes in mood and mental health symptoms, constipation, dry skin, hair loss, changes to the menstrual cycle, and reduced immune function.

In addition, people with various diseases and disorders, especially digestive conditions, can end up experiencing obesity because of strict diets. For example, someone with irritable bowel syndrome or inflammatory bowel disease might need to avoid fibrous foods such as whole grains, legumes, fruits, and vegetables, and instead eat more processed foods such as white bread and white rice, since these are easier to digest. However, this less satiating diet can cause a person to need to eat more calories to feel satisfied, leading to weight gain.

"The role of gastrointestinal conditions in relation to obesity is extremely important. GI conditions can be intensely disruptive to a person's life, exercise routines, and dietary/eating patterns. A severe GI condition can easily cause a person with healthy weight to become chronically obese."

For those living with obesity, these factors can lead to an endless cycle of weight gain and weight loss, each time thinking this diet or treatment will be the key, that this time will be different. And they might lose a good amount of weight, but then gain it back. Over and over again. The best treatments are those that an individual can adhere to. People don't fail diets, diets fail people.

"I don't believe in dieting. All my life, I've seen people lose weight and gain it back by following these diets. Diets give people who are too big a 'simple' solution to a consequence. But there's no point in tackling a consequence without addressing the cause. I've always seen dieting as someone handing me a towel to wipe my hair because it's wet, while I'm standing under a huge breach in a dam. There's no point in wiping my hair before repairing the breach in my dam."

## **Exercise and Activity**

Staying active is an important part of weight management, as well as general health. Most people with obesity are told to exercise more to increase muscle mass and burn more calories. While exercise is not as effective for weight loss as dietary changes, it is very beneficial for health no matter an individual's size. In our survey, 50% of respondents were not regularly active. Even among those who were active, many still found they had trouble staying active. The most common reason for this was a lack of motivation (49%). In addition, exercise can be particularly difficult for individuals living with obesity, as those who are heavier have higher risks of injury during many activities. 33% of our survey respondents found that their weight

#### **OBESITY JOURNEY SURVEY REPORT**

made exercise difficult. They can also struggle with self esteem and social anxiety, with many having experienced ridicule or teasing while going for walks/runs or at the gym. For 22% of respondents, fear of social ridicule was a reason that they find it difficult to exercise. Also, people with obesity might have other disabilities, related or unrelated to their weight, that make exercise difficult. This can include physical injuries (which 27% of respondents said interferes with their ability to exercise), genetic conditions, mental health issues, and more. Older individuals might also struggle to stay active when they are at a higher weight.

While many think they need to have a strict exercise regimen, staying active is really the most important thing. In our survey, 30% of respondents were active in their daily life, such as working a physical job, having outdoor hobbies, or walking or biking for transportation. These are great ways to enjoy the health benefits of activity without feeling constricted by a strict workout schedule.

Exercise and staying active are important for good health, but exercising enough to encourage weight loss is difficult for most. For instance, those with injuries, disabilities, and time constraints, as well as older individuals, can find it difficult to get enough exercise to affect their weight.

#### **Behavioural Interventions**

Some individuals will continue their treatment journey by learning techniques to help manage hunger, binging, boredom eating, and any other mental blocks that prevent a person from sticking with a healthy diet routine. This can include therapy or counselling, especially cognitive behavioural therapy (CBT).

"I would love some financial support for my weight loss journey. I feel the only way to get the support I need is by paying a lot of money for services like counselling (trauma and emotional eating) and personal training."

# **Medications and Surgery**

The next step if diet, exercise, and behavioural modifications don't lead to lasting weight loss, is to look at medical interventions such as medications and/or surgery. Many people find that these medications finally turn down their food noise so that they can stick with a lower calorie diet.

In our survey, 38% of respondents had used some type of medication to treat their obesity. When we asked participants what weight loss tool was most effective, many listed a medication and bariatric surgery was also common.

However, medication and surgery are not magic, and they do have drawbacks. Medications can be very expensive and bariatric surgery often has long wait times. Both come with a slew of side effects, ranging from mild gastrointestinal distress to rare life-threatening challenges. Some individuals are unable to access medications or surgery, such as those with physicians who won't provide prescriptions or referrals, and those who have other health issues. While some individuals have fantastic

results, they don't work for others. In addition, a medication might show an average weight loss of 15% of total body weight, but for an individual who is very large, this loss would leave them still in the obese category. Bariatric surgery is a serious medical procedure that permanently alters your body, and not everyone is interested in going through with that. Surgery includes risks, such as sepsis, hemorrhage,

reaction to anesthesia, wound infection, and more. In our survey, 37% of respondents said that they would never consider surgery for weight loss and 18% hadn't really thought about it. However, 29% said they would consider surgery and 15% had surgery for weight loss. A person must also undergo a permanent change to their lifestyle after bariatric surgery, since it is an extreme modification of the digestive system.



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#### PAGE | 9

In a focus group we conducted, several individuals who had bariatric surgery experienced weight loss and almost complete re-gain. One person, sadly, passed away from bariatric surgery complications just days after we met with her.

One sociological side effect of these increasingly effective treatments is that they can increase stigma, since people will say "there is no reason for you to be obese, why don't you just take medications or get surgery." Of course, this ignores the complex reasons for obesity, the lack of perfect results from these interventions, and the fact that some people don't have access, and others might not want to take medications or have surgery. Conversely, those who choose to use these treatments often hear from others that they are "cheating," and they should lose weight through diet and exercise alone. The pressure never ends, and the stigma show goes on.

"Weight loss medications and surgeries are bandaids. They take off the weight, but don't address why the weight was gained."

## **Side Effects of Weight Loss**

While obesity itself can lead to health complications, treating obesity and losing weight come with their own complications. As mentioned in the previous section, surgery and medications can have many side effects. In addition, constantly dieting can lead to mental health side effects such as obsession with food, calories, and nutrients, as well as physical symptoms. Individuals who lose large amounts of weight, especially when it is rapid, often end up with loose skin, which can lead to skin conditions in some cases, and are at greater risk for some medical conditions, such as gallbladder disease.

In our survey, 46% said they didn't experience any side effects of weight loss, but 38% did and 16% weren't sure. It is also important to consider that some of the 46% might not have lost enough weight to experience these issues.

Even if someone loses enough weight to be considered ideal, they are still living with obesity. In a focus group we held, those who had achieved an ideal weight still continually suffered with the fear of gaining weight and felt that they had to be "on" all the time to maintain this ideal.



# **Mental Health and Social Experiences**

Other research has shown that those living with obesity have higher rates of mental health conditions. In our survey, 59% indicated having an anxiety disorder, 58% insomnia/difficulty sleeping, 52% a mood disorder, 28% an eating disorder, and 4% another mental health condition. Many of our respondents had also experienced trauma, including childhood trauma (35%) and adulthood trauma (22%). Only 11% indicated having no mental health condition. It is unclear how many of these mental health concerns arose from the social interactions related to obesity.

While many people turn to support groups when dealing with chronic conditions, 72% of respondents had never attended a support group for obesity, 15% had tried a support group but found that it wasn't helpful, and only 13% had attended a support group that they found helpful.

Stigma is another big part of the obesity journey. Many experience shaming and judgement from those who believe that obesity is a choice, so it is okay to be cruel to people for their weight. 71% of our survey respondents had experienced social stigma related to living with obesity, including being shamed or discriminated against because of their body size. Only 19% said they hadn't experienced stigma, and 10% were unsure.

This stigma can come from all directions: family, friends, peers, colleagues, random strangers healthcare professionals, teachers, coaches, and spiritual leaders. After all these external sources of stigma, many begin to internalize the messages and turn them on others, and even themselves. Regularly experiencing insults and dehumanizing treatment can lead to lifelong problems with self esteem, confidence, anxiety, and depression.

Some battle weight gain in other ways. Bulimia is an eating disorder with uncontrolled, typically short, episodes of overeating (binge eating) followed with purging by self-induced vomiting, misuse of laxatives or diuretics, fasting, or exercising excessively, or a combination of these. These individuals might be thin or large, but are fighting obesity with these behaviours. Regardless of changes in their weight, some suffer from body dysmorphia and still see the same body in front of the mirror. On the other hand, anorexia nervosa is an eating disorder in which a person typically has an abnormally low body weight due to an intense fear of gaining weight and a distorted image of body weight. These conditions are more common in females than males.

People living with obesity can also face barriers to physically fitting into a world not built for them, such as seats on planes or buses, chairs with arms, or small toilet stalls. They might feel unwelcome in gyms, where they sometimes face judgement for not being in good shape. These experiences can cause so much shame and embarrassment.

# What People Living with Obesity Want Others to Know

"The world needs to know that obesity is a chronic disease and that those who live with it deserve respect and care, not judgement."

"The general perception that it is entirely my own fault, and that if I simply "ate less and moved more" and just cared about it that all the weight would somehow magically go away. If it were that simple, NOBODY would actually be living with this!"

"There is a huge misconception that people living with obesity are lazy and don't care about their situation. The reality is it is so much more complicated than that. Obesity is a chronic medical condition that our society chooses to blame the patient for. Obese patients living in poverty have a practically impossible mission to conquer."

"People think that because I'm a person with a disability that I'm being lazy and that I don't want to lose the weight."

"Please help, not blame, people suffering with obesity. We blame ourselves enough, hating what we have become."

# **The Hardest Part About Living With Obesity**

"Food is advertised everywhere. Eating disorders are not accepted unless it has other effects such advertised bulimia & anorexia. Using food as a crutch is sneered at, if it was an alcohol or drug dependency there is help. With food, people just expect you to stop it."

"The daily grind. Every movement being harder, not being able to do the activities my smaller friends and colleagues do. Constantly aware of people looking and judging me on my size. Feeling awful about my body, the clothes I have to wear."

"Social stigma, shame and bias in medical field, can't do everything I'd like physically, lack of confidence, expensive and hard to find clothing."

"Not being fit enough to play with my grandson. Not doing certain activities because of the weight issue Always having people thinking I eat too much when really the reverse is true."

"Moving without pain. People's preconceptions, equal opportunity for jobs."

# Outlook

As research continues into techniques that help people lose weight and keep it off, as well as understanding what causes obesity, there might be more options to help manage this chronic disease. We hope for a world that will display increased understanding of the persons living with obesity and ending stigma.

People living with obesity are normal people in larger bodies who live regular lives, from mundane to extraordinary, with all the same experiences, goals, and dreams as everyone else. Many spend countless years of their life trying diet after diet, medication, surgery, and anything else that might work, in search of that smaller body. Conversely, a person might also be content at a weight that is not perfect according to current guidelines.

Like many chronic conditions, living with obesity is not easy, even when someone tries their best to do all the right things. The journey is complex, but people living with obesity can still enjoy the ride by knowing that their worth is not attached to their weight.

Go to www.badgut.org/obesity to learn more about obesity, including information on its causes, associated health effects, medications, bariatric surgery, and how hunger and appetite work.



## **Please Note**

Thank you to those who participated in our focus group and completed our survey online. We could not have done this without you.

Percentages rounded to whole numbers.

Obesity journey images created by Fuselight Creative Inc.

Quotes in highlighted text are from our survey respondents.

 Statistics Canada. Overweight and obese adults, 2018. Available at: https://www150.statcan.gc.ca/n1/pub/82-625-x/2019001/ article/00005-eng.htm.

The Gastrointestinal Society does not intend that this report replace the knowledge or diagnosis of your physician or healthcare team, and we recommend seeking advice from a medical professional whenever a health problem arises.

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