SECTION I  ALL ABOUT ARFID
1 WHAT IS ARFID?

“I’ve been a picky eater all my life.”
“I’m terrified of food.”
“I’m just not hungry. Ever.”

These are the kinds of statements we hear every day at the Massachusetts General Hospital Eating Disorders Clinical and Research Program in Boston, where we are privileged to take care of children, adolescents, and adults with avoidant/restrictive food intake disorder (ARFID). People with ARFID struggle with the hallmark symptoms of food avoidance and restriction. Avoidance means rejecting entire food groups (e.g., eating only grains and dairy, but hardly any fruits, vegetables, or proteins), whereas restriction means not eating enough food overall (e.g., eating extremely small portions or skipping meals and snacks). Individuals with ARFID can have one or both problems.

ARFID is more than just having preferences for certain foods. Most people like some foods and dislike others. That’s normal. For example, the three of us – Jenny, Kendra, and Kamryn – share a mutual dislike for mayonnaise. One of our colleagues, Dr. Helen Murray, another expert on ARFID, hates chocolate. However, because each of us is able to meet our nutritional needs with other foods, none of us would meet criteria for ARFID. Indeed, the food avoidance and restriction characteristic of ARFID goes beyond normative likes and dislikes. As described in Figure 1.1, the disorder causes major problems in people’s lives. If you are struggling with ARFID, you likely already know this. It may be the reason you picked up this book.
What is ARFID?

Avoidant/Restrictive Food Intake Disorder

ARFID is different from other eating disorders, like anorexia nervosa, because people with ARFID do not worry much about how they look, or how much they weigh. Instead, people with ARFID might have one, two, or all three of these important concerns:

1. Some people with ARFID find that novel foods have strange or intense tastes, textures, or smells, and they feel safer eating foods that they know well.

2. Others have had scary experiences with food, like throwing up, choking, or allergic reaction, so they may avoid the foods that made them sick, or stop eating altogether.

3. Still others don't feel hungry very often, think eating is a chore, or get full very quickly.

Figure 1.1 What Is ARFID?
Some individuals with ARFID are dangerously underweight, whereas others are very short in stature. Still others are normal weight, overweight, or even obese, but are diagnosed with nutritional deficiencies (e.g., low vitamin C) or other physical problems (e.g., anemia) due to their limited diets. Beyond...
physical health, ARFID can cause problems in the day-to-day functioning of those who live with it. We have worked with patients who have had to quit jobs that they loved (ranging from physicians to animal handlers) because they no longer had enough energy to work. We have seen patients who were unable to travel, go to college, or eat outside of their own kitchens due to their extreme concerns about food.

Individuals can struggle with ARFID at any age – from toddlerhood to older adulthood. However, because children and adolescents typically require intensive involvement from their parents or other caregivers to recover, we have written this book specifically for adults (i.e., those over 18 years old) with ARFID. Many of the concepts we present in this book will be relevant to individuals of all ages, but the treatment approach itself (i.e., a self-help version of cognitive–behavioral therapy) is most appropriate for adults who are living independently. Many adult readers will have been living with ARFID for years by the time they read this book. In fact, the majority of individuals who present to our clinic at Massachusetts General Hospital for the treatment of ARFID have been dealing with this problem since early childhood. Many of them report feeling demoralized by years of unsuccessful attempts at past treatments that are a great help to some people but little help to others. Whether you have had ARFID throughout your lifetime or have developed avoidant or restrictive eating patterns more recently, we consider your age and your experience to be tools that you can leverage in treatment. Often adults with ARFID will have great insight into the difficulties that their selective eating creates for them and, in turn, be even more motivated to make changes. Harness your drive!

Common Presentations of ARFID
Although ARFID bears some similarity to the better-known eating disorders – such as anorexia nervosa (a disorder of food
1 What Is ARFID?

Restriction leading to extremely low body weight) and bulimia nervosa (a disorder of binge eating and purging) – it is actually fairly distinct. Anorexia nervosa and related eating disorders are typically characterized by body-image problems, in which people think that they are too fat. People with anorexia nervosa and bulimia nervosa usually engage in disordered eating behaviors such as dieting, self-induced vomiting, or compulsive exercise to achieve or maintain a low weight. In contrast, people with ARFID usually give very different reasons for consuming a limited volume or variety of food. These different motivations typically include sensory sensitivity, fear of aversive consequences, or a lack of interest in eating or food, though there can be others. To illustrate the common presentations of ARFID, below we will share the stories of three adults who presented to our clinic seeking help. Although we have given them pseudonyms to protect their privacy, they have each graciously agreed to share their inspiring stories. We will introduce you to each of them here and then return to their stories in future chapters to illustrate how they ultimately overcame their eating problems, and how you can, too. Indeed, throughout the book, whenever we provide examples of individuals who have tackled their ARFID, we are always sharing the stories of real people, though we have sometimes changed key details to maintain their confidentiality.

Kojo – Sensory Sensitivity

When we first met Kojo, a 33-year-old African-American male, he was eating just nine foods – saltine crackers, French fries, Doritos, peanuts, peanut butter, ice cream, oranges, and spaghetti with tomato sauce. Truthfully, on most days it was just the saltines and fries. Even within this very short list, foods needed to be just right in their preparation for him to feel comfortable eating them. For example, he strained the tomato sauce to take out any errant tomato chunks before eating it. It was difficult for him to explain exactly why he couldn’t eat other foods. To him, it just felt like a mental block. Foods with
the wrong taste, temperature, texture, or appearance would instantly turn him off. For as long as he could remember, it had always been this way. In our initial meeting, he shared vivid memories of sitting at his kitchen table at five years old, gagging and trying to hold back vomit, while his loving but exasperated father paced for hours, pleading with him to try a new food.

By the time he sought treatment, ARFID had already taken a major toll on Kojo’s health. At 10 years old, he had suffered a pulmonary embolism of unknown cause. However, his physicians worried that his multiple nutritional deficiencies (i.e. dangerously low folate, iron, and vitamin D) may have put him at increased risk. “It was a wake-up call,” he said grimly. “I almost died.” Over the years, he was placed on multiple vitamin and mineral supplements by doctors. Interestingly, even though he was not getting enough nutrients, he was getting enough calories. His body mass index (BMI) was technically in the overweight range and his blood sugar levels were elevated, putting him at risk for type 2 diabetes.

Although Kojo enjoyed a successful job at a professional services firm and had many friends, his social life was profoundly affected by ARFID. Many times, when he visited his extended family in Africa, he shipped fries in advance, so that he wouldn’t have to starve during his trip. He felt guilty that he couldn’t eat treasured family recipes, such as chicken and peanut stew, that had been passed down for generations and were often served at family gatherings. Indeed, he often declined social invitations that involved eating, such as taco nights or barbeques. Sometimes, he participated without eating, telling friends he’d already eaten (even if, in reality, he was famished). He felt guilty about having to lie, but also somewhat justified, given the prior bullying he had endured. For example, once when Kojo attempted to eat a new food at a baseball game, a friend began teasing him and pulled out his phone to take video documentation of the anomalous occurrence. Kojo felt humiliated. Perhaps most notably, given his life
stage, his romantic life was also suffering; Kojo hadn’t gone on a dinner date in six years.

Like Kojo, individuals with the sensory sensitivity presentation of ARFID typically eat a very limited variety of foods due to difficulties with taste, texture, temperature, and/or appearance. They most often rely on processed grains and dairy foods, and eat few to no fruits, vegetables, or proteins. Biological differences – such as taste preferences or taste-bud concentration – may put people at risk for developing sensory sensitivity and thus limiting their dietary variety. (In fact, we are actively researching the etiology of sensory sensitivity at Massachusetts General Hospital.) Once established, these patterns of food restriction can create a vicious cycle that becomes highly resistant to change. Figure 1.2 provides further detail about the sensory sensitivity presentation of ARFID.

Astrid – Fear of Aversive Consequences

When we first met Astrid, a 24-year-old Caucasian female, our team was immediately worried. Astrid was an avid runner with plans to run the prestigious Boston marathon in just a few weeks, but both her weight and heart rate were dangerously low. Astrid explained that she’d never had any difficulties with eating until a few years ago. Prior to this, she explained, “food was always a really big part of my life. I liked to cook, and I loved to bake.” However, seemingly out of the blue, she suddenly developed nausea and vomiting after eating a bowl of pasta. She visited a gastroenterologist, who performed some tests and diagnosed her with celiac disease (an autoimmune disease in which consuming gluten causes damage to the small intestine). The gastroenterologist recommended that Astrid follow a gluten-free diet to prevent nausea and vomiting going forward. This worked for a little while, but after a few accidental gluten exposures, her symptoms returned with a vengeance. She began experiencing nausea and vomiting every time she ate – even when she knew the food did not contain gluten. In a desperate effort to keep the vomiting at bay, she
What happens when you eat a limited variety of food?

- You may even be a "supertaster" - meaning you could have been born with a high concentration of taste buds on your tongue and dislike bitter foods, like vegetables.
- There may be evolutionary advantages to food preferences.
- Certain nutrition deficiencies can change the way food tastes, making new food even less appealing.
- Eating a particular food over and over may also make you tired of that food and stop eating it, further limiting your diet.
- Eating a very limited diet can also cause serious health problems. Eating preferred foods high in sugar and fat has been associated with diabetes and heart disease. Avoiding non-preferred foods, like fruits and vegetables, is associated with certain cancers.
- It may be hard to eat with others, causing you to miss out on opportunities to learn about new foods.

**Figure 1.2** What happens when you eat a limited variety of food?