

# 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

- People with ARFID eat a very limited variety or amount of food and it causes problems in their lives
- These problems may be health-related, like losing too much weight, or not getting enough nutrients
- These problems may be social, like not being able to eat meals with others

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:



**Figure 1.1** What Is ARFID?

## ARFID is a psychiatric disorder

It's important to understand that someone with ARFID is not just being "picky" or "stubborn"



People with ARFID have underlying biological traits that initially made their eating habits a logical choice

Once established, a pattern of food avoidance can become longstanding and highly resistant to change

### GOOD NEWS!

There are helpful steps patients and families can take to interrupt these patterns of behavior

**Figure 1.1** (cont.)

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

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 barbecues. 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?



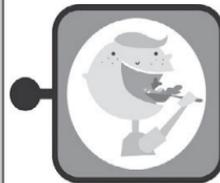
- Flavor preferences are partly genetic
- You may even be a "supertaster" - meaning you could have been born with a high concentration of taste buds on your tongue and dislike bitter foods, like vegetables



- There may be evolutionary advantages to food preferences
- Foods like fruits, vegetables, and meats were those most likely to be poisonous when our ancestors were hunting and gathering

## How does a limited diet keep ARFID going?

- Eating the same foods all the time makes new foods taste even more different
- 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?

began avoiding any food that had ever been linked to an episode of nausea (even if the nausea was only slight). Over the next few months, she found herself cutting out oats, onions, garlic, meat, coffee, alcohol, chocolate, and processed gluten-free foods (e.g., crackers, bread). She developed other safety behaviors, including obsessively reading labels on packaging, avoiding eating any food that had been prepared by others (even her mother and boyfriend), and eating less and less at each meal to prevent herself from feeling overly full. By the time she sought treatment, she only felt safe eating a handful of very bland foods that felt easy on her stomach – such as sweet potatoes and brown rice – and was consuming alarmingly small portions.

Although cutting back on her eating helped her to stop vomiting, insidiously, it began to create problems of its own. Astrid, who was already a runner with a fairly low body weight, lost 25 pounds, resulting in a dangerously low BMI, well into the underweight range. She stopped getting her period and began to feel tired, weak, and cold most of the time. The mobile app that she had been using to track her running mileage began to send her angry warnings that her heart rate was too low. She knew that she was unhealthy and wanted to gain weight, but she didn't know how to do it. She was also becoming increasingly isolated. To avoid accidental gluten exposure, she stopped going to restaurants and bars, which made it difficult to socialize with her circle of friends, whose social lives featured an active nightlife. She and her boyfriend, who had previously shared dinners together each evening in their cozy apartment, began eating separate meals. She even began visiting family less frequently, as they lived out-of-state and she didn't feel comfortable eating outside of her home.

Like Astrid, individuals with the fear of aversive consequences presentation of ARFID limit their food intake – whether by volume or variety – in order to avoid having a negative experience with food. In Astrid's case, the negative

experience was nausea and vomiting. For other people, the negative experience might be choking, allergic reaction, gastrointestinal distress, or something else. Typically, individuals begin by limiting the food or types of food that were specifically associated with a traumatic experience, but – all too often – like Astrid, they begin to cut out so many foods that there is almost nothing left that feels safe. Individuals like Astrid who have experienced a food- or eating-related trauma often engage in safety behaviors (e.g., taking small bites, eating very slowly) that they think will protect them from harm in the short term, but ultimately make the problem worse over time. We have worked with patients who only felt safe eating one or two foods, or who were so terrified that they could not even swallow their own saliva. Figure 1.3 (*What happens when you become more careful about your eating after a negative experience with food?*) provides further information about the fear of aversive consequences presentation of ARFID.

### **Penny – Lack of Interest in Eating or Food**

At 25 years old, Penny sought out care at our clinic with the support of her mother after finding the program through an online search. Penny was a high-functioning young Caucasian female living with roommates, in a romantic relationship, working full-time, and contemplating returning to school for a graduate degree. At odds with her general high functioning was her poor physical health. At our initial evaluation, Penny was severely underweight. Penny explained, “I don’t have much of an interest in food or eating and I’m never really hungry. I do occasionally have sensations of hunger – I may feel mildly uncomfortable – but I don’t have any desire to eat to fix it.” Most days, she ate just two small meals, one at midday and one in the evening. She described, “If I’m not thinking about it *really hard*, I won’t eat much. I’ll always skip breakfast, then have some leftovers for lunch and dinner, and sometimes have candy or a granola bar as a snack.”

## What happens when you become more careful about your eating after a negative experience with food?



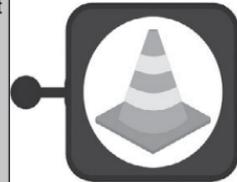
- Negative experiences with food such as choking, vomiting, an allergic reaction, or pain after eating can be traumatic



- These experiences might cause you to limit your diet to prevent further trauma
- You might even avoid any food that reminds you of the traumatic experience or stop eating altogether

## How does avoiding foods or eating altogether keep ARFID going?

- You may be using “safety behaviors” to try and prevent another traumatic experience from happening
  - Taking very small bites
  - Chewing for much longer than needed
  - Only eating at familiar restaurants
  - Not eating at all
- Safety behaviors prevent you from testing negative predictions about eating
- The more you avoid eating, the scarier it becomes!



**Figure 1.3** What happens when you become more careful about your eating after a negative experience with food?

Penny endorsed a longstanding lack of interest in eating and food, and likewise, a “lifelong” low weight. Upon medical evaluation, she was given a possible diagnosis of Ehlers–Danlos syndrome, which is a group of genetic disorders affecting connective tissues that can manifest in multiple ways, including gastrointestinal symptoms, poor growth, difficulty chewing, and early satiety. She reflected that she had struggled with eating throughout her life, but that because her height had always been on track, and because her siblings were also very slender, no one had really identified that she had a problem. Her food repertoire was limited in volume but relatively wide in scope, allowing her to eat pastas, bread products, all types of meats, cheeses, and many vegetables; she generally avoided fruits, fish, and most dairy products.

Penny scheduled her life such that her restricted eating patterns and limited diet interfered only minimally in her day-to-day activities. She ate lunch at her desk at work, often had dinner with her partner or friends, and was known by friends and colleagues for having a small appetite and somewhat of a quirk for snacking on candy. As she had always eaten very little, friends, family, and even her boyfriend, didn’t push her to eat more. Furthermore, she had always been very slender and denied wanting to be thin, instead describing that she’d like to have more curves. In addition to what her records showed to be a chronic low weight, Penny had diagnosed vitamin D deficiency, and osteopenia (reflecting low bone density). Penny described struggling with eating “all [her] life” and “hoping [she] could change it on [her] own,” but finally feeling fed up with trying.

Figure 1.4 provides further detail about the lack of interest in eating or food presentation of ARFID. Like Penny, individuals with the lack-of-interest presentation of ARFID struggle to eat enough, particularly in terms of volume. Many of them forget to eat and, once they start, become full very quickly. Some say that eating feels like a chore, rather than a pleasurable experience. Many, if not most, individuals with this presentation are



## What happens when you eat a limited volume of food?

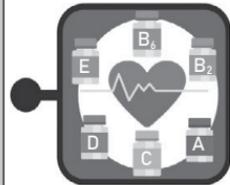
- How hungry you feel and how much pleasure you get from eating is partly due to your genes
- Eating very little can cause you to feel full quickly, even though you are not getting enough nutrients



- Eating without a regular schedule of meals and snacks can dull hunger cues, especially if you go long periods without eating
- Eating too little can promote excessive fullness when you do eat an adequate amount because your stomach capacity decreases with chronic food restriction

## How does eating very little keep ARFID going?

- Even if you are born with a smaller appetite than others, eating very little may further reduce your appetite. This is particularly true if you also limit food variety
- Eating a limited variety can decrease your ability to eat a sufficient volume of food because you get bored of eating the same things and then eat less of them
- You may experience low mood, irritability, anxiety, apathy, difficulty concentrating, or social isolation
- You may also experience significant weight loss, osteoporosis, loss of menses, muscle wasting, decreased heart rate, or other medical problems



**Figure 1.4** What happens when you eat a limited volume of food?

underweight. Over time, chronic undereating has the effect of dulling hunger cues and promoting excessive fullness, leading people like Penny to feel satiated even when they haven't taken in enough calories.

### **Overlap Between Presentations**

Kojo, Astrid, and Penny highlight the diversity of lived experiences that are subsumed under the broad umbrella of ARFID. However, these three presentations are not mutually exclusive. Some people with ARFID have two or even three presentations. For example, we have worked with patients who have had picky eating (i.e., the sensory sensitivity presentation) and low appetite (i.e., the lack of interest in eating or food presentation) since childhood, but experienced a traumatic experience later in life that left them terrified to eat anything at all (i.e., the fear of aversive consequences presentation). In such cases, they may struggle with symptoms similar to those of Kojo, Astrid, and Penny – but all at the same time! Whichever presentation – or presentations – of ARFID you have, it is likely to be associated with problems in your physical health or day-to-day life.

### **How Does ARFID Affect Your Physical Health?**

Like other feeding and eating disorders, ARFID can affect nearly every part of your body – from the hair on your head to the tips of your toes. One of the most obvious impacts is on body weight. Some individuals, like Kojo, eat a limited variety of high-calorie foods (e.g., fries), but eat enough of these that they gain significant weight, resulting in overweight or obesity. They may develop complications related to obesity, such as type 2 diabetes or high blood pressure. Other individuals – like Astrid and Penny – eat such a limited volume of food that their body weight becomes dangerously low. They can experience medical complications due to low weight, including low heart rate, low blood pressure, bone loss, delayed puberty (in young people), and loss of menses (in females) (Aulinas et al., 2020).

Similarly, young people with ARFID may fail to grow in height and ultimately achieve a shorter stature than their genetic potential due to inadequate intake. We have worked with young boys who have, heartbreakingly, been mercilessly bullied for being shorter than their peers. Still others with ARFID are normal weight, but are at risk for other health problems, such as nutritional deficiencies.

Because of their limited diets, individuals with ARFID rarely meet the daily recommendations for nutrient intake suggested by the United States Institute of Medicine. Indeed, research from our team suggests that people with ARFID and related symptoms consume significantly less vitamin K and vitamin B12 compared to those without ARFID (Harshman et al., 2019). While some nutrient deficiencies may not produce obvious symptoms, others can be quite severe. A recent case report highlighted permanent vision and hearing loss in an adolescent boy with ARFID, who had a deficiency in vitamin B12, among other important nutrients (Harrison et al., 2019).

## **How Does ARFID Impact Day-To-Day Life?**

The stories of Kojo, Astrid, and Penny underscore that ARFID can lead not just to physical health problems but also to profound psychosocial impairment. Because so many work and social activities revolve around food and eating, living with ARFID can be very socially isolating. We have worked with patients whose partners have declined to move forward with marriage or having children because the partners were so concerned about the patient's health. Still others are close with family but feel guilty that they cannot fully engage in important life events. One man we worked with presented to treatment in part because he desperately wanted to support his daughter, a budding chef in culinary school, but felt too nervous to attend the special events in which she showcased her novel creations.

Even work and educational activities can be disrupted. Some patients have come to our clinic after dropping out of college because they could not find anything they felt safe or comfortable eating in the university dining hall. As mentioned earlier, we have worked with individuals who have had to quit their jobs because they felt too weak to go to work. Still others worry that they have missed out on promotion opportunities because they could not attend networking dinners or feared that people would be judgmental of their food choices.

Travel is often difficult, particularly trips very far from home. We worked with one patient who had to pack an extra suitcase full of Ensure (a high-calorie supplement drink) for any extended trip, to make sure he got enough to eat. Another patient who took annual trips to visit his family in a remote area of Asia needed to make a two-hour car trek to the nearest pizza shop each time. Still others have simply resigned themselves to staying at home. One young man we treated desperately missed his girlfriend, with whom he was in a long-distance relationship, but he felt too scared of anaphylaxis to eat anywhere but his own apartment, so he hadn't seen her in months.

Of note, ARFID is often accompanied by other mental health conditions. In one study from our group, more than half of people with ARFID and related symptoms had a lifetime history of another psychiatric disorder, usually an anxiety disorder (Kambanis et al., 2020). In the same study, 14% of individuals with avoidant and restrictive eating endorsed a lifetime history of suicidal thinking. Indeed, we worked with one woman who felt so deeply ashamed about the constant barrage of negative judgments from others about her ARFID that she tried to take her own life. Fortunately, she survived.

## The Recognition of ARFID as a Psychiatric Disorder

Despite the significant toll that ARFID can take on people's physical and psychological health, until recently, it was a

problem with no name. The disorder wasn't officially recognized as a psychiatric diagnosis until 2013, with the publication of the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* (American Psychiatric Association, 2013). The addition of a new diagnostic term enabled a large number of previously undiagnosed individuals to recognize that they had a problem and to seek help. However, the symptoms characteristic of ARFID have been well known to professionals for decades. Indeed, a subset of individuals with what is now called ARFID were previously captured under the *DSM-IV* category feeding disorder of infancy and early childhood (American Psychiatric Association, 1994). However, this diagnosis only included children under the age of six years who were underweight. Importantly, it left out the many older children, adolescents, and adults who struggled with avoidant and restrictive eating. Although ARFID often first onsets in childhood or adolescence, without intervention it can become chronic. Furthermore, it can certainly onset later in life, particularly in response to acute food-related traumas. Indeed, we have evaluated and treated many men and women in their twenties, thirties, forties, fifties, and beyond in our outpatient clinic, many of whom have been struggling for decades. Although there are an increasing number of resources for the parents of young children with ARFID, there are precious few for adults. That is why we wrote this book.

## How Common Is ARFID?

Many individuals with ARFID feel alone and misunderstood. They often worry that they are the only ones who struggle with avoidant and restrictive eating. But research suggests otherwise. To figure out how common a disorder is, researchers typically conduct detailed interviews with a very large group of people who are selected to represent a larger population of interest (perhaps an entire country) in terms of key demographic features such as age, race, ethnicity, and geographical

location. Few studies have looked at ARFID in such a rigorous way, so it's difficult to answer the question of just how common the disorder is. The only two studies to date that have looked at the prevalence of ARFID in nationally representative populations have taken place outside of the United States. For example, in a recent study of Australian adolescents and adults ages 15 and older, roughly one in every 300 had ARFID (Hay et al., 2017). Another study in Taiwan found the same figure in children 7 to 12 years old – roughly one in 300 had the disorder (Chen et al., 2020). Although this prevalence may sound fairly low, it is important to note that in both studies ARFID was just as common as anorexia nervosa (Chen et al., 2020; Hay et al., 2017), a more widely recognized eating disorder that most people would agree is an important public health problem.

Moreover, we think these estimates are probably conservative. Here's why: in 2017, our team was fortunate to be featured on Boston's local television station to discuss our ongoing studies on the neurobiology of ARFID on the evening news. At the end of the segment, the news station provided our phone number so that individuals who recognized ARFID symptoms in themselves or a family member could call to inquire about participating. We were hopeful that we might receive perhaps a dozen queries. Over the next couple of days, more than 100 people called! Our phone line was so inundated that we had to ask colleagues who had been working on other studies to drop everything and help us return calls to prospective participants. (Luckily, we have very gracious colleagues.) This mirrors our clinical experience at the Massachusetts General Hospital where, every week, we receive many calls from people looking for help with ARFID and related symptoms. There may also be some settings in which ARFID is especially common. In our team's study of 410 adults seeking care at our hospital's neurogastroenterology clinic, 6.3% met criteria for ARFID and 17.3% had significant symptoms of avoidant or restrictive eating (Murray et al., 2020). In summary, whatever the exact

prevalence of ARFID, our experience suggests that, if you struggle, you are not alone.

## **Putting It All Together**

ARFID is a psychiatric disorder that affects children, adolescents, and adults across the lifespan. It is different from having normal food preferences, and it causes major problems in people's physical health and social lives. There are three common presentations – sensory sensitivity, fear of aversive consequences, and lack of interest in eating or food – which can occur by themselves or together. More research is needed to determine the exact prevalence of ARFID, but available data suggest that it is at least as common as the other more well-known eating disorders. Now that you know what ARFID is, you can use the self-test in the next chapter to determine whether you might have it.