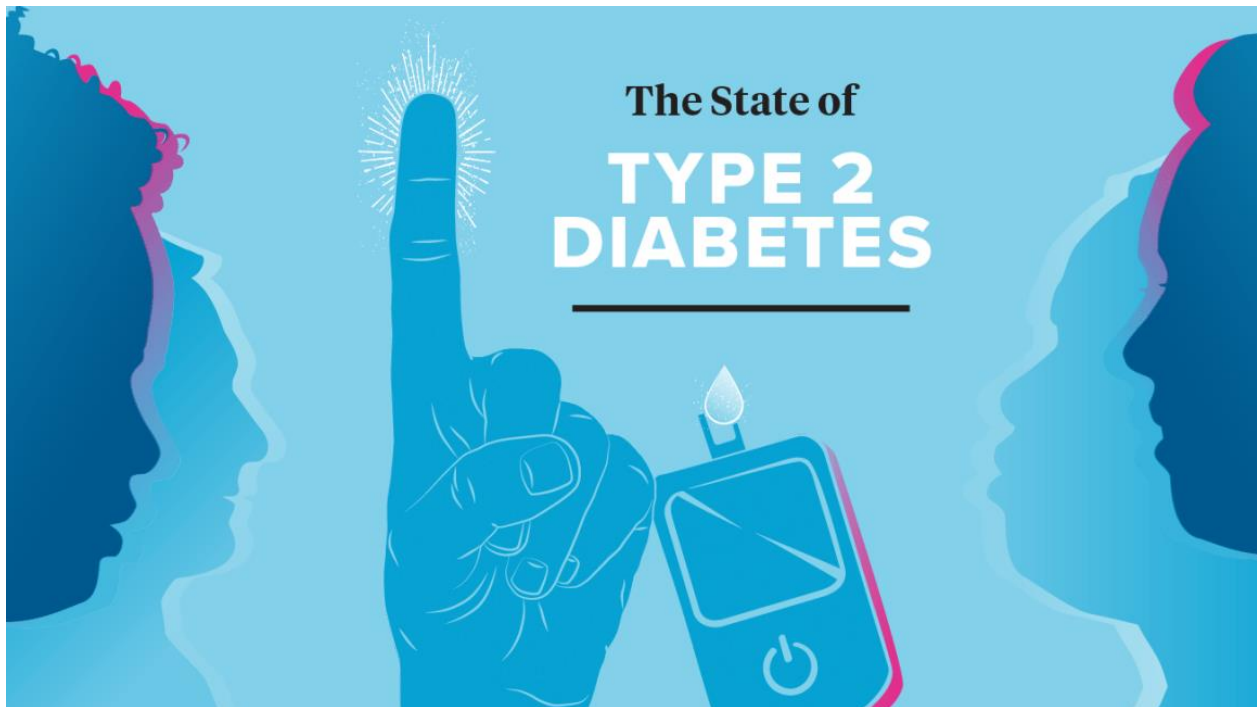


The State of Type 2 Diabetes: When Health Becomes a Full-Time Job

[Key findings](#) ❖ [Type 2 diabetes overview](#) ❖ [Lifestyle work](#) ❖ [Weight and stigma](#) ❖ [Stress and fatigue](#)
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A deeper dive into type 2 diabetes

If type 2 diabetes isn't on our minds, it should be. The United States is the [developed-world capital](#) of the disease. Close to [half](#) of Americans either have type 2 diabetes or its precursor condition, prediabetes. It accounts for [1 of every 7](#) dollars we spend on healthcare, according to the American Diabetes Association. And it increasingly [affects](#) millennials.

Many studies have been done on various aspects of type 2 diabetes: how treatments work, who is most affected, and the roles that diet, exercise, stress, and sleep play. Healthline decided to delve deeper into this world by looking at the day-to-day experiences and feelings of people who live with a condition that never gives them a day off.

How are people with type 2 diabetes managing the condition? Can they afford healthcare and lifestyle changes? How does the diagnosis change their perceptions of themselves and their future? Who helps them? And do the answers to these questions vary among generations? These are key questions that most studies don't explore as completely as we would like.

To get the answers, Healthline commissioned a survey of more than 1,500 people with type 2 diabetes. We asked millennials, Gen Xers, and baby boomers to tell us about their perceptions, worries, and

experiences. Then, to put our findings in perspective, we talked with individuals living with the condition and medical experts who have experience treating it.

Some people claimed to be thriving with type 2 diabetes, while others said they're struggling. The vast majority are concerned about serious complications of the condition, such as vision loss or heart attacks. Many people, already busy with careers and families, find it hard to cope with the work of managing the disease — what one specialist called “a full-time job.” Substantial numbers are deeply concerned about whether they will be able to afford the treatments they need.

They have trouble sleeping.

And yet, many people with type 2 diabetes have succeeded in making big changes in their lives — eating better, exercising more — and see their diagnosis as the day they woke up and started paying attention to their health.

“

I didn't have any motivation to make those changes until I got the diagnosis. I had a very stressful job, I was traveling all the time... But as soon as I got the diagnosis, **that was the wake-up call.**

SHELBY KINNAIRD, 56



Key survey findings

Healthline's State of Type 2 Diabetes survey investigated the emotional challenges of the condition, identified stark disparities between generations, and explored people's most pressing concerns.

Here's a snapshot of the key findings:

Weighty work

Weight loss is a major challenge. More than two-thirds of those with type 2 diabetes said their current weight negatively affects their health. Nearly half have tried losing weight multiple times, without long-term success. At the same time, more than 40 percent reported rarely exercising hard enough to break a sweat.

A surprising challenge

One of the biggest challenges reported might surprise you: most people with type 2 diabetes — 55 percent — have trouble getting a full night's sleep.

Success stories

For some people, a diagnosis of type 2 diabetes may feel like a wake-up call to kick start a healthier lifestyle. Many people reported their diagnosis led them to:

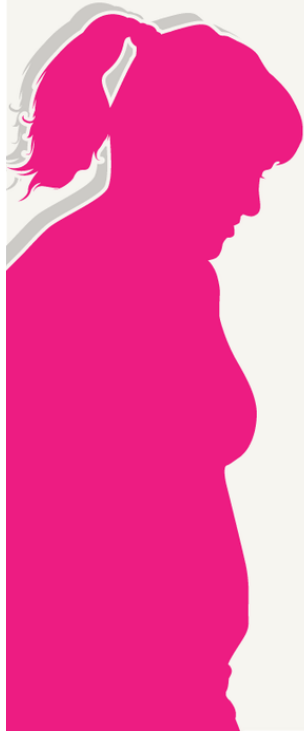
- eat more healthfully (78 percent)
- manage their weight better (56 percent)
- drink less alcohol (25 percent)

Generational and gender divides

Younger people have a harder time than older people with the emotional and financial challenges of type 2 diabetes. There's still a stigma attached to the condition — and millennials bear the brunt of it.

- Nearly half of millennials surveyed, and about a third of Gen Xers, reported hiding their condition out of worry about what others think.
- About the same number reported feeling negatively judged by some healthcare providers.
- Cost prevents more than 40 percent of millennials from always following their doctor's treatment recommendations.

of millennials with **TYPE 2 DIABETES**



MORE THAN
40%

sometimes
**don't follow doctor's
treatment instructions
due to high costs**

healthline

There's also a gender divide: women are more likely than men to say they put others' needs before their own, and they face more challenges balancing their self-care needs with other responsibilities.

Negative feelings

Living with type 2 diabetes is hard work, often compounded by worry. The four most common negative feelings people reported were:

- exhaustion
- worry about complications
- concern about financial costs
- guilt for not managing the condition well

Moreover, the majority reported feeling like they've failed if the results of an A1C test are too high.

Positive outlook

Though many people experience negative feelings, most survey participants expressed a sense of empowerment and indicated that they frequently felt:

- interested in finding new ways to manage the condition

- knowledgeable
- self-reliant
- self-accepting

Many also reported feelings of strength, resilience, and optimism.

Complication concerns

People with type 2 diabetes are well aware of the medical complications that can accompany the condition: two-thirds reported concern about all of the most serious complications. The biggest worries? Blindness, nerve damage, heart disease, kidney disease, stroke, and amputation.

Specialist shortage

More than 60 percent of survey participants have never seen an endocrinologist or a certified diabetes educator, and the majority have never consulted a dietitian. That fits with research that shows a [widespread shortage](#) of professionals who specialize in type 2 diabetes — a problem that's getting worse.

Money versus health

Diabetes is a costly condition. Nearly 40 percent of survey participants are worried about their ability to afford treatment in the future.

Healthline's State of Type 2 Diabetes original survey and data can be provided to professional media and researchers [by request](#). All reported survey data comparisons have been tested for significance at a 90 percent confidence level.

The work of type 2 diabetes

Living with type 2 diabetes can feel like a full-time job. On a basic level, this chronic condition affects the way the body metabolizes sugar, which is an important source of fuel. More than most, people with type 2 diabetes need to eat in ways that maximize their health, exercise regularly, and make other healthful lifestyle choices every single day. On top of that, they need to monitor their blood sugar levels. Many take medication daily.

Although type 1 and type 2 diabetes differ in [important ways](#), both involve problems with insulin, a hormone that regulates the movement of sugar into the body's cells. When the body doesn't produce insulin, or stops using it effectively, sugar builds up in the bloodstream and causes a condition called [hyperglycemia](#). In the early stages, this high blood sugar causes subtle symptoms, such as thirst and frequent urination. Left unchecked, it can damage blood vessels, nerves, eyes, kidneys, and the heart.

Some diabetes medications raise the risk of [hypoglycemia](#), or very low blood sugar. This condition can cause serious problems, including loss of consciousness or even death.

Type 2 diabetes develops when the body becomes [resistant to insulin](#) — meaning the hormone isn't used effectively — or doesn't produce enough insulin to keep blood sugar within a target range. It differs from type 1 diabetes, which is an autoimmune disease that halts the production of insulin. Type 1 diabetes often develops over the course of weeks, usually in children or young adults.

In contrast, type 2 diabetes often develops slowly. People can go years without knowing they have it. To manage it, doctors generally recommend blood sugar monitoring, lifestyle changes, and daily oral medications. In some cases, treatment with insulin is needed. Depending on [body mass index \(BMI\)](#) and other factors, doctors may [recommend](#) weight loss surgery. According to the National Institutes of Health, a high BMI is [linked to insulin resistance](#).

It's overly simplistic — even hurtful — to call type 2 diabetes a “lifestyle disease.” No one is to blame for developing it. The exact cause is unknown. Both [genetic and environmental factors](#) likely play a role, reports the Mayo Clinic. Family history puts people at higher risk. Certain racial or ethnic groups, such as African-Americans, Native Americans, and Latinos, are also at increased risk. The disease is more common in people older than 40, though it increasingly affects young adults.

No matter when it's first diagnosed, type 2 diabetes irrevocably changes people's lives. Frequent doctor visits and tests to monitor blood sugar levels are recommended. Many people set dietary and exercise goals. They might need to address [risk factors](#) for complications too, such as high blood pressure or cholesterol levels.

Learning to reduce stress is also crucial. Mental stress can [raise blood sugar levels](#) — and living with type 2 diabetes can be stressful. It takes effort to juggle everyday life with the demands of a complex chronic condition.

Lifestyle affects the risk and severity of type 2 diabetes, and in turn, the condition can transform a person's lifestyle. That's why Healthline's survey focused on how people with type 2 diabetes fare on a day-to-day basis and how they feel about the disease's impact on their lives.

Lifestyle work

Healthline's survey found that most adults — especially older adults — feel pretty good about how they're managing type 2 diabetes. The vast majority said they're well supported by loved ones. More than half reported feeling knowledgeable, self-reliant, or resilient on a daily or weekly basis. Following their diagnosis, most said they started eating more healthfully, exercising more, and managing their weight better.

But there's a flip side to that sunny picture. Two-thirds of survey participants said their current weight negatively affects their health. More than 40 percent said they rarely exercise hard enough to break a sweat. And sizable minorities — especially younger adults — reported feeling exhausted, anxious, or guilty about how they manage the condition.

of people living with
TYPE 2 DIABETES



2/3

say their
weight
negatively affects
their health

healthline

These results may seem contradictory, but type 2 diabetes is a complex condition. It's a rare person who can follow all their doctor's directions to a T. That's why it's important to stay realistic. Managing the disease is a balancing act: a small square of chocolate once in a while is fine, but a king-sized candy bar every day isn't.

"You're meeting people where they are, and you're helping them to make realistic lifestyle choices," said Laura Cipullo, RD, CDE, who authored the book "[Everyday Diabetes Meals: Cooking for One or Two](#)." In her practice, she helps people focus on long-term changes, not quick fixes.

But even people who commit to changing their habits might find their efforts stymied by the occasional birthday party, work commitments, or factors beyond their control.

"When I was diagnosed, I was 45 pounds heavier than I am now," said Shelby Kinnaird, author of the blog [Diabetic Foodie](#) and the book "[The Pocket Carbohydrate Counter Guide for Diabetes](#)."

Though she's kept the weight off, her busy travel schedule makes daily exercise tough. Lately, she's been experiencing the "dawn phenomenon," which refers to high morning blood sugar caused by a surge of

hormones. So far, she hasn't found a long-term solution. "Everything I've tried doesn't work consistently. That's the biggest challenge I'm facing at the moment."

Similarly, Cindy Campaniello, a leader for the Rochester, NY, chapter of the support group [DiabetesSisters](#), works hard to balance the requirements of managing type 2 diabetes with the responsibilities of a busy life. Trying to stay on a specific diet is "horrendous," she said, not because the food isn't tasty but because of the time it takes to plan and prepare meals.

"You know, we have a life," said Campaniello. She told Healthline about the challenges of raising two active boys while preparing healthy meals with proteins, fresh produce, and limited carbohydrates. "You can't say to your kids, 'We're going to have McDonald's tonight,'" she explained. "You can't function with diabetes by getting some processed food on your lunch break."

Weight and stigma

Despite the effort they've poured into making healthy changes, close to half of participants in Healthline's survey said weight management remains a big challenge: they've tried to lose weight multiple times without long-term success.

Dr. Samar Hafida, an endocrinologist at the Joslin Diabetes Center in Boston, told Healthline that on average, the people she treats have tried three or more fad diets. "There is no diabetes management that doesn't include healthy eating and physical activity," she said, but trendy diet advice can lead people astray. "There is an abundance of misinformation out there."

That's one of the reasons why permanent weight loss eludes so many. Another is that people facing weight challenges may not receive helpful medical interventions, or any help at all.

Piled onto these challenges is the stigma associated with type 2 diabetes and weight, especially for younger people.

"I had a girl just the other week who was slightly overweight," said Veronica Brady, PhD, CDE, a spokesperson for the [American Association of Diabetes Educators](#) who also works at a medical center in Reno, NV. "What she said to me when I met her was, 'I really hope I have type 1 diabetes and not type 2.'" With type 2, the young woman feared, "'people are going to think I have diabetes because I didn't have any self-control.'"

Actress S. Epatha Merkerson, of *Law and Order* and *Chicago Med* fame, knows the stigma of type 2 diabetes — largely from experiences with family members who had the disease but never talked about it. Her relatives didn't even say the word "diabetes."

"I remember when I was a kid, the older folks in my family would always say 'Oh, she has a touch of sugar,'" Merkerson told Healthline, "So I found myself saying that and not really understanding, what is a touch of sugar? You're either diabetic or you're not."

By being forthright about her condition, Merkerson hopes to lessen the embarrassment that many people feel. That's why she's an advocate for [America's Diabetes Challenge](#), sponsored by Merck and

the American Diabetes Association. The initiative encourages people to make lifestyle changes and follow treatment plans to improve type 2 diabetes management.

When Merkerson was diagnosed 15 years ago, she had to come to terms with how much weight she had gained. By the time she left *Law and Order*, she said, “I had a closet that went from a 6 to 16.” She felt some embarrassment about seeing her size increase on national television — but also was motivated to make changes.

“I was 50 when I was diagnosed,” she explained, “and I realized at the time that I was eating like a 12-year-old. My table, my food, and my choices were so off the chart. So, that was the first thing I had to do, was to figure out how to eat better, how to cook, how to shop — all of those things.”

“
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and my choices
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eat better, how to cook, how to
shop — all of those things.

S. EPATHA MERKERSON, 65



Stress and fatigue

Given all the work involved in managing type 2 diabetes, it's little wonder that nearly 40 percent of people surveyed said they feel exhausted on a daily or weekly basis. Just as often, more than 30 percent said they feel guilty about how they're managing the condition.

Lisa Sumlin, PhD, RN, a clinical nurse specialist in diabetes, finds these perspectives familiar. Her clients in Austin, TX, tend to be low-income immigrants, often working multiple jobs to make ends meet. Adding the tasks needed to manage type 2 diabetes requires yet more time and energy.

“I tell patients all the time: this is a full-time job,” she said.

And it's not one for which they can take shortcuts.

Even essential medical tests can trigger stress. For example, doctors order an [A1C test](#) to learn about an individual's average blood sugar levels over previous months. According to our survey, nearly 40 percent of people find it stressful to wait for their A1C results. And 60 percent feel like they've "failed" if the results come back too high.

It's an issue that Adam Brown has heard about time and again. Brown, senior editor of diaTribe, lives with type 1 diabetes and writes the publication's popular "Adam's Corner" column, offering tips to people with type 1 and type 2 diabetes. He's also tackled the topic of A1C stress in his book, "[Bright Spots & Landmines: The Diabetes Guide I Wish Someone Had Handed Me.](#)"

"People often go into their doctor appointments feeling judged and feeling like if the numbers on the [glucose] meter or their A1C are not in range, they feel like they get a bad grade," Brown told Healthline.

Rather than approach those numbers like grades, he suggests treating them as "information to help us make decisions." This reframes the test results, he said: "It's not saying, 'Adam you're a bad person with diabetes because your number is really high.'"

Stress around test results contributes to another big issue: "diabetes burnout." According to the [Joslin Diabetes Center](#), this is a state in which people with diabetes "grow tired of managing their disease or simply ignore it for a period of time, or worse, forever."

Some people fantasize about doing just that.

"As somebody told me in my [support group] meeting the other night," Kinnaird said, "'I just want to take a day off from diabetes.'"

Generational and gender divides

Generation gaps

You could almost say that younger adults with type 2 diabetes deal with a different disease altogether, compared with older people with the condition. That's how distinct their experiences are, especially when you compare millennials with baby boomers. The contrasts are striking, and not in a good way for younger adults.

Healthline's survey revealed a sliding scale of feelings and experiences between the different age groups. Most baby boomers, aged 53 and over, reported positive outlooks on their efforts to manage type 2 diabetes, their interactions with others, and their sense of self. In comparison, higher proportions of millennials, aged 18 to 36, said they have negative experiences in these areas. Gen Xers' responses usually fell between the other two groups, just as they do age-wise.

For example, more than 50 percent of millennials and more than 40 percent of Gen Xers reported feeling ashamed about their bodies on a daily or weekly basis. Only 18 percent of baby boomers feel similarly. Likewise, feelings of guilt, embarrassment, and anxiety are more frequently experienced by millennials and Gen Xers than older adults.

When Lizzie Dessify learned at age 25 that she had type 2 diabetes, she kept the diagnosis a secret for more than a month. When she eventually confided in others, their reactions didn't inspire self-confidence.

“I don’t think anybody was surprised,” said Dessify, who works as a school mental health therapist in Pittsburgh, PA. “I didn’t realize how badly I had let my health go, but obviously everyone around me had seen it.”

People in her life were sympathetic, but few believed she could reverse the progression of the disease. That was “a little discouraging,” she said.

David Anthony Rice, a 48-year-old performer and image consultant, has also been keeping quiet about the condition since his 2017 diagnosis. Some family members and friends know, but he’s reluctant to discuss his dietary needs.



“You don’t want to go around telling everybody, ‘Oh, I’m a diabetic, so when I come to your house, I can’t eat that,’” he said. “It’s one of my biggest challenges, just not isolating myself.”

Rice resists testing his blood sugar at work, or even in front of his kids. “Pricking my finger in front of them — I don’t like doing that because it scares them,” he explained.

Healthline’s survey suggests it’s fairly common for millennials and Gen Xers to hide the condition. Compared with baby boomers, these age groups were more likely to say that type 2 diabetes has interfered with romantic relationships, caused challenges at work, or led people to make negative assumptions about them. They feel isolated more often than baby boomers, too.

These challenges might have something to do with the fact that the condition is often seen as an [older person’s disease](#).

Rice had never heard anyone of his generation talk about having type 2 diabetes until he saw TV personality Tami Roman [speak out](#) about her experiences on the VH1 series *Basketball Wives*.

“It was the first time that I heard it spoken out loud by someone of my age group,” he said. It moved him to tears. “She was like, ‘I’m 48.’ I’m 48, and I’m dealing with this.”

In some cases, a sense of shame or stigma may even affect younger adults’ healthcare experiences. Close to half of millennials and nearly a third of Gen Xers reported feeling judged by some healthcare providers for how they manage type 2 diabetes. About the same proportion said they’ve delayed seeing a healthcare provider because they fear such judgments.

That’s a problem, since healthcare professionals can provide enormous support to help people manage the condition. Dessify, for example, credits her doctor with helping her understand the changes she needed to make to improve her health. She made over her diet, revved up her exercise routine, and lost 75 pounds over three years. Now her A1C test results are at near-normal levels. She’s even started a small business as a [fitness coach](#).

While such success stories are an important part of the picture, many millennials aren’t faring so well.

A 2014 [study](#) in Diabetic Medicine found that compared with older adults with type 2 diabetes, those aged 18 to 39 were less likely to eat healthfully and take insulin as recommended. Younger people also had worse depression scores than older people.

“They don’t have the conceptual framework for a chronic condition that necessitates lifelong vigilance and monitoring,” explained Dr. Rahil Bandukwala, an endocrinologist at MemorialCare Saddleback Medical Center in Southern California.

It’s more depressing for younger adults to realize that type 2 diabetes will be with them for the rest of their lives, he added, because the rest of their lives is such a long time.

of **younger people** with
TYPE 2 DIABETES



hide their condition

at times out of worry about what others think

feel negatively judged

by some healthcare providers for
how they manage the condition

delayed seeing a healthcare provider

because they fear negative judgments

healthline

Younger people with type 2 diabetes face other pressing issues, too — like money. More than 40 percent of millennials said they sometimes don't follow through with recommended treatments because of cost. Nearly a third reported having little to no health insurance coverage. Many of those who have insurance said they're left with big bills.

Millennials, and to a lesser extent Gen Xers, were also more likely than baby boomers to say they find it hard to balance self-care needs with other responsibilities.

Dr. Bandukwala isn't surprised. He's found that in general, millennials are a highly-stressed generation. Many worry about finding and keeping jobs in a fast-moving world with a competitive globalized economy. Some also help care for parents or grandparents with financial or medical needs.

"It makes it potentially very challenging," he said, "to add diabetes care as another job."

Gender divides

Generational divides weren't the only disparities on display in the survey findings — significant gaps also appeared between women and men. Far more women than men reported difficulties with weight. Women were more likely to say their management of type 2 diabetes needs improvement. They also have more trouble balancing self-care with other obligations.

Andrea Thomas, an executive at a nonprofit organization in Washington, D.C., often feels like she doesn't have time to manage type 2 diabetes as carefully as she would like.

"I hate to say I'm in bad habit mode, where I'm working a lot, I'm traveling a lot back and forth to California because my father is sick, I'm chairing this committee at church," she said. "It's just, where do I fit it in?"

Thomas feels well educated about her condition. But it's hard to stay on top of every element of managing it — exercising, eating well, blood sugar monitoring, and all the rest.

"Even as I tell people I want to be a very old woman someday, who travels the world, there's that disconnect between what I need to be doing to take care of myself, and what I'm actually doing."

Thomas' story might resonate with many women who responded to Healthline's survey.

Nearly 70 percent said they put others' needs ahead of their own, despite living with a chronic illness. In comparison, slightly more than 50 percent of men said the same. Is it any wonder that women have more trouble balancing self-care with other responsibilities?

"I do think that women have their own set of unique challenges when it comes to type 2 diabetes," Thomas said. It's important for women to consider how they take care of themselves, she added, and make it a priority.

Sue Rericha, a mother of five and author of the blog [Diabetes Ramblings](#), agrees.

"A lot of times, we put ourselves last," she said, "but I keep on remembering, when you're on an airplane and they do their safety check and they talk about the oxygen mask, they tell people who travel with children, put your own mask on first and then help somebody else. Because if we're not good to ourselves, we're not going to be where we need to be to help others."

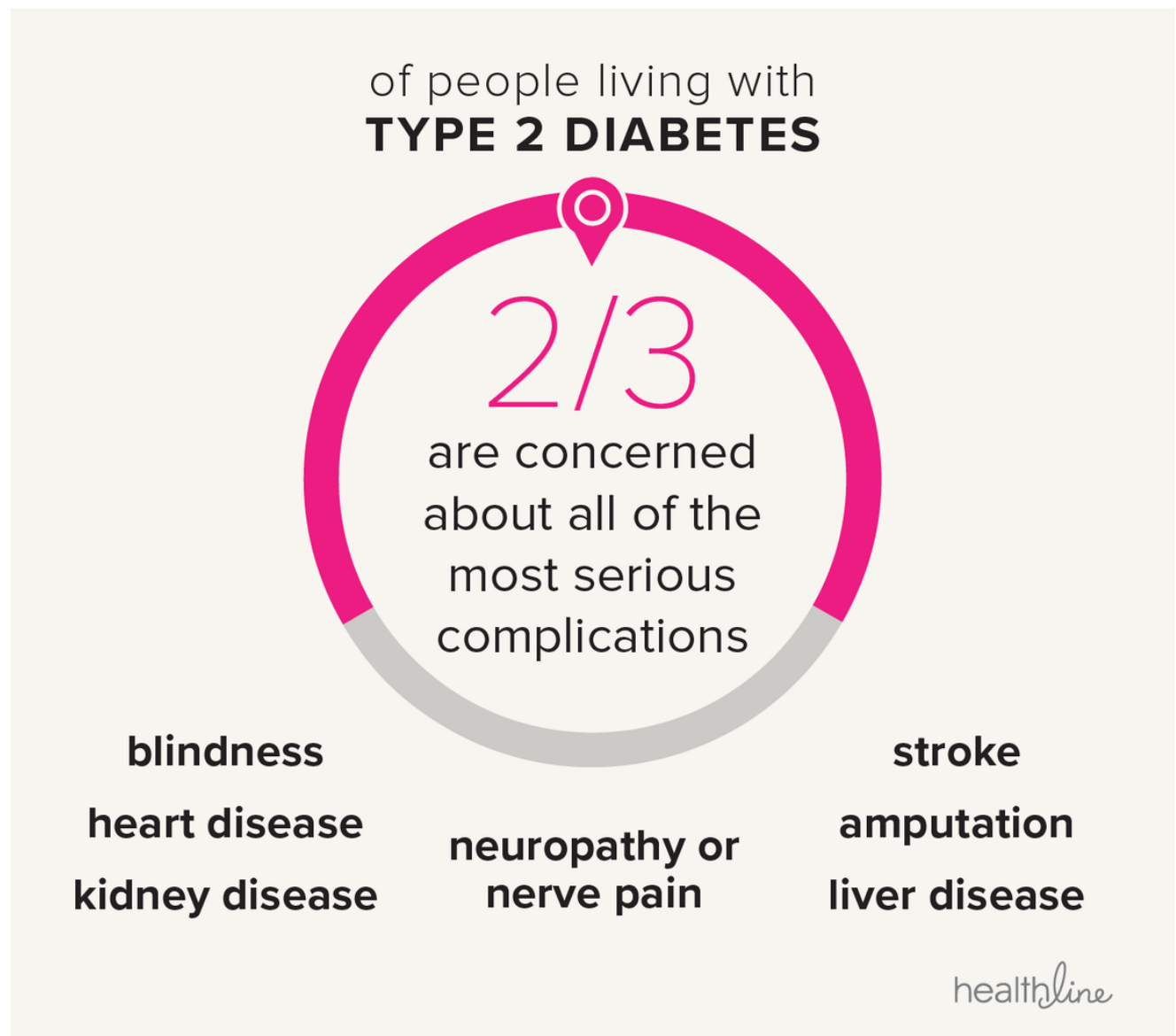
Medical concerns and decisions

Complications

Many of the people with type 2 diabetes that Healthline interviewed said they live with a burden of grave concerns about the potentially dire consequences of the disease.

Those [complications](#) can include vision loss, heart disease, kidney disease, and stroke. Diabetes can also cause pain- and numbness-inducing [neuropathy](#), or nerve damage, in the hands or feet. That numbness can leave people unaware of injuries, which can result in infections and even amputations.

The survey found that two-thirds of people with type 2 diabetes worry about all of the most serious complications of the disease. That makes this issue the most common concern reported. The greatest number — 78 percent — worry about [vision loss](#).



Merkerson has witnessed some of the disease's worst consequences among her relatives.

"My dad died from complications," she said. "My grandmother lost her sight. I had an uncle who had lower extremity amputations."

Survey respondents who identified as African-American or Latino, and women of all backgrounds, were the most likely to report complication-related worries. People also tend to worry more if they live in or near the “[diabetes belt](#),” a swath of mostly southern states that the U.S. Centers for Disease Control and Prevention has identified as having high rates of type 2 diabetes.

This may not be surprising, given that studies have found higher rates of diabetes-related complications in [ethnic minorities](#) and [women](#), compared with white people and men.

Dr. Anne Peters works as an endocrinologist at two Los Angeles-area clinics — one in affluent Beverly Hills and one in the lower income neighborhood of East Los Angeles. She’s noticed that people tend to develop complications earlier in life at the East L.A. clinic, which serves a population that’s uninsured and primarily Latino.

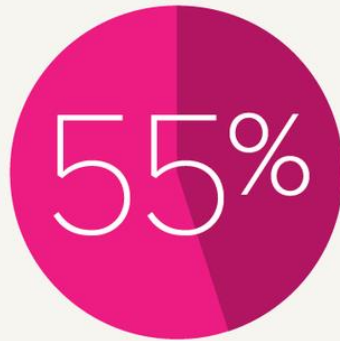
“In the East L.A. community, they get all these complications young,” she said. “I’ve never seen blindness and amputations in my Westside practice in 35-year-olds, but I do here because there’s not been lifelong access to healthcare.”

[Sleep](#)

Healthline’s survey found that more than half of people with type 2 diabetes have trouble sleeping. That might sound minor, but it can create a problematic cycle of ill health.

The [Joslin Diabetes Center](#) notes that high blood sugar can lead to thirst and frequent urination, so people with type 2 diabetes may wake several times a night to drink or go to the bathroom. On the other hand, low blood sugar can cause sleep-disturbing feelings of shakiness or hunger. Stress, worry, and pain from neuropathy can also interfere with sleep.

of people living with
TYPE 2 DIABETES



more than half
have trouble getting
a good night's sleep



A 2017 [study](#) reported that sleep disorders and sleep-disrupting depression are more common in people with type 2 diabetes. In turn, when people don't sleep well, it can make their diabetes worse: a 2013 [study](#) in Diabetes Care found that blood glucose levels were negatively affected when people with type 2 diabetes slept for too short or too long a time.

"I always ask people, especially if they're having high morning blood sugars, how much sleep are you getting and is your bedroom environment conducive to sleep?" said Brown. He's corresponded with many people seeking tips on managing diabetes. In his opinion, many don't realize the importance of sleep.

"Addressing sleep can have really big impacts on the next day, in terms of less insulin resistance, more insulin sensitivity, less sugar and carb cravings, more desire to exercise, and better mood," he added. "The amount of impact you can derive from helping someone get more sleep, I think, is very underrated."

[Metabolic surgery](#)

Despite concern about complications from type 2 diabetes, less than a quarter of survey respondents are willing to consider metabolic surgery as a treatment option. Half said it's too dangerous.

Such attitudes persist despite the documented benefits of metabolic surgery, also called bariatric or weight-loss surgery. The potential benefits can extend beyond weight loss.

For example, about [60 percent](#) of people with type 2 diabetes who undergo one type of metabolic surgery achieve remission, reported a 2014 study in *The Lancet Diabetes & Endocrinology*. “Remission” generally means that fasting blood sugar levels drop to normal or prediabetes levels without medication.

In a [joint statement](#) published in 2016, a group of international diabetes organizations advised doctors to consider metabolic surgery as a treatment option for people with type 2 diabetes who have a BMI of 30.0 or higher and have trouble controlling their blood sugar levels. Since then, the American Diabetes Association adopted the recommendation into its [standards of care](#).

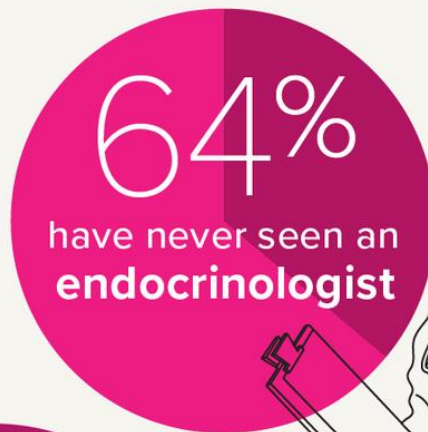
Dr. Hafida, at the Joslin Diabetes Center, isn’t surprised by resistance to the surgery. “It is underutilized and highly stigmatized,” she said. But in her opinion, “it is the most effective treatment we have.”

Access to care

Specialists in type 2 diabetes care can make a major difference to people living with the condition — but many aren’t accessing their services.

Among Healthline’s survey participants, 64 percent said they had never seen an endocrinologist. More than half said they’ve never seen a dietitian or nutritionist, who could help them adjust their diet. And only 1 in 10 reported seeing a therapist or counselor more than three times a year — even though a quarter of participants said they’d been diagnosed with depression or anxiety.

of people living with **TYPE 2 DIABETES**



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Type 2 diabetes is a disease related to the endocrine system, or the body's hormones and glands. According to Dr. Saleh Aldasouqi, chief endocrinologist at Michigan State University, a primary care doctor can manage the treatment of "uncomplicated" cases, as long as they're well educated about the condition. But if someone with type 2 diabetes is having difficulty with blood sugar levels, if they have symptoms of complications, or if conventional treatments aren't working, seeing an [endocrinologist](#) is recommended.

In some cases, a person's doctor might refer them to a [certified diabetes educator](#), or CDE. This type of professional has specific training in educating and supporting people with diabetes. Primary care doctors, nurses, dietitians, and other healthcare providers can all train to become CDEs.

Since so many different types of providers can be CDEs, it's possible to see one without realizing it. But as far as they know, 63 percent of survey participants said they've never consulted one.

So, why aren't more people with type 2 diabetes getting specialized attention?

In some cases, insurance won't pay for specialist visits. Or specialists won't accept certain insurance plans.

Brady has seen this problem up close, working as a CDE in Reno, NV. "Every day you hear, 'the people in the private sector are not accepting my insurance,'" she said, "and depending on your insurance, they will tell you, 'we're not taking any new patients.'"

A widespread shortage of endocrinologists also poses barriers, especially in rural areas.

The nation has 1,500 fewer adult endocrinologists than it needs, according to one 2014 [study](#). Among those working in 2012, [95 percent](#) were located in urban areas. The best coverage was in Connecticut, New Jersey, and Rhode Island. The worst was in Wyoming.

Given such disparities, it makes sense that our survey found regional differences. People in the Northeast were the most likely to report seeing an endocrinologist multiple times a year. Those in the West and Midwest were the least likely to say they've ever seen one.

Without a concerted effort to address shortages of endocrinologists, the problem is expected to grow.

It might hit younger adults particularly hard.

As one [commentary](#) in The Lancet Diabetes & Endocrinology noted, the younger a person is when diagnosed with type 2 diabetes, the greater the impact on their life expectancy. In part, that's because younger age of onset can lead to earlier complications.

While many young people with type 2 diabetes might benefit from specialist care, our survey found that 1 in 3 millennials who has been advised to see an endocrinologist is having difficulty finding one.

of millennials with **TYPE 2 DIABETES**



needs to see an
endocrinologist
BUT
has difficulty
finding one

healthline

Cost of care

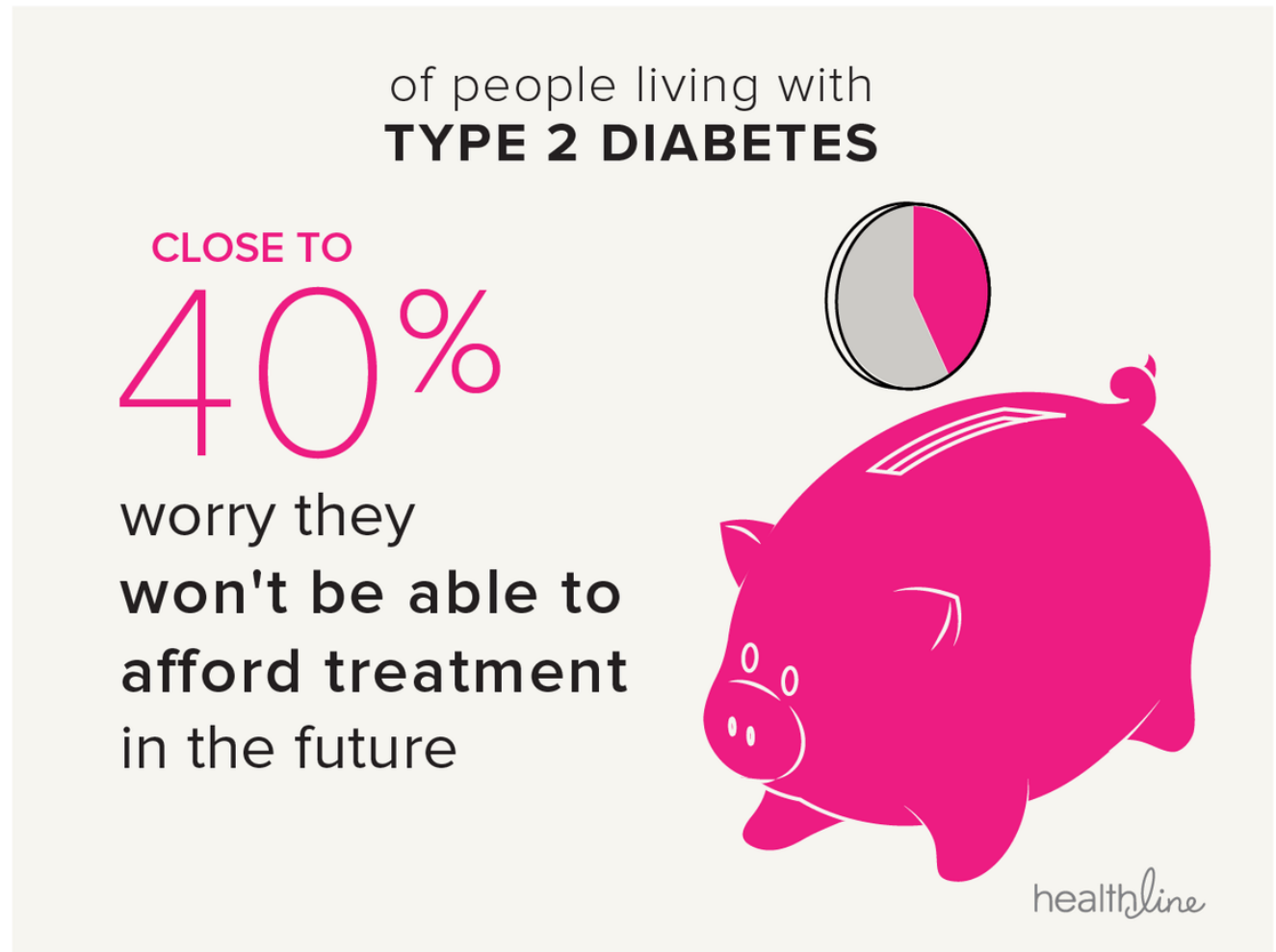
The financial costs of type 2 diabetes are a matter of serious concern, the survey found. Close to 40 percent of respondents worry about their ability to afford care in the future. Perhaps even more troubling, nearly 1 in 5 said cost has at times kept them from following their doctors' treatment instructions.

According to a report by the American Diabetes Association, the countrywide cost of type 1 and type 2 diabetes — [\\$327 billion in 2017](#) — has increased by 26 percent over five years. The latest tally amounted to \$9,601 per individual with diabetes. Many people can ill afford the stiff share of the tab they have to cover.

Among survey participants, almost 30 percent said they have insurance coverage that leaves them with big bills. Nutritious food, gym memberships, and exercise gear cost money. Of course, so do healthcare visits and treatments — including medications.

“The costs of antihyperglycemic medications, especially insulin, have become a barrier to diabetes treatment,” reported a 2017 [study](#) in Current Diabetes Reports.

Like many people, Kinnaird has felt the sting of medication costs. Self-employed, she had to buy new insurance after her previous insurer pulled out of the Affordable Care Act exchanges. The switch hasn’t been good for her wallet: a three-month supply of medication that used to cost \$80 now costs \$2,450.



Sometimes, people with diabetes take less medication than prescribed to make it last.

This issue garnered [attention](#) after a young man with type 1 diabetes died last year. When Alec Raeshawn Smith aged out of his parents’ insurance coverage, the price of his insulin got too high. He began rationing doses to make it last. Within a month, he was dead.

Campaniello has done a little rationing of her own. Years ago, she remembers paying \$250 every three months for a new type of long-acting insulin. The drug brought her A1C levels down dramatically. But when her doctor reviewed her test results, she suspected that Campaniello had been “playing” with her insulin.

“I said, ‘Well, if you’re telling me that I kind of save it sometimes towards the end of the month, because I can’t afford it,’” Campaniello recalled, “‘you’re right!’”

Predictably, the Healthline survey found that lower-income people were more likely to report concerns about cost of care and insurance coverage. The same was true for those in the diabetes belt.

Research in the wider population has also found ethnic and racial disparities: among people under the age of 65, 17 percent of Hispanic-Americans and 12 percent of African-Americans were uninsured in 2016, compared with 8 percent of white Americans, [reported](#) the Kaiser Family Foundation.

When a person can’t afford to pay more than a few dollars per month, it can limit their treatment options, said Jane Renfro, a nurse practitioner who volunteers at a health clinic in Falls Church, VA, for underserved and uninsured populations.

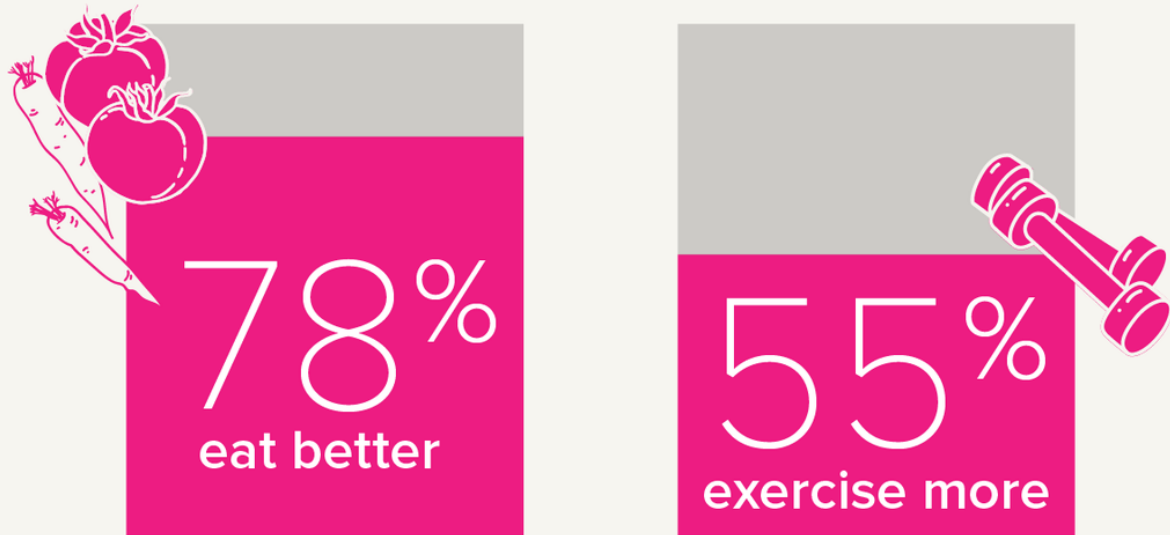
“We have to make sure that the medications we select are those that are generic and offered for very low prices — for example, \$4 for a month supply, \$10 for a three-month supply,” she explained. “That limits the scope of therapies that we can offer.”

The wake-up call

No one chooses to have type 2 diabetes — but the decisions that people make can potentially affect how the disease progresses. For many of those that Healthline interviewed, the diagnosis felt like a wake-up call that pushed them to kick off healthier habits. Despite the challenges they’ve faced, many reported making serious strides to improve their health.

Healthline’s survey found that 78 percent reported eating better as a result of their diagnosis. More than half said they exercise more and are either losing weight or managing their weight better. And while many find the path rough going, only about a quarter think there’s a lot more they should be doing to manage their health.

of people living with **TYPE 2 DIABETES**



as a result of their diagnosis

healthline

Gretchen Becker, the wordsmith behind the blog [Wildly Fluctuating](#) and author of "[The First Year: Type 2 Diabetes](#)," shared some thoughts with Healthline about how the diagnosis led her to stick with changes she wanted to make:

"Like most Americans, I had been trying unsuccessfully to lose weight for years, but something always sabotaged my efforts: maybe a big party with tempting treats or just a dinner out with too much food. After diagnosis, I took things more seriously. If someone said, 'oh, one little bite won't hurt you,' I could say, 'yes it will.' So I stuck with a diet and lost about 30 pounds."

"If I hadn't gotten diabetes," she continued, "I would have kept gaining weight, and I would now be uncomfortable. With diabetes, I've not only reached a normal BMI, but my diet is actually more enjoyable than what I was eating before."

Dessify also credits the diagnosis for pushing her to make a shift in her life.

While pregnant with her son, she was diagnosed with [gestational diabetes](#). Six weeks after his birth, Dessify's blood sugar levels remained high.

When she got the diagnosis of type 2 diabetes, Dessify felt guilty about how the condition might shorten her life and her time with her son. “I couldn’t even promise to be here for as long as I possibly could be with him,” she told Healthline.

A few months later, she started seeing a new doctor and asked him to be honest with her. He told her that the choices she made going forward would determine how severe her condition was.

Dessify changed her diet, pushed herself to exercise, and dropped significant weight.

As a parent, she said, her primary goal was to be the best role model she could be for her son. “I was at least blessed with a situation that really kicked me into gear in wanting to be that role model.”



To help stay on track, Dessify uses a smart watch. According to Healthline’s survey, this kind of exercise- and diet-tracking device is more popular among millennials like Dessify than older generations. Millennials are also more likely to value the internet as a source of diabetes-related information or social support.

“The folks that use the apps consistently, I have to tell you, have better A1C readings,” said Brady, describing some of the benefits of new technologies.

But any method that helps people stay on track is good, said Dr. Hafida. Whether it relies on digital devices or pen and paper, the most important thing is that people stick with it and make their health a long-term priority.

Kinnaired, like many of her fellow baby boomers in the survey, has found the drive to make significant changes to her life.

“I didn’t have any motivation to make those changes until I got the diagnosis,” she explained. “I had a very stressful job, I was traveling all the time, I was eating out three meals a day, five days a week.”

“But as soon as I got the diagnosis,” she said, “that was the wake-up call.”

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