More Than a Number

Diabetes distress: Identifying and addressing the burden behind the numbers

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Navigating the Emotional Landscape of Diabetes

01. OVERVIEW

Name It

- Types of diabetes
- Statistics of diabetes management
- Myth busting
- Defining diabetes distress and emotional impact

02. ASSESSMENT

Measure It

- Prevalence and key risk factors
- Validated screening tools for practice
- Interpretation

03. LIVED EXPERIENCE

Understand Context

- Living in a medicalized body
- Examining the 42 factors affecting blood glucose

04. ACTIONABLE STEPS

Respond to It

- Safety-first clinical strategies
- Use of empathetic language in practice

Common Misconceptions

MYTH

"There are only 2 types of diabetes."

A widespread belief that diabetes is strictly binary—categorized only as Type 1 (autoimmune) or Type 2 (lifestyle/resistance).

This oversimplification can lead to misdiagnosis, inappropriate treatment plans, and unaddressed patient distress.

FACT

7–8 Types

Are clinically recognized today.

Clinical Takeaway: Accurate classification is critical. Recognizing the distinct clinical profiles ensures targeted therapies, better management outcomes, and reduced patient burden.

Types of Diabetes

Autoimmune — insulin deficiency

Type 1: T-cell destruction of beta cells. Antibody positive. DKA risk lifelong. Staged 1–3; **Most new cases are diagnosed in adults** — 59% in a 14-year US cohort; 65% in China.

LADA: Same process, slower. Adults hold C-peptide for months/years. Routinely misdiagnosed as type 2.

Insulin resistance + progressive beta-cell failure

Type 2: Resistance in muscle, liver, fat + declining secretion. Regimens intensify because disease progresses, not patient failure.

β-cell function already impaired at diagnosis~50% reduced secretory function — UKPDS, 713 newly presenting patients *(UKPDS V, 1988)* **~34%** below normal — pooled analysis, 15 trials *(Blüher 2023)* **40–80%** functional deficit — broader evidence incl. histology *(Davies 2026; Eizirik 2020)* **−7.2%/year** for the first ~4 years, then −0.8%/year *(Blüher 2023)*

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Genetic — single gene

MODY: Autosomal dominant. GCK needs no treatment; HNF1A/4A are sulfonylurea-sensitive. Antibody negative, C-peptide positive.

Neonatal (<6 mo): KATP channel mutations. Many transition off insulin onto sulfonylureas

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Pancreas damaged or absent

Type 3c: Pancreatitis, cancer, pancreatectomy. Insulin + glucagon deficient — brittle, high hypoglycemia risk.

CFRD: Islet fibrosis. Insulin only; caloric restriction is contraindicated.

Hormonally or pharmacologically driven

Gestational: Placental hormones drive resistance; high lifetime type 2 risk. 5–10% autoimmune unmasked.

Drug-induced: Steroids, antipsychotics, calcineurin inhibitors, checkpoint inhibitors.

Endocrinopathies: Cushing's, acromegaly, pheochromocytoma. Often reversible.

Malnutrition-related

Type 5: Undernutrition in childhood impairs pancreatic development. Lean, BMI <19, severely insulin deficient, ketosis-resistant. IDF recognized in April 2025; 20–25M affected.

Clinical Takeaway: Accurate diagnosis matters—if the clinical presentation does not fit typical Type 2 diabetes, check C-peptide/insulin levels and test for autoantibodies.

Common Misconceptions in Clinical Practice

Understanding Progressive Disease Dynamics and Remission Realities

MYTH

"Type 2 diabetes is curable if patients just eat better and exercise."

A common oversimplification assuming lifestyle changes alone can permanently reverse or eliminate diabetes.

This belief fosters unrealistic expectations, promotes patient self-blame when disease progresses, and overlooks underlying physiology.

FACT

Chronic & Progressive

Full remission in the absence of ongoing treatment is exceedingly rare.

Clinical Takeaway: Framing diabetes as an easily curable condition creates unfair psychological strain. Recognizing its chronic, progressive nature helps ground patient expectations and care strategies. (Stats on next slide)

Sustained, Lifelong Remission in Type 2 Diabetes

Long-term Outcomes: Medical / Lifestyle vs. Bariatric Surgery

Medical / Lifestyle Management

6.2% In Remission at 7 Years

0.0% In Remission at 12 Years

DPP/Look AHEAD-style individualized counselling, exercise instruction, and self-monitoring (mean baseline duration ~8.8 yrs).

Medical arm was not left to struggle alone: 25% crossed over to bariatric surgery & 37% used incretin-based agents, yet remission reached zero at 12 yrs.

Bariatric Surgery Interventions

18.2% In Remission at 7 Years

12.7% In Remission at 12 Years

The most durable option available — yet the vast majority of patients still experience relapse over time.

Even with surgical intervention, long-term medication-free glycemic durability remains a profound physiological challenge.

Clinical Takeaway: Medication-free remission is rarely sustained long-term. Progressive disease requires continuous management, not an expectation of permanent cure. Type 2 is not an easier diabetes.

Common Misconceptions in Clinical Practice

MYTH

"Most people can achieve an A1c at goal if they just follow treatment and lifestyle."

A widespread assumption that glycemic targets are purely a matter of personal adherence, discipline, and effort.

This framing creates individual blame, increases diabetes distress, and ignores the progressive biological realities of the condition.

FACT

Most People

Are not at target, including those doing everything right.

Suboptimal glycemic control remains widely prevalent across global cohorts, regardless of high access to specialty care or strict protocol adherence.

Clinical Takeaway: Glycemic struggle is largely physiological and systemic, not a personal failure. Recognizing this reality is critical to reducing patient stigma and optimizing clinical care.

Glycemic Control Statistics

Type 1 Diabetes (A1c < 7%)

~28% US Adults
(Fang et al., JAMA Netw Open 2025)

19% → 38.8% Children (2013 to 2022)
>100,000 registry cohort (Zimmermann et al., Lancet Diab Endocrinol 2025)

*data gathered from people who are accessing speciality care

People with an A1C above 7% are **STATISTICALLY THE MAJORITY**

Type 2 Diabetes (A1c < 7%)

44% Global meta-analysis (1.6M patients)
Only 12% meet combined A1c + BP + LDL target (Kacha et al., 2025)

71% Failed to maintain <7% over 5 yrs
GRADE trial: metformin + one agent (NEJM 2022)

Clinical Insight: Suboptimal glycemic control remains widely prevalent across populations globally, emphasizing that struggle is systemic, not an individual failure.

The Unseen Burden of Self-Management

MYTH

"Diabetes management is easy—it's just a few shots or pills a day."

FACT

8,760 Hours / Year

~24 hours per day, every day, with no days off. This is the cognitive and emotional load of diabetes management.

Breakdown of stats on next slide

The Three Dimensions of the Diabetes Burden

01 · The Tasks

~130 Hours / Year

~2 hours a day — the discrete physical actions of management: injections, blood glucose checks, and pharmacy calls.

Like feeding, changing, or bathing a newborn — specific, countable actions measured in time.

02 · The Instructions

~730–1,460 Hours / Year

Full Guideline Adherence — what optimal self-management actually requires in daily discipline, planning, and execution.

Like doing everything the parenting books recommend — the ideal regimen standard.

03 · The Condition

8,760 Hours / Year

Every Single Hour — constant cognitive background load. No evenings off, no vacations, and never truly off duty.

Like being a parent — occupying 100% of your life and head space, even in the shower.

Clinical Takeaway: Patients are graded on the second number, living inside the third, while clinicians often only ever see the first. When we ask "are you checking your sugars?", we ask about discrete tasks while they are managing a full-time condition.

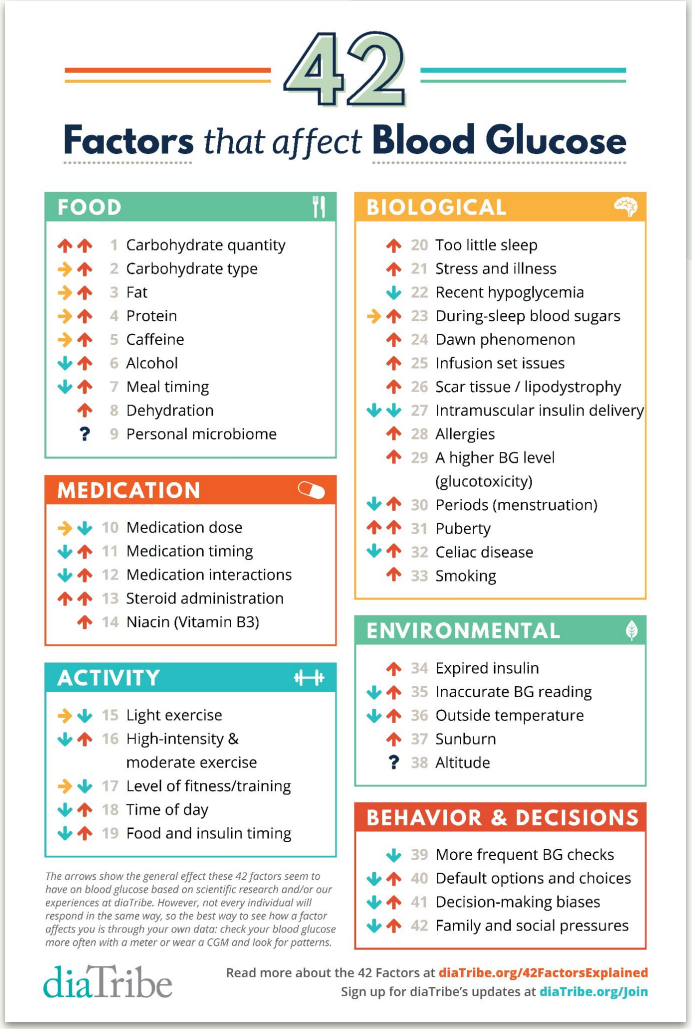
3 vs 42

The Oversimplified Promise

Standard education promises target blood glucose if patients simply eat right, exercise, and take medication.

When a person is taught three variables and then judged on an outcome driven by forty-two, every out-of-range number becomes evidence of personal failure rather than evidence of a complex system. This leads to self-blame, shame, and eventual disengagement..

Without awareness of the full set of variables, people lose both the explanation and the levers — they cannot make sense of a number they did nothing to cause, and they cannot act on the sleep, timing, stress, site rotation, or dosing-interval factors that genuinely move time in range. The result is a person working hard inside a small set of options, which produces helplessness rather than skill.



Understanding Diabetes & Appetite Control

MYTH

"People get diabetes because they have no will power and can’t control themselves"

FACT

Neuroendocrine Pathology

Disrupted appetite regulation in diabetes is a neuroendocrine driven pathology, not a personal character flaw or lack of willpower.

Multiple complex physiological drivers—including central insulin resistance, altered brain sensing, and gut-hormone dysregulation—actively alter hunger, satiety, and food reward signals.

Physiologic Disruption of Hunger & Satiety in Diabetes

1 · Central Insulin Resistance

Chronic overnutrition and mediobasal hypothalamic inflammation blunt insulin action on arcuate POMC and AgRP neurons. Signal arrives but is not heard. (Roden & Shulman 2019; Gallardo 2025)

2 · Leptin Resistance

Dominant long-term adiposity signal acting on arcuate circuits. High circulating leptin fails to produce satiety despite ample fat stores. (Roden & Shulman 2019; Yaribeygi 2019)

3 · Amylin Deficiency

Co-secreted with insulin to signal meal termination. T1D causes complete loss; T2D brings progressive loss. Acts as leptin sensitizer. (Walker 2025; Lutz 2012)

4 · Blunted Ghrelin Suppression

Insulin normally suppresses ghrelin, the preprandial hunger signal. In type 2 diabetes that suppression is significantly less pronounced — a brake that slips. (Anderwald 2003)

5 · Disrupted Reward Valuation

Central insulin inhibits ventral tegmental → nucleus accumbens signalling to reduce palatability. In insulin resistance, this modulation is aberrant. (Tiedemann 2017)

6 · Hypothalamic Lipid Sensing

Ceramide accumulation and altered fatty-acid handling disrupt AMPK-dependent regulation of AgRP/NPY, further destabilizing intake. (Le Stunff 2026)

Secondary Distress & Psychological Impact

Being unable to control biologically driven hunger generates profound distress — and that distress in turn shapes eating. Hunger, cravings, and preoccupation are biologically generated, not merely psychological.

Clinical Takeaway: Six independent satiety mechanisms are impaired by the disease itself. When a person with diabetes says they are hungry all the time, they are describing their physiology accurately. Disrupted appetite regulation is neuroendocrine pathology, not a failure of willpower.

The bigger picture

The Unspoken Burden

A person with diabetes carries this every hour of every day—overriding neuroendocrine appetite signaling that doesn't respond to intention.

Controlling an outcome with 42 known inputs, having been taught two.

Measured against a target more than half of adults with diabetes don't meet—and nobody tells them that.

The Misinterpreted Signal

An A1c comes back at 8.2. The patient reads it as a verdict of themselves. Often the language around it confirms that reading. Uncontrolled. Poorly controlled. Failed. The number gets attached to the person instead of the disease.

This is where **diabetes distress** grows. It is also the most common explanation when a patient looks unmotivated, avoidant, or noncompliant. The emotional burden has outpaced the support available to carry it.

Diabetes Distress is Common

>50%

CDC Report (2021)

Over 50% of US adults with diabetes experienced distress, with **7% reporting severe** and **24% moderate** levels.

36%

Adults with Type 2

Meta-analyses reveal distress affects over a third of Type 2 adults.

39%

Adults & Youth with Type 1

Prevalence remains high across both adults and youth living with Type 1.

38% – 48%

18-Month Cumulative Incidence

Nearly half of all patients experience significant distress within 1.5 years.

Diabetes Distress

The emotional burden arising from living with and managing diabetes.

The Four Domains of Diabetes Distress (DDS):

1. Emotional Burden

Reflects general overwhelming feelings, fear, and exhaustion stemming from the relentless, 24/7 self-management requirements of living with diabetes.

2. Regimen Distress

Distress related to the complexity, constant vigilance, and difficulty of adhering to daily treatment tasks, medications, blood glucose tracking, and dietary demands.

3. Clinician-Related Distress

Arises from negative interactions with healthcare providers, feeling unsupported, judged, or receiving inadequate guidance and empathy regarding care management.

4. Interpersonal Distress

Strains caused by lack of understanding, unhelpful nagging, isolation, or friction with friends, family, and coworkers who do not comprehend the burden of diabetes.

Who Is at Risk, and When

Person Factors

- Ages 18–64
- Women
- Lower income
- Anxiety history
- Depressive symptoms
- **Insomnia**
- Family conflict (youth)

Disease & Treatment

- Complications
- Higher HbA1c
- Insulin / injections
- Intensive regimens
- Duration >15 yrs
- Severe hypos

Care & Context

- Visit gap >6 mos (5.3 ×)
- Care costs & food insecurity
- Stigma & weight bias
- Low social support
- Provider judgment / rush

High-Risk Moments

- Diagnosis / treatment changes
- Starting insulin / severe hypos
- Unmet targets & complications
- Life transitions (job, aging)
- Any gap in care

Prior Distress Predicts Future Distress

88% of adults with elevated distress remain elevated 6 months later. It does not resolve on its own.

Screen Everyone Annually

Predictors explain only a fraction of cases.

ADA recommends universal annual screening rather than screening by risk profile. A1C at goal doesn't mean absence of distress.

Validated Tools Enable Rapid and Accurate Assessment of Distress Levels

Rapid Screeners

DDS-2 & DDS-17

The DDS-2 provides a 2-item rapid screen, triggering the full DDS-17 assessment if elevated scores are detected.

Clinical Thresholds

PAID-5 Tool

The PAID-5 tool indicates significant diabetes distress at a score of 8 or higher, signaling immediate clinical attention.

Targeted Populations

Tailored Assessment Tools

T1-DDS & T2-DDAS: Address specific type-related burdens.

PAID-T: Evaluates youth ages 12–18.

Holistic Care

Complete Psychological Profile

These tools should be used alongside the PHQ-9, GAD-7, and Hypoglycemia Fear Survey-II to capture a full psychological picture.

Clinical Guidelines & Toolkit Resources

ADA Standards of Care (2026)

Section 5: Facilitating Positive Health Behaviors and Well-being to Improve Health Outcomes.

- Psychosocial care integration
- DSMES and MNT guidelines

https://diabetesjournals.org/care/article/49/Supplement_1/S89/163932/5-Facilitating-Positive-Health-Behaviors-and-Well?searchresult=1

Mental Health Questionnaires

Validated assessment tools and screening scales for clinical practice.

- Problem Areas in Diabetes (PAID)
- Diabetes Distress Scale (DDS-17)
- PHQ-9 & GAD-7 screeners

https://professional.diabetes.org/sites/default/files/media/ada_mental_health_toolkit_questionnaires.pdf

7 As Practice Model

A step-by-step clinical pathway for addressing mental health in diabetes care.

- Aware, Ask, Advise, Assess, Assist, Agree, Arrange
- Actionable care implementation

https://professional.diabetes.org/sites/default/files/media/ada_mental_health_toolkit_7as_r2.pdf

https://behavioraldiabetes.org/scale-and-measures/diabetes-distress/

American Diabetes Association resources and clinical toolkits above.

Interpreting the Score and Acting On It: Reading the Result

PAID (out of 100)

- **Total ≥40:** Severe diabetes distress
- **Any single item ≥3:** A problem area worth exploring

DDS-17 (mean, 1–6)

- **2.0–2.9:** Moderate distress
- **>3.0:** High/severe distress
- **Any single item ≥3:** A problem area, regardless of total
- **Scores ≥2.0:** Threshold where self-management & A1c impacts begin

T1/T2-DDAS Core (1–5)

- **≥2.0:** Clinically significant
- **MCID for change:** ±0.27

The Rule That Matters Most

Review every item, not just the total. A normal total with one item scored 3 or higher still identifies something to talk about.

What to Do Next: A Practical Action Framework

01
Name it, out loud
Explain what diabetes distress is. Say plainly that living with diabetes is hard, and that feeling frustrated, anxious, overwhelmed, or angry is a normal response, not a personal failure.

02
Find the source
The total score says how much; subscales say what. Don't just record the score—ask which flagged areas they most want to talk about today, and let them pick.

03
Match response to source
- **Regimen:** Simplify plan, review reality
- **Hypo:** Safety protocol, dextrose, tech
- **Physician:** address directly if it's you
- **Stigma:** Mindful language, remove blame
- **Access/Cost:** Formulary, programs
- **Interpersonal:** Delegate support

04
Build the plan together
Start with what burdens them most, not what worries you most. Prioritize their list to ensure meaningful alignment and active commitment.

05
Rescreen with same tool
Agree together on an appropriate interval. Use the Minimal Clinically Important Difference (MCID) so both provider and patient know what improvement looks like.

06
Refer only if unequipped
People prefer their primary diabetes clinician handle distress directly. If a specialized referral is necessary, remain in continuous active communication.

If distress isn't elevated but something is still off
Consider screening for depression (PHQ-9), anxiety (GAD-7), fear of hypoglycemia (HFS-II), or disordered eating. A negative distress screen does not close the clinical question.

Source-Directed Problem Solving

Regimen burden

Fewer steps.

Automate what can be automated. Ask which single task they'd drop if they could.

Food is a tool that can be leveraged and relaxed.

Hypoglycemia

Safety protocol first.

Dextrose products within reach everywhere. Glucagon & trained support. Review tech. The next 24 hours after a low is higher risk for additional lows.

Targets that feel impossible

Widen the range.

More time in range means success. Set the next target, not the final one.

Dosing and timing

Fit their day, not vice versa.

Move schedules around their lifestyle. Address stacking and rebound lows directly.

Long-term health worry

Accurate personal risk.

Focus on realistic outcomes rather than worst-case scenarios. Name what you are actively protecting. Life happens in the moment, not next decade, ground to the present.

Shame and stigma

Change your language.

Remove blame from the clinical visit. This costs nothing and can start immediately today. It helps expand their language as well.

The care team

Yours to fix in this visit.

Provide clearer direction, allow more time, and ensure better continuity of care.

Cost and access

Formulary review & assistance.

Identify programs and cheaper equivalents. Name barriers out loud so it stops being a private failure. Oral agents can be found on Mark Cuban Cost plus

Interpersonal

Delegate support.

Who else could carry part of this burden. Bring a support person into the management plan. Feeling judged by others, give them boundary language, “I do not consent to discussing my food, my diabetes, or my body” “I have a licensed professional who advises me, that is not you”

01

Start with their priority

Start with what burdens them most, not what worries you most. Ask which flagged area they want to work on today, and follow their answer.

02

Change one thing

A plan they can actually execute beats a comprehensive one they abandon. Small, highly achievable steps build momentum.

03

Then rescreen

Same tool, agreed interval. A 0.27 change on the DDAS Core is real improvement — tell them so when it happens.

How you talk to someone about their life and their disease is some of the most powerful medicine you have access to.

They will never forget whether you made them feel like a failure or like someone who is doing hard things well.

Health Re-defined

Health is not a data set, a summit to reach, or a singular state.

Health is the state of being we are currently in.

You can be in a state of health while living with cancer. Or with diabetes. Health is not the absence of disease.

Beyond Metrics

There is no single data point that measures worth, commitment, sacrifice, or possibility.

Only the human spirit determines that.

The data we gather is only for use to make informed decisions about our care.

The data confirms we still live in a body that does not automate glucose control.

Present Life & Joy

There is no secret code to a life well lived.

Nothing has to change for joy, peace, hope, or love to exist here. Not the number. Not the body. Not the a1c. Not the presence or absence of anything. We can allow the full breadth of a lived experience to exist here.

I can be anxious and joyful. I can be fearful and hopeful. I can let more of life in even if it feels hard. I'm not doing life wrong, I'm just living inside hard circumstances.

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Additional Links

Behavioral Diabetes Institute, more screening tools available there.

https://behavioraldiabetes.org/scales-and-measures/#

Free PDF book bright spots and landmines for people living with diabetes

https://diatribe.org/bright-spots-and-landmines/

2 amazing Endocrinologists who also live with type 1 and are a great resource for all types of diabetes

https://tcoyd.org/