

**RECOVERY**

# TOOLKIT



**WE ARE  
DIABETES**

[WEAREDIABETES.ORG](http://WEAREDIABETES.ORG)

The material in this Toolkit is for informational purposes only and is not intended to constitute or be a substitute for medical advice from a qualified medical or mental health professional. The individuals associated with **We Are Diabetes** are not medical or mental health professionals. Always consult your physician or other qualified healthcare or mental health provider for advice, diagnosis, and treatment of any health-related matter relating to diabetes and/or eating disorders.

The **We Are Diabetes** Recovery Toolkit is made possible with funding from Diabetes Hands Foundation through a Big Blue Test Grant.

© 2017, **We Are Diabetes**. All rights reserved. No reproduction permitted without written permission.

## TAKING YOUR INSULIN AND THE

# WORRY

## OF WEIGHT GAIN

When your blood glucose runs high, you become dehydrated as your body works to clear itself of that excess glucose (i.e. you pee all the time). You think you've lost weight, but you've only lost water.

This fluid related "weight loss" isn't real and it doesn't last. You may have noticed that as soon as you start taking your insulin again the weight returns rapidly, but this is not what is happening. Fat cannot be lost or gained that quickly. The weight you're gaining and losing and gaining and losing is mostly water and electrolytes. Tricking the body through extreme dehydration and ketones

cannot be maintained for very long without severe, sometimes deadly consequences.

When you start taking insulin again your body will start over-retaining fluid initially to make up for

*CONTINUED ON PAGE 2*



dehydration, which makes you think you're rapidly gaining weight.

You may associate this weight gain with taking your insulin, but that's not what is really happening. During the initial phase of insulin reintroduction, taking your insulin is enabling your body to properly absorb nutrients and maintain a healthy fluid balance. This allows your body to heal and rebuild itself.

Ironically, the longer you engage in insulin omission, the more you're compromising your body's natural ability to regulate your weight. Prolonged high blood sugars can actually damage your thyroid and metabolism, thus making it even HARDER to maintain a healthy weight.

**YOU CAN**

## **ACHIEVE**

**A HEALTHY WEIGHT AND HAVE A BETTER RELATIONSHIP WITH FOOD.**

**It will require more effort and patience than you may be used to, but the end results are REAL and can be maintained over the long term WITHOUT resorting to damaging your body.**

“The first challenge many patients face is the significant amount of water retention associated with appropriate insulin levels and improved blood sugar. This is sometimes referred to as “insulin edema.” It is more likely to be a problem if patients have been regularly restricting insulin and are dehydrated at the start of treatment. Patients should be educated about edema and warned that they may feel fat, bloated, and uncomfortable with this fluid-related weight gain. For example, clothes, shoes, and rings may not fit. The fluid most often settles in the lower limbs and feet, but it can also be seen in the abdomen, arms, and even the face. Experiencing edema just at the start of treatment can be especially frightening and can trigger relapse. Patients benefit from frequent reassurance from all team members that this fluid retention is not reflective of weight gain due to increased fat and is temporary. Unfortunately, how long it takes to pass varies between individuals and cannot be predicted. They should be encouraged to drink plenty of liquid and avoid caffeine if possible.”

**Dr. Ann Goebel-Fabbri**

Prevention and Recovery from Eating Disorders in Type 1 Diabetes: Injecting Hope (2017), Routledge Press

## IT'S VERY IMPORTANT TO UNDERSTAND

This initial phase of recovery is hard, and there is no way to avoid it. You need to accept that you're going to be uncomfortable for a while. You're going to be challenged physically and emotionally, and may be tempted to give up and resort to skipping your insulin again. If you can breathe through these frantic moments when your eating disorder tries to regain control and choose NOT to react negatively to these urges, you will find that it becomes easier over time. We Are Diabetes offers two useful resources for these challenging times in recovery. Our [Relapse Prevention Strategies](#) and [Recovery Projects](#) can both be helpful when you feel like giving up!



### **“WHAT IF I’VE DEALT WITH THE INITIAL BLOAT THAT COMES WITH INSULIN REINTRODUCTION AND I’M STILL GAINING WEIGHT?”**

After the initial fluid retention, some of the causes of weight gain for individuals who are in their first year or two of recovery include a continued struggle with binge eating and insulin resistance. These issues can be addressed and resolved with patience, self-exploration and determination.

# BINGEING

If you've committed to taking your insulin no matter what, but you're struggling with emotional eating or binge eating symptoms, you will gain weight. If you've been struggling with this for a long time your body is probably used to consuming a high volume of food, especially in the evening/late night hours. That eating routine is going to take some time to change.

It's important to seek the support of a therapist with experience in eating disorders to work on managing these symptoms. Ending binge eating is not about willpower. It's about identifying the root causes of why you're bingeing and/or restricting food, and developing skills and behaviors to manage things differently.

## SOME TIPS THAT CAN HELP TO COMBAT THE URGE TO BINGE

- Drink more water! How about a cup of delicious herbal tea?
- Try to eat a balance of carbohydrate, fat and protein. Fat and protein help you feel satisfied and full for a longer period of time.
- Keep healthy snacks available in between meals. These don't just have to be carrot sticks. They can be any type of snack that is easy to incorporate into your meal plan that you actually enjoy, and that you don't feel tempted to binge on.
- Remove foods that trigger you to binge. Don't buy these foods right now, there's no reason to tempt yourself. If you live with other people who eat snacks or foods that you know you'll want to binge on, then have a gentle conversation with them to see if they would be willing to keep their snacks in their own personal space (their bedroom, for example). This way they're not an option for you to reach for when you feel the urge to binge.
- Quit dieting! Starving yourself and limiting foods that you enjoy leads to bingeing. When you're hungry, food cravings are triggered, and often so is the compulsion to overeat. It's important to keep foods you enjoy in your meal plan so you don't feel deprived and triggered to binge.
- Take a nap! If you're reaching for food because you're tired, allow yourself to slow down and rest.
- Remember that you don't need to use food as a "reward", especially if you're going to regret it later and be angry at yourself.

## INSULIN RESISTANCE

Insulin resistance refers to a state where your body is no longer using insulin as effectively as usual. Insulin resistance tends to be associated with weight gain. After exposure to elevated blood sugar levels for long periods, some people find themselves experiencing temporary insulin resistance. With time and improved blood sugar levels, this issue can slowly diminish. However, for those that continue to experience prolonged insulin resistance, there are treatment options! A number of insulin sensitizing drugs are currently available. They are mostly intended for people with type 2 diabetes, but some endocrinologists prescribe them off label for their type one diabetes (T1D) patients. If you want to discuss these options, ask your CDE or endocrinologist at your next appointment. Gary Scheiner discusses medical treatments for insulin resistance, as well as some of the myths associated with insulin and weight management [in our interview with him](#).

## GET YOUR THYROID TESTED

Thyroid hormones affect your metabolism rate. They also affect how fast or slow your brain, heart, muscles, liver, and other parts of your body work. People with T1D are more likely to have thyroid problems, even though T1D doesn't directly cause thyroid disease. According to the American Diabetes Association's 2016 Standards of Medical Care in Diabetes, autoimmune thyroid disease occurs in 17 to 30 percent of people with T1D. Be sure to have a full thyroid panel ordered annually by your endocrinologist to ensure your TSH, Free T3 and Free T4 levels are in a healthy range. If not, there are medications you can take to rebalance those hormones.

## WHAT DO PEOPLE MEAN BY A "HEALTHY BODY WEIGHT?"

Our culture emphasizes an overly thin body size as what makes a person attractive. This culture can also include our town, our school, our friendship circle, and our homes. When so much focus is placed on weight, eating, and appearance, it can be very difficult to figure out how to define healthy weight for your own body. One way to determine this is to find the weight and size you can maintain over time without dieting, bingeing, or skipping insulin. You may find it somewhat easier to maintain this if you try to work at changing your immediate culture (home and friendships) so that dieting, weight, and appearance are no longer discussed - "no body talk" - and the pressure to get to an unnaturally thin size is decreased. When you're at a healthy weight, it becomes easier to notice and to value the energy and strength you feel when your blood sugars are in a healthy range. Even your thinking, memory, attention, and mood improve. Finally, learning what helps you to feel this way and what pulls you off track will teach you how to maintain not only your weight, but your overall health.

**THE MOST IMPORTANT THING TO  
REMEMBER ABOUT YOUR WEIGHT  
AND YOUR RECOVERY IS:**

**YOUR OPTIMAL WEIGHT  
IS WHATEVER WEIGHT  
YOU REACH WHEN  
YOU'RE LIVING  
THE HEALTHIEST LIFE  
THAT YOU CAN  
ACTUALLY ENJOY.**

# TREATING LOW BLOOD SUGARS

If you're experiencing lows more often now that you're consistently taking your insulin, you may find yourself struggling with over-treating those lows, or even bingeing during a low. This is another reason for weight gain with T1D. In the early stages of recovery, you may need ongoing assistance from your diabetes team to adjust insulin doses to match your body's needs as well as possible. This can help you to avoid frequent lows that may trigger overtreatment or binge eating.



## **OVER-TREATING LOW BLOOD SUGARS**

Overeating and emotional eating certainly aren't habits that exist only in people living with diabetes. Over-treating your low blood sugars, however, is a challenging habit that is unique to a life with diabetes.

**Fact:** the human brain relies on a second-by-second delivery of glucose (sugar) in order to function properly, to think, to wonder, to know the difference between red and blue. This fact helps explain why, during a low blood sugar, we can feel as though no amount of food will ever possibly be enough.

Binge-eating during a low blood sugar is common. It's easy to do because your brain keeps telling you: "More. More. More." Worst of all, it will absolutely lead to further guilt and shame because overeating during that low blood sugar inevitably leads to weight gain, and an eventual high blood sugar.

The high blood sugar leads to guilt, and a required correction dose of insulin. And the glucose from that high blood sugar will eventually be stored as body fat, which leads to further weight gained from over-treating that low blood sugar.

## **HABITS THAT LEAD TO OVER-TREATING LOW BLOOD SUGARS**

- Using low blood sugars as an excuse to eat all of the foods you usually think of as “off-limits” or “bad.”
- Being unprepared to treat lows by having specific foods nearby, which leads to impulsively eating any food in sight.
- Telling yourself that it’s okay to overeat, because this is normal during a low blood sugar, and everybody does it.

## **NEW GUIDELINES TO PREVENT OVER-TREATING YOUR LOWS**

- Foods you love (like ice cream, etc.) will be included in your nutrition plan and eaten when your blood sugar is in a safe range so you can enjoy the meal. The foods you love will not be used to treat low blood sugars.
- Whenever possible, you will keep sources of carbohydrates for your low blood sugars nearby. These foods will be things you don’t mind eating, but that you don’t necessarily love. If you have a low right before a meal, you will use these foods to treat your low so you can enjoy your meal without overeating.
- You will work to create a new habit in your way of thinking during a low: “My brain only needs \_\_\_\_\_ grams of carbohydrate in this moment. I need to be patient and give my brain time to catch up with my blood sugar. I will not abuse my body with food during this low.”

**Ginger Vieira**

Emotional Eating and Diabetes  
2012, Living In Progress Publishing

# EXERCISE

“Slowly easing into an exercise routine is crucial, especially when transitioning into recovery from an eating disorder. When you first begin exercising, the most important thing to consider is WHY exercising is important to you. In order for exercise to be effective in helping maintain healthy blood sugars and body weight, the reason WHY must be based on the fact that exercise makes you feel empowered and confident.

You are choosing exercise as a form of self-love that you deserve because you respect your body and mind. You are giving yourself the gift of conscious exercise, NOT because you see exercise as a punishment towards a body you are desperate to change or as a way to burn off unwanted calories. This is a mindset shift that MUST happen for exercise to be truly effective in healing and building a healthy lifestyle. Excessive “all or nothing” attitudes towards exercise are just as destructive, both physically and emotionally, as the eating disorder itself.”

**Daniele Hargenrader**  
Diabetes Coach

Once you start taking insulin again and start getting your blood glucose under control, you now have enough insulin circulating in your blood to help the glucose get into the body’s cells where it can be used as energy! Your physical energy level will perk up, and the calories you burn during exercise (and just daily living) will help you maintain your weight.

Getting started with a regular exercise routine can feel especially daunting for a person who is new to recovery from eating disorder in T1D. The unexpected lows, as mentioned before, can potentially trigger the desire to binge, and some may have the urge to take on too much exercise too fast resulting in injury and frustration.

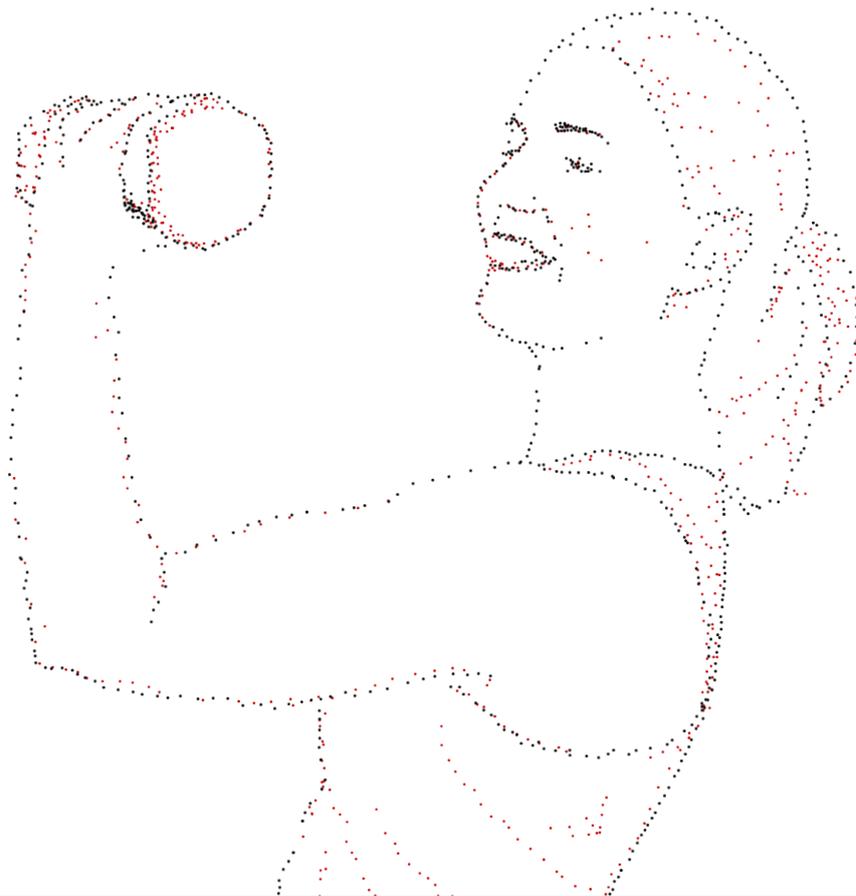
Some individuals may even be tempted to let their blood sugars run higher than normal to avoid the potential of lows during exercise. It may seem logical, but we urge you to seriously consider the negative impact this can cause for you long term.

“In a nutshell: exercising with a blood sugar over 250 mg/dL without a dose of correction insulin to help bring your blood sugar down while you exercise will cause overall stress to your entire body.

In fact, it’s a very dangerous thing to do, and there isn’t one benefit your body will gain from it--high blood sugar levels during exercise will even interfere with any diabetic’s efforts to lose weight.”

**Ginger Vieira**

The other frustrating thing about exercise is figuring out what KIND of exercise you want to do and how to manage your diabetes according to that activity. Luckily, we chatted with our friend Daniele Hargenrader (aka “[The Diabetes Dominator](#)”) about this and [she has tons of advice](#) on this topic.



## GETTING ORGANIZED AND DEALING WITH

# ANXIETY

After omitting insulin for a while, you've been able to avoid the daily grind of taking care of your diabetes. Managing all the responsibility and complexity of T1D can be overwhelming. In fact, it may even feel like being newly diagnosed all over again. We chatted with our friend Susan Weiner MS, RDN, CDE, CDN [about getting \(and staying\) organized with your diabetes](#), and we loved her ideas.

Living with T1D requires you to constantly plan, calculate and assess. It can be emotionally exhausting, and it can trigger a sense of anxiety that can be hard to escape. We DO have to stay one step ahead of our bodies, we DO have to have a healthy sense of worry about low blood sugars (and high blood sugars), but how do we prevent that worry from escalating too much? How do we avoid berating ourselves for every miscalculation or "diabetes roller coaster" day? We chatted with Leann Harris about [dealing with anxiety and finding self-compassion](#) and she has some wonderful advice!

## CREATING YOUR OWN

# RECOVERY

## CARE TEAM

It's not always easy to find health care providers who have experience with the T1D population, and even though it's nice to work with a provider that "gets it," it's ok if a provider doesn't have a lot of previous experience. The most important thing is that the providers you choose to work with are **WILLING** to learn about the complexity of T1D and how it plays a role in your eating disorder.

It's important to find providers who can work with you in a collaborative and nonjudgmental way, who can follow your pace, and who don't push you to make changes too quickly. For example, if your current endocrinologist is not aware that diabetes complications can be related to a rapid drop in A1C, then it might be time to "endo shop" to find one who understands that you

need to move at a more gradual pace, both for your physical and emotional health. Another example is if you find a therapist in your area with a lot of experience in eating disorders but doesn't have direct experience with T1D. Don't despair! If this therapist is open to doing a little extra "homework" and learning more about the complicated relationship that T1Ds have with food, numbers and control, you've found yourself a great addition to your Recovery Care Team.

The best-case scenario is that you find providers that are willing to **COMMUNICATE** with the other members of your Recovery Care Team, even if it means they have to reach outside of their clinic system to do so.

If you have the ability to receive care at a qualified eating disorder treatment center, we highly recommend taking that opportunity. A qualified eating disorder treatment program will ideally have staff that understand the unique set of challenges a person struggling with an eating disorder and T1D faces, and would be aware of the many factors that can affect blood sugar levels. However, eating disorder treatment centers with specialty diabetes care can be difficult to find. For information on treatment centers that are capable of treating type one diabetics with eating disorders visit our [Recovery page!](#)

Many individuals we've worked with have mixed feelings about the idea of seeking inpatient treatment. They may believe that they're not "sick enough" or they worry that they will feel out of place. Please [contact us](#) for support and empathy on these concerns.

Please visit  
[WEAREDIABETES.ORG/RECOVERYTOOLKIT](https://www.wearediabetes.org/recoverytoolkit)  
to access all the video interviews mentioned as  
well as other helpful resources!

## **SUGGESTED LIST OF PROVIDERS FOR YOUR RECOVERY CARE TEAM:**

- Licensed Psychologist and/or Psychiatrist to manage the emotional hurdles of this eating disorder and other possibly co-occurring mental health conditions
- Medical Doctor to help manage potential edema and other general health concerns
- Registered Dietitian (preferably with T1D experience)
- Endocrinologist
- Certified Diabetes Educator (CDE)
- Physical Therapist to help your body regain strength and flexibility, and to potentially help with pain management

# A DEEP AND HEARTFELT THANKS TO OUR CONTRIBUTORS!

## **DR. ANN GOEBEL-FABBRI**

[anngoebel-fabbri.com](http://anngoebel-fabbri.com)

Author of

- *Prevention and Recovery from Eating Disorders in Type 1 Diabetes: Injecting Hope*  
(2017, Routledge Press, also available on Amazon)

## **GINGER VIEIRA**

Author of

- *Emotional Eating and Diabetes*
  - *Dealing with Diabetes Burnout*
  - *Your Diabetes Science Experiment*
- (Ginger's books are available on Amazon)

## **DANIELE HARGENRADER**

[diabetesdominator.com](http://diabetesdominator.com)

Author of

- *Unleash Your Inner Diabetes Dominator*  
(Available on Amazon)

## **GARY SCHEINER**

[integrateddiabetes.com](http://integrateddiabetes.com)

Author of

- *Think Like A Pancreas*
- *Until There Is A Cure*
- *The Ultimate Guide to Accurate Carb Counting*
- *Practical CGM*  
(Available at [integrateddiabetes.com](http://integrateddiabetes.com))

## **SUSAN WEINER**

[susanweinernutrition.com](http://susanweinernutrition.com)

Author of

- *Diabetes: 365 Tips For Living Well*
- *The Complete Diabetes Organizer*  
(Susan's books are available on Amazon)

## **LEANN HARRIS**

[DelphiDiabetesCoaching.com](http://DelphiDiabetesCoaching.com)

- Visit [wearediabetes.org/RecoveryToolkit](http://wearediabetes.org/RecoveryToolkit) for links to Leann's articles.

# WE ARE DIABETES TREATMENT AFFILIATES



Melrose Center

**Park Nicollet Melrose Center**

Website: [parknicollet.com](http://parknicollet.com)

Phone: (952) 993-6200



**Center For Change**

Website: [centerforchange.com](http://centerforchange.com)

Phone: (888) 224-8250



**Eating Recovery Center**

Website: [eatingrecoverycenter.com](http://eatingrecoverycenter.com)

Phone: (877) 711-1690



**Center for Hope of the Sierras**

Website: [centerforhopeofthesierras.com](http://centerforhopeofthesierras.com)

Phone: (755) 828-4949



**The Renfrew Center**

Website: [renfrewcenter.com](http://renfrewcenter.com)

Phone: (800) RENFREW



**Gaudiani Clinic**

Website: [gaudianiclinic.com](http://gaudianiclinic.com)

Phone: (720) 515-2140

**We Are Diabetes** is an organization primarily devoted to promoting support, education and awareness for type 1 diabetics who suffer from eating disorders. We are dedicated to providing guidance, hope and resources to those who may be struggling, as well as to their families and loved ones.

We Are Diabetes also advocates for living well and living strong with type 1 diabetes. The daily challenges of living with this disease, as well as the emotional and financial toll it takes, can oftentimes result in a sense of defeat or isolation. We help those who feel alone in their chronic illness find hope and courage to live healthy, happy lives!

Services offered by We Are Diabetes include:

- Referrals to credible providers and treatment centers across the United States.
- One-on-one mentorship and guidance through the recovery process.
- Support for both the individual who is struggling as well as their family and loved ones.
- Unique resources designed specifically for the ED-DMT1 population.
- Monthly online support groups.

If you or someone you know is a type 1 diabetic who is struggling with an eating disorder and are seeking support, please visit [wearediabetes.org](http://wearediabetes.org). Recovery is possible, and we can help!

**We Are Diabetes** is a 501(c)(3) nonprofit  
Contact us at [info@wearediabetes.org](mailto:info@wearediabetes.org)