Getting Started with T1D

Carb DM

Carb DM’s mission is to build a supportive community that improves the quality of life and health of all those affected by type 1 diabetes. The Carb DM community fosters connections among people with diabetes, their loved ones, and medical professionals; promotes learning; and develops strategies for thriving with diabetes.

Carb DM offers the following programs throughout the year across the Bay Area:

- **Coffee & Carbs**, a gathering for parents and caregivers of children with T1D;
- **Carbs in the Park**, a gathering for families living with T1D;
- **Dia-Buddies**, outings and gatherings for teens with T1D;
- **Little Carbs**, a playgroup for children under 5 with T1D and their parents;
- **Beer & Basals**, a gathering for adults with T1D;
- **Type 1 Topics**, a speaker series covering a variety of topics relevant to the type 1 community.

In addition, Carb DM in collaboration with other organizations hold an annual Bay Area Diabetes Summit in March, a Mother Daughter Weekend in the Spring, an Asian Outreach Day, a World Diabetes Day Celebration in November, and other annual programs throughout the year.

For more information and a calendar of events, please visit our website at [www.carbdm.org](http://www.carbdm.org) and join our email list.

**Presentation on “Getting Started with Diabetes”** given by Carb DM Founder Tamar Sofer-Geri: [http://www.ustream.tv/recorded/29936526](http://www.ustream.tv/recorded/29936526)

**General Tips:**

- The diabetes community is the friendliest, most helpful community you can find. Use it!
- Go to diabetes events. It will help you feel normal again.
- Give yourself time. You don’t have to learn it all right away.
- Take breaks! Take time for yourself - you really, really need it and deserve it, now more than ever! Go out by yourself. Diabetes will be still there when you come home.
- Make sure you and your spouse/partner are equal partners in diabetes care. It’s a heavy load that’s easier when shared.
• DON’T listen to what other people say. No one who isn’t living with diabetes understands what life with diabetes is really like.
• DON’T read too much about diabetes. Most of it isn’t relevant to people with type 1 diabetes diagnosed in this day and age who are well managed from the beginning.

Language is Powerful

How you talk about diabetes can strongly influence how you and your family think and feel about diabetes. Try to avoid some of these common pitfalls:

• Blood sugar checks are “checks” not “tests.” You can’t fail a check. If they feel like they are failing BG tests and you are disappointed or judging them by their numbers, then they will stop wanting to check or as they grow older, just stop checking all together.
• There are no “good” or “bad” blood glucose results. It’s all just information. The only “bad” BGs are the ones you don’t know because you didn’t check.
• When they’re high you’re “adjusting,” not correcting. You didn’t make a mistake that you need to “correct.” Your child’s body is doing its thing and sometimes you just need to adjust.
• Remember: You cannot “control” diabetes. All you can hope for is to manage it as best you can.
• When your child is eating foods you’d rather they didn’t eat, they are not “sneaking” foods, or “cheating.” They are just “eating.” Every child will have candy and snacks you don’t want them to. Teach them that they’re there are no forbidden foods, as long as you know what they’re eating, you / they can bolus for it. If you encourage openness and honesty, they will tell you when and what they are eating and that will make your life a whole lot easier.

Seven things to tell others about T1D (taken from a mother’s blog)

1. Type 1 Diabetes is an autoimmune disease in which the body attacks and destroys all of the cells in the pancreas that produce insulin. No one knows for sure what exactly triggers this autoimmune response, but it is currently not anything that can be prevented and is NOT caused by poor eating, lack of exercise or bad parenting.

2. INSULIN IS NOT A CURE!!! There is currently no proven cure for Type 1 Diabetes. Unlike Type 2 Diabetes (the more commonly discussed type), eating better and exercising won’t reverse it.

3. People with type 1 Diabetes will be dependent on insulin for their entire lives and must take it to survive.
4. Monitoring blood sugar levels is a must! Some people check their children’s blood sugar levels 10 or more times a day.

5. Exercise can cause high blood sugars or low blood sugars – and lows can happen up to 12 hours after exercise.

6. Children with Type 1 Diabetes CAN have things with sugar! In fact, they, like everyone else, need sugars to produce energy. While foods with rapid acting sugars like juice, candy and frostings are to be used sparingly, they can still be had.

7. Parents of children with diabetes NEED other people in their lives to learn how to monitor and care for their children in case there is an emergency or in the rare event they actually have a date night.

**Helpful T1D Resources:**

**Carb DM** [www.carbdm.org](http://www.carbdm.org)

**Carb DM's online forum: Brave Buddies**, a online forum for parents and caregivers of children with T1D: [bravebuddies.group.io](http://bravebuddies.group.io)

**Diabetes Youth Families**: Diabetes camps for kids and families: [www.dyf.org](http://www.dyf.org)

**JDRF** [www.jdrf.org](http://www.jdrf.org)

**diaTribe** [http://www.diatribe.org](http://www.diatribe.org)

**Local Bay Area JDRF chapter** [www.jdrfbayarea.org](http://www.jdrfbayarea.org)

**Request the Bag of Hope**: a backpack filled with goodies for kids (primarily Rufus the bear with diabetes) and interesting information for the parents. [http://bayarea.jdrf.org/get-support/bag-of-hope/](http://bayarea.jdrf.org/get-support/bag-of-hope/)

**American Diabetes Association** [www.diabetes.org](http://www.diabetes.org)

**Children with Diabetes** [www.childrenwithdiabetes.com](http://www.childrenwithdiabetes.com)

**ABC Diabetics** provides diabetes supplies to people with no health insurance or to people who need extra supplies who are willing to make a nominal donation: [www.abcdiabetics.org](http://www.abcdiabetics.org)
Diabetes and Sports Health camp provide sports camps for children with diabetes [www.dashcamp.org](http://www.dashcamp.org)


Beyond Type 1: [www.beyondtype1.org](http://www.beyondtype1.org)

**Diabetes Device Companies:**

- Medtronic [www.minimeddiabetes.com](http://www.minimeddiabetes.com). Maker of the Minimed 670G Hybrid Closed Loop pump and CGM.


- Tandem Diabetes: [www.tandemdiabetes.com](http://www.tandemdiabetes.com) maker of the T-slim, T-slim Flex, T-Slim X2 touchscreen insulin pump.

- Dexcom: [www.dexcom.com](http://www.dexcom.com) Continuous Glucose Monitor with Share that allows for remote monitoring.

- Companion Medical: [https://www.companionmedical.com](https://www.companionmedical.com) maker of InPen, a Bluetooth connected pen that keeps track of insulin dosing, insulin on board, as well as the temperature of your insulin.

- Bigfoot Biomedical: makers of an all-in-one solution for Automated Insulin Delivery system, connected pens, supply management, and more. In development. [www.bigfootbiomedical.com](http://www.bigfootbiomedical.com)

- Beta Bionics: makers of the iLet Bionic Pancreas, a bi-hormonal pump that delivers insulin when you’re high and glucagon when you are low. In development [www.betabionics.org](http://www.betabionics.org)

- TypeZero: makers of the inControl platform which includes advisory applications for smart insulin pens and smartphone-based artificial pancreas systems that automatically regulate insulin delivery, drastically reduce hypoglycemia, and significantly improve blood glucose levels. In development. [www.typezero.com](http://www.typezero.com)
Diabetes Apps and Online Tools:

- **Tidepool**: [www.tidepool.org](http://www.tidepool.org). The best way to see all your diabetes data from all your devices in one place.

- **Glooko**: [www.glooko.com](http://www.glooko.com). Download your data to your iOS or Android device, integrate food and lifestyle data, share it with your medical professional.

- **MySugr**: [https://mysugr.com](https://mysugr.com) The most popular app for keeping track of all your diabetes data.

- **OneDrop Meter, App, and Diabetes Coach**: [http://www.onedrop.today/](http://www.onedrop.today/)

- **Dario all in one meter + app** that uses your smartphone as the “meter”: [https://mydario.com/](https://mydario.com/)

- **Livongo**: a meter that connects to the cloud and to a real live coach. [www.livongo.com](http://www.livongo.com)

**Insulin Manufacturers:**

**NovoNordisk:**
- Novolog – fast acting insulin [www.novolog.com](http://www.novolog.com)
- Levemir—long acting insulin [www.levemir.com](http://www.levemir.com)

**Lilly:**
- Humalog – fast acting insulin [www.humalog.com](http://www.humalog.com)

**Sanofi:**
- Apidra – fast acting insulin [www.apidra.com](http://www.apidra.com)
- Lantus – long acting insulin [www.lantus.com](http://www.lantus.com)

Many companies offer co-pay assistance programs, check out our list of them [online](http://www.carbdm.org).
Useful diabetes products & supplies:

Shots (these require prescriptions)
- ½ unit syringes—allow for more accurate dosing than the 1 unit syringes.
- Insulin pens—more convenient and portable than syringes and insulin vials. There are reusable ones and disposable ones for Novolog and Humalog and disposable ones for Lantus. Unfortunately, they’re only available with full unit dosing (not ½ units).
- Saline – good for “Shots of Support”. Parents can practice giving themselves shots or take a “shot of support” whenever their child takes a shot. Helpful in comparing the pain in the arm compared to the pain in the stomach; comparing the pain of six units compared to two, etc. Have your child give you a saline shot!

For children having trouble with shots & pump changes:
- InjectEase is a device that holds the syringe and somewhat dulls the sensation of the needle. Doctors don’t tell you about it but parents swear by it. Available on Amazon.
- Pen Needles with Covered Tips: BD Autosheild Duo Pen Needle: These needles are covered so they aren’t seen before giving a shot with them. They’re another good tool for kids who are afraid of needles.
- Buzzy Bee: www.buzzy4shots.com is a vibrating device that distracts you from the shot.
- EMLA: numbing cream that’s great for pump site insertions. Needs to be put on one hour before the skin is completely numb. Also good for blood draw. (Prescription required.)
- Glad Wrap Stick and Seal: Use to cover the EMLA cream. It’s better than IV 3000 or other stickier things because it doesn’t pull on the skin when removing it.

Lancets & Meters
- Accu-Check Fastclix lancing device: a great lancing device that has a cartridge with six lancets in it. When it’s done, you just replace the cartridge, so you’re never exposed to sharp needles. You can use this lancing device regardless of what glucometer you’re using.

Medical ID bracelets
- Road ID: www.roadid.com. Offers a similar service to Medic Alert, but you can also just order their ID bracelets without the membership. Try the Wrist ID Slim! These seem to be the most popular. You can add badges to indicate that it’s a medical alert bracelet, for T1D, and also for fun stuff.
- Medic Alert: www.medicalert.org Your information is kept on file and the ID bracelet includes your membership number.
- MediBand: www.mediband.com A really simple, really cool medical alert band.


- Lauren’s Hope [www.laurenhope.com](http://www.laurenhope.com) for fancier designs.

### Diabetes bags and packs
- **D-Packs for carrying around the meter, etc.:** There are plenty of diabetes packs online.
  - Out of Sight cases: [https://www.outofsightcases.com](https://www.outofsightcases.com)
  - Myabetic: [http://www.myabetic.com](http://www.myabetic.com)
  - Sugar Medical: [http://sugarmedical.com](http://sugarmedical.com)
  - Diabe-tezy: [http://www.diabe-ezy.com](http://www.diabe-ezy.com)
  - Adorn: [https://adorndesigns.com](https://adorndesigns.com)

- You can also get one that’s not intended as a diabetes pack. Some suggestions that can be found online:
  - AmeriBag Esopus Microfiber Bag with detachable strap;
  - Baggellini Pocket Crossbody
  - LeSportsSac
  - Manhattan Portage City Lights is a good bag for boys, too.
  - Brett Michael has bags out that should appeal to boys.

- **SPIbelt Pack** [www.spibelt.com](http://www.spibelt.com). For children 9 and younger, order the kids size. 9 and up, order the adult size. Don’t bother ordering the “diabetic belt” - it doesn’t really improve upon the regular belt and it doesn’t have as many colors to choose from.
- Too Sweet Boutique [www.toosweetboutique.com](http://www.toosweetboutique.com). Fully customizable pump and CGM waist packs hand made to order.
- **FlipBelt** are strips of neoprene that wrap around the waist and have multiple pockets.

### Cooling Devices: (insulin must be kept between 36 - 86 degrees Fahrenheit but never frozen)
- **Frio pouches**: for keeping insulin cold without refrigeration. Reusable pouches come in a variety of shapes, colors and sizes [www.frioinsulincoolingcase.com](http://www.frioinsulincoolingcase.com)

### Temperature Tracking Device:
- **MedAngel** ([medangel.co](http://medangel.co)) connect to your phone via BlueTooth and tracks the temperature in your fridge or in your travel pack and alerts you if your insulin is out of safe temperature range. Can be purchased on [Amazon](http://amazon.com).

### Pump & CGM Accessories
- **Groovy patches**: [www.groovypatches.com](http://www.groovypatches.com)
- **Skins**: [www.skinit.com](http://www.skinit.com)
- **GrifGrips**: colorful patches that fit over the Dexcom transmitter, OmniPod, and infusion sites. Can be purchased on Amazon or at [grifgrips.com](http://grifgrips.com)

**For hands-free night time BG checks**
- Try a headlamp such as these: [www.rei.com/search?query=headlamp](http://www.rei.com/search?query=headlamp)
  It may look silly, but it’s really helpful!

**Adhesives for covering pump sites and CGMs** (available on Amazon):
- **Tegaderm** - transparent film great for covering pump sites or CGMs.
- **Hypafix** – cloth mesh available in rolls great for covering pump sites or CGMs. Breathes more than Tegaderm. Can be purchased on [Amazon](http://www.amazon.com).
- **Opsite Flexifix** helps to keep sites and sensors on in the water. Just put over IV 3000 or Tegaderm. It comes in rolls and is available online.

**Adhesive Removal**
- **Unisolve**: alcohol-swab like wipes that dissolve the sticky stuff from pump sites making them easier to remove.
- **Sensi Care**: spray and wipes for adhesive removal that doesn’t smell of alcohol and doesn’t leave sticky residue like Unisolve does.
Getting Used to the new “normal”

- **Create Cheat sheets**: Carb counts for frequently eaten foods so you’re not constantly checking the book or looking it up online.
- **Sliding scales**: Carb ratios on one sheet so you don’t have to keep printing them out whenever carb ratios are changed.
- **Cool measuring cups**: Use interesting measuring cups at the table so it doesn’t feel so much like a scientific experiment when serving food. The store Anthropology has some cute geese measuring cups: “Can I have a papa / mama / baby goose of pasta?” There are measuring cups available that masquerade as nesting dolls – great for sending to school.
- **Round “garage sale” stickers**: Use them to label snack and lunch containers with carb counts. Available at Long’s, Walgreens, Target, Office Depot.
- **Chain restaurants are required to provide nutritional information** so places like Starbucks, Chipotle, California Pizza Kitchen, etc. have carb counts available usually in a binder by the register. They also often include them on their websites.
- Find a diabetic babysitter! *We’ve got a list for you.*
- For some lighthearted humor:
  - [http://www.youtube.com/watch?v=LFIVVHQod5o](http://www.youtube.com/watch?v=LFIVVHQod5o)
  - [https://www.youtube.com/watch?v=Es2f5MsEWmg](https://www.youtube.com/watch?v=Es2f5MsEWmg)

Good foods to have on hand:

**For lows:**

- **Sensible sippers** – juice boxes with 7 or 8 g of carb available at Whole Foods.
- **Hansen’s Junior juice boxes** – 4 oz. juice boxes with 15 g of carbs available at Safeway.
- **Marshmallows** – about 6g each.
- **Trader Joe’s All Natural Fruit Jellies** – gummy candies that are fast to eat and only 7 carbs each so good for lows.
- **Gu Chomps**: gummies that have electrolytes and other good stuff to be having while exercising and also carbs so that they’re good for lows while exercising.
- **Shot Bloks**: same as Gu Chomps just by another brand and some claim they are tastier.
- **Sport Beans (by Jelly Belly, but without food coloring or artificial flavoring)**. Same as the Gu Chomps, but more fun.
- **Cliff Gel Shots** – fruit flavors without caffeine (chocolate & coffee flavors contain caffeine) with 24 g of carbs available online and at Whole Foods.
- **Level Glucose Gel** – 15 g fast acting gel in interesting flavors available online.
- **Elovate 15** – single serve powder glucose with 15 g carbs. Available online. Developed by a type 1 mom.
• Many people also use **Skittles, jellybeans, Smarties, Butterscotch candies, Swedish fish, Life Savers Gummies, etc.** When possible, buy the fun size for carb portion control.

• **Glucolift** – all natural, non chalky tasting glucose tablets Developed by a person with type 1 diabetes. Glucolift.com

**Free foods (0 carbs):**

- Beef Jerky
- Cheese sticks
- Seaweed
- Nuts
- Veggie sticks
- Sugar-free Jell-O
- Leaf & Love Lemonade.

**Low carb snacks (up to 15g of carbs):**

- **NuGii Bars:** gluten free bars protein bars. Individually wrapped 12 grams of carbs. Available on Amazon.com
- **Mini Kind bars** - available from amazon.com and only 9-13 g of carbs. Great for pre-sports practice or during a game.
- **Crystal Light Pure Fitness:** all natural drink mix that contains 6g of carbs per 16 oz of juice. Can be found at Safeway.
- **Extend bars and chips:** are specially formulated to release the glucose slowly to keep blood sugars stable over a period of 9 hours. Good for bedtime snacks especially after a day with a lot of activity. Available at Walgreens and online.
Diabetes books (available on amazon.com)
THE FIGHT TO SURVIVE
A YOUNG GIRL, DIABETES, AND THE DISCOVERY OF INSULIN
CAROLINE COX

The Sugarless Plum
A MEMOIR
ZIPPORA KARZ

SUGAR LININGS
FINDING THE BRIGHT SIDE OF TYPE 1 DIABETES
STEFANY SHAHEEN

ELLE & COACH
Diabetes, the Fight for My Daughter's Life, and the Dog Who Changed Everything
with Mark Dagostino
GETTING A GRIP ON DIABETES

Quick Tips & Techniques For Kids & Teens

Spike and Bo Loy

My Sister Has Diabetes and How That Makes Me Feel

by Grace Rooney

Illustrated by Michele Pensà

If I Kiss You, Will I Get Diabetes?

A first-hand account of negotiating life with a chronic illness.

Quinn Nystrom

"A wonderful story written by an inspirational woman!" - Dr. Minna Johnson, Miss America 1990