Children’s Hospital of Philadelphia
Diabetes Center for Children

Learning to Manage Diabetes at Home

Cystic Fibrosis Related Diabetes
General Facts about Cystic Fibrosis Related Diabetes (CFRD)

What is CFRD?
- CFRD is a type of diabetes that occurs in people who have Cystic Fibrosis (CF).
- CFRD can be chronic (happening all of the time) or acute (happening only sometimes).

What are the causes of (CFRD)?
- CF causes damage to the pancreas, which contains beta cells that make insulin.
- If enough cells in the pancreas are damaged, the body can no longer make insulin.

What is insulin and what does it do?
- Insulin is a hormone made by the beta cells in the pancreas.
- It allows sugar (glucose) to enter the body’s cells to give them energy.
- Your child needs this energy to think, play, and work.

CFRD causes:
- a decrease in Pulmonary Function Test (PFT).
- sugar to build up in your child’s bloodstream.
- frequent urination and extreme thirst.
- weight loss, muscle loss or muscle wasting.
- lack of energy.
- high levels of ketones in the body that will make your child very sick (in severe cases, ketones may develop due to fat breakdown).

Sometimes, children with CFRD do not have these symptoms. This is because CFRD is a problem with blood sugar control that occurs mostly at meals. A high blood sugar 2 hours after meals is a symptom of CFRD.

What tests are needed to diagnose CFRD?
- Blood Glucose Testing: a finger stick
- Fasting Blood Sugar: first morning blood sugar before eating
- Random Blood Sugar or Post-prandial (post meal) blood sugar: 2 hours after a meal
- Hemoglobin A1c or Fructosamine: determines blood sugar control over weeks to months
- Oral Glucose Tolerance Test (OGTT): measures blood sugar after a meal

It may take several tests to make a final diagnosis.
What is the treatment for CFRD?

- Insulin by injection (possible). Insulin injections will replace the insulin your child no longer makes on his own.
- Medication by mouth (possible for children at least 10 years old).
- Meal plans including:
  - fewer sweetened drinks (regular soda, iced tea, punch)
  - whole milk
  - spreading carbohydrates throughout the day at meals and snacks
  - high sodium (high in salt) foods
  - high fat
  - extra calories

A CF dietitian will develop a meal plan based on your child’s needs.

What will happen to my child’s diabetes if he has a pulmonary exacerbation (an increase in respiratory symptoms)?

- Your child’s body will need more insulin when sick.
- Exacerbations, infections, stress, or steroid use can cause the body to need more insulin.
- Your diabetes provider will work with you to adjust your child’s insulin needs.
Glucose and Urine Monitoring

Blood Glucose Monitoring

What is the purpose of blood sugar testing?
- Blood sugar testing tells you if the insulin dose is working.
- You need to know blood sugar results to make insulin dose changes.

What should my child’s blood sugars be when taking insulin?
- Your child’s target blood sugar range is based on age.

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How do I check my child’s blood sugar?
- Follow the instructions for your lancing device and glucose meter.
- The nurse will teach you how to use them.
- Make sure fingertips are clean and dry.
- Use one drop of blood.
- Hold fingertips lower than the heart.
- Lancets are for one use only. Use a new lancet with each finger stick.
- Keep your lancing device and glucose meter clean.
- Never share a lancet or a lancing device with anyone

What times do you test blood sugar?
Blood sugar testing will be determined by your diabetes team. Your child may need to check:
- Before breakfast
- Before lunch
- Before dinner
- Before bedtime snack
- 3 a.m. to 4 a.m. for the first week or so and whenever you change an evening insulin dose
- 2 hours after meals
- When you need more information due to a change in symptoms
- You should always check if your child is “feeling” low or has symptoms

Will I always have to test blood sugars this often?
- Yes. Frequent blood sugar testing is necessary for good diabetes control.
How do I know if the number on the glucose meter is correct?
- If a number on the meter does not make sense, always recheck it.
- The most common mistake is not putting enough blood on the strip. This gives a false low reading.
- Wet fingers can dilute the drop of blood and also give a false low reading. Wash and dry hands well.
- Food on the hands may give a false high reading. You can use glucose control solution to check the accuracy of the meter.

What is Alternate Site Testing (AST)?
- Some meters allow you to test blood sugars on the palms and forearms.
- Some children find this less painful.
- In the beginning, we will teach you to use your child’s fingertips.
- Discuss AST testing with your diabetes provider before using.

Are there times I should not use AST?
- Do not use AST when your child’s blood sugar could be rising or falling.
- Do not use AST when your child is:
  - Exercising
  - Sick
  - Testing a blood sugar before driving a car
  - Unable to feel a low blood sugar (hypoglycemia unawareness)
  - At these times, check blood sugar on fingertips to make a decision
  - Repeat any high or low blood sugar reading using the fingertips

What if the meter doesn’t work?
- Call the 1-800 telephone number on the back of the meter.
- Describe the problem. Often they can talk you through the problem over the phone.
- If they cannot fix it over the phone, ask the company to send a new meter.

Urine Monitoring

What are ketones?
- Ketones are very strong acids that come from fat breakdown and make the body sick.
- Fat breaks down when there is not enough insulin.
- The body makes ketones when it needs more insulin.
- Ketones are a sign that the body is breaking down fat for energy.
- Ketones are found in the urine and blood.
- Ketones in the urine are a concern.
- Ketones are not a common problem for children with CFRD, but they can occur.
When should I test urine for ketones?
- When the blood sugar is over 240 mg/dl.
- If your child is sick. Test urine at least twice a day even if the blood sugar is not high.

How do I test the urine for ketones?
- Dip a ketone strip into a fresh urine sample or have your child urinate on the end of the strip.
- Ketones will turn the strip a pink or purple color.
- If there is no color change, there are no ketones.
- Refer to the package insert for color codes for your brand of ketone test strips.
- Wait the amount of time stated in the directions.

One pad will turn pink or purple if you have ketones. You need to call the Diabetes Center (215-590-3174) if your child has ketones.

What else do I need to know about ketone strips?
- Some strips test the urine for more than just ketones. Look for a pink-purple ketone color.
- Ketone strips will not work correctly if they have expired. Check the bottle for expiration date. Throw out old strips.
- Make a note of the date you open the box. Write it on the box. Ketone strips expire in 6 months after opening, or on the expiration date listed on the box (whichever is first).
- Protect your ketone strips from moisture and light.
- Keep the bottle tightly closed when not in use.
Giving Medication

Insulin: Your diabetes team may prescribe insulin to treat your CFRD.

What is insulin?
- It is a hormone that is made by the beta cells in the pancreas.
- Insulin moves sugar into body cells for energy to think, play and work.
- It makes the blood sugar go down.

Why does insulin have to be given as an injection?
- Insulin would be destroyed by stomach acid if taken by mouth.
- Insulin does not come in a pill.

What kind of insulin will we be using?
- Your diabetes team will talk to you about which insulin(s) you will use.
- Your diabetes team will teach you about the insulin(s) you will be using.

Where do I give the injection?
Inject insulin into the fat layer under the skin.
- This helps it absorb slowly and last the right amount of time.
- These areas (sites) include:
  - Back of arms
  - Back of hips
  - Outside of thighs
  - Abdomen (stay 1-2 inches away from belly button.)

How do I rotate injection sites?
- Inject the needle into different places in the body as described above.
- Give injections about 1 inch apart from the last injection site.

What will happen if I do not rotate injection sites?
- A lump will develop in the area where you inject too often.
- This is called lipohypertrophy.
- If you inject into this lump, insulin will not be absorbed and blood sugar will increase.
What happens if insulin leaks from the injection site?
- If insulin leaks out, blood sugars may increase because the entire dose did not get into the body.
- Test blood sugar 2-3 hours after an injection. Check for ketones if the blood sugar is greater than 240.
- Call the Diabetes Center if you find ketones in the urine or if insulin leaks from the injection site often.
- Counting to 5 after injecting the insulin dose will help all of the units of insulin absorb and not leak out.

Where should you keep the unopened bottles of insulin? How long do they last?
- Keep unopened bottles on the refrigerator door.
- Insulin can freeze. Keep insulin on refrigerator door to avoid freezing. Bottles are good until the expiration date if they are unopened.
- Always check the expiration date when opening a new bottle.

Where should I keep opened bottles of insulin? How long do they last?
- Keep opened bottles of insulin at room temperature.
- Opened bottles should be thrown away after 1 month except for pre-mixed insulin. These expire after 14 days.
- Date the bottle to keep track of when to open a new one.
- Expired insulin does not work as well and may cause high blood sugars.

What should I do with used syringes and lancets (sharps)?
- Many people (your family and sanitation workers) are at risk for injury.
- It is important to throw sharps out safely.
- Check with your township to find out a safe way to get rid of the sharps.

To find out more about throwing sharps away safely:
- Search the internet using the name of your city, county, or township using the words “sharps disposal.”
- Call your city, county or township and ask about sharps disposal. Some areas will provide a disposal device at no cost.
Oral Medication

Your diabetes team may prescribe oral (by mouth) medication to treat CFRD.

What oral medication will my child use?
- Prandin (Repaglinide)

How does Prandin work?
- It helps the pancreas make insulin.
- It helps lower the blood sugar when it rises after eating.

When should my child take Prandin?
- Take only with meals.

If your child skips a meal or snack, he should not take Prandin.

What are the side effects of Prandin?
- Low blood sugar
- Dizziness
- Sweaty
- Diarrhea
- Back pain
- Shaky
- Irritable
- Cold and flu-like symptoms
- Joint aches

Some medicines taken with Prandin can make low blood sugars worse.
Check with the diabetes team about taking Prandin with other medications.

How do I treat a low blood sugar?
- Check blood sugar immediately if your child has any symptoms.
- If blood sugar is less than 70 or your child is having low blood sugar symptoms, treat by taking 4 glucose tablets or 4 ounces of juice.

Laboratory work should be done at least once a year. This includes:
- Liver function tests
- Kidney function tests
- HbA1c or Fructosamine test

What about Prandin and Pregnancy?
- Prandin cannot be taking during pregnancy.
- Make sure your teen is using birth control (condom, birth control pill or patch), if sexually active.
- If you have questions about this, please discuss with the diabetes provider.
Managing High Blood Sugars

What should my child’s blood sugars be when taking insulin?
Your child’s ideal blood sugar range is based on age.

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Many children with CFRD have stable blood sugars using insulin (and oral meds when needed) until they get sick, start or change steroid dose or have a pulmonary exacerbation. It is important for high blood sugars to be lowered.

What happens with high blood sugars?
High blood sugars cause 2 problems:

1) When the blood sugar is above 180, the kidneys get rid of the sugar in the urine. This causes your child to go to the bathroom a lot.
   - Your child is losing fluid in the urine and this is why he is thirsty.
   - This causes dehydration (loss of fluid).

2) When sugar is lost in the urine, the body is not able to use the food that your child eats.
   - Your child may not gain weight and grow.
   - Your child might have a hard time healing from surgery or infections.
   - This can contribute to a decrease in your child’s lung function.

What are signs of a high blood sugar?
- very thirsty
- frequent urination
- dry skin
- blurry vision
- confusion

Remember that young children cannot tell you how they are feeling. If you are concerned, check their blood sugar.
Should I worry about blood sugar readings that are in the 200-600 range? That depends. There are two kinds of high blood sugars:

**Highs with ketones:**
- Highs with ketones are a problem.
- **Call the Diabetes Center right away at 215-590-3174**
  - weekdays 8 a.m. to 5 p.m.
- At all other times call 215-590-1000 and ask for the diabetes doctor on call.
- Encourage your child to drink sugar-free fluids.
- Have your child rest and not exercise.

**Highs without ketones:**
- Highs without ketones are not immediately dangerous.
- Encourage your child to drink sugar-free fluids.
- Encourage your child to exercise.

**How much sugar-free fluid should my child drink when the blood sugar is high?**
- Every hour, give one ounce for every year of age. Examples:
  - 5 years old = 5 ounces every hour
  - 9 years old = 9 ounces every hour
  - 12 years old = 12 ounces every hour
  - Maximum of 16 ounces per hour

**When should I call the Diabetes Center Emergency Number?**
- If your child has ketones in the urine.
- If your child won’t eat/drink (call before giving the insulin).
- If your child is vomiting.
- If your child’s blood sugar is low and not coming up.

**What should I do when my child’s steroid dose is being increased?**
- Watch the blood sugar readings. They usually change within 12-24 hours with a change in the steroid dose.
- Contact your diabetes provider **weekdays from 8 a.m. to 5 p.m.** for insulin dose adjustments. **Call 215-590-3174** and leave a message. A diabetes team member will call you back within 24 hours.
- Insulin doses may need to be increased every day until blood sugars are in control.
Managing Low Blood Sugars

What are some other names for low blood sugars?
- Insulin reaction
- Insulin shock
- Hypoglycemia
- Low blood glucose
- Feeling shaky
- Lows

What are signs of a low blood sugar?
- Shaky
- Tired
- Headache
- Sweaty
- Dizziness
- Hungry
- Confused
- Crying/irritable

Remember young children cannot tell you how they are feeling. If they are pale, cranky, and tired, they may have a low blood sugar.

What causes a low blood sugar?
- Decreasing your child’s steroid dose will cause lower blood sugars.
- Expect low blood sugars when you decrease steroid doses.
- You will need to decrease insulin doses to prevent lows.
- Not eating enough carbohydrates at meals and snacks for the insulin dose given.
- Skipping meals or snacks
- More activity than usual
- Too much insulin (such as a dosing error)
- Giving insulin at the wrong times
- Contact your diabetes provider **weekdays from 8 a.m. to 5 p.m.** for insulin dose adjustments. Call **215-590-3174** and leave a message. A member of the diabetes team will call you back within 24 hours.

When should I check my child for a low blood sugar?
- When you decrease steroid doses, check more often.
- Even though lows will happen mostly when you decrease steroids, lows can happen any time. Check if you see symptoms of a low.
How do I treat a low blood sugar?
- Give 15 grams of a quick acting carbohydrate. Treating with more than 15 grams at a time will cause high blood sugars later.
  - 4 ounces of juice
  - 8 ounces of sports drink
  - 3 to 4 glucose tablets
- If it is a mealtime, do not give insulin until blood sugar returns to target range.

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If it is mealtime, do not give insulin until blood sugar returns to target range. Call the Diabetes Center if the blood sugar does not come up.

Why is it important to treat a low blood sugar right away?
- Low blood sugars can be dangerous.
- Fainting, seizures, and even death can result from serious low blood sugars that are not treated.

How do I treat a low blood sugar if my child cannot drink or eat?
- Your child may be unresponsive (cannot wake up).
- Use cake icing, glucose gel, or glucagon.
  - Rub cake icing, glucose gel inside the cheeks and onto the gums.
  - It will take 10 minutes to work. OR…
  - Inject glucagon into a muscle.
  - It takes 10 minutes to work and last 60 minutes.

Call 911 if your child does not wake up in 10 minutes.
Call 911 if your child cannot eat or drink carbs once they wake up.

Call your nurse practitioner whenever you use cake icing, glucose gel or glucagon to treat a low blood sugar.
Who needs to know how to treat a low blood sugar?
- Babysitters
- Coaches
- Family members
- Teachers
- Best friends

What should your child carry at all times to treat a low blood sugar?
- 15 grams of a fast-acting carb:
- 4 ounces of juice
- 8 ounces of sports drink
- 3 to 4 glucose tablets

Why does my child sometimes feel low, but when I check, blood sugars are in range?
- Symptoms can happen if the blood sugar is dropping quickly.
- Do not treat.
- Recheck the blood sugar every 15 minutes if symptoms continue.
- Monitor the blood sugar until symptoms are gone.
- If the blood sugar drops below 70, follow the rules for treating a low blood sugar.

Why is it important to wear a Medic Alert bracelet at all times?
- Medic Alert bracelets alert people that your child is taking insulin.
- In an emergency, people need to know that your child has diabetes.
- If your child has a medic alert bracelet for another health problem, you may be able to add diabetes to that bracelet.
Day to Day Care of Diabetes

What will a typical day look like when we go home?
- Your nurse will help you to fill out your Daily Schedule at the end of this unit.

Keep a log of blood sugars, urine tests and insulin doses.
- Written records are the best way to keep track of what works and what doesn’t work.
- This is the best way to make good decisions about insulin.

What information should I write on my log sheets?
- All blood sugars
- All insulin doses
- All steroid doses
- If there are ketones in the urine when blood sugar is higher than 240
- Reasons why the blood sugar is high or low

Why might the blood sugars be high?
- Steroids: Steroid medication was started or the steroid dose was increased.
- Food: - Carbohydrates not covered by insulin.
- A blood sugar reading taken too close to the last meal or snack.
  (There should be at least 2 to 3 hours between eating and testing.)
- Insulin: Too little insulin
- Exercise: Less activity than usual
- Illness: Usually illness (other than vomiting) causes blood sugars to run higher than normal, even when your child isn't eating much.

Why might the blood sugars be low?
- Steroids: Steroid dose was decreased or the medication was stopped.
- Food: Less food (carbohydrate) than usual
- Insulin: Too much insulin
- Exercise: More activity than usual
- Illness: Sometimes illness (especially vomiting) will cause low blood sugars.

What should I do about school?
- Meet with the school nurse, principal and teachers before your child goes back to school. They need to know what to do for your child’s diabetes.
- You will get a Diabetes Medical Management Plan from the diabetes team.
- Arrange with the school a way for them to communicate the lunch blood sugar numbers to you.
What diabetes supplies will my child need at school?

- Your child needs all the same supplies at school that you use at home.
  - Blood Glucose Meter
  - Test strips
  - Lancet device and lancets
  - Insulin if your child will get insulin at school
  - Pens/syringes if your child gets insulin at school
  - Ketone strips
  - Glucose tablets or juice to treat a low blood sugar
  - Glucagon Emergency Kit
  - Blood sugar records

When should I be seen in the Diabetes Center and what should I expect?

- Your child should be seen in the Diabetes Center within 2 weeks of discharge from the hospital.
- At this visit, you will meet a diabetes provider that will be your ongoing contact for any questions about changing the insulin dose.
- The diabetes team will be available to answer any other questions.

Bring your child to every visit, along with the following:

- Blood sugar meter,
- A snack
- The log sheets
- A list of questions
- A referral if required by your insurance company
The Emotional Side of Living with Chronic Illness

How does our family adjust to life with diabetes and CF?

- Both CF and diabetes are a lot of work.
- You need to help and support one another.
- Share the burden of daily tasks.
- Talk about how you are feeling.
- Identify support people:
  Spouse/partner
  Friend
  Neighbor
  Grandparents
  Support groups
  School

How can I support my child with two chronic conditions?

- It is often difficult for a parent to listen to their child’s sad or angry feelings.
- You child needs to express feelings without you trying to fix them right now.
- Talking about emotions and fears helps to make living with diabetes and CF easier.
- Be honest in answering your child’s questions about having both CF and diabetes.
- Answer questions in a way that your child can understand.
- If you need help with this, ask to talk with a social worker.

Should I change the way that I discipline my child?

- Rules and discipline should not change.
- Continue to use appropriate rewards and consequences as you did before the diagnosis.
- Set clear expectations for what your child will do for his diabetes care.
- Diabetes care must become a part of your child’s daily routine.

How do blood sugars affect my child’s behavior?

- Low blood sugars can make your child feel cranky and irritable.
- If you child is not behaving, test the blood sugar.
- If blood sugar is in range, discipline as usual. If blood sugar is low, treat it as outlined in his treatment plan. When the blood sugar is back in target range, discuss the behavior.

Will diabetes affect my child’s school performance?

- Your child’s school performance should not be affected.
- Set up a “Plan of Care” or a 504 Plan B Plan of Care to ensure your child’s diabetes needs are met at school. Your social worker can explain this to you.
My child does not want to wear a medic alert bracelet. What should I do?
- Wearing a bracelet is a safety issue. Make the bracelet an expectation from the very beginning.
- Ask your child what makes it difficult to wear a bracelet. Some children feel:
  - It is uncomfortable
  - It makes them stand out as being different
- It is ok for your child to wear a medical alert necklace under his clothes if he wants to keep his diabetes and CF private.
- Talk to your child’s diabetes provider or social worker if your child is extremely secretive about the CF and diabetes and refuses to wear a medical alert.

Can stress affect my child’s diabetes and CF?
- Stress can:
  - Make your child’s blood sugars go high.
  - Make your child forget to check his blood sugar or take his insulin.
  - Managing stress in a healthy way can help your child’s overall health.

Remember: You are not alone. Your child, you and your diabetes providers are a team.
Call us: 215-590-3174

What about diabetes and depression?
- Children with diabetes have an increased risk for depression.
- There are signs and symptoms of depression (seen over a period of weeks):
  - Change in sleep (sleeping all the time, not sleeping)
  - Change in appetite (increase or decrease)
  - Poor concentration (drop in grades at school)
  - Often in a “bad mood” or easily frustrated
  - Feeling overwhelmed
  - Feeling guilty
  - Not wanting to do things they used to like, such as sports or hanging out with friends.

When should I get professional help?
- If you or your child:
  - Feels like giving up.
  - Feels overwhelmed.
  - Experiences changes in mood.
  - Experiences a drop in school/work performance.
  - Is abusing alcohol or drugs.
  - Is being dishonest about diabetes care (not telling the truth about things like food, insulin injections, and blood sugar results)
  - If you and your spouse/partner cannot agree on the diabetes care at home
Where should I get professional help?

- Talk to the diabetes social worker.
- Talk with your primary care doctor.
- Contact your insurance company to get the name of a therapist who can work with you, your child or your family.