

ONLINE SUPPLEMENTAL MATERIAL

Appendix

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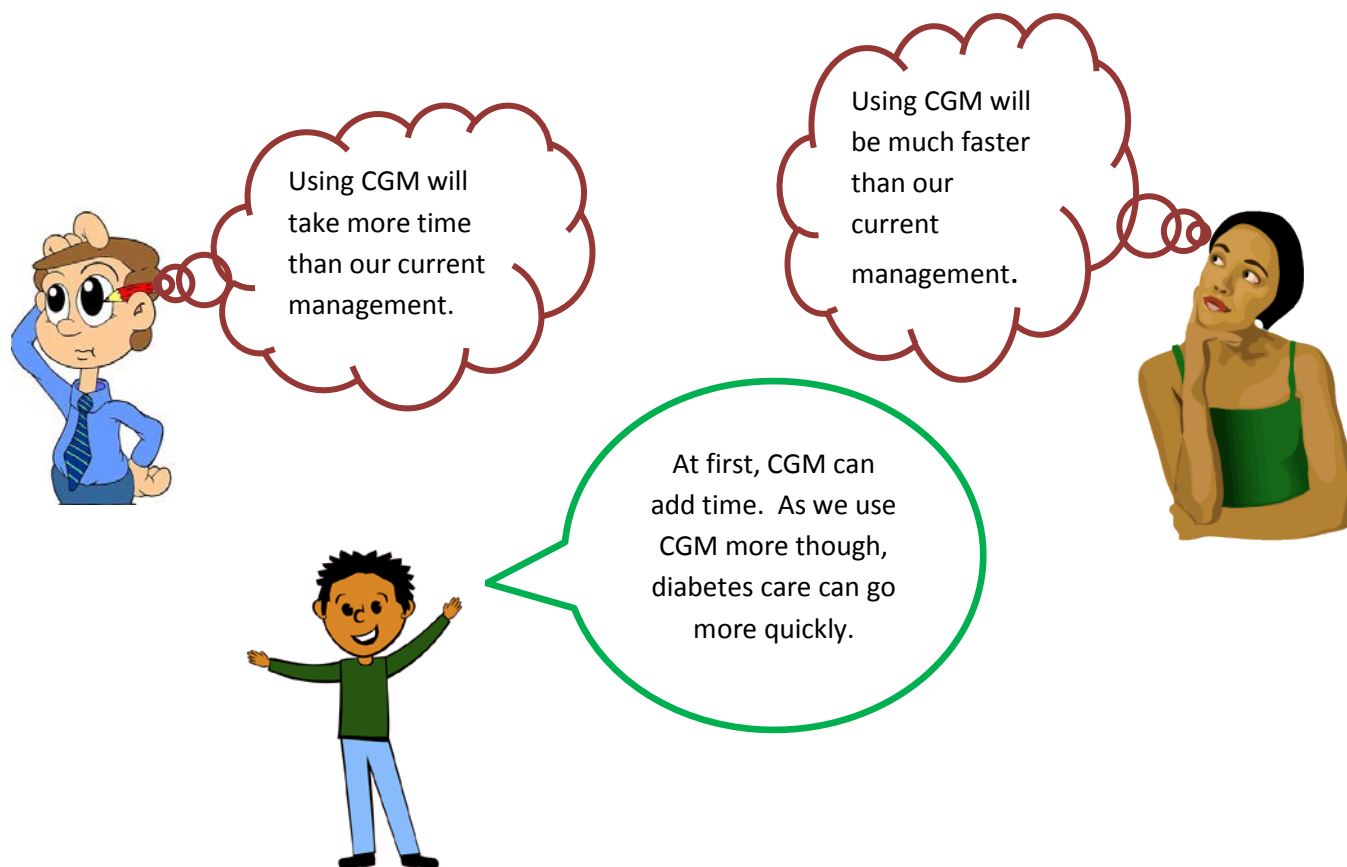
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Module 1: Getting Used to CGM - Common Questions and Tips

Common Questions about Life with CGM

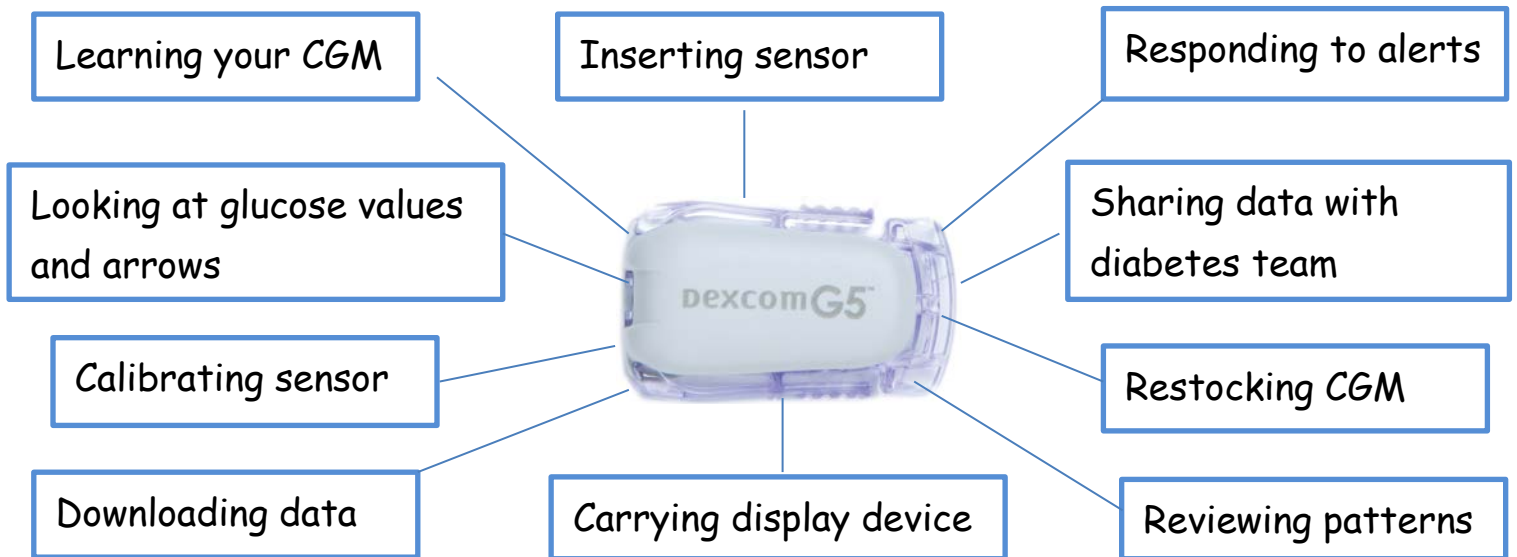
Question 1: How Much Time Will it Take to Use CGM?



So which is it?

We have seen that CGM can take a little more time, especially in the beginning, as you are becoming more familiar with it. Things might go more quickly as you get more comfortable. When you have more experience with CGM, you may be able spend less time worrying about your child's diabetes management.

Some Examples of CGM Tasks



Making Time for CGM Tasks: - clock from module 5

1. For site insertions, start 10 minutes earlier than you are planning to start.

- Have supplies prepared before informing your child, or ask your child to help prepare for the tasks!

Gathering supplies or icing the new site can be part of the routine!



2. Ask others for help with getting supplies organized

- An extra set of hands may make things go faster
- Lightening your load might help you feel more relaxed

3. Plan the task at the same time as another recurring event or at the same time each week

- This might help you remember and make it part of the routine
- Examples: calibrate the CGM at breakfast and dinner, review CGM trends for 10 minutes after your child goes to bed

Question 2: Will My Child's Time in Range Increase?



Because my child wears a CGM, his/her glucose levels will **always** be in the target range: **Never** high or low!

All children with diabetes have some glucoses that are high or low. Over time, the CGM can help you increase the amount of time your child's glucose levels are in range, reducing the highs and lows.



Diabetes management is different for everyone and there are so many things that impact glucose levels. CGM is a tool to help you manage your child's diabetes and to help you decide what treatment your child may need.

There will be unexpected highs and lows no matter what technology you use.

- While diabetes can be unpredictable in a young child CGM information can help remove some of the mystery of highs and lows because you can see glucose trends.

Strategies for Sensor Insertion

Diabetes management in general involves lots of details; using a CGM adds even more. Sensor insertions can be challenging, especially in young children. Time and experience will help but here are some tips to get started.

1. **Distraction** - This can reduce the time to prepare your child for the insertion and might even help your child SENCE less discomfort!



Ideas:

- having another adult or sibling to talk or play with your child
- watching TV
- playing on the iPad or mobile phone
- singing favorite songs
- coloring
- playing with toys while lying down
- squeezing a favorite stuffed toy or pillow
- saying rhyming words or ABCs
- making funny faces
- telling a silly story
- blowing bubbles
- petting the family pet

2. Pain Prevention

- Frozen spoon, bag of frozen vegetables, numbing spray, or an icepack
- Ask your healthcare team about a topical numbing cream
- Buzzy® - a device that provides physical and visual distraction with icepack wings and a buzzing belly



3. Ask another person for help - Plan the site change at a time when you have another person to help. This can reduce overall stress.

- Sometimes there isn't anyone around to help. Feel confident that over time your skills will improve and things will get easier.



4. Celebrate Successes - Celebrating and praising your child for doing

a sensor insertion can leave your child with a positive memory from the insertion. (And congratulate yourself too!) Focus on the fun celebration afterwards and less on how much it hurt! Here are some ideas for small rewards or celebrations:

- Stickers or other small tokens
- Alone time with a parent
- Choosing the supper menu or where to go out to dinner
- Eating on a special plate just used on sensor insertion days
- Getting extra play/outside time
- Getting extra screen time
- Dancing and being silly together
- Letting your child pick out a small token or toy (less than \$1) at the dollar store



5. Relaxation - Take time to calm your mind and muscles (and your child's!) before a sensor insertion to make the process less stressful for both of you

- Gently massage your child
- Try planning insertions after bath time
- Play soft music
- Use a calm, comforting tone of voice
- Try a child-friendly relaxation activity - see next page for a fun example

A Relaxation Activity for Kids

Here is a fun script to help your child relax before inserting a new sensor. Remember, it's best for both parent and child to relax first and do the sensor insertion after once your mind is calm and muscles are loose. Feel free to change the script up to include your child's favorite animals! You may find that when you make this funny and silly for your child it can help with some of the more challenging CGM-related tasks.

Ok, time to get comfy and close your eyes! Don't fall asleep because this is going to be so much fun!



Pretend you have a round orange in your hand. Squeeze it really hard so you can get all of the juice out- you are going to make the best orange juice ever. Feel how tight your hand and arm feel

as you squeeze that orange. 1-2-3, drop the orange. Feel how relaxed your muscles are now. Oops, we need more juice! (Repeat- and have them squeeze even harder this time!)

Pretend you are a cute soft furry kitten just waking up from a long nap. You want to stretch. Stretch your arms out in front of you. Raise them high over your head. Way back behind your head. Feel the stretch in your shoulders. Stretch higher kitty! Kitty wants to relax- drop your arms by your side. (Repeat and have them stretch even more trying to reach the ceiling.)



Take 2 super big deep breaths- so big that you can feel them in your belly and your shoulders get so tall. Now breathe out nice and sloooooow.

It's time to smile bigger than you have ever smiled before- let me see how big you can smile- now show me your teeth and all of your mouth- hold that smile I need to take a picture, say cheese. Now relax that cute smile. (Repeat- I need one more picture...)



Do you see that beautiful butterfly? Oh my goodness he landed right on your nose, how silly! Try to get him off by scrunching up your nose so you can see how pretty he is. Make more wrinkles in your nose and try to wiggle it- this butterfly is SO pretty and I want you to see him. You did it! He flew off, relax your nose and tell me what colors he is. (Repeat)

Take 2 super big deep breaths- so big that you can feel them in your belly and your shoulders get so tall. Now breathe out nice and sloooooow.

I see the cutest baby elephant and he is not watching where he is going. Silly baby elephant doesn't see you lying down and he's about to step on your tummy. Here he comes, get ready- there's no way he can hurt you if you hold in your tummy. Make your tummy muscles tight and get ready for him to step on you! Oh my goodness, you have a baby elephant on your tummy and he is so cute! Hold your muscles tight. Ok, he sees a big ball and is walking away- you can relax your tummy. Uh-oh, he turned around and is coming back. Get ready! (Repeat)



Now let's pretend you are standing barefoot in a big fat mud puddle. Squish your toes deep into the mud. Squish so hard so you can get really really messy and get your toes all the way to the bottom of the big mud puddle. Push down with your legs and spread your toes apart. Feel the mud squish through your toes. Ooooooh! Now step out of the mud and relax your toes and legs. Oh my goodness you are so messy! (Repeat)

Relax your whole body, hang your arms down low. Take a few deep breaths, breathe them out and open your eyes. You did so well relaxing your whole body! Super job.

Key Points:

1. As you become more familiar with CGM, you may worry *less* about your child's diabetes management. Using CGM may take more time at first, but it will likely help decrease the burden of diabetes management over time.
2. Sensor insertion can be difficult but using distractions and/or pain prevention tips can help ease the process.



3. Look around your family and friends to find someone who can help or support you with your child's diabetes care. Praise your child and celebrate with him/her when he or she gets through the tougher parts of diabetes management, like sensor insertion.
4. It may be helpful to relax yourself and your child before sensor changes.

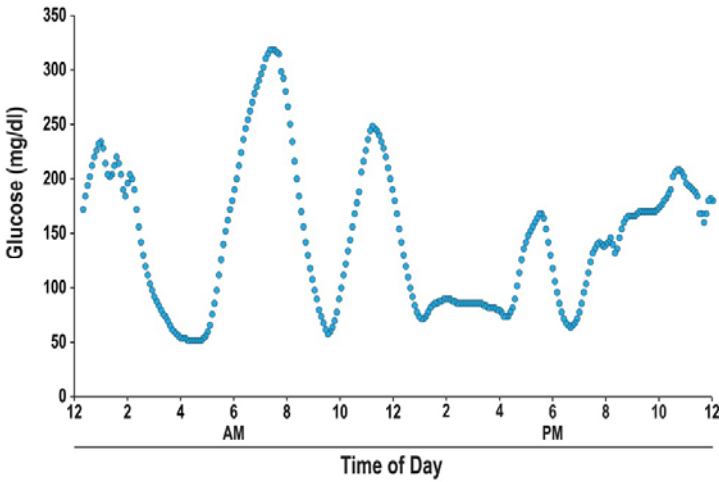
Module 2: CGM and Glucose Ups and Downs

1. The Glucose Roller Coaster

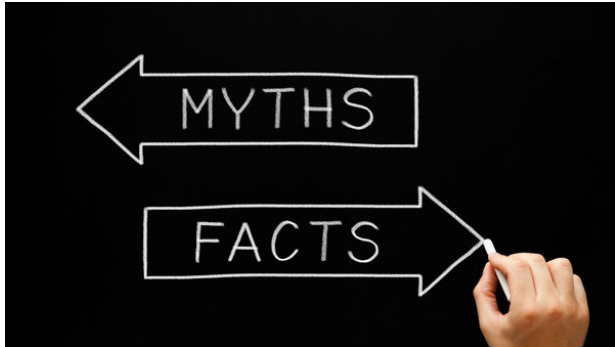
Guess what?

This graph represents a typical day for a child with type 1 diabetes! All children with T1D experience lots of glucose ups and downs (variability) over the course of a day.

Ups and downs can be expected... and when using CGM, you will see even more of them!



“Using CGM will get rid of the high and low glucose levels we see every day.”



“Using CGM is a tool that will let us know when the glucose levels are rising or falling and give us a chance to get glucose levels back in range more quickly.”



2. Signs and Symptoms of Highs and Lows

What are your child's most common symptoms of low or high glucose levels?

CGM can help you identify the highs and lows.

Many young children do not show clear symptoms of their low or high glucose levels and they cannot communicate clearly how they are feeling.

Your child is irritable.
What is going on?
When has this happened to you?



Let's revisit the example from earlier:

Is she crying because of a low glucose, or is she just having a temper tantrum? Do I need to do a blood glucose



Without CGM

She's been quite cranky. Is she having a low? Let me check her CGM. The CGM says 175 and the arrow is horizontal.

WOW! CGM made that easy!

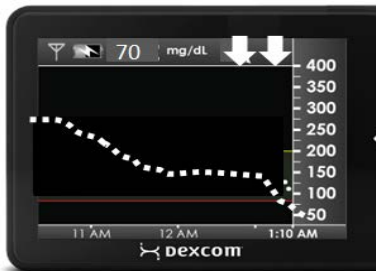
Now that I know hypoglycemia isn't the reason, I can figure out what is making my young child so upset.



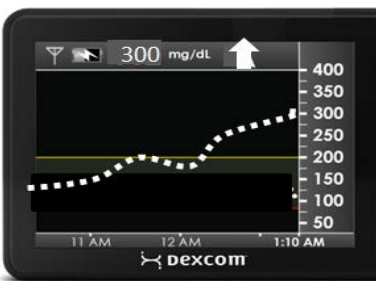
With CGM

3. Identifying your Emotions Associated with CGM use

CGM glucose values and trend arrows are very helpful. Some parents report that the glucose values or trend arrows can make them feel nervous or frustrated.



How do you feel when the display device looks like this?



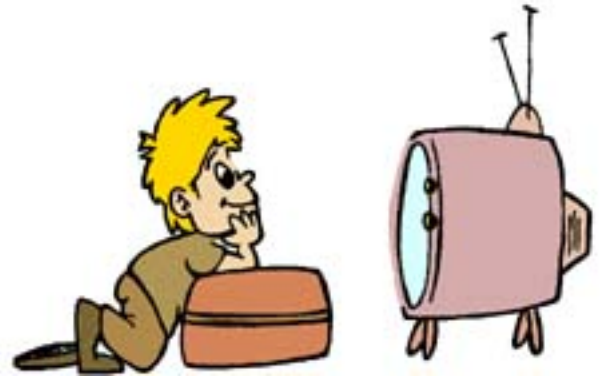
How do you feel when the display device looks like this?

Feelings can impact how we act:

- When we are feeling upset or worried, we might act in a rash way without carefully thinking through what to do next, OR we might wait too long to decide what to do.
- On the other hand, when we feel **calm and confident**, we can think clearly about our options and take a smart course of action.
- CGM gives so much more information and may bring on more or different emotional reactions than you had been used to having.
- Understanding how you're feeling about the CGM information can help you find a way to act in a calm and confident way as you take care of your child's diabetes.

Consider this scenario:

Billy's mom, Sharon, gave him a bolus before dinner. After dinner while watching TV, Billy's mom takes a look at his display device and it shows a high glucose with trend arrows up. This makes her anxious and she wants to give another bolus. She knows she should wait 2-3 hours to let the initial bolus lower the glucose but this is difficult to do because of how she is feeling.



We all experience intense emotions at times that do not make us feel good, emotions like anxiety or anger. At times these emotions may drive different behaviors.

If Sharon acts on her anxiety she may give Billy a bolus he doesn't need, possibly leading to a low glucose.

If Sharon recognizes her anxiety as the reason she wants to give a second bolus, she may be able to take a step back and consider other options with **calm and confidence**.

Learning to recognize emotions around glucose values/trends arrows and being able to still make good decisions will make you an excellent role model. Over time your child will learn from you how to react and manage out of range glucose values

Remember:

- CGM provides valuable information to guide diabetes management and it is natural to have feelings with the varying glucose numbers.
- You know what to do to help your child! (e.g., how to treat a low, a high, or just wait to see how your recent treatment is working)
- If you have any concerns or questions at all, you can always call your diabetes team

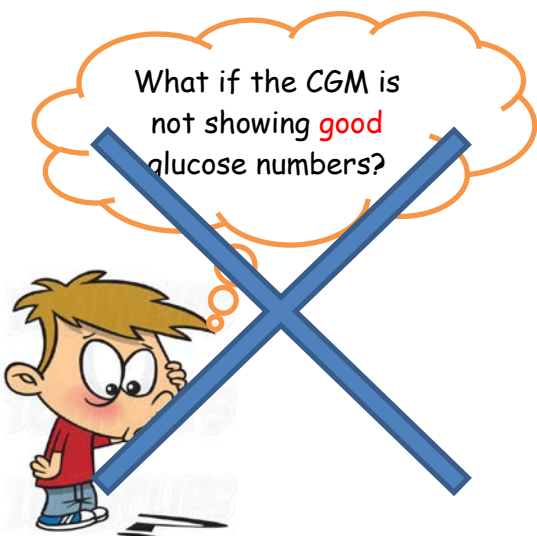
4. Addressing your emotions associated with CGM use

- Feeling nervous or upset with out of range values is natural
- It is important to identify these emotional reactions so that they do not direct our behaviors
- It is also important to come up with strategies to stay calm or to calm down when experiencing emotions associated with CGM use
- Your child will remain safe and healthy when you can react to these numbers in a calm and confident way.



What helps you to calm down when you are anxious or upset about out of range glucose values?

5. Talking about high and low glucose levels



No glucose number is a **GOOD** or **BAD** number - all results are important information to help direct your child's diabetes management.

ALL glucose levels are either HIGH, LOW, OR IN RANGE - and arrows show that the glucose levels are either *RISING, FALLING, or STABLE (or flat)*.

Your diabetes research team can help you identify the best ways to manage your child's diabetes when the glucose levels are out of range.

Key Points:

1. Highs and lows are expected and with *CGM* you will see even more of the glucose rollercoaster ups and downs.
2. *CGM* trend arrows can help you make informed decisions about diabetes treatment.
3. *CGM* is a tool that can help identify if your child's behavior is related to out-of-range glucose values, for example, it can help distinguish a typical toddler tantrum from a low glucose level.
4. Seeing out-of-range glucose values you didn't know about before starting *CGM* can be upsetting. It is important to recognize those emotions and focus on the confidence that you have related to caring for your child's diabetes; you can be calm and confident in caring for your child.
5. The way you respond to *CGM* data will teach your child on how to respond - you have an opportunity to be a model! Show your child how to manage stress and how to respond in a **calm** and **confident** way.



Module 3: Life with CGM

Common Experiences

Many families experience various feelings and challenges related to CGM.

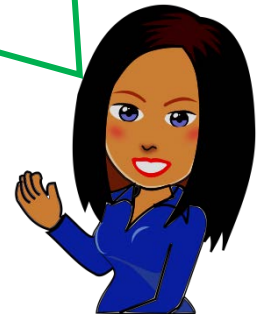
Experience 1: Management Success



Since everything has been going so well, I don't think we need the CGM this week!

Every family figures out how the CGM fits best into their child's diabetes management.

With physical growth, changes in schedules and many normal childhood illnesses glucose levels can be affected!



Experience 2: Glued to the Display Device



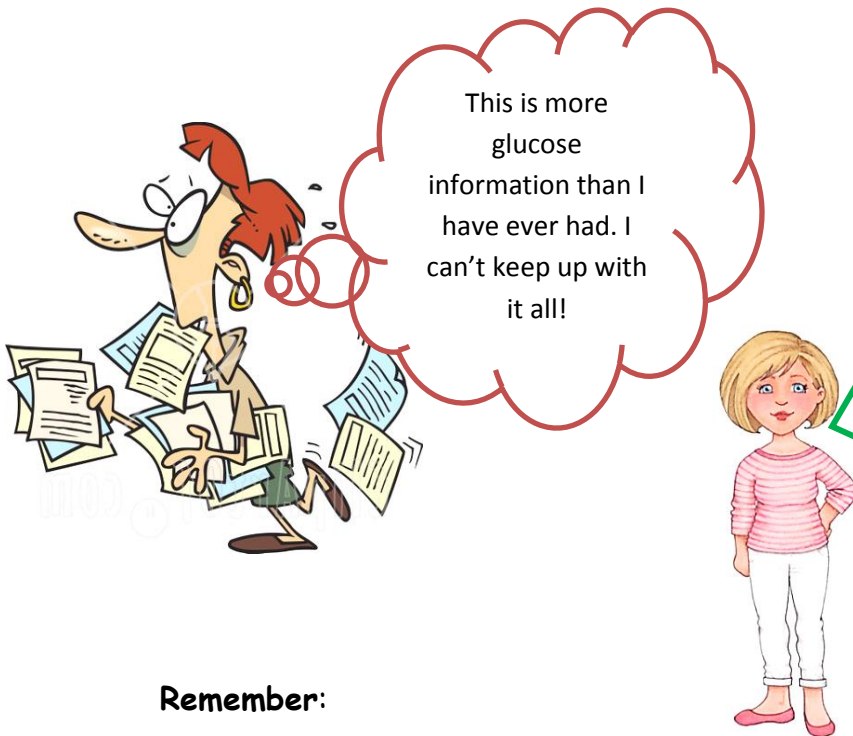
I seem to look at the display device almost every second of everyday to check the glucose value!



At first, it can feel exciting to keep up with every value and arrow.

In time, you figure out what works best for you. How often you look at the display to stay informed without feeling glued to the display device all the time is a personal decision.

Experience 3: Information Overload



This is more glucose information than I have ever had. I can't keep up with it all!

CGM gives you a lot of information every day and downloading the CGM gives you even more data. Some people may feel burdened because it is a lot of information to process.

Talk to your study team to help you make sense of all the data. Or you can try looking at only 1 aspect of the data at a time such as seeing how a particular food or activity affects glucose levels.

Remember:

- The CGM display updates glucose readings every 5 minutes.
- You should not expect to see a big difference between readings.
- With the frequent readings, the CGM provides **valid and important information about glucose trends**.
- Downloaded CGM data (called "retrospective review") provide lots of information to help make overall insulin adjustments.

CGM & Correcting High Glucose Levels:

Insulin can take 2-3 hours to lower a glucose level. You **WILL NOT** see a change in glucose 5 minutes after dosing and it can take 15-45 minutes to see a trend arrow downward.

A trend arrow downward lets you know that the insulin is working to lower the glucose - so the CGM can give you confidence that your management is working!



CGM & Treating Lows:

After giving carbs to your child, it can be helpful to look at the CGM 10-15 minutes later to ensure the glucose is rising.

Experience 4: Alert Fatigue

Alert fatigue - when there are many alerts that begin to feel annoying or like *nuisance alarms*.

Many families tell us that alerts can be overwhelming. First we want to discuss how the alerts are tools. We also want to discuss some tips to make them more manageable.



Alerts:

- High alert
- Low alert
- Rise rate alert
- Fall rate alert
- Out of range alert (communication lost between transmitter and display device)



Use the alerts as aids so you do not feel like you have to consult the display device every 5 minutes.



- Remind yourself of the benefits of alerts - they can make you aware of highs and lows you would not otherwise know about
- Talk to your study nurse or study doctor about possible adjustments to your alert settings to avoid "nuisance alarms"
- Practice using relaxation exercises if helpful to you

Experience 5: Burnout

Think about a time when just managing your child's diabetes was exhausting - even **before** CGM. How does CGM add to that possibility?



Wow. There's a lot of information from that CGM. And those alerts! They can be so frustrating and annoying. It's all too much!

Understanding how the CGM works can help prevent burnout

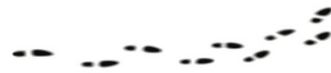
Remember:

- ❖ The CGM reading and the blood glucose meter may not match exactly. That's why it is important to calibrate the CGM twice a day.
- ❖ CGM gives a lot of information and can get tiring! CGM also requires extra work and thought, but all of the information is valuable for your child's diabetes management.
- ❖ If you ever get frustrated, remember you are NOT alone. Use some of these tips to help you.

If you are feeling overwhelmed:

1. Focus on one aspect of diabetes management at a time. Food? Activity? Insulin?
2. Try a relaxation activity or any of the other strategies we've talked about.
3. Pick certain times each day to look at the CGM display so it doesn't feel as overwhelming
4. Ask others for help and support

Making *SENCE* of CGM problems



What are you trying to find a solution for? Be as specific as you can!

S: state the specific problem

E: explore possible solutions

What are the pros and cons of each idea? Which ones are most realistic?

N: narrow the choices

Come up with every possible idea: what actions can you take? How can you manage emotions? Don't worry about picking the best solution yet, just come up with a bunch of ideas.

C: choose the best solution

E: evaluate the plan

Pick a solution and try it out!

How did it go? Did you solve your problem? If not, pick another possible solution and try again!

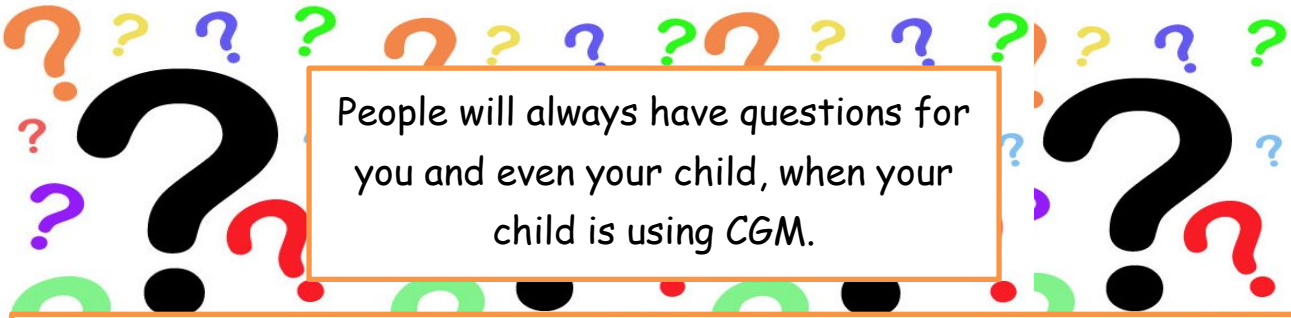


Key Points:



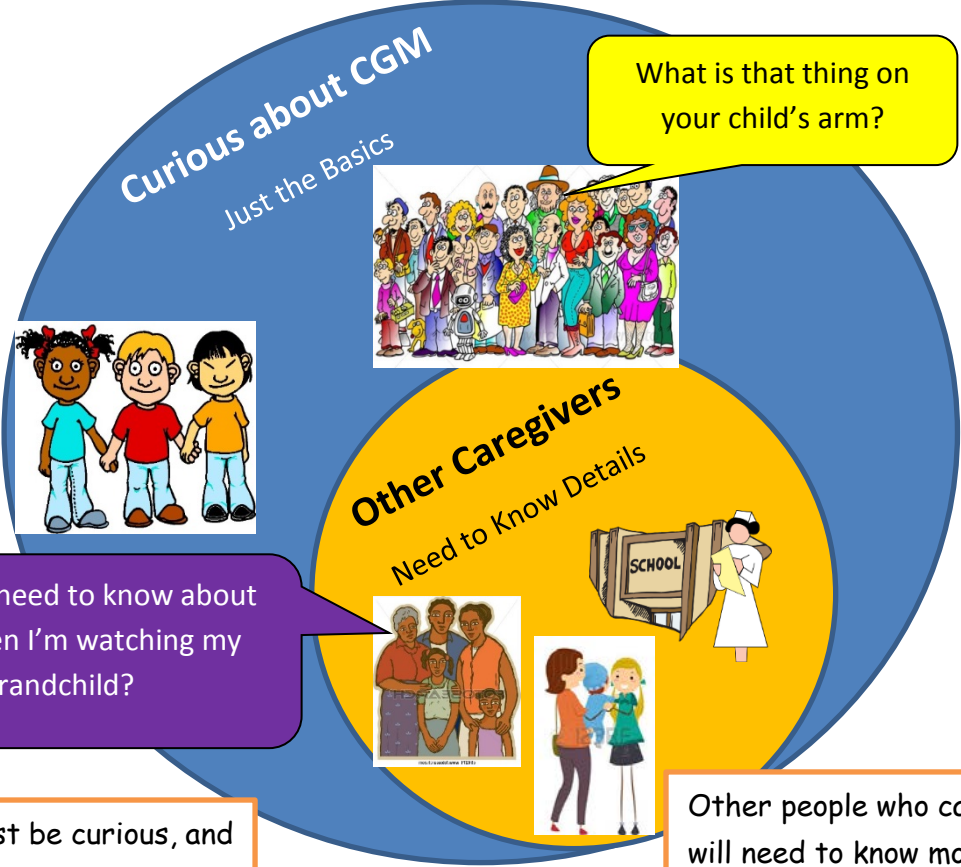
1. Reward yourself for your hard work and commitment to your child's diabetes care.
2. Try some of the strategies you have learned here to relieve any stress you may feel.
3. If you encounter problems with the *CGM* alert settings, talk to your study nurse or study doctor.
4. Who else can offer you support? Think about friends, family, other parents whose children use *CGM*
5. Over time the *CGM* data can help you identify factors associated with out of range numbers so that you can make more informed management adjustments.

Module 4: CGM Away from Home and with Other Caregivers



People will always have questions for you and even your child, when your child is using CGM.

Some people may *want* to know and others will *need* to know about your child's CGM.



Some people may just be curious, and you can share a little bit of information with them if you choose.

Other people who care for your child will need to know more information to help in your child's diabetes management.

It takes your time and energy to explain diabetes and CGM to others in your child's life. It is natural to have different thoughts and feelings about this process.

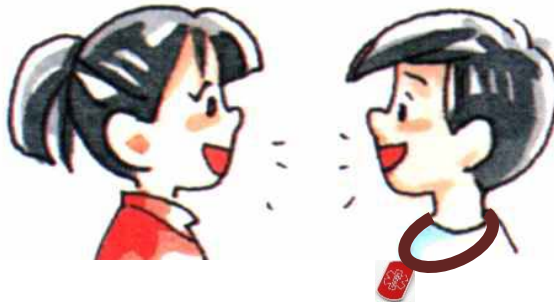
The Curious People - Just the Basics

It's the first week of school, and your family decides to go to the Welcome Back Carnival. Your child is having a great time, and you're keeping an eye on the *CGM*. Then another parent says to you, "What's that on your child's arm?"

How will you answer people's questions?

HELPING YOUR CHILD EXPLAIN THEIR *CGM*:

Hey, what's
that thing
you're wearing?



It's for my diabetes!
It helps me do
everything that I want
to do while the grown-
ups care for my
diabetes.

- Think about how much information you want to share with your child.
- Keep in mind that children of different ages need different amounts of information.

Talking to your child about *CGM*:

- Use clear, simple words to describe *CGM*
- Try not to use a panicky tone of voice or negative language about *CGM*

Other Caregivers - What they need to know



Your child's other caregivers need to know about your child's diabetes management and now about your child's *CGM*.

Teaching Other Caregivers about CGM

All you have learned about *CGM* over the past few weeks will be brand new to other caregivers.

Topics to discuss with other caregivers



1. Benefits of *CGM*
2. Components of *CGM*
3. How to understand the display device
4. How should other caregivers respond to alerts and trend arrows? i.e. *CGM* comes off, low alert, high alert, two arrows down
5. How you will communicate with other caregivers
6. How you will prepare for questions and comments from other caregivers

1. Benefits of *CGM* for Other Caregivers

CGM can:

- Allow other caregivers to see what is going on with your child's glucose levels without doing fingerstick checks
- Help the caregivers know when they need to do something or when they need to call you
- Provide reassurance to the other caregivers (alerts and trend arrows will help them)
- Provide reassurance to you when your child is in the care of others
- Alert for high or low glucose levels are useful as reminders and a means for other caregivers to not be glued to the display device

2. Components of the CGM



The take-home message:
CGM helps keep your child safe.

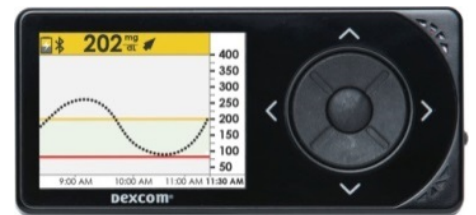
- CGM helps keep your child safe in their daily activities and overnight.
- By being aware of high and low glucose levels sooner, you can manage diabetes more easily and with less worry.

CGM gives your child the freedom to do what he or she wants to do, and also permits adults responsible for your child's care to be alerted to out of range glucose levels.

The child wears the **sensor and transmitter** on his or her body

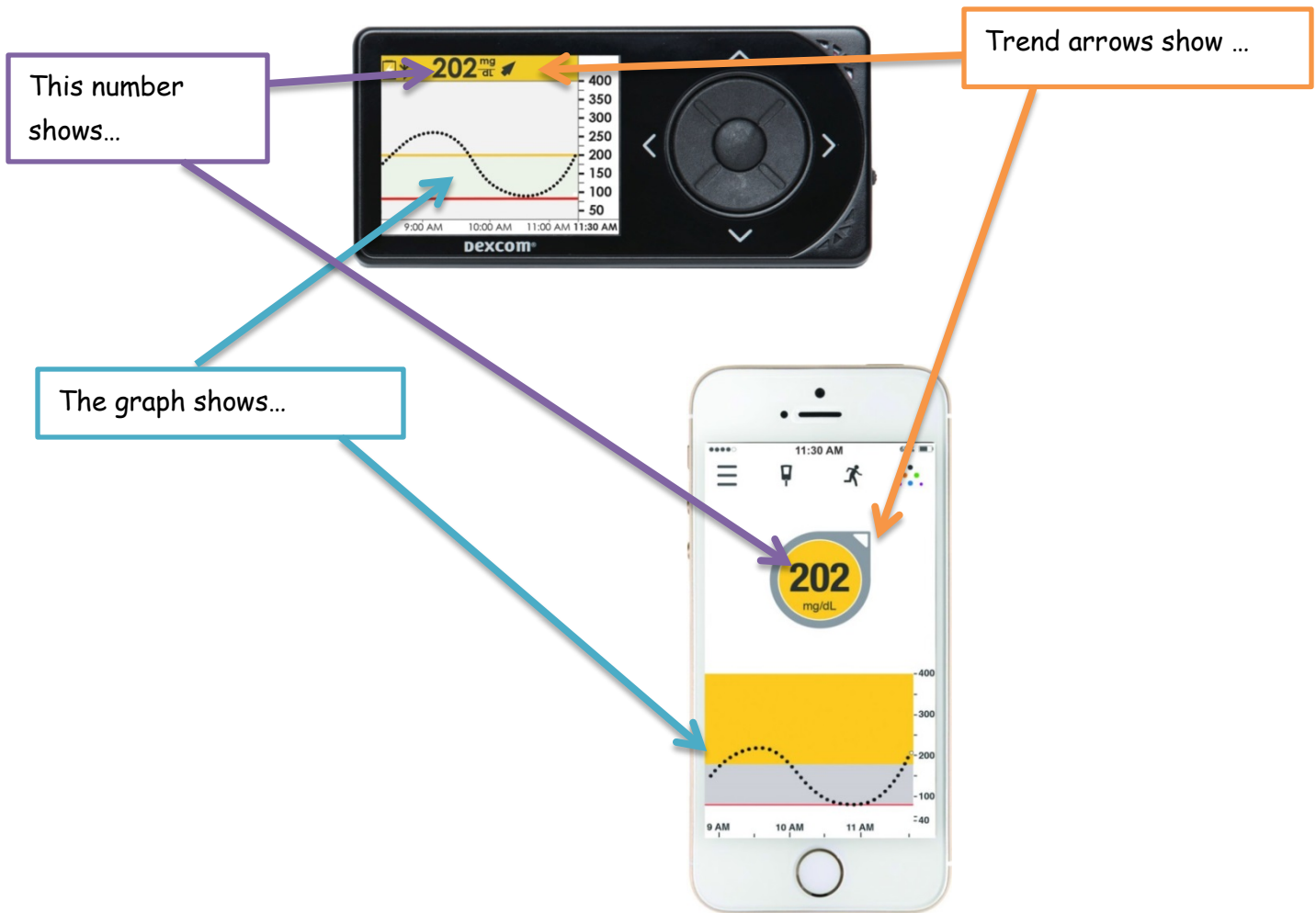


The transmitter sends info to the **display device** (receiver or a smart phone) via Bluetooth.



(Phone is optional)

3. How to understand CGM Display Device



4. How should other caregivers respond to alerts and trend arrows?

- Remind your caregivers they likely have time to react to the CGM numbers and trend arrows! Although low glucose levels may need to be confirmed by a fingerstick and treated immediately.
- CGM gives great information, and remember, the CGM and blood glucose fingerstick reading may not match exactly but they may be both functioning correctly.
- While the other caregivers will likely not be accessing the screen that sets alerts they do need to know how to respond and silence any alerts that they may hear

5. Plan ahead to inform other caregivers about CGM

Communication is Key! Make a plan for communication with the other caregivers BEFORE your child is in their care.

Things to address:

How will we communicate? (text, email, phone?)

When will we communicate?

Which CGM readings or alerts require immediate attention? Which can wait?

How should the caregiver speak to your child?
(language about CGM, tone of voice?)



6. Preparing for questions and comments from other caregivers

Be prepared for comments or questions from other caregivers related to your child's glucose levels

Remember:

- Glucose levels vary and you are doing your best to keep your child healthy. You do not have to respond to questions by other caregivers immediately.
- If you are feeling overwhelmed:
 - Consider the relaxation exercises you have learned.
 - You can let the other caregivers know that you will get back to them after you discuss their questions with your health care team.
 - Answer questions with phrases like:
 - "Thank you so much for your concern. The CGM sure gives us a lot of information, and it's helping me take great care of my child's diabetes. We are following the instructions our healthcare team has given us."



Key Points:



1. Consider which people in your life fit in the curious people group, and which people fit in the need to know group.
2. When explaining the *CGM* to friends, you can keep it simple and describe the purpose of the device overall
3. Helping your child understand the importance of the *CGM* can help them explain the *CGM* to friends and classmates - use simple language and just the basic concepts.
4. Other caregivers can learn to use the *CGM* and treat your child as you deem appropriate
5. Have a conversation with your secondary caregiver about how to use the *CGM* for appropriate treatment for your child!

Module 5: Moving Forward with CGM

Getting to know CGM:



CGM can take extra time:

- CGM takes time - some tasks take longer than others (insertions, supplies, etc.)
- The time is well spent - CGM is a valuable tool that can help your family manage diabetes
- Hopefully, you and your family are starting to feel more confident with CGM and the time it takes is manageable

Sensor insertions:

- Distracting your child to ease the process
- Asking others to help you
- Icepacks or topical numbing cream

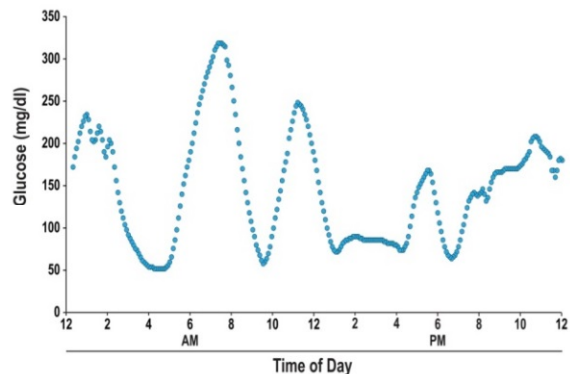


Alleviating stress and celebrating with your child:

- Try relaxation activities
- Celebrate with your child after completing the more challenging tasks related to diabetes management



CGM and glucose ups and downs:



Trend Arrows and Tracings

CGM information can be a tool to help you decide what to do next.



- High and low glucose levels are expected. With CGM, you have more opportunity to see these ups and downs.
- Being aware of the highs and lows can help you decide what to do next to best manage them - this way you can **increase your child's glucose time in range!**
- CGM data can also help you make sense of behavior changes in your child.

Remember:

- What you're doing moment to moment makes each day go better. As more days go well, that can add up to overall improvements in diabetes-related health and well-being.
- While this can be hard work, using the information CGM gives you can hopefully make it feel worthwhile.

- If you see a glucose value that upsets you, remember to take a moment to yourself. You will make your best decisions when you manage your emotions.
- This is an opportunity to be a role model for your child. Stay calm and keep stress at bay.

Life with CGM:



Experiences with alerts:

- Alerts are an opportunity to manage glucose levels before they get too far out of range and become a problem.
- Think about when you first started hearing alerts. Hopefully, you are now able to use the alerts to your advantage.

CGM Burnout:

- You put a lot of effort into caring for your child using CGM. From time to time most parents feel tired or burned out from it all.
- You've learned a lot of strategies to manage this burnout. Hopefully, some of these strategies have been helpful to you.



Problem solving:

SENCE problem solving

- **S:** state the specific problem
- **E:** explore possible solutions
- **N:** narrow the choices
- **C:** choose the best solution
- **E:** evaluate the plan

Support:

- It is important to ask for help when needed - we all need a hand sometimes or need to talk to a friend for support.
- Being able to ask for help may provide you the chance to take a small break or to take a deep breath.

CGM Away from Home and with Other Caregivers:

Other people in your child's life:

- Remember the difference between the **curious crowd** and those who **need to know more**.
 - Think about which bits of information you feel confident sharing.





Other caregivers:

- *CGM* can give other caregivers more information about your child.
- Other caregivers can easily check the display device or hear an alert to see how things are going.

Your child and *CGM*:

- Use simple terms when explaining *CGM* to your child.
- Share age appropriate information.
- Using a calm and positive tone can really help your child understand the benefit and importance of *CGM* without being annoyed or scared by it.
- Your child learns from you. The way you talk about and respond to *CGM* information teaches your child how to use *CGM* now and in the future.



As you move forward:

- Please refer back to the packet of information when needed. You have worked hard to learn about and use the *CGM*. Your commitment seems to really have helped in managing your child's diabetes and glucose levels.
- When you get stressed, remember how far you've come and what a great job you and your family have done!
- Your growing confidence with *CGM* helps your child in general and your child's diabetes care overall.



Think about how far you've come!

- See how much you have learned about your child's diabetes care by using *CGM*.
- Also, look ahead and think about how you can continue to grow with *CGM* over time, even after our meetings end.
- **AND** all of your efforts help **increase your child's glucose time in range.**