



**T1D**  
*Exchange*

**PPAC**

April 12, 2023

# Agenda

- Welcome
- Brainstorm sick day guide dissemination ideas
- Discuss creating a resource guide to help clinics engage PWD and their families into care team QI projects
- Discuss November 2023 Learning Session

# Updated Sick Day Guide



When a person with type 1 diabetes (T1D) gets sick, blood glucose (or sugar) can increase drastically. This can cause the blood to become acidic and lead to diabetes ketoacidosis (or DKA), a dangerous and life-threatening condition that requires immediate medical attention.

T1D Exchange Quality Improvement Collaborative (T1DX-QI)'s Patient Parent Advisory Committee and physicians have created this Sick Day Management guide for people living with type 1 diabetes to manage their blood glucose when ill and provide tips to prevent DKA.

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## What to do if sick:

1. Check your blood glucose level every 2-4 hours.
2. Check for ketones using a ketone meter or urine ketone strips.
3. Drink plenty of fluids, such as water, sports drink, or broth (diet or regular depending on blood glucose levels.)
4. Never stop giving yourself insulin completely. In fact, more insulin may be needed when you are sick. Contact your healthcare team for guidance on whether, when, and how to adjust your insulin doses.
5. Vomiting with ketones could be a symptom of **DKA** which means you may need more insulin. *(Note: Some providers will prescribe anti-nausea medicine (Ondansetron) to reduce vomiting and nausea. However, because this medication can mask symptoms of DKA, consult with your healthcare provider about what is right for you.)*
6. Contact your healthcare team if you:
  - a. Vomit (**assume it is DKA**)
  - b. Have moderate or large ketones
  - c. Experience any **DKA** symptoms (listed below)
  - d. For any point you have concerns
7. If you can't reach your healthcare team quickly
  - a. If you experience DKA symptoms, go to the nearest emergency care center.
  - b. Contact a friend or family member to help you.



## SIGNS & SYMPTOMS OF DKA

- inability to drink fluids or urinate
- BG above 240/250 mg/dL
- very dry mouth/excessive thirst
- “fruity” smelling breath
- nausea, vomiting
- stomach cramps
- fast and/or deep breathing

**DKA** - Diabetes Ketoacidosis develops when your body doesn't have enough insulin to allow blood sugar into your cells for use as energy.

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# Updated Sick Day Guide

## What to do in advance:

1. Discuss a sick day plan with your health care provider at your next appointment
2. Have supplies ready for treating low blood glucose (hypoglycemia)
  - a. For mild hypoglycemia, have fast acting carbohydrates (ex. juice, full sugar sports drinks, full sugar ginger ale or candy such as glucose tabs, honey, or fruit snacks)
  - b. For severe hypoglycemia, have glucagon available (injectable and/or nasal) and know how and when to use it. Determine if mini-glucagon injections may be helpful to you (discuss this with your healthcare team)
3. Keep an updated list of emergency contact numbers nearby
  - a. Friends/family who can help
  - b. Physician's office and physician's office on-call number
  - c. Street address of your closest 24-hour care center and/or emergency team
4. Bookmark a reputable, online sick day app or website. Here is one good option:  
<https://www.umpedsdiabetes.com/sick-day-guide>

## Sick Day Guide Citations:

- <https://onlinelibrary.wiley.com/doi/10.1111/pedi.13415>  
Phelan H, Hanas R, Hofer SE, James S, Landry A, Lee W, et al. Sick day management in children and adolescents with diabetes. *Pediatric Diabetes*. 2022;23(7):912-25.
- <https://diabetesonthenet.com/wp-content/uploads/pdf/dotn024ae8fb1b78500b7bc752b98e9b6d92.pdf>  
Down, Su. "How to advise on sick day rules." *Diabetes Prim Care* 22 (2020): 47-48.
- <https://pubmed.ncbi.nlm.nih.gov/30079506/>  
Laffel LM, Limbert C, Phelan H, Virmani A, Wood J, Hofer SE. ISPAD Clinical Practice Consensus Guidelines 2018: Sick day management in children and adolescents with diabetes. *Pediatr Diabetes*. 2018 Oct;19 Suppl 27:193-204. doi: 10.1111/pedi.12741. PMID: 30079506



**This Sick Day Management plan should not replace the need to reach out to your diabetes team. In an emergency call 911.**

### Acknowledgments:

Thank you to T1D Exchange's Quality Improvement Patient Parent Advisory Committee and our network of clinics for contributing to this resource.



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# Sick Day Guide Dissemination

- T1D Exchange website
- Collaborative clinics' websites
- ADCES website
- Remaining needs
  - Translation (prioritizing Spanish first)
  - Other translation opportunities?

# November Learning Session

Tuesday November 14 and Wednesday November 15

New York, New York, in collaboration with the T1DX-QI centers in NYC (Albert Einstein, Cornell, Mount Sinai, Northwell Health, and NYU Langone.)

# Engaging PWD

How can we help clinics to meaningfully and authentically engage with PWD and their families?

Goal: make a guide that can help clinics engage with patients and families in the QI work and present this at the November 14-15 Learning Session.

# What do clinics see about involving patients in QI work when they join?

Language that is written into their contracts:

## Patient/Caregiver Team Representative

- If desired, receive training in QI fundamentals.
- Attends in person Learning Sessions during the first year to supplement the fundamentals training and share with the other selected sites the team's experiences testing interventions.
- Engaged in local QI efforts at the clinic level
- Participates in 90-minute Collaborative calls quarterly to report on progress and discuss issues.
- We also recommend a patient/parent representative from each clinic participates on the Patient/parent Advisory Committee, but that does not have to be the same team member involved in the above efforts. Those meetings are held quarterly.



# Engagement

- Video from IHI: clinician talks about her hospital's experience of engaging patients. They tied it to safety and specifically asked patients that they had harmed if they would give advice- to help prevent future harm.

<http://www.ihi.org/education/IHIOpenSchool/resources/Pages/Activities/Bintz-EngagingPatients.aspx>

- Guide developed in Ontario, offers practical tips on how to involve patients in QI.

<http://www.hqontario.ca/portals/0/documents/qi/qip/patient-engagement-guide-1611-en.pdf>

- Amy- made this short video for us on this topic.

<https://www.youtube.com/watch?v=gse9W6WV87U>

# Engagement suggestions

- Involve PWD from the beginning to ensure that the decisions reflect what is meaningful for them.
- Be humble and transparent in your approach. Don't pretend that everything is perfect or that you have everything figured out.
- Don't be afraid to show real numbers/data to PWD with poor results. You can acknowledge the health inequities and how the hospital/division is working to address them and change them.
- Invest time in building a cohesive team of people who care and contribute to its success.
- Patient advisors don't want to advise without their opinions being heard/incorporated. When I worked with a group of primary care patient advisors, one of them talked about a bad experience she had with her care. When she saw her primary next- she could see her PCP was really stressed out so she let the issue slide. She acknowledged that the "systems" are imperfect. She recognized her doctor's humanness, and she gave her a pass/break. Her telling that story led us into a future conversation about the problem of systems and how the patients could be advocates for systems change- it was powerful.

# Next Meeting

- Wednesday July 12<sup>th</sup>