

OFF TO COLLEGE WITH DIABETES



GUIDE FOR CAREGIVERS

LETTER FROM A PARENT

Dear Parent,

My name is Moira, and I know your pain. You're scared, anxious, overwhelmed and maybe even just plain freaked out. Whether you are about to drop your child off at college or just starting the planning process (or hey, maybe your kid is 9. You know how we D-parents plan ahead!), you are probably feeling all of this and more.

I'm here from the other side to tell you the one sure thing about it all: It is going to be fine. I repeat: It really is going to be fine.

Six years ago when I dropped my daughter off at college 500 miles away from home, I was as unsure as a mom could be. To be frank, she was not paying the utmost attention to her daily diabetes care. But her amazing (and new!) adult endo had told me with all certainty that letting her go was the right thing to do.

I had friends who had sent kids off to college with diabetes, and almost every one of them had told me that it was all going to be fine. I adore them, but it was hard to believe them. They were right.

College is a mini world where our kids (diabetes or not) practice being in the real world. In college—unlike real life—they have support and back up; departments and people to help them learn to navigate it all. So here is my biggest tip: let them learn to navigate this world by not doing it for them.

That manager in the student health center? He knows that your child has probably never walked into a place like that and advocated for herself before. He's ready to ease her into that experience. Those folks in the advising office? They know these kids are planning out their schedules on their own for the first time.

Letting my child do all that on her own was a big reason that when she graduated, she was ready. Today, my daughter is a hard working health care advocacy lobbyist who lives 500 miles away from me and juggles working full time, graduate school courses, babysitting on the side, bottomless brunches, volunteering for JDRC, mentoring children, and oh, right: diabetes.

College was a lesson for her and for me. It was our time to transition to a place where she rules her life and I am her back-up and support (I always will be, I'm her mom!) I'm proud of how brave we both were on that day in September six years ago.

I encourage you to be brave too. And if you need to, reach out to me. You know what I'm going to say? It's going to be fine.

Moira McCarthy

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Thank you to the CDN Clinical Advisory Committee Members for their assistance in developing the content for these booklets.

INTRODUCTION

Your child is heading off to school soon and you're filled with so many different emotions.

This is what you've been working towards with your child for 18 years, but this exciting time can also be filled with worry for any parent (*let alone a parent of a child living with type 1*).

This booklet is here to help ease your mind. Young adults with diabetes from across the country have helped assemble the following wisdom based upon their real-life experiences. We at the College Diabetes Network (CDN) are here to help you and your child navigate all the stages of college life.

DISCLAIMER

This booklet contains no medical advice. Discuss any medical decisions with your doctor. All information shared by peers is regarding their own personal experiences. The information contained in this booklet was reviewed by the American Diabetes Association® and TCOYD.

The College Diabetes Network

The College Diabetes Network (CDN) is the only organization focused exclusively on helping teens and young adults with T1D transition to independence – facilitating peer camaraderie and programs, and providing life-changing information -- giving young adults the confidence to take ownership of their health to live a full life without compromise.

CDN equips young adults with the confidence to manage T1D while in college by providing information on topics that, let's be real, aren't typically the highest priority during a typical endo appointment. *Some of these topics include, but are not limited to:*

- ▶ Scholarships
- ▶ Drinking with diabetes
- ▶ Technology and data sharing
- ▶ How to communicate effectively with family members
- ▶ Emotional wellbeing
- ▶ Accommodations and student rights
- ▶ **We've got it all—and more.**

CDN Membership You can sign up online for free at collegediabetesnetwork.org/signup! CDN Membership can provide you and your child with:

Benefits, promotions, and giveaways from our partnering organizations and corporate members, and exclusive access to internship and job openings.

Notifications about clinical trials and patient advisory committees looking for participants.

Alerts on new things affecting the diabetes community and updates from CDN students across the country.

CDN Campus Chapters Visit the CDN website for a list of all the active campus Chapters in our network. Don't see your child's school? Don't worry! There are other ways to connect, or your child may want to start a Chapter of their own. Email chapters@collegediabetesnetwork.org to learn more.

Online Resources Our website has tons of resources. You'll also find an awesome blog full of real-life experiences from students.

Parent Facebook Group CDN moderates a private Parent Facebook group where you can connect and chat with other parents of T1D young adults who get what you're going through. Visit facebook.com/groups/CDNParentgroup to request access.

CDN Direct Contact Lastly, CDN staff and students are always available for questions, concerns, or just to chat. Don't be shy, say hi! info@collegediabetesnetwork.org



The content in these booklets has been reviewed by



Thank you to our distribution partners



THANK YOU TO OUR SPONSORS

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We want you to spend your time searching for schools, not scouring the internet for diabetes resources.

CHRISTINA ROTH
CEO AND FOUNDER

The College Diabetes Network would like to thank our 2018 project sponsors Dexcom, JDRF, Insulet Corporation, Lilly Diabetes, Novo Nordisk, Sanofi, and Tandem Diabetes Care, for their support of this project and their commitment to easing the transition from high school to college for young adults living with diabetes. We would also like to thank the American Diabetes Association and TCOYD for reviewing these materials, and AADE, NCBDE, and Children with Diabetes for being distribution partners. Together, with these partners, we are combining forces to make resources and support available to any family in the United States going through this transition—helping to simplify, rather than further complicate it. The content of these booklets is, as always, based on the views and experiences of the CDN and our students. The content is entirely our own, and has been developed independently from any and all sponsors/partners and may or may not represent their views and opinions. So, to sum it up: CDN student wisdom—real tips, real experiences, no bull, and a little bit of sass.

PREPARING FOR COLLEGE







COMMON CHALLENGES FOR STUDENTS ON CAMPUS

STUDENT CHALLENGE

HOW YOU CAN HELP

Dining hall

The dining hall can present a challenge to students with diabetes. It can be tough to access things like nutritional information and serving size, making carbohydrate counting and bolusing feel more like picking lottery numbers.

Staple items

Many students can find all the dining hall options overwhelming, and can sometimes overeat (hence, the 'freshman 15'). Your student may have the same problem. Know that it is very common and your student is making their own food choices, often for the first time. They may make some poor selections, which can impact their blood sugar. Instead of getting frustrated, you can help by offering to stock their room with healthy meal options. Once the novelty of eating grilled cheese each night wears off, your student is likely to start eating a more balanced diet.

Having a sporadic schedule and no routine

College students are known for having crazy schedules. Classes take place at different times on different days; homework, studying and social events dictate their free time, and their eating and sleeping schedules are captive to the above factors each day. This can be a tough environment in which to manage diabetes because it can make seeing patterns difficult.

Support

It may be impossible for your student to keep the same schedule and routine each day. For the first semester or two, ask if your student wants to share their schedule with you so you can help them figure out how to fit diabetes in around their busy days. Your child is learning how to manage this disease, while also balancing the hectic life of a college student—and this is no easy feat. Show empathy and ask what you can do to help from afar.



WHAT YOU CAN EXPECT WHEN YOUR CHILD GOES TO CAMPUS

CAREGIVER CHALLENGE

SOLUTION

Anxiety

This is probably the first time your child is living away from home. Aside from the worries all parents have, you are also concerned about their diabetes management. You may be anxious about them going low or high and missing a test, or having an emergency and not knowing what to do.

Lack of Control

You have played a large role in your child's diabetes management. With them heading off to college, you are suddenly on the back burner of daily management activities. This can be a hard change for many parents to adjust to.

Believe in Your Child

First of all, take a breath. You have raised your child well and taught them how to care for themselves. You have provided them the tools they will need to be successful young adults. They may have some missteps and they will need to learn from them. College is a space in which your child can safely stumble and pick themselves back up. There are many people on campus—from friends, resident advisors, professors, to administrators who they can reach out to for help. They have a larger support system now and they should be encouraged to use it.

Offer Support

While you are no longer the primary caretaker for your child's diabetes, you can still be involved in other ways. Many parents handle insurance questions and ordering supplies while their student is at college. Others transition to the role of moral support and cheerleader from afar, encouraging their student when they get overwhelmed by all that T1D entails. Talk with your student before they leave and ask them what support they would like while they are at school. If you need some support of your own, join the CDN Parent Facebook Group to get advice from other parents who have made it through this transition. Request to join at facebook.com/groups/CDNParentGroup.

FAMILY COMMUNICATION AGREEMENT

Students want their loved ones to get off their back about their diabetes.

Caregivers and loved ones, you're worried about how your child is going to manage their diabetes while away at school.

You can refer to this as a guide to create your own college communication agreement so that everyone feels comfortable with the transition.





CAREGIVERS I promise to...

- ✓ not ask what your blood sugar is unless you bring it up
- ✓ let you be the one to tell other people about diabetes
- ✓ send you care packages and/or help pay for extra supplies
- ✓ Not overreact or get mad when you tell me the truth



STUDENTS as long as you promise to...

- ✓ wear a medical alert ID
- ✓ find support on my campus
- ✓ register with Disabilities Services
- ✓ keep low supplies on hand, always

MORE IDEAS

When will you check-in? How often?
 How often will you discuss their blood sugar?
 What can be said? Who will bring it up?
 Who will be responsible for scheduling appointments?

LOOKING AT SCHOOLS GUIDE

It may be hard to believe, but soon your child will be graduating from high school and heading off to college!

College is a new and exciting time in their life, but it also requires a lot of planning. Encourage your child to start spending some of their free time checking out schools, talking to friends and family about college, and beginning to put together an idea of what they want for the next four years. It's okay if they don't know what they want yet—that's what looking is for.

Make sure your child knows what kinds of things they care about in a school—then they'll know what questions to ask. There is a lot to consider when choosing a college. Be sure that your student takes the lead when visiting a school. This includes booking the visit, asking questions once on campus, and following up after you are home. The key thing to remember is that diabetes shouldn't affect where your child goes to school.

BEST OF LUCK IN THIS SEARCH!

Visit our site throughout your college experience for more resources, tips, and support!

COLLEGEDIABETESNETWORK.ORG





LOOKING AT SCHOOLS GUIDE (Continued)

Scholarships

There are a number of scholarship opportunities for students living with diabetes—so start browsing. We strongly suggest checking our scholarships webpage ASAP so that your child has enough time to apply. Many scholarships are due before students commit to college. Don't forget to check with your child's financial aid office at school too.

CDN Chapters

CDN consists of campus Chapters all across the country that are made up of students just like yours. These Chapters are student-led groups that allow students to connect with others who get it. If your child is interested, they can check out the map on our website to see if the schools they are considering have CDN Chapters. Don't worry if your child has already fallen in love with a school that doesn't have a CDN Chapter. CDN can easily help your child create one at their school or put them in touch with local students living with diabetes. And remember, while having a Chapter is great, it may not be a huge factor in your child's decision of where they go.

Your child can connect with students at a college they are interested in by contacting **chapters@collegediabetesnetwork.org**. They will be able to get a firsthand account of what life is like on campus and ask current students about their diabetes-related concerns. If your child isn't interested in getting involved, don't push it! Many students will come around in time.

Disabilities/Auxiliary Services

Many students don't think of diabetes as a disability, but when it comes to being prepared, registering with the school's Disabilities/Auxiliary Services can be a smart move. At this point in the game just check to see if they've had previous experience with students with diabetes and how they have helped accommodate them in the past.

Health Services/Clinical Care

Make sure your student is aware of where they would seek medical care for their diabetes and what the campus health center is capable of helping with.

Some questions to ask admissions/health center staff:

- ▶ Does the health center have experience with students living with diabetes on campus?
- ▶ Can your student help them to create a plan for how to work with students with T1D?
- ▶ What services does the health center provide?

Residential Life

Dorms are an important part of college life. Consider the following questions regarding campus life at potential schools:

- ▶ How many roommates will your child have?
- ▶ Will your child have a resident director and/or hall advisor?
- ▶ Is there kitchen access in the dorm?
- ▶ Could your child have a fridge/microwave in their room?
- ▶ What does first year housing generally look like?
- ▶ Where are the dorms?
- ▶ Is there any specialty housing your child might want to apply for?

Dining Services

Eating on campus can be a challenge without proper planning. Make sure that your student is aware of what each school provides in terms of dining services.

Consider the following questions:

- ▶ How does the meal plan work? Are there options that will suit your student's needs?
- ▶ Is there access to supplemental food (*i.e. cafés, stores on campus*)?
- ▶ What are the hours of operation for the dining hall?
- ▶ Where are dining halls located relative to resident halls and classes? How many are there?
- ▶ Are there gluten free options (*if your student also has celiac disease*)?
- ▶ Does the dining hall provide nutrition information and/or measuring cups?

(Note: your student can advocate for themselves once on campus and request these—see the 'Dining Hall Eating' section of our website).

Access to Supplies

Your student will need to restock their diabetes supplies while at school.

Consider how and where these supplies will come from.

- ▶ Where is the closest pharmacy? Is there an easy way to get there?
- ▶ How does the mail room handle packages that need to be refrigerated (*insulin*)?
- ▶ Does the health center help with supplies?

Distance from Home

There are schools all across the country and your student might find they fall in love with a school far from home. Make sure they consider what it would be like to be a one-hour car ride vs. a six-hour plane ride away from home. Distance from home is an important consideration for all college students but especially for students living with diabetes.

How far is your student comfortable taking their diabetes from home? For some students, the distance might be too much; for others, it is exactly what they want.

REGISTERING FOR ACCOMMODATIONS FOR STANDARDIZED TESTS

Standardized tests, while stressful, can be essential for your child's higher education. Because of the importance of these tests, the rules can be strict on what your student is allowed to have in the testing room. Many T1Ds apply for accommodations to use for these tests in case they run into any problems with their care during test time. This application process can be long and will differ for each separate test (like the SAT and ACT), but these accommodations can help your child in the case of a diabetes-related event.

Registering for testing accommodations is the perfect time for your young adult to practice self-advocacy before they head off to college. Allowing your student to take the lead on getting these accommodations will kick start the confidence they need to manage their diabetes in college.

While we do suggest that your child registers for accommodations while taking these tests, we know that some students choose not to register. If they don't want to register, it's important to remind them that there could be potential consequences if they don't and that these accommodations are meant to aid in their success during the tests. However, at the end of the day, it is ultimately their decision.

If they do want to register, great! Here are some recommendations for accommodations that they could register for and some hints to help to make the process easier.



How You Can Help

- ▶ Make copies of all accommodation materials and remind your child to show them to their testing proctor.
- ▶ Help your child stay organized and on top of filing paperwork before the deadlines. *(a calendar with important dates and reminders will be a huge help).*
- ▶ Encourage your child to start as early as possible. They only have to apply for accommodations once for each test, so giving themselves ample time increases the likelihood they will get the accommodations they need, and allow them to focus on studying for the exam rather than stressing about their accommodations.

SOME COMMON TESTING ACCOMMODATIONS FOR T1D INCLUDE:



Extended testing time



**Stopped clock to check
and treat blood sugars**

(for glucose testing, bathroom, etc.)



**Bringing food, glucose,
meter, CGM and pump/
shots into the room**



SAT®/ACT® GUIDELINES FOR ACCOMMODATIONS

FIRST STEP LETTER FROM A PROFESSIONAL

If your child is applying for accommodations for either the SAT® or the ACT®, they will need an official letter from their doctor to provide proof that they have diabetes.

This letter should include:

- ✓ Age of diagnosis ✓ Course of medical treatment
- ✓ Limitations diabetes puts on their testing experience
- ✓ How accommodations can help them

** both SAT® and ACT® have a supplemental form for a teacher to fill out to strengthen your application for accommodations.*

GOOD TO KNOW

- ▶ For both tests, if your child is under 18, you (*their parent or guardian*) will need to sign a medical information release form when applying for accommodations.
- ▶ It is up to your child to hold their school administrator/disability officer accountable for submitting their request. Have your child regularly check-in with them to make sure they have submitted the request, or your child may not be approved in time.
- ▶ Your child should only request accommodations that they absolutely need. Requesting excess accommodations can weaken their application and potentially hurt their ability to get the accommodations they truly require.
- ▶ Help your child keep records of the accommodations they receive. If they end up taking tests for graduate school (GRE®, MCAT®, etc.), a record of the accommodations they received on past exams will make the application process much easier.

SAT®

The SAT® is run through the College Board and uses Services for Students with Disabilities (SSD) to register students for accommodations.

- ▶ Your child will register through their high school's disability officer, because they are the only people who have access to submit the request through SSD. If your child is registered for accommodations at their high school, the school will already be familiar with their needs as a T1D.
- ▶ The whole process takes about seven weeks to be approved, so encourage your child to start as early as possible.
- ▶ The College Board website has a list of accommodation deadlines for tests, so remind your child to keep an eye on those and mark them in their calendar!

After Approval

- ▶ Once your child is approved for accommodations, they will receive an SSD number via email and an Eligibility Letter. They will use these when registering for the SAT®. Once your child applies for the accommodations through the College Board and is approved, they will be approved until one year after their high school graduation date. Their accommodations are also approved for all other College Board tests, including SAT® Subject tests, PSAT®, and AP exams.
- ▶ On test day, remind your child to make sure to bring their SSD Eligibility Letter and double check that their accommodations are in place.

ACT®

The ACT® uses a similar process, but a different platform than the College Board for accommodations. It is called the Test Accessibility and Accommodations Center (TAA).

- ▶ Like the SSD system, only your child's high school's disability officer can access the TAA, so the same approach applies with the ACT® test.
- ▶ With the SAT®, your child applies for accommodations before they register for the test, but with the ACT® your child can request accommodations when they register for the test itself. From there, ACT® will email them instructions on how to proceed with the process. It will take approximately two to four weeks for approval.

After Approval

- ▶ Your child will receive an email from ACT® with their approval, TAA pin number, and a list of their approved accommodations.

REGISTERING FOR ACCOMMODATIONS ON CAMPUS

This is a decision your child needs to make for themselves, but here are some talking points you can use when discussing the pros of registering with your child.

Many students with diabetes don't register with the Disabilities/Auxiliary Services office at their school. Although some students simply aren't aware of the option, others actively choose not to register and are turned off by the term 'disability'.

Reasons to Register



PLAN BEFORE AN EMERGENCY

If your student isn't registered with Disabilities Services, they aren't guaranteed any sort of accommodations for problems that may arise due to diabetes. Students can't register for accommodations retroactively. Therefore, if your student fails or misses a test because of high or low blood sugar and they haven't registered, they will have to accept the grade.



SCIENCE!

It is scientifically proven that low or high blood sugar can seriously affect academic performance. Perhaps your student can get a passing grade on a test while their blood sugar is high, but imagine what they could get if it wasn't? Help them set themselves up for success.



HAVING AN ADVOCATE

Most professors are extremely accommodating, but once in a while your student will encounter one who isn't. Registering with Disabilities Services overrides whatever rules they've established around food and drinks in the classroom, the use of technology, and ability to make up exams.



MORE THAN JUST ACADEMICS

Accommodations can also extend to housing, dining, and registering for classes. This can include where your student lives, roommate situations, meal plans and class registration.

A photograph of three young people, two women and one man, looking down at a device, possibly a smartphone, outdoors. The woman in the foreground has dark hair tied back with a red scrunchie and is smiling. The woman behind her has blonde hair and is also smiling. The man on the left is partially visible, looking down. They are all wearing casual clothing. The background is a soft-focus outdoor setting with green foliage.

Suggested Resources

1. CDN Professor Cheat Sheet (for student use, available on our website)
2. The American Diabetes Association's Going to College with Diabetes: A Self Advocacy Guide for Students
 - ▶ PDF available on ADA website, diabetes.org
 - ▶ Sample medical documentation for diabetes
 - ▶ Sample request for accommodations letter
 - ▶ Sample accommodations letter from college
 - ▶ Diabetes basics for students and postsecondary institution officials
 - ▶ Sample adjustments for internships, clinicals, and work
 - ▶ Accommodations for standardized tests and licensing exams

REGISTERING FOR ACCOMMODATIONS

Ultimately, it is your student's decision as to whether or not they choose to register. Having an open and honest line of communication is the best way to support your student through this decision making process. Check out these tips to effectively talk to your child about registering for accommodations.

How to Discuss Registering

EMPOWER YOUR STUDENT

This is a time when you can help to empower your student to advocate for themselves. They will need the ability to self-advocate as they progress through college and into the workforce and this is a great way to learn. Encourage them to speak up about their diabetes so they can receive the accommodations that will help them succeed.

REVIEW THE REASONS

Take time to review the reasons to register together. Discuss any concerns or questions your student has before they decide if they will move forward with the registration process.

IT'S THEIR CHOICE

While you can encourage them to register, they need to be the one to make the final decision. Even if they decide not to register in their first semester, they may change their mind after dealing with the stress of college. This is a time when your student should be making their own choices, even if you do not agree. We know, easy for us to say, but we speak from personal experience and on behalf of medical providers, campus administrators, and most importantly, other parents.

KNOW YOUR CHILD'S RIGHTS

Learn more on the 'Advocacy and Student Rights' section of the CDN website: collegediabetesnetwork.org/advocacy. Watch the joint webinar from CDN and the American Diabetes Association on the rights students living with diabetes have on campus.

POSSIBLE ACCOMMODATIONS

While these are some of the most basic accommodations your student can ask for, everyone is different.

(It's up to your student to communicate with the staff in charge of accommodations about what else they may need.)

Below are some sample accommodations:

- ▶ Agreement to reschedule an exam if, at the time, their blood glucose is out of target range. High or low blood glucose can impair cognitive function
- ▶ Permission to eat/drink in class
- ▶ Approval for diabetes care in class
- ▶ Early class registration in order to maintain a specific schedule
- ▶ Kitchen access in housing
- ▶ A living situation that will make your child feel comfortable when managing their diabetes

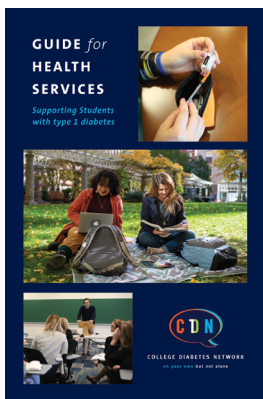
Navigating the transition to independence at college is challenging for any student, but for young adults with diabetes—or other invisible diseases—managing physical and mental health on top of academics, extracurricular, and social life is a daunting responsibility.

That's why CDN is partnering with leading higher education and diabetes organizations to launch CDN REACH™, a multi-faceted framework designed to augment campus resources and help administrations support the wellbeing of students with diabetes and deliver upon their mission for all students enrolled.

CDN REACH™ is designed to provide administrators with the information and tools they need to reduce physical and mental health risks for their students with T1D and liability for their schools.

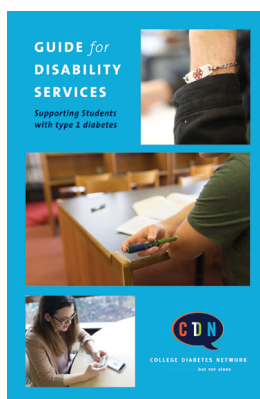
As part of CDN REACH™ CDN is launching a series of three new guides designed for campus administrators. These guides provide a primer on diabetes and its impact on campus life, and how staff in Student Health Centers, Disability Service Centers, and Counseling Centers can best support students with diabetes.

HELP CDN ON THIS IMPORTANT MISSION BY LETTING ADMINISTRATORS ON YOUR CAMPUS KNOW ABOUT THESE GUIDES!



HEALTH SERVICES:

For campus health professionals to better understand how to best support their students with diabetes.



DISABILITY SERVICES:

For campus accessibility staff to inform about what accommodations are frequently found to be helpful for students with diabetes.



MENTAL HEALTH SERVICES:

For campus mental health professionals to provide insight into how diabetes can affect the mental health and well-being of students.

PREPARING TO MOVE OUT: A TIMELINE

**3 Months, 2 Months,
1 Month, Move-in Day!**

To help your student get packed and ready to go, we put together a timeline so that they know what steps they can take to be prepared for the big move.

Your child has already used the CDN 'Looking at Schools Guide', picked the school for them, and been accepted! Remember, packing should be your student's responsibility. You can offer support and advice, but when and what they pack is up to them. If they forget anything, you can always mail out a care package (*which students love, trust us*).

3

MONTHS BEFORE MOVE-IN

Create a Plan for Supplies

There are many options for getting supplies while at school (*mail-order companies, local pharmacies, restocking at home.*). You and your student can discuss these questions together and make a plan before they leave for campus.

- ▶ Where will they be getting supplies from?
- ▶ Where will diabetes supplies be sent?
- ▶ Who will be ordering them?
- ▶ Who is responsible for making sure any payments for supplies are made?
- ▶ How long will their supplies last?
- ▶ How will they know when to reorder them?
- ▶ Where will they go to restock low supplies and how will they get there?
- ▶ When will they need to update prescriptions?
- ▶ Where will their prescriptions be filled?

Don't Forget About Back-up Supplies

Many students find it helpful to have a backup meter in case their meter breaks or gets lost. Most students also bring syringes, long acting insulin, and anything else that may help them in case their main method of care fails. Having your student gather these supplies is a good first step in having them take more responsibility for their diabetes management.

Staying Cool

Your young adult will want to have a plan for refrigerating their insulin. This may be by purchasing or renting a mini-fridge or by utilizing a cooling case. For short trips or travel, the FRIO® cooling case only requires water to keep your insulin from getting warm. Sign up for CDN membership to take advantage of discounts!

Think About Sharps

Where will your student dispose of sharps? Sometimes the school health center will have a sharps container, or one can be ordered. An empty, opaque laundry detergent container can also work.

3 MONTHS BEFORE MOVE-IN (Continued)

Schedule Appointments

We know sometimes it's a few months before your child can be seen by a provider and once they get to campus it might be hard to find the time. Suggest to your child that they can schedule appointments now and move them later if needed.

Make the Space

Encourage your student to consider how they will store their supplies. If they plan on lofting their bed, they may need to call the school and preorder the lofting package. Risers can be bought at home supply stores and can add a few inches off the ground. Many students use plastic storage bins to house supplies while living in the dorms to better utilize a tight space and keep things organized.



Get a Flashlight

It's a good idea to have your student keep a small lamp or flashlight by the bed so they can see what they are doing when they wake up to check or treat a late-night low. That way they don't have to turn on the light and wake up their roommate. Headlamps are a good hands-free option!

Connect with Roommates Over the Summer

Encourage your student to reach out via text, social media, or email to their new roommate over the summer. If your student wants, they can tell their roommate about their diabetes then. If not, your student can wait until school starts to have 'the talk'. We have found that it is helpful for students to refer to CDN's 'Talking to Friends and Roommates' section of the student Off to College guide. When and how your student tells their roommate about T1D is their decision—it is best not to rush them on this point. They may be feeling awkward about it and might need some space. You should bring up this topic at a time when you and your student can talk about this in a constructive way, like at the dinner table.

Create a Communication Plan

When your child goes to school, you don't want to be constantly asking them about their diabetes. In order to avoid any conflict, create a communication plan for all of you so that they get the freedom they want and you get the peace of mind you need.

Refer to CDN's 'Family Communication Agreement' on page 8 as a guide as you and your child create something that works for everyone. Keep in mind that this agreement may change throughout the college years.

It can also be helpful for your child to think through how they will communicate with their diabetes care team while at school. Here are some questions for you and your child to consider.

- ▶ What is the best method of communication for both your child and their provider to connect? Email? Phone? There are a lot of free apps that make logging and sharing blood sugars with doctors easy.
- ▶ What will your child do if there's an emergency and they need to see an endocrinologist right away?
- ▶ How often will your child be scheduling check-up appointments with providers and when?



2

MONTHS BEFORE MOVE-IN

Get a Medical Alert ID

We know that sometimes young adults find it hard to find the right medical alert ID, but it's especially important for them to have one while they're away from their normal support system.

Get Some Bags

Make sure you send your student to school with a couple of different bags that can hold all of their belongings and diabetes supplies—especially for when they are traveling back and forth between home, going on weekend trips, vacations, and just trekking across campus.

MOVE IN DAY

Have Some Low Snacks Ready

Your student will probably go low carrying boxes up hills and stairs, unpacking all of their things, and constructing shelving units—have some low supplies ready for move-in day.

Check the Fridge

As silly as it sounds, make sure their fridge is plugged in. Remember to check the temperature settings—some high settings freeze insulin.

Go Food Shopping

Take a trip with your student to the local grocery store and load them up with low supplies and snacks for their room. Try some of these student-approved snacks that are good to keep in the dorm room to treat lows, highs, and general study-induced hunger:

LOWS

- ▶ Glucose tabs
- ▶ Juice boxes
- ▶ Fruit leather
- ▶ Crackers
- ▶ Sports drinks (*also good for the gym and hangovers*)
- ▶ Raisins
- ▶ Candy without fat (*i.e., jellybeans or gumdrops*)

HIGHS

- ▶ Water bottles
- ▶ Powdered drink mix (*try the no-carb individual packets for on the go*)
- ▶ Tea bags
- ▶ Fresh veggies like cucumbers or celery

1

MONTH BEFORE MOVE-IN

Prepare a Sick Day Kit

It's important for your student to take care of themselves while sick. Prepare a sick day kit with your student before they leave, as getting sick can come on suddenly. You can find some suggestions of items to include in a sick day kit on page 47.

PACK!!

All the items we've been discussing? Make sure your student takes them all.

Create a List of Contacts

Before your student leaves, sit down with them and create an important contacts list. Make sure they have the phone numbers and contact information for all their diabetes-related needs, as well as important people. This includes: insurance company, pump company, CGM company, pharmacy, mail-order supplier, endocrinologist, diabetes educator, and all other doctors your child sees. Have your student put these contacts and numbers in their phone for when they need them.

Make Sure Supplies Are Accessible

Encourage your student to think carefully about where they store supplies. Making sure they are easily accessible is key. Having them close by at night, as to not to disturb a roommate, is always best.

Have a Glucagon Kit Readily Available

Suggest that your student tell others where the Glucagon kit is, how it is used, and when to use it. This way in case of an emergency, their new friends will be able to help.

Find the Closest Pharmacy

Take some time for you and your student to look for the closest pharmacy. Help your student figure out the easiest way to get there from campus, then encourage them to store that information in their phone. Even if your family normally uses mail-order pharmacies, there may be times when your student needs to visit a store in person.

RIGHTS DURING EMERGENCY SITUATIONS

As your student turns 18, you may be wondering how you can be notified in the event of a medical emergency

Let's look at a common scenario that many parents of a young adult with T1D worry about to help you better understand what legal documents you may need in the case of an emergency.

Scenario

While away at school, your young adult comes down with the flu, causing them to develop ketones and go into DKA. They are then brought to the emergency room. You want to be able to call the doctor to find out their medical status and get information about their care. Because your child is over the age of 18, the doctor is unable to give you information about your student because of HIPAA (a federal law that protects patients' privacy).

In this case, it may be useful to implement a **HIPAA Right of Access Document**, which allows your young adult to decide who has access to their

protected health information. If your young adult names you (their parent/caregiver) on the HIPAA Right of Access form, you would be able to speak with your child's doctor about their condition and treatment.

Some of the common rights of access your child may want to grant you can include the ability to: make or change medical appointments; order medical supplies; pick up lab reports; allow you to speak to medical providers in case of an emergency; discuss your child's treatment and management options with their doctor; and be present during appointments or medical consultations. A HIPAA Right of Access document also

WHICH OPTION WOULD WORK BEST FOR MY CHILD?

The legal decision of how and to whom your students' medical decisions and history is shared is personal and unique to each individual situation. Ultimately, this decision can only be made by your young adult. Your child's personality, maturity level, comfort with leaving home, and other medical conditions could all be factors in their decision as to what and how much of their medical information they would like to share with you once they turn 18. While this can be a challenging decision, and certainly one that many T1D parents are highly anxious about, allow your child the freedom (*and the time*) to make an informed decision about sharing their medical information with you moving forward.

allows your child to exclude access to certain sensitive medical information, such as mental health or sexual health information.

It is important to note that the HIPAA Right of Access form DOES NOT give anyone appointed the power to make medical decisions. So, in the case that your child is in the hospital because of DKA, you would be able to have as much access to your students' health information as they would like, but you would not be able to actively make medical decisions on their behalf.

Another legal option that many parents may think to implement in this type of situation is a **Medical Power of Attorney** (which may be called something slightly different depending on each state). A Medical Power of Attorney is essentially a legal document that allows an individual to select who they would want to make medical decisions for them if they are unconscious and unable to make the decision themselves.

It is important to note that if your child does end up in in any kind of life-threatening situation, healthcare providers will do whatever it takes to keep them alive because they are so young. Therefore, a Medical Power of Attorney may not be necessary unless your child has specific requests for medical procedures or care that they do not want to be carried out on them (for example, being put on life support).

Keep in mind that a Medical Power of Attorney requires your child to think about end of life treatments (no food, no resuscitation, etc.) and typically is not in effect until incapacitation occurs. In most situations, parents find that implementing a Medical Power of Attorney may not be the appropriate legal document for their needs at this time. For the caregiver who is hoping to remain involved in their young adult's diabetes management, a HIPAA Right of Access form is often sufficient.

CAREGIVER DOs AND DONTs

For many parents, dropping your T1D child off at college is probably one of the hardest things you'll ever have to do.

To help this transition go as smoothly as possible, here are some tips from our students and caregivers about what to do (and not to do).



**DO**

Instill a sense of independence in your child.

If you haven't already, now is the time to start transferring responsibility of diabetes care to your child. It may seem scary, but you'll feel 100 times better when you're driving away from campus knowing that your child can manage their diabetes without you. By the time they leave for college, they should be completely self-sufficient when it comes to their daily diabetes management, including the following:

- ▶ Checking blood sugar regularly
- ▶ Cleaning and changing pump/CGM sites
- ▶ Carb counting
- ▶ Taking injections
- ▶ Having an understanding of a sick day plan
- ▶ Dosing insulin
- ▶ Being able to tell friends/roommates that they have diabetes
- ▶ Registering for accommodations on campus
- ▶ Knowing when something isn't right and acting on it by calling a doctor or going to the hospital
- ▶ Knowing what low and high blood sugars are and how to correct them.

**DO**

Breathe.

Is your child not taking responsibility “the way they should be”? It is very common for people with diabetes to have a hard time in their teenage and young adult years. Remember, you cannot force anyone to do something, even your child. It takes time for some young adults to realize how important it is to take care of themselves. Sometimes it takes a few rough patches to get on the right path. Be patient. Be supportive. Breathe. This is a marathon, not a sprint.

**DO**

Continue to help your child with the more logistical elements of diabetes management.

- ▶ Navigating health insurance and payment for medical services
- ▶ Ordering/receiving medical supplies
- ▶ Providing motivation and emotional support

CAREGIVER DOs AND DONTs (Continued)



DO

Create a communication agreement.

Have a conversation with your child and come to an agreement about their expectations of you, and vice versa—and stick to it. Use CDN's 'Family Communication Agreement' on page 8 as a starting point.



DO

Keep busy after move-in.

While you're probably a little bit sad that your child is at school, remember that this is an exciting time for them—and you. Do something for yourself. Join a club. Exercise more. Go dancing. Get involved in something that you may not have had time for before—it will help you focus on things other than worrying about your child. *(We promise we're not being patronizing; this is advice that parents have shared with us.)*



DO

Send your child a care package.

Diabetes or not, it's really exciting to get mail from home when you're at school. Send your child a package to let them know you're thinking of them. You can include whatever you want, but here are some suggestions:

- ▶ Powdered drink packages ▶ Extra low snacks ▶ Streaming movie subscription
- ▶ Colorful pens/pencils ▶ Their favorite candy ▶ Gum ▶ Old/funny photos
- ▶ Socks with a silly design on them *(it sounds funny, but they get lost very easily at school)*
- ▶ Hand lotion/sanitizer ▶ A batch of their favorite homemade baked goods



DO

Join the Parents of the College Diabetes Network Facebook Group!

This group is for parents of teens and young adults with diabetes who are thinking about, getting ready for, or already in college. Share successes, get support and advice, and learn from other parents who've been in your shoes. Request to join at facebook.com/groups/CDNParentGroup

**DON'T**

Ask your child what their blood sugar is all the time.

Some families have worked out agreements where the student texts their parents what their blood sugar is at a specific time of day. Others don't share this information at all. Whatever you decide on, don't send your child a slew of text messages requesting constant blood sugar updates. College is about them, not their blood sugar.

DON'T

Get angry with your child for having a high HbA1c.

College is incredibly tough on diabetes management. Even the most proactive student is bound to have some bad days (or weeks, or months). Instead of getting angry, talk to your student and ask if there's any way you can help.



LIFE ON CAMPUS



CLINICAL CARE: FINDING A NEW DOCTOR

There are a million things that can get in the way of your student seeing their doctor once they arrive on campus, but it is extremely important for them to continue to do so.



This section will walk you through how you can support your young adult while they search for another provider. It also gives advice on how to handle challenges that may arise when it comes to seeing a provider on a regular basis. Keep in mind, there is no 'right' time for when your student should switch from pediatric to adult care. It depends on your child, their relationship with their provider, and their clinic's rules.

Reasons to Begin Looking

- ▶ Your student attends school hours away from home and is unable to see their health care provider(s) as regularly as they would like.
- ▶ Your student aged out from their pediatric provider.
- ▶ Your student feels guilty or not empowered after leaving appointments.
- ▶ Your student feels their health care provider doesn't understand their needs or is unable to help them.

How to Find an Adult Provider

Finding the right provider, especially when transitioning from pediatric to adult care, can be a lot like dating. Personality types, approaches to diabetes management, priorities, and location are all important points to consider. Encourage your student to take the following steps:

- ▶ Talk to their doctor about which adult providers they think would be a good fit.
- ▶ Read reviews of health care providers online.
- ▶ Check out the CDN 'Doctors Appointments' webpage for directories where they can search for health care providers in their area.
- ▶ Contact members of the CDN Chapter on their campus and ask who they see for their diabetes management and whether or not they would recommend them.

Ask Questions

To help your child determine if a health care provider is right for them, we suggest they ask the provider or team the following questions. Your child can then evaluate their answers after the first appointment:

- ▶ How much time do you spend in an appointment?
- ▶ Who does the diabetes care team consist of?
(CDEs, exercise physiologist, nutritionist, psychologist, social worker, etc.)
- ▶ What do you think are the most important parts of diabetes care?
- ▶ How much personal experience do you have with T1D?
- ▶ How open are you to new technologies, research, and therapies?
- ▶ Who is on call when you are not available?
- ▶ Are you available between scheduled appointments and can I stay in contact with you remotely?
- ▶ Have you ever worked at a diabetes camp?

CLINICAL CARE: FINDING A NEW DOCTOR

Last Meeting: Former Provider

Have your young adult do the following:

- ▶ Discuss any concerns they have about transitioning providers.
- ▶ Ask for the former provider's office to transfer patient records to the new provider.
- ▶ Make sure your young adult has the fax number for the new provider.

First Meeting: New Provider

Make sure your child is prepared for their first visit. Have them follow these steps:

- ▶ Find out what they will need before the appointment. Some doctors require lab work to be done prior to the appointment. Have your child call the doctor's office to find out exactly what they need to do before getting there.
- ▶ Encourage your child to be open and honest about what they want and expect from their doctor. That might be a kick-in-the-butt or acknowledgement and support. Either way, encourage them to be assertive.
- ▶ Make sure they bring everything they need to the appointment.
- ▶ Encourage your child to write down questions for the new doctor before the visit. Your child may find it helpful to write down what they have been struggling with.
- ▶ Offer to go to the first appointment with your child. You can serve as a support system before and after the appointment.
- ▶ It is very easy for patients to leave the doctor's office and forget about the changes they agreed to. Encourage your child to program all of the technical adjustments into their pump as soon as they leave and make sure they wrote down everything else for future reference.

Evaluate the First Visit

Help your child evaluate their visit. Did they like the doctor? Did they feel more empowered about their diabetes care after leaving? Were your young adult's questions/concerns addressed? These are the really important questions to have your young adult ask themselves. If their answer is 'no', encourage them to consider finding another doctor.

Suggest to your young adult that they schedule their next appointment. Whether with the same doctor, or a new one, scheduling this next appointment ASAP is important so your young adult doesn't forget. It can always be rescheduled for a later time.

Challenge	Solutions
Your child's school is in a rural area and the nearest endocrinologist is hours away.	<ul style="list-style-type: none"> ✓ Some students may borrow a friend's car or schedule appointments at the same time as another T1D on campus to make travel to appointments a little easier. ✓ Students often schedule appointments to take place while they are at home for breaks or holidays. ✓ Many doctors now allow patients to connect with them virtually using video chat, email, or phone.
Your child's HbA1c isn't within target and they are hesitant to see their doctor.	<ul style="list-style-type: none"> ✓ Your child's doctor should be helping them to better manage their diabetes and identify what is and is not working for them. Talk to your child about their relationship with their doctor and if they feel empowered or discouraged after appointments.
Your child says they don't have enough data (<i>e.g. they don't check frequently</i>) to make the appointment worthwhile.	<ul style="list-style-type: none"> ✓ Diabetes isn't just about the numbers. Your child should be able to have a productive appointment with their doctor, even if they are lacking a large amount of a data.

YOU ARE NOT ALONE

Many other T1D parents have gone through this process. If you want to ask other parents who 'get it', request to join the CDN Parent Facebook group at facebook.com/groups/CDNParentGroup. We also recommend Moira McCarthy's book *Raising Teens with Diabetes: A Survival Guide for Parents*. Check out the back cover of this booklet to read a letter from Moira herself!

MANAGING SICK DAYS

As a parent who may be far away, we know you will probably be feeling helpless and worried when your student gets sick at school.

The key is to prepare ahead of time—because let's face it, nothing we are going to say is going to make you worry less in that moment. One way to do this is to prepare a 'Sick Day Ready Kit' for your student to have in their dorm so when they do get sick, they are prepared for it.

Below are some things to remember as you put your student's 'Sick Day Ready Kit' together!

- ▶ Make sure supplies and snacks aren't expired (*common things that expire before use are ketone strips and Glucagon*).
- ▶ Consider including some syringes along with your student's glucagon kit in case they can't keep anything down and need to micro-dose.
- ▶ Print-outs of basic sick day information and care team contact information (*templates can be downloaded from CDN's website*) are a great addition to your student's 'Sick Day Ready Kit'. While you may have these memorized by heart, your student may find them handy when they can't think straight thanks to that sinus infection.
- ▶ Ask your young adult if they'd like you to check-in more frequently while they aren't feeling well. Your young adult who normally hates for you to ask about blood sugar might want you to call every few hours when they are sick. If they still don't want worried calls from their parents, suggest that they be in touch via phone with their nurse or doctor while they aren't feeling well.

Sick Day Ready Kit

Prepare this kit before your student leaves for school. The following items will come in handy when they start feeling crappy and don't want to see anything but the inside of a pillow:



GLUCAGON—YOUR SAFETY NET

Do you carry glucagon with you when you leave your home? Do you keep glucagon easily accessible where you sleep? Do your close friends and family (roommates) know how to use it?

No? That's okay - you're not alone. Not many people with diabetes carry glucagon with them, or even know what it does.

Glucagon is a hormone that raises blood sugar. Anybody who takes insulin is at risk of low blood sugar because of insulin's effects, and while some fast-acting carbohydrates are usually enough to bring blood sugar levels back to normal, in severe cases, people with diabetes may experience inability to swallow, unconsciousness, or seizures due to hypoglycemia.

In those cases, a glucagon emergency kit can save your life. Keeping one handy and showing others how to use it is a simple way to protect yourself from the worst.

There are great innovations in glucagon products on the horizon for people with diabetes - ones that will make this safety net even easier and more accessible for people with diabetes. Be on the lookout for news from CDN as these therapies become available!

CDN is dedicated to ensuring our members have information regarding all of the options available to them. The companies shown above are CDN Corporate Members. CDN receives no benefits, financial or otherwise, related to product sales.



EMOTIONAL WELLBEING: DEALING WITH “BURNOUT”

College can be mentally and emotionally demanding without diabetes. Add diabetes and it can be downright overwhelming. But keep in mind—not only is it normal for your child to feel burnt-out by their diabetes sometimes, it should be expected. Here are some ways to help them avoid burnout as well as how to support them if it comes up.

What is Burnout?

Burnout is a little bit different for everyone, but basically, it's when someone is sick of their diabetes. But there is a difference between everyday annoyances with diabetes and burnout. Our students have described it in a few different ways. They were overwhelmed, frustrated, and exhausted. For some students, they stopped taking their meter with them to class—or stopped checking altogether. They didn't rotate their pump sites. The list goes on.

KNOW THE SIGNS

Everyone is different when it comes to diabetes, including burnout.

A few common signs include:

- ▶ Canceling doctors' appointments. ▶ Avoiding carrying medical supplies.
- ▶ Disregarding blood sugar levels. ▶ Not sticking with usual care.
- ▶ Self-destructive behaviors. ▶ Increased A1c.
- ▶ Signs typically associated with depression or anxiety, such as lethargy, a lack of interest in hobbies, and seclusion.
- ▶ Anger, exhaustion, sadness, guilt, apathy, or resentment regarding diabetes.
- ▶ Less frequent blood sugar checking or pump site changes/rotation.

How to Deal

It is important to realize that diabetes burnout is not laziness or a lack of concern about health. If your child is experiencing burnout, it's likely they aren't going to want discuss it—at least not until they are ready. But even if you don't have a deep, soul-searching discussion about how they are feeling, ask if there is anything you can take off their plate to help ease the burden they are feeling. We often hear burnout referred to as feeling like you are drowning and all you can do is to try to just keep your head above water.

CAREGIVER BURNOUT

Don't forget to take care of yourself! For however long your child has had T1D, you and your family have been impacted by T1D. You are not alone in caregiver burnout.

Find other parents who get it! This can be in your community, but also in the CDN Parent Facebook Group. Request to join at facebook.com/groups/CDNParentGroup

Helping them deal with that insurance issue or ordering those supplies would be like throwing them a life raft (*or at least a pool noodle*).

It is also important to know that in addition to burnout, there are other mental health conditions to be aware of—such as depression, anxiety, and eating disorders. People with diabetes are more at risk for these conditions and often require clinical support in order to navigate them.

Unfortunately, mental health often carries a stigma in today's society, and your child may or may not feel comfortable admitting that they are struggling. In our experience, discussing mental health can often feel clinical and makes students feel “labeled”. It can be helpful to normalize mental wellness and self-care with your child before it becomes an issue.

Try to reinforce the following:

► Feelings of anger, frustration, sadness, lethargy, shame, and guilt are very

normal parts of life, especially while managing diabetes. If your child talks to others living with diabetes or reads blogs, they will see how common it is to have these feelings (*and how helpful discussing them can be*). CDN has several blogs about mental health and T1D which you can find on our website at collegediabetesnetwork.org/blog.

- These feelings will likely happen at some point and are no reflection on your child's management, strength, competency, or commitment. They may impact your child's management and their motivation to care for their diabetes—this is very normal. During these times, try to focus less on the numbers of diabetes, and more on the person behind them.
- If your child does start to feel like they are burning out, it can be helpful for them to talk with peers, professionals, or their diabetes care team. Doing so is a helpful tool to manage these emotions and keep them from becoming overwhelming.

DRINKING WITH DIABETES



Talk to Your Child About Alcohol

Giving your child information about drinking is not encouraging them to drink. Most adults will drink some alcohol during their lifetime, and it's important that your child has this information before they start drinking.



Encourage Your Child to Talk With Their Doctor

Having honest conversations with their care team can help them decide if drinking alcohol is safe for them and what they need to know in order to do so responsibly.

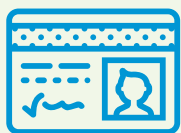


Glucagon Will Not Help Treat Alcohol-induced Hypoglycemia

Make sure your child knows this. After a few drinks, the liver's primary function is cleaning the alcohol from the blood, not producing and releasing glucose. Glucagon will not work until the liver has finished this process, which can be hours after your student left that house party.

It's really helpful to have a CGM on hand when drinking. It can help to discreetly monitor the effects of alcohol on blood sugar. In addition, a CGM will alarm if blood sugar starts going low or high while drinking.

*Thank you to the folks at [DrinkingWithDiabetes.com](https://drinkingwithdiabetes.com) for their help on this page.



Remind Them to Carry Identification That Says They Have Diabetes

This can be in the form of a medical alert bracelet, wallet card, tattoo, or whatever works for them



Let Them Know You're There if They Need You

It's important that your child feels comfortable calling you if they need help. Let them know you're there for them, no judgement or shaming, if they need you.



Make Sure They Have a Drinking Buddy

Remind your child that a low looks a lot like being drunk, and if nobody around them knows that they have T1D, they may assume they are just passed out from being wasted. Encourage your child to find a friend (the more the better) who will stick with them during the night and make sure they are OK.

LEARN MORE ABOUT DRINKING AND DIABETES

DRINKINGWITHDIABETES.COM



COMMON MYTHS DEBUNKED

Many of the questions we receive can be summed up into a handful of ‘myths’ related to diabetes management and college. Check out some of these myths, and learn the reality about these common misconceptions!

MYTH 1

The campus health center will be trained and ready to handle all of your student's T1D needs.

Reality: The majority of campus health centers lack adequate training on how daily management of T1D functions. Your student will likely need to be an advocate for themselves when it comes to visits to the health center.

MYTH 2

My student has good management now that they live at home, but I don't think they will take good care of themselves when they go to college.

Reality: There is no such thing as 'good' or 'bad' management. Numbers are only part of the story when it comes to managing T1D. Your child's numbers (*blood sugar, A1c*) may fluctuate when they are in college. This does not necessarily mean they aren't taking care of themselves. College can be a very stressful time when it's hard to maintain a consistent schedule. They need to learn how to manage diabetes (*and everything else life throws at them*) on their own and college is a great way to let them start this process in a safe environment. As hard as it may be to let go of some of the control of your child's management, they have to learn how to balance everything at some point—and college is a great place to practice. Try to focus on how your child feels about their management and what they see as their struggles, then help them to come up with solutions.

MYTH 3

My child will be able to transfer their 504 plan from high school over to college.

Colleges don't have 504 plans, but your student can register for accommodations through their school if they want to. Some students choose not to register—and that's OK, too! Many students are averse to being labeled as having a disability or simply want to test out what it's like to be in the 'real world' (i.e., in a job that may not be as forgiving as college can be). While we recommend registering, the decision to register is one your student must make. Keep in mind your student may not want to register in their first semester, but they might change their mind by the second semester.

TECHNOLOGY ON CAMPUS

These days diabetes technology is changing so rapidly that it can be hard to keep up. Because of this, and the fact that every person with diabetes is different, there can be a lot of confusion and ambiguity related to what technology your child ‘should’ be using, or the ‘right’ way to use it.

Whether it’s new pump features (touch screen!), new therapies (‘untethered’ pumping), or the age-old question of how you use diabetes data, this section will give you some insights into making sense of diabetes technology and all the options your child has at their disposal—while also giving you tools to empower your child to own this part of their diabetes.

As your child transitions into adulthood, they should be encouraged to take the lead in terms of the choices they make about the type(s) of diabetes technology they choose to use. This shift in ownership is key and will help to empower them in their management.

Insulin Pumps

Pumps can be extremely helpful to support the spontaneity of college life. Temporary basal rates give your child more control over their insulin delivery, decreasing it to avoid late-night lows after a night out, or increasing it to cover finals-week stress. Extended boluses allow your student to take some insulin immediately and add in more over a longer period of time—avoiding pesky blood sugar spikes hours after dining hall pizza.

There are also many great options available to fit a variety of lifestyles—from waterproof/ watertight to touchscreen to tubeless. Have your student check out our ‘Technology’ web page for links to resources, reviews, and more information on pump options. And remember, no matter what your student decides, be supportive as they figure out what works best for them.

CGM is the most important advancement for people with type 1 diabetes since the discovery of insulin.

DR. STEVE EDELMAN

”

FACT Whether a person with T1D takes shots or uses a pump, using a continuous glucose monitor has been shown to improve blood sugars and lower A1c. *Source: T1D Exchange 2015*

Continuous Glucose Monitors (CGMs)

CGMs are exactly what they sound like— small devices that constantly monitor blood sugar thanks to a small sensor inserted under the skin. Here are a few benefits that a CGM may offer your student while they're away at school.

- ▶ Constant monitoring of blood sugar and alerts can help ease your student's mind—and yours.
- ▶ CGMs can help alleviate fear of a serious low happening while they're living alone by alerting your student and you (if they choose) when their blood sugar drops.
- ▶ Because they monitor your blood sugar 24/7, CGMs can help identify trends, making it easy for your student (and their doctor) to make adjustments.
- ▶ CGMs provide the ability to wirelessly share glucose data.

To Device or Not To Device?

Since college is the first time many students start to manage their diabetes care on their own, it is often the time that students try out new approaches to their management. This may mean switching brands of insulin, or trying a whole new device. For some students it may even mean taking a break from a device for a little while. It is best to let your child try these new management strategies and see what works for them. While it might seem counter-intuitive to much of what you hear these days, injections are in no way inferior to pump therapy—and being attached to something 24/7 can be exhausting.

Whatever your child's decision, we suggest supporting them and letting them know how proud you are that they are being proactive about identifying what they need to live well with their diabetes.

ADVOCATING FOR YOUR STUDENT

Unfortunately, we have seen providers refuse to prescribe an insulin pump at this time in life because they feel their patient can't handle the responsibility.

To be clear, this is something that we at CDN disagree with. This is a time when your child might need your support and assistance.

If your child is taking an interest in their diabetes, and is making a decision for themselves related to their management, this should be supported as much as possible. There is a chance it won't work out but your child will learn from that AND have the experience of being empowered and in control of their care.

DATA SHARING



Many blood glucose meters and CGMs allow the user to share their data with whomever they choose via a mobile device.

If your student has a device with share capability, it is their decision if they want to share their data with you. Some students really enjoy the share feature, as it allows conversations with parents to be focused on things other than diabetes. Other students fear that their parents panic every time they see a high or low pop up. Whatever your student decides, it is important to respect their choice. If they do decide to share, it is best to agree on terms beforehand so there is no tension once your student is on campus.

Also, it's totally normal for you to feel completely overwhelmed by the shared data. Being far away from your child and seeing their data with no context as to what is actually going on in their life at that moment can be too much for some. It's OK to recognize that maybe there are only certain times you want to see your child's share data (such as during finals week, at night, or if they are on a trip). Talk with your child and figure out a plan that is realistic and works for both of you. While this can be a great tool, it does need to be managed appropriately to account for the needs and expectations of everyone involved.

What if your student doesn't want to share their data?

It is possible that your student will not agree to share their data with you. While this can be frustrating, we encourage you to accept their decision not to share. While they may not want you to see all of their blood sugar numbers, it doesn't mean that they won't talk to you about their diabetes management. Going off to college is the ideal time for a young adult to become independent with their diabetes, and as they learn how to manage it on their own, college is a great place to start.

Avoid using data-sharing as leverage or an ultimatum (e.g. "I'll stop paying for college if you don't share your data with me") as this can breed resentment between you and your child, and between your child and their diabetes.

Also, it is important to remember that your student won't be completely alone at college. While you may not always be there to remind them about their diabetes management at school, they may make great friends to help them out. They may even join a CDN Chapter that gives them a network of people to reach out to when they may be having issues.

DATA SHARING (Continued)



How do you balance your needs with your students' needs?

While creating a sharing plan is dependent on you and your child's personal situation, these are some tips for creating a plan that you both may find useful:

1 Set hours in which you will communicate with your student about their blood sugar.

For example, you could decide that they will manage their blood sugar during the day and you will only text/call your student about their blood sugar at nighttime.

2 Come up with a “quick text” system to indicate that a low/high blood sugar is being treated.

For example, you could pick an emoji that your student will send you if they are treating a low so that you aren't worrying that your student is dropping without treating.

3 Create a timeframe for communication if they are dropping low/spiking high.

For example, you may wait 15 minutes after you see that they should be treating a low to text them to confirm that they did. If they don't seem to be coming up within 15 minutes, then you are allowed to text them about it.

Then, discuss next steps if they don't respond to the 15-minute text. Do you call them, a roommate, or campus security?

4 Make sure to build in time to talk with your student about things that are not diabetes related.

For example, you can decide that you only discuss your students blood sugars using the quick text system that you set up, and the rest of your communication with your student is about the other aspects of their new life at college.

5 Give your student the time they need to transition and establish this system.

Many aspects of their life are changing when they transition to college, but they still are aware of their blood sugars and the great need there is to manage them. Chances are they won't forget about treating, but they may need some help along the way.

DATA SHARING STORIES FROM STUDENTS

Student Spotlight

COURTNEY Bryant University



Courtney goes to Bryant University, and uses “share” technology with her parents to keep in touch about her diabetes while she is away at school. Hear from Courtney about how her and her parents navigate this useful but sometimes anxiety-inducing management tool.

COURTNEY

One weekend during school, I was in a ceremony for my sorority and we weren’t allowed to use our phones, so I didn’t have access to my CGM data. After a while, I felt a little off. I ignored it until someone violently knocked on the door. It was EMTs and campus security. They asked for me and told me to grab my phone, and that my sugar was dangerously low. I was humiliated and nervous that my sorority sisters would be furious. My “big” ran out with me and grabbed soda and snacks and waited until my numbers were better. Afterwards all my sorority sisters came to check on me and told me not to feel bad at all. I’m now allowed to have my phone during all ceremonies, and I know I have their love and support.

COURTNEY’S MOM

Although our rule is to only reach out to Courtney at night time if she is experiencing a low, I’ve had to break that rule a few times. One afternoon, I started receiving low blood sugar alerts on my Dexcom Share app that quickly turned into the urgent low alerts. I waited over 15 minutes to see if her blood sugar stabilized or started to increase but it wasn’t -in fact it was decreasing. When I looked on the app and saw the 39 with a diagonal arrow down there were no rules as far as I was concerned. I frantically started texting her and didn’t even wait for a response before I started calling her. My husband started calling her, too, as I started calling her roommate. When her roommate didn’t answer I texted a few of her other friends who quickly started an email thread to all of their friends asking if anyone knew of her whereabouts. It was determined that she was in the student center, at which time I called campus security to help me locate her. Through all of the texting someone shared with me that she was at her sorority ritual so that’s where I sent campus security. They walked in and called out my daughter’s name and pulled her out to have a juice - she hadn’t felt the severe low as she was up super late the night before and was extremely tired. Thankfully it all worked out!

“

My parents and I agreed on an overnight system because I don't wake up to low blood sugars (even with my Dexcom). I manage everything completely during the day.

Our system is a 15-minute rule where if I wake up and send a random Emoji to my parents, they know I'm treating my low. If I don't answer for 15 minutes they try calling me, then my roommate and finally DPS, my school's on campus security system.

I can't say I've loved the two times I've been woken up by security, but it is reassuring to know that my parents will do whatever they can to make sure I'm safe. And as embarrassing as it can be, I'm healthy and alive because of those dramatic wake up calls.

“

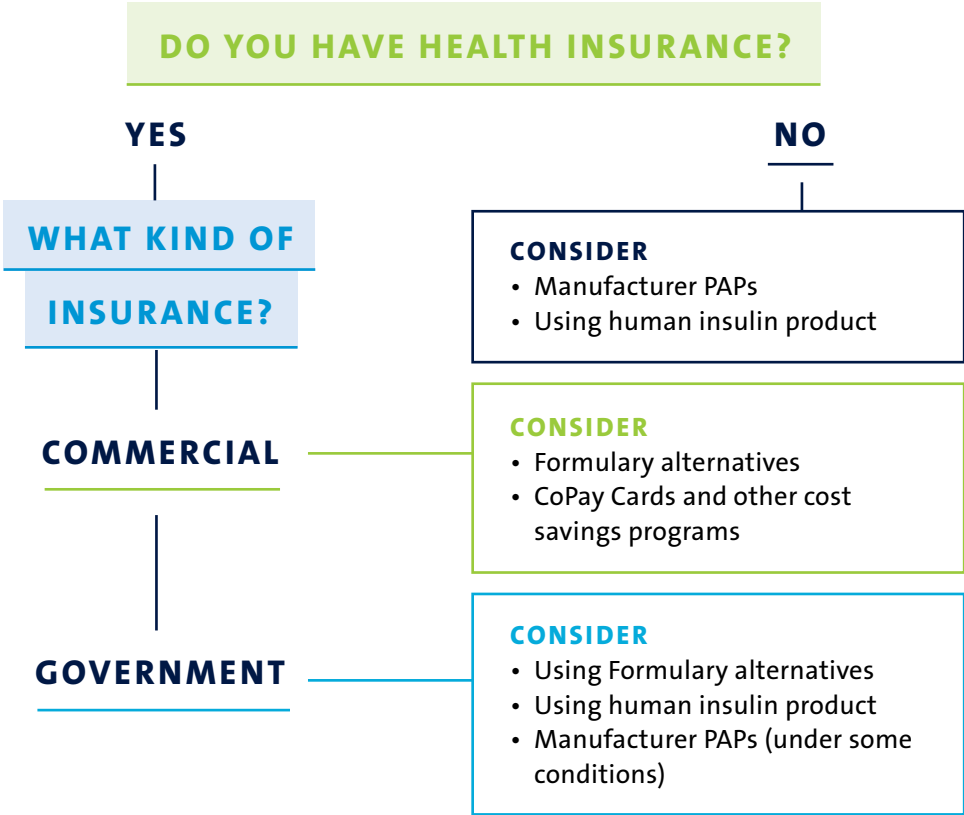
My friends from college knew I managed my diabetes to the best of my ability, and always tried to support me however they could. One weekend, I started acting strange, and while some thought it was a girl who had too much to drink, my roommate knew it could be a severe low. She immediately found me and asked what the password to my phone was to check my Dexcom. Though I was low, it wasn't severe and she grabbed me a juice as well as downloaded the Dexcom share app and requested to follow me. She only turns the alarms on for weekends or sick days, but it meant the absolute world to me that she wanted to keep tabs and help me manage it in every aspect she could.

”

Insulin Affordability—What are your options?

Diabetes is expensive. It’s estimated that people with diabetes have healthcare costs totaling almost three times that of people without diagnosed diabetes. The healthcare marketplace is often confusing. People with type 1 diabetes and many people with type 2 diabetes have no choice but to take insulin to stay alive. For individuals with inadequate, or no insurance coverage, the cost of insulin can be a major burden and barrier to staying healthy.

Here are some options to consider if you find yourself in those situations:



FOR MORE INFORMATION ON INSULIN AFFORDABILITY VISIT:

collegediabetesnetwork.org/patient-assistance-programs

for links to more resources, specific manufacturer programs, and other organizations dedicated to insulin access.

Formulary Alternatives

Good for: *Individuals covered under commercial or federal insurance plans*

Many insurance plans provide preferred coverage to certain drug manufacturers over others. For example, your plan may cover fast-acting insulin in the form of Humalog, but not Novolog, or vice-versa. In most cases, going with the preferred brand on your plan's formulary (list of covered drugs) will be the most affordable and hassle-free option. However, there are some cases where that isn't acceptable based on individual needs. In this case, work with your doctor to obtain a prior authorization for the brand that you need.

Co-Pay Cards

Good for: *Individuals covered under commercial insurance*

Co-pay cards are coupons offered by drug manufacturers that cover all or some of the cost of co-pays at the pharmacy. Most co-pay cards are available for specific products, and usually individuals must already be enrolled in a commercial private insurance plan to qualify.

Patient Assistance Programs (PAPs)

Good for: *Uninsured, qualifying individuals*

Every major producer of insulin, including Eli Lilly, Novo Nordisk, Sanofi, and Mannkind, offers a PAP to aid qualifying individuals. Each have specific eligibility requirements, most often that individuals are not covered by any insurance plan, and fall within household income thresholds. If eligible, PAPs can provide prescriptions at little to no cost.

Human Insulin Products

Good for: *Uninsured individuals; people with inadequate coverage under commercial or government plans*

Older formulations of insulin (referred to as "human insulin") are usually available over-the-counter at low cost from big-box pharmacies such as Wal-Mart. These alternatives can be life-savers in an emergency, but it is important to understand that older formulations of insulin work differently than modern fast or long-acting insulin analogs, and therefore require special consideration regarding size and timing of dosing. For your own safety, talk to your doctor before using over-the-counter insulins.

I'M HAVING TROUBLE AFFORDING INSULIN. WHAT CAN I DO?

Talk to your medical care team. Your team is in the best position to help you according to your specific needs. They may have access to samples that they can provide you with until you and they can find a long-term solution.

Consider one of the options above. For more information on specific PAPs, co-pay cards, and other savings programs, visit your insulin manufacturer's website.

Rationing, diluting, or forgoing insulin is dangerous and life-threatening. There are always other options—don't give up. Reach out to your doctor, the Diabetes Online Community (DOC), or within your local community if you need help.

FIRST BREAK HOME

Congratulations!

If you're reading this, then you got through the hardest part

(or will be well prepared for it!) -- your T1D child's first semester of college. The first break home is an exciting time for both you and your child, but it shouldn't be ruined by arguments over diabetes care.

As much fun as college can be, college students also look forward to coming home on breaks. Diabetes shouldn't get in the way of your child enjoying his/her time at home. The main thing to remember is to communicate and respect one another.

WHAT TO EXPECT

Their Self Care Plan Has Changed: By the time your child comes home for break, they have been independently managing their diabetes for at least two months. During that time, it is likely they have developed new management techniques that best fit with their new lifestyle in college. They might be different from what they have previously done in high school. This is a good sign that your child is starting to feel confident and empowered in their diabetes management. Finding out what works best for them is all part of your child becoming more independent in their care – be proud.

A Higher A1c: College life is an extremely tricky time for managing diabetes. Between a busy class schedule, adjusting to the dining hall, and balancing extracurricular activities, there are a lot of obstacles to overcome and adapt to when managing diabetes. It is normal for your child to return home with a higher A1c. It is unrealistic to expect them to have perfected their routine after a few months. Instead of worrying or questioning, ask them if they want help brainstorming ways to better balance their lifestyle next semester.

DO

BE OPEN TO ADJUSTMENTS

Your child's management routines may have changed from home to school. If they found something that works for them, let it happen. At the end of the day, it is important for them to have the control over what works best for them.

ENCOURAGE INDEPENDENCE

The best thing you can do for your child while they are home for break is to encourage them to be independent. They have spent the past two months managing diabetes by themselves, so reassure them to continue that while at home. Make diabetes something they can be proud of.

STICK TO YOUR COMMUNICATION PLAN

Whether you have a written or spoken plan, don't be afraid to talk about what each of you expect from the other. Communication is key to relationships and resolving differing expectations now can prevent later arguments. If you don't have a communication plan, it might be helpful to set up some ground rules for the break (*e.g. I promise not to ask you what your blood sugar is while you're home if you promise to check your blood sugar before you drive*).

TREAT THEM LIKE AN ADULT

After living on their own for several months, your child will likely expect to be treated as an adult. Respecting their newfound independence throughout the break will empower them to take control of the management of their diabetes.

DON'T

GET HUNG UP ON THE NUMBERS

By now, your child has gotten the hang of daily diabetes management on their own, so try to avoid falling back into old habits. Instead, try asking questions such as: How have you been feeling about diabetes since you've gone to college? Is there anything I can help to take off your plate while you're at home for break?

QUESTION WHAT THEY EAT

Your child has been choosing what they eat for several months now, and you may have opinions about the choices they make during break. Analyzing what they eat will likely lead to frustration and arguments. Especially during the holidays, it is common to stray away from the usual guidelines and indulge a little (*we all do it*). As hard as it may be, try to avoid judgmental comments or questions!

MAKE ASSUMPTIONS

Mistakes made at home are not necessarily the same mistakes made at school. The transition from care at school to care at home is not as easy as you may think. Don't let one mistake be the end of their newfound independence. Continue supporting your child and encouraging the steps they've taken to control their T1D management on their own.

PARENT QUESTIONS

Here are some common questions CDN has received from parents as they help their child through the college process. Many questions were asked (and answered) on the CDN Parent Facebook Group. Be sure to join so you can connect with this great community of caring parents at [**facebook.com/groups/CDNParentGroup**](https://facebook.com/groups/CDNParentGroup).



Q: I still wake up to check my child's blood sugar in the middle of the night. Who will do this if my child goes away to school? My child doesn't wake up to the alarms.

You will not always be able to wake up with your child to check blood sugar. Think of when they are living on their own after college or raising a family of their own. Now is a great time to start to transition this aspect of care to your child. Many students find setting alarms to wake up and check helpful, while others use an alert on their CGM for if they go high or low. To make sure this transition isn't compounded with the stress of adjusting to college, we suggest making some changes the summer before college starts. This includes having your student start to manage their nighttime checks (or whatever their management preference) while they are still living at home. This gives your student (and you) some time to adjust to these changes.

As for not waking up to alarms, many students find that they don't wake up to the alarms because they know their parent is around to check. Once they know that safety net is gone, well, they wake up. There are many ways people with diabetes make their alarms louder, from turning up the volume on their phone to putting their receiver in a glass.

Q: My child's management is out of control! Are they responsible enough to go away to college?

Your child can handle more than you think. You have worked hard to raise a wonderful young adult who is getting ready for the next steps in their life. Part of their journey is learning how to manage diabetes on their own and many students find going away to college a great way to learn. It allows for them to be independent with their care while having their parent a phone call away. And as mentioned previously, 'bad' or 'good' management does not really exist. Managing diabetes is a marathon, not a sprint.

Q: I want my child to join a CDN Chapter. How do I make them connect with you?

It is great that you are so excited about all that CDN has to offer. However, the decision to join a Chapter is your child's to make. We find that students who are pressured into getting involved with CDN do not stay involved. Students that decide to participate in CDN activities on their own are much happier and get more out of the experience. Some students may decide to join CDN later in their college careers, but again, that is up to them. Give them time! In the meantime, you can stay connected with CDN through the CDN Parent Facebook Group and our Parent Newsletter, which you can sign up for on our website at collegediabetesnetwork.org/signup

Student Membership is a great way for your child to receive CDN information even if they aren't quite ready to get involved with a Chapter yet. Check out page 1 for more information.

ENJOY THIS GUIDE?

CHECK OUT CDN'S OTHER GREAT RESOURCES!



SIGN UP FOR MEMBERSHIP ONLINE

Join with other caregivers supporting young adults with T1D at collegediabetesnetwork.org/join! CDN Members gain exclusive access to the complete range of information and resources for students and young adults. You'll be in the know about the latest resources and opportunities from CDN. You'll also get awesome deals and discounts on diabetes products, accessories, apps and events to make life with T1D a little sweeter.



FIND A CDN CHAPTER!

CDN Chapters are communities of students on college campuses across the country, all started and led by students. While their size and activities can vary from school to school, region to region, they all provide a way for students with type 1 diabetes (T1D) to connect with others who “get it”. Any student with a connection to diabetes can start a Chapter - encourage your child to find or start one today by visiting collegediabetesnetwork.org/find-a-chapter.



NEXTGEN LEADERSHIP OPPORTUNITIES

Is your child interested in working within the diabetes sector after college? Our NextGen Leadership Program is for them- CDN offers opportunities for students with diabetes to grow as leaders. Students can apply to attend a national diabetes conference with CDN over the summer, represent their Chapter at our annual Leadership Summit in April, or explore job, internship, and mentorship opportunities anytime on our website. Learn more at collegediabetesnetwork.org/nextgen.



AMBASSADORS

Connect with alumni, parents, and clinicians in your area through the CDN Ambassador program. Ambassadors can provide support to local students, parents, and Chapters. Ambassadors also help to raise awareness for CDN in other ways, like raising awareness, distributing materials and fundraising. Contact CDN to get in touch with ambassadors near you, or to learn more about becoming an ambassador yourself at collegediabetesnetwork.org/cdn-ambassadors.



OTHER RESOURCES FROM CDN

Visit collegediabetesnetwork.org/resource-hub to view more great guides just like this, including CDN's Off to Work guide - a comprehensive resource to help young adults with diabetes transition into professional life - and our Guide for Newly Diagnosed Young Adults - a primer on living with diabetes independently.





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