



A Guide to College Transition

for Sickle Cell Warriors



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A Guide to College Transition *for Sickle Cell Warriors*

Preparation: Introduction and Questions to Consider

If you are reading this guide, you may be a sickle cell warrior preparing to transition from high school to college—congratulations! Or you may be making the transition soon or thinking about this for your future. It's never too early to start preparing for this transition, wherever you are on your transition journey.

Starting college is often a happy time, but also requires planning and preparation. For young adults, going to college often means living in a new environment, which can present complex considerations. It is also a time where you will need to establish your independence, as schools will look to you for decisions while you are a student. As a young adult sickle cell warrior, there may be additional things you need to learn and think about as you become more, or completely, in charge of your health. This guide can help you focus on several key areas, including medical care, social and emotional well-being, and navigating college accommodations on campus.

This guide does not cover every aspect of college preparation, but it will point you to areas that are important to look into well before your first day of classes. Some of the topics are complicated, so you may need additional support or information. You are encouraged to share this guide with your care team, caregiver(s), appropriate college staff, family, and friends as you prepare for college.

Questions To Ask Your Pediatric Doctor Before You Transition to Adult Care

Your current care team may have already started a plan to support you as you move into adult care. Whether or not this is the case, consider asking your pediatric or adolescent provider the following questions if you are not seeing adult providers yet.

1. When should I become more responsible for my own health and healthcare (e.g., making my own appointments, communicating with my providers, requesting medication refills)?
 - a. How will my adult care differ from my current care?
2. What skills do I need to get ready for adult healthcare?
 - a. Where should I get help with making health decisions?
3. What is important to know about health care privacy and medical consent?
 - a. What age(s) does information get restricted from my caregiver(s) and what information becomes unavailable to them?
4. What types of adult providers (e.g., a primary care provider, a specialist/sickle cell clinic, a behavioral/mental health provider) do I need as I move away from pediatric care?
 - a. Does my current care team have suggestions of adult doctors or other specialists/providers?
5. Can my current care team help me prepare my pediatric medical summary for school and a plan for what to do in case of an emergency?
 - a. Will my current care team be able to communicate with a new adult doctor?
 - b. What do I need to ensure my pediatric and adult doctors are allowed to communicate?
6. Before my first visit with my new adult doctor, should I refill my medications?
 - a. What can I do so there is no gap in receiving medications while I am at school?

Transitioning to College: Medical Care

Starting college is a time of many changes. One change is that you will shift your care team from pediatric to adult providers.

My Transition to a College Care Team Checklist:

- Disease Knowledge:** I know what type of SCD I have and feel confident communicating it to care providers and others. I have worked with my provider to get access to my medical records and create an emergency/pain plan and I can easily share my medical records and emergency/pain plan (e.g., a copy is saved on my phone, my emergency contact has a copy).
- Medication Management:** I know the names of my medications, doses, and purposes (taking a picture and keeping on your phone may be helpful!). My provider and I have discussed a pain prevention/treatment plan and I feel confident managing it.
- Appointments:** I can schedule my own medical appointments. I feel comfortable asking and answering questions during my appointments. I keep track of my medical information and can easily access this information when needed.
- Insurance:** I understand my insurance plan and coverage. I know the contact information for my insurance provider. I have an up-to-date copy of my insurance card (or a photo of the front and back on my card on my phone).
- Privacy of Information:** I understand that health privacy policies change once I turn 18. If I want to continue sharing my health information with my caregivers, I know how to give them that access.

Preparing for Medical Transition When Going to College

Health Insurance

Students can often stay on their family's health insurance plan while they are attending school. You may also be able to get health insurance through a college or university. It is important to know your options, make a decision, and complete the paperwork before you leave for school.

Colleges or universities vary in their requirements for insurance coverage, so work with your caregiver, current insurance provider, and university to find out the following information:

- Can I stay on my family's insurance plan while at school and/or can I get insurance through my college or university?
 - If I keep my health insurance: Are there providers near my school that will take my health insurance?
 - If I switch to the insurance offered by my college or university: What services or coverage changes?
- Is there a minimum number of classes or credits I must maintain each semester or academic year to keep my insurance, whether it is my family insurance or insurance through the school?
- For all insurance plans: Does it cover the care that I think I will need? Look specifically at the emergency department guidelines. What will I need to pay if I have a pain crisis or other emergency and need to take an ambulance?
 - If I move out of state or network, my coverage for appointments and medication may change. If I use school health insurance, the coverage may differ than my current

insurance. It is important to have up-to-date coverage question answers and contact information to find out answers.

- Medicaid questions:
 - If I receive Medicaid as a child, will it continue after I turn 18? Will my coverage change when I turn 18?
 - If I am not currently on Supplemental Security Disability Insurance (SSDI), will I be eligible at age 18, so I can get Medicaid? States differ in Medicaid coverage; it is important to review the federal websites and state specific guidelines for current information.
 - If you have not applied for SSDI, you can look into applying for it here: <https://www.ssa.gov/benefits/disability/>
 - <https://www.medicaid.gov/>

University Student Health Services

Most universities have a student health services center where you can receive medical care on campus. Even if you have a provider outside of your university while you are at school, it is important that you establish a relationship with student health services. University health services, in addition to several other university departments, may be helpful during your time on campus (e.g., counseling, disability accommodations, academic offices). Although they often coordinate and communicate with each other, this is not guaranteed. It is important that you communicate your needs and circumstances to each department.

Colleges or universities vary in their offerings of health services. Most information can be found on your school's health services website, but schools also welcome your calls or emails to make sure you get the information you need. Here are some topics to look into before you get to campus:

- **Find the contact information for your school's health services center and look into the type of care that is offered** through your university. Determine if the health center care is provided at no cost or if you will be charged and ask if they can provide a referral for a local hematologist or primary care provider in the area.
- **Do you need to submit any health forms or health records (e.g., immunizations) before getting to campus?** Complete and submit required forms as soon as possible.
 - Keep a copy of all forms that you fill out and sign. Keeping forms electronically may be easier for you to access when needed, but a paper copy is also okay.
- **Is there a way for you to submit additional health records to your university?** If so, provide the university with your medical summary, treatment and pain plans, and your emergency treatment plan.
 - [Sample Template for Medical Summary and Pain Plan](#)
- **Review, sign, and submit medical record releases** for your university health services to allow communication between your school and home providers, and your caregiver (if you would like them to receive information about your health status).

Deciding on a New Primary Care or Specialist Provider

Print this worksheet as you decide on a new primary care or specialist provider.

What to Ask	Provider 1 _____	Provider 2 _____	Provider 3 _____
1. Do you take my health insurance? Do you require payment at the time of the visit?			
2. Where is your office located? Do I need to drive? Is there parking or a nearby metro/bus stop?			
3. What are your office hours and do you have walk-in times?			
4. What is your policy about making, scheduling, or canceling appointments?			
5. Am I able to communicate directly with the doctor after an appointment or if I have a question?			
6. As needed, can the new adult doctor help me find other adult specialty doctors?			
7. Based on answers for questions 1-6, is there a best fit for me? Which doctor/office seems the most beneficial for my health and best fits my needs?			

Transitioning to a New Provider

Preparing for Your First Visit with a New Provider

Before the first visit with your new provider, ask what you should bring to the appointment. It is a good idea to have a copy of your medical summary or ask your pediatrician to send it before your appointment. In your medical summary request, include the new provider's name, clinic name, and the date and time of your first appointment.

What to Bring to My First Visit with a New Provider or Specialist

- Insurance card and co-pay payment
- Medical records and summary (immunization records, results from recent tests/exams, dates/reason for any hospitalizations, dates/reason for any surgeries)
- Medications (preferably the bottles, or a complete written list, or pictures of the labels with names/doses)
- Other: _____

Transition to College: Navigating College Accommodations

It is important to know that schools will look to you to make decisions about your needs.

Because you are a college student, usually regardless of your age, your school will communicate directly with you about any decisions.

Where to Start:

Americans with Disabilities Act (ADA) and College Reasonable Accommodations.

Both public *and* private colleges and universities must provide equal access to postsecondary education for students with disabilities. Many people with SCD are protected by specific laws because SCD can be disabling. All private and public schools that receive federal funding are required, under Section 504 of the Rehabilitation Act, to make their programs accessible to students with disabilities.

Important things to know:

- A postsecondary school may *not* deny your admission simply because you have a disability.
- You do *not* have to inform a postsecondary school that you have a disability, but if you want the school to provide an academic adjustment, you must identify yourself as having a disability.
- For ADA and Section 504 to apply, you must self-disclose, self-advocate, and qualify for services.
- Parents and caregivers have access to information *only* with the student's consent under the Family Educational Rights and Privacy Act (FERPA).

Disability/Accessibility Services (DAS) Office. The DAS office provides a wide array of reasonable, appropriate accommodations for students with learning, physical, psychological, or medical challenges. This office might be named something else at your school, so find the office that helps with these kinds of things, or search 'disability' on the school website. Even if you have not applied or qualified for disability benefits, most people with SCD will need support and accommodations while at school. Sometimes, at smaller schools, a dean or other person is assigned to provide reasonable accommodations. The information you provide to DAS is protected by FERPA. The only information that can be shared with teachers and other campus employees, without your consent, must be on a need-to-know basis. Teachers will know about approved reasonable accommodations, but will not be told about your underlying medical condition unless you request in writing that your medical condition be shared.

Steps to Receive Accommodations:

- ❑ **Be able to express how your condition affects you in all aspects of your life:** learning, sleeping, eating, physical activity, and other daily activities. Share all this important information with the DAS staff.
- ❑ **Research the process** for requesting reasonable accommodations at your school and contact the disability office **as soon as possible**.
 - a. **The earlier that you connect with the DAS office, the better.** Let them know you need accommodations. If you need accommodations related to housing (e.g., temperature control, elevator use), deadlines for requesting those accommodations will likely be soon after submitting your deposit.
- ❑ **Submit the proper documentation** to your school's DAS office.
 - a. You may need to fill out forms before you can request accommodations. Schools may have different standards for documentation.
 - b. Documentation may include the diagnosis of your current disability (e.g., date of diagnosis, tests/criteria for diagnosis, credentials of diagnosing professional), information on how your disability impacts activities of daily life, or how your disability affects academic performance.
 - c. Documentation should provide enough information for your school to decide what is an appropriate academic adjustment.
- ❑ **Ask for specific accommodations you need** on the correct forms and/or letters.
 - a. **[Sample Accommodation Request Letter](#)**
- ❑ **If necessary, negotiate what accommodations your school will provide.** If they will not provide the accommodation you asked for, see if there is a different accommodation that can address the situation. This is the time to **advocate for yourself and be clear about what you need or want.**
- ❑ Once accommodations are approved, the DAS staff will either provide you with a letter to share with your professors or communicate with teachers directly to **ensure they know the approved accommodations.**
 - a. When you talk to your professor(s), explain how the accommodations are needed to ensure your success in the course and your long-term goals.
 - b. Some students send emails to their professors to explain their needs.
 - i. **[Brown University Sample Letters/Emails to Professors for Accommodations](#)**

What Are Reasonable Accommodations?

Reasonable accommodations are modifications or adjustments to the tasks, policies, practices, environment, or to the way things are done that enable individuals with disabilities to have an equal opportunity to participate in an academic program or job (U.S. Department of Education, 2007). This description covers **both** academic and non-academic accommodations.

Reasonable accommodations *do*:

- Provide an alternative way to accomplish course requirements
- Eliminate or reduce disability-related barriers to success

Reasonable Accommodations *do not*:

- Compromise the essential elements of a course
- Weaken collegiate academic standards (unlike K-12, where accommodations can alter standards)

Academic Accommodations

Examples of academic accommodations for SCD include:

- Exam accommodations (may include: 50% or 100% extended time, readers, scribes, laptop use, exam room use, remote proctoring)
- Note-taking assistance for classes
- Extended deadlines or given assignments early
- Leniency with tardiness and attendance
- Recording classes or attending remotely
- Classes in a building with an elevator
- Reduced course load - changing the amount of time or courses required to finish your degree (less common)

If an accommodation would change a “fundamental” part of an academic program, it is not “reasonable,” and your college does *not* have to do this; the college has the authority to decide what is “fundamental.”

Who to Contact for Academic Accommodations

After contacting your DAS office, you may want to reach out to other offices or support centers on campus, including:

- **Educational Resource Center** or other office(s) that provide tutoring services
 - If tutoring is offered, an accommodation might be to extend the amount time allowed for tutoring
- **Professors**
 - Use the [sample templates](#) to introduce yourself and reasonable accommodations you will need

- **Academic advisors**

- Create a connection with your academic advisor and meet with them regularly (1 time per week or every other week) so they can be a support for you. If they cannot meet weekly, find another academic employee on campus who you can enlist as a resource.

Non-Academic Accommodation

Examples of non-academic accommodations for SCD include:

- Having the heat for your dorm room turned on earlier in the year.
- Staying in a dorm closer to classes if getting to class is difficult or painful.
- Using the elevator in a building if you have a class on a high floor or being in a dorm with guaranteed elevator access.
- Being able to call the campus shuttle to get to and from class when walking is difficult.
- Having access to specific dining/meal plans or halls.

Who to Contact for Non-Academic Accommodations

After contacting your DAS office, you may want to reach out to other offices or support centers on campus:

- Residence Life/Housing
- Dean of Students
 - To support you if you must be absent from class for longer than course attendance requirements allow
- Transportation services
 - This could be located in public safety or campus police
- Dining services

Transition to College: Social and Emotional Well-Being

In the rush of meeting new people, trying new activities, and adjusting to academic demands, you may put your emotional and social well-being aside. But, planning for your overall well-being is important! Reflect on what has worked for you in the past and consider these ideas to manage your SCD and emotional needs while at school and beyond.

❑ Create an On-Campus Network

You may have shared information about your SCD with people growing up and feel comfortable doing this with new friends and acquaintances. If you have not done this or are hesitant to share your SCD journey, **now may be the right time to tell friends, advisors, professors, and other university staff**. Letting others know may help you build strong interpersonal relationships but can also be essential in the event of an emergency. Some SCD warriors noted that **developing trusted friendships in college was crucial as these people helped them manage their SCD**. Friends provided support when they were not feeling well, reached out with a helping hand, simply (but importantly!) checked in to make sure they were okay, and even called an ambulance or accompanied them to the emergency department.

In addition to developing individual relationships, it can be valuable to **join local support groups and community-based organizations for people with SCD or other chronic conditions to share your experiences with others**. These groups help provide a sense of understanding and belonging, as well as support and advice that may help you manage your condition, especially while away from home. The Sickle Cell Disease Association of America has chapters across the country. If you need a place to start looking, this is a good, trusted resource: [Find Member Organizations: Sickle Cell Disease Association of America Inc.](#)

Finally, in addition to having a day-to-day support network, it might be essential to **connect with an academic advisor, on-campus counselor, and/or staff from the DAS office**. Although these people can help with academic needs, they can also **advocate for you when you need social or emotional help**.

❑ Maintain Healthy Habits

Often, social and emotional well-being are connected to physical health. **Maintaining healthy habits can help all these areas**. Because college is a time of transition, this can be challenging. However, it is important to focus on your well-being! Here are some healthy habits that you may already have. If not, now may be a great time to start **as you begin to be more fully in charge of your health**:

- Fuel your body with a healthy foods and drink 8 to 10 glasses of water per day
- Stay active, but drink plenty of water before, during, and after physical activity. Make sure to rest enough to avoid becoming overheated
- Take precautions to prevent infections and illnesses, and practice good hygiene
- Maintain a consistent sleep schedule
- Manage stress (especially time management concerns) by asking for help, requesting accommodations, and using healthy coping skills
- Minimize unhealthy behaviors, such as drinking and illicit drug use

□ Understand Your Triggers

It may take you time to figure out your new environment. College may activate things that cause your SCD to act up. Sometimes these are called “triggers.” **Before you leave for school, it is important for you to understand what these triggers are and be aware of places or times where they may be most likely to show up.** If you do not know what your triggers are, some sickle cell warriors suggest keeping a journal to track what causes or increases your symptoms. A written list can be easily shared with doctors, campus health staff, and other college departments.

For some SCD warriors, triggers include stress and exhaustion, both of which may be difficult to avoid while in school. In these cases, **developing strategies to combat these triggers is important.** For example, if stress increases your SCD symptoms, you will want to plan your work and socializing more effectively. This may involve creating your own study guides, starting your work early to minimize the stress of deadlines, and prepping in advance of exam periods. If lack of sleep causes issues, you will want to make a plan so that you can get rest after a party, being out with friends, or late nights of studying.

Common triggers, such as extreme temperatures, dehydration, or stress, may also be managed by requesting accommodation. Working with your DAS office (or other related offices) to receive resources and accommodations for your SCD will be important.

Before You Go...

Starting college is an exciting time, but it can feel like a lot of change at once! It is totally normal to have a swirl of emotions. But young adult SCD warriors **do not have to navigate the college transition alone!** Using this guide, making lots of contacts inside your university, and reaching outside of it to find support systems are all ways you can use to make your transitions smooth. Asking for help and sharing your experiences with SCD with other warriors and people you meet at school can be immensely empowering and help ensure that you have the best college experience possible!

Resources for additional support:

- [Sickle Cell Community Consortium](#)
- Scholarships: SCD warriors may be able to apply for and receive scholarships and assistance in paying for their education. Here is a [resource of SCD-related scholarships](#) that may be worth exploring.

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