



Going from high school to college is a big life transition, and there are many factors to consider before you even get on campus. For young adults living with neuromuscular disease, there are some extra steps you can take to ensure you feel supported academically and physically through this change.

Following the timeline below, students and caregivers can work together to ensure a smooth transition to college. Preparation for this transition can begin as early as middle school, however, if you find that you are beginning your planning further along the timeline, you can always go back and address important points at any time. It is also important to review this timeline often to update information and account for changes in your plans. Items for parents/guardians to complete are marked, the rest is for students to complete.

## Middle School

- Take a skills assessment and interest-based assessment to find out:
  - Preliminary interests and discover aptitudes/strengths;
  - Long and short-term goals regarding those interests;
  - How to hone these skills through activities and academic pursuits;

*While there are many free assessments available, a good one to check out is [UCanGo2 Career interest survey](#).*

## 9<sup>th</sup> Grade

- Schedule plenty of time to study and work on executive functioning skills for academic success (calendars, weekly planning, long term planning, goal setting).
- Get involved in extracurriculars and maintain an activity list/resume. Some families might struggle to find time for these activities -- don't panic. Explore online connections and volunteering. Think of places where you may already be involved such as occupational and physical therapies, parasports, church communities, etc. and ask about volunteer or engagement opportunities in these communities.

## For Parents/Guardians

*(To complete before the end of high school)*

- Discuss IEP/504/Accommodations
  - Aid your student in articulating their disability(s)/health conditions accurately as well as their needs;
  - Educate your student in understanding their accommodations and support them in understanding their role and the school's role in providing the accommodations.
- Aid your student in developing executive function skills.
  - Actively support your student in creating and maintaining a calendar/schedule (weekly/daily);
  - Engage your student in understanding the shadow work that parents and guardians do such as laundry, medication management, ordering supplies, etc.;
    - Make a list of the things that you, as guardians, are doing and show your student;
    - Demonstrate tasks for your student until they have mastered skills independently;
- Discuss [Family Educational Rights and Privacy Act \(FERPA\)](#) waiver which allows guardians to access your student's educational record.
- Discuss and prepare legal documentation including:
  - Power of Attorney (POA) Form: In the event an individual is unable to make their own medical, financial, or legal decisions, this document allows them to designate someone they trust to make those decisions on their behalf.
  - Health Proxy Form: Allows a person to designate a trusted person to make medical decisions on their behalf.
  - HIPAA Authorization Form: This allows a person to designate who can access their protected health information, communicate with healthcare providers, and help manage their medical care.



## 9<sup>th</sup> Grade (continued)

- Do something engaging over the summer such as attending camps, taking online or in person courses, volunteering, getting a job, etc.
- Register with [CollegeBoard](#), a not for profit organization that connects students with information and resources for college prep and apply for accommodations for tests like the SAT and ACT allowing a minimum of seven weeks for approval.
- Begin to engage in [healthcare transition planning](#).
- Identify and begin practicing independent living skills such as simple food prep, laundry, waking up independently, using public transportation, or other independent skills.
- Start thinking about your daily routines and identify tasks where a personal care attendant (PCA) may be needed.

## 10<sup>th</sup> Grade

- Take a strong course load;
- Meet with guidance counselor to discuss longer term goals.
- Keep building your activity list/resume
- Take another interest/aptitude assessment to see if anything has changed.
- Take a practice standardized test using approved accommodations
- Continue to plan engaging summer activities
- Talk about the cost of college with your parent/guardian and start thinking realistically about a college budget plan.
- Start thinking more critically about college transition for students with physical disabilities. Below are some suggested resources.
  - [Navigating the Transition to College with Paralysis](#)
  - [Wheels on Campus: A Guide to Wheelchair-Friendly Higher Education](#)

## 10<sup>th</sup> Grade (continued)

- Identify colleges of interest based on major, size, location, weather, accessibility, and more.
- Visit colleges during the spring/summer.
  - Take notes so you remember your likes, dislikes and impressions;
  - Take pictures/videos to gather information on physical accessibility;
  - Schedule a meeting with the disability/accessibility office at the college if possible.
- Study the differences between high school and college accommodations for example:
  - IEP and 504 plans do not transfer to college;
  - Colleges do not provide one-on-one aides or personal care attendants.
- Start thinking about accommodation needs holistically (academic, residential, dining, recreation, transportation).
- Start a spreadsheet of the colleges you are interested in and include:
  - Disability/Accessibility office website and contact information;
  - Documentation the college requires to confirm disability;
  - Housing accommodation process and personal care attendant policy (if available);
  - Office contact information for admissions, financial aid and any other office you may need to communicate with regularly;
- Continue to practice independent living skills
  - Open a bank account and practice using the teller and ATM;
  - Check out MDA's [Access to Financial Independence Workshop](#);
  - Use a virtual calendar for appointments, assignments, and other activities;
  - Create a professional sounding personal email account that you can use to contact colleges.





## 11<sup>th</sup> Grade

- Take PSAT; Take ACT/SAT in spring using approved accommodations.
- Develop a list of colleges including those that typically accept students below your GPA, those that accept students with your GPA and those that accept above your GPA. Visit additional schools meeting criteria for your interests/needs.
- Request letters of recommendation during the spring semester.
  - Two core academic teachers and one school counselor letter.
- Create a [common application](#) account using the same email you registered for college tours with previously.
- Work on drafting applications/essays.
- Book interviews at colleges that permit/ require them.
- Create a list of questions for disability/accessibility office at your top choice schools.
  - Reach out to the disability/accessibility offices;
  - Ask to be connected with current students with similar disability (if possible);
  - Document responses and your impressions in your spreadsheet.
- Continue to practice independent living skills:
  - Consider summer options away from home to test the waters (apply for programs during winter-spring of junior year), including high school summer programs at college;
  - Medication management; practice taking/ administering medications using apps, alarms, etc.;

## 12<sup>th</sup> Grade

- Complete standardized tests if needed; look at test-optional colleges, or colleges that let students decide if they want to submit SAT and ACT scores along with their application, if applicable.
- Apply for financial aid and additional scholarships. Note the net costs of each college on your list including aid packages.
- Complete all applications based on deadlines (early action, early decision or regular decision).
- If you need PAS (Personal Assistant Services) start:
  - Identifying daily needs and writing them down (thinking about needs 24/7);
  - Having conversations about the transfer of personal care to non-family member;
  - Review the "[Making the Move to Managing Your Own Personal Assistance Services](#)" Toolkit;
  - [Read about other students experiences:](#)

*Make college choice by May 1, National Decision Day.*
- Once you are accepted, consider revisiting the campus and outline any additional questions you have for the disability/accessibility office.
- After committing to a college register with office of disability services/accessibility office as soon as possible (housing accommodation requests are usually due between May 1 -July 1 depending on the college).
  - Submit necessary documentation;
  - Schedule intake meeting;
- Continue to practice independent living skills:
  - Practice using Venmo, Zelle<sup>®</sup>, and other apps;
  - Work on budgeting in preparation for leaving home;
  - Practice making upcoming doctor appointments and locate medical doctors in proximity to campus;
  - Ensure you have a list of medications you take and that you have a plan to refill these nearby your selected college or via mail service;



Remember throughout this process that you are the best advocate for yourself. Lean on the support people in your life: your parents/caregivers, teachers, school counselors, and mentors.

MDA is also here to support you. If you have questions, are looking for additional resources, or would like to connect with others in the neuromuscular community, please contact our Resource Center at 1-833-ASK-MDA1 (275-6321) or [resourcecenter@mdausa.org](mailto:resourcecenter@mdausa.org).

## MDA Resources

MDA Access Workshops

- [Access to Education: Higher Education](#)
- [Access to Financial Independence](#)

MDA Print Materials

- [Transition Guide: Pediatric to Adult Care](#)

MDA Events and Workshops

- [Next Steps Seminars: Transition to Adulthood](#)
- [MDA Let's Play](#)
- [MDA Summer Camp](#)
- [MDA Mentorship Programs](#)



## Resources From This Guide

[uCanGo2 – Career Interest Survey](#)

[123 Test](#)

[College Board](#)

Christopher and Diane Reeve Foundation – [Navigating and Transitioning to College with Paralysis](#)

New Mobility - [Wheels on Campus: A Guide to Wheelchair-Friendly Higher Education](#)

The National Collaborative on Workforce and Disability for Youth, HeiTech Services, Inc. - [Making the Move to Managing Your Own Personal Assistance Services Toolkit](#)

Accessible College – [How to Secure Housing and Manage PCA Services at College](#)

US Department of Education - [Family Educational Rights and Privacy Act \(FERPA\)](#)

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