

SMAshing My Limits: Making the Move to Adulthood

Stepping into adulthood brings new life milestones — starting college, landing your first job, and possibly living on your own for the first time.

While this transition can seem intimidating, it can be an exciting change! Read on to receive helpful information from others living with spinal muscular atrophy (SMA) that can help make these transitions easier.



Going to College

Navigate campus and class with ease

Find a college that meets *all* your needs

Along with finding a good academic program, there are a few other elements to consider when choosing the right college. A great first step is connecting with your high school guidance counselor — they can help you start narrowing down your list based on your interests, goals, and any specific support you may need. Keep in mind that reaching out to a college’s disability services office is also key to learning about the on-campus resources available to you.

Location

- Consider the school’s local climate: snowy areas can pose challenges for wheelchair users if sidewalks aren’t well maintained. If upkeep is limited, a drier climate might be a better fit.
- Schools with public or campus transit can make it easier to get to class but be sure these services can accommodate your mobility devices.
- Try to visit schools in person to identify any additional support that may make this decision process easier.

Quick Tip: Visit the Nursing Program



If your college has a nursing school, consider connecting with nursing students for caregiving help. They get extra practice, and you may make friends!



Consider on-campus vs off-campus living

Some colleges have accessible on-campus housing for students who need it.

However, on-campus housing isn’t your only option! Before you commit, weigh the pros and cons of your housing options.

| Off-Campus Living | |
|--|---|
| + Potential Positives | - Potential Negatives |
| <ul style="list-style-type: none">• Possibly easier to access caregiving services• Generally have more living space• Usually more parking, if you have a vehicle | <ul style="list-style-type: none">• Often farther from school facilities• Can make it tougher to participate in on-campus activities• Community-building can take more effort |

| On-Campus Living | |
|--|--|
| + Potential Positives | - Potential Negatives |
| <ul style="list-style-type: none"> • Usually easier to get to class • Closer to easy food options (like dining halls) • Dorms can offer a ready-made community • Potentially easier to participate in extracurriculars | <ul style="list-style-type: none"> • Campuses may have limited accessible housing options • Can be more expensive than off-campus options • May be harder to access caregiving services |

One choice isn't inherently better than the other — it's about making the right decision *for you*.

Living Independently

SMASH your limits and make the shift to living on your own

Look into Vocational Rehabilitation (VR) programs

VR programs can empower you by helping you access specialized equipment and assistive technology that support independent living. Additionally, VR programs may even connect you with important caregiving services, help you find a job, give training, and provide support so you can have long-term success at work.¹

While many VR programs are state funded, some cities have other organizations that provide similar support. Reach out to your state's Department of Human Services to see what's available in your area.¹



"VR will go the extra mile to get you the support you need. They've provided me with a ramp, hoverlift, and a shower chair — all to help me stay in school and work. They also helped me navigate social security and Medicaid."

– Sir Patrick W., SMA Patient Advocate, SMA Type 2



Get plugged in with transportation services

While public transport is a great option for some people living with SMA, others may live in places where those options are limited. Many cities have services for wheelchair users that can pick you up and drop you off as needed. For instance, paratransit services are federally mandated public transit options for people with disabilities that run alongside other public transportation options.² Talk to your doctor or local advocacy organization to learn more.



"The hardest part is asking for help, but once you get over that hurdle, there are doors that can be opened you never knew existed."

– Januel G., SMA Patient Advocate, SMA Type 2



Connect with caregivers for extra help

You may need extra assistance performing tasks that allow you to live independently. Caregiving services can provide you with help and the confidence to live on your own. VR programs, your insurance care coordinator, or your doctor's office can connect you with caregiving services and potentially help offset financial costs too.

Getting a Job

SMASH limits in the workplace

Consider your preferences and needs

Think about how you like to work. Do you thrive when you're surrounded by people and can bounce ideas off your colleagues? Is meeting new connections face-to-face important to you? Or do you work better independently and in quiet environments?

The way you answer questions like these can help inform whether you pursue in-person, hybrid, or remote opportunities. No matter which path you choose, remember to be proactive about asking for the accommodations you need. Visit [SMAshingMyLimits.com](https://www.SMAshingMyLimits.com) and check out the *How to Explain SMA to Others Guide* for tips and sample emails that can make asking for accommodations from your employer easier.



"The biggest resource that I have found when it comes to finding remote work is YouTube. There are multiple channels where people dedicate their content to finding and informing viewers of remote opportunities."

– Sir Patrick W., SMA Patient Advocate, SMA Type 2



Network, network, network

Community groups — at work, school or beyond — are great places to make connections. For example, finding the right job gets easier when you reach out to your network for help. Let your friends, teachers, mentors, and community groups know you're looking, and they can recommend you!

Quick Tip: Take Advantage of Generative AI



Using tools like ChatGPT or Claude can help you stay organized as you become more independent. Use it to build medical transition plans, draft cover letters... and even create grocery lists!

Owning Your Medical Care

Access the care you deserve so you can keep SMASHing your limits

Ask your insurance provider about care coordinators

Care coordinators serve as intermediaries between doctors, patients, and insurance providers to help patients get the care they need. Contact your insurance provider or Medicaid about being assigned a care coordinator that can help you navigate medical claims, get referrals, and ensure you receive your prescriptions on time. It can be a lot to remember, so taking notes can help you keep track of important information and questions to bring to your next doctor's appointment.



"Establish a relationship with a care manager through your insurance. They are great at finding resources, home care companies, and more."

– Sir Patrick W., SMA Patient Advocate, SMA Type 2

Set up reminders for appointments and prescriptions

Balancing work, school, and medical visits can be tricky. Set up a calendar — either in your planner or online — to help you schedule visits and track them. Additionally, putting reminders in your phone about upcoming appointments or prescription refills can help you stay on top of your health.

Building Community

Having people to lean on can make a big difference

Make the most of college

Although school is busy, this is the time to build connections with your classmates. This can feel scary at first — especially if you're in a new environment — but joining study groups, clubs, and other on-campus activities can make it easier. (Just make sure you get enough rest, too!) Having a strong community gives you people to lean on for support if you need it.



"My community has always had my back. Building that kind of network didn't happen overnight. It took showing up and being active in the community, like late nights working on projects, freezing at outdoor events, and hours of teamwork in student groups, to build the relationships I needed."

– Januel G., SMA Patient Advocate, SMA Type 2



Grow your community over time

As you grow, you'll meet new people and develop new interests. Be intentional about how you grow your community with people who share your passions.

College provides you direct access to many on-campus organizations and extracurriculars that are available for all students to join. Additionally, some companies have special interest groups, including ones focused on diversity and disability representation. You can also find local community groups that match your interests, too!

Quick Tip: Focus on Balance



A focus on balance can help you succeed

Strive for work/life balance

New jobs are exciting, but make sure you're taking time to manage your health. Taking breaks, getting good nutrition, and maintaining healthy sleep habits will help you SMASH your limits in the classroom or the office — and beyond.



"I have had to make life changes in terms of how I utilize my time to give my body the rest it needs. I have been spending more time in my chair than I normally do, so I have to make sure I carve out time for a nap or to simply lay down for a while."

– Sir Patrick W., SMA Patient Advocate, SMA Type 2



There are a lot of changes that come with adulthood. With the right resources — and a little advice — you can confidently navigate this and new stages of life.

SMASHING MY LIMITS

Visit **www.SMAshingMyLimits.com** to sign up for updates and be the first to know when new resources are available.

References:

1. U.S. Department of Education. State Vocational Rehabilitation Services Program. Accessed May 2, 2025. <https://rsa.ed.gov/about/programs/vocational-rehabilitation-state-grants>
2. ADA & Paratransit. National Aging and Disability Transportation Center. Accessed May 7, 2025. <https://www.nadtc.org/about/transportation-aging-disability/ada-and-paratransit>