

SMAshing My Limits: Making the Move to Adulthood

Stepping into adulthood brings new life milestones: starting university, landing your first job, or thinking about living on your own for the first time.

These changes can feel exciting but can also bring uncertainty or feel like a big shift, especially when you're used to established routines, environments, and support systems that work for you in your daily life. Read on to receive helpful information from others living with spinal muscular atrophy (SMA) that can help make these transitions easier.

This guide is provided by Novartis for educational purposes only and reflects general information to support young people with SMA through key life transitions. The information is not intended to be exhaustive or fully up to date and may change over time. It does not constitute medical advice and is not a substitute for consultation with your healthcare professional. The availability of services, programs and support described may vary by country. References to external organizations or third-party tools are for information only; Novartis is not responsible for their content.

Going to university

Navigate student life and class with ease

Find a university that meets your priorities

You should prioritize finding the right academic program for you. Alongside this, there are a few other elements to consider when choosing the right university or educational provider.

A great first step is connecting with your teacher, careers counsellor, or support service, who 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 **university's disability, accessibility, or student support services** is also key to learning about the on-campus resources available to you and how they can work with you to help meet your needs.

Location

- Universities with public or campus transport can make it easier to get to class but make sure that these services can accommodate your mobility devices.
- Try to visit universities in person to identify any additional support that may make this decision process easier.

Quick tip: connect with support networks



If your university or education provider offers health, social care, or support programs, consider connecting with students or services that may be able to support your day-to-day needs. It can be a great way to build connections and find practical help.

Consider on-campus vs off-campus living

It may be helpful to check with your university to understand whether accessible housing options are available, but this isn't your only option!

Before you commit, consider all your housing options:

- Accessibility of existing on-campus accommodation
- Receptiveness of the university or educational provider to make the necessary adjustments and provide support
- Cost consideration of on-campus living vs any necessary travel to classes
- What support, care packages or grants are available
- Distance from family and friends

Living independently

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

Explore disability and employment services

Many countries offer government-funded programs designed to empower and support people with disabilities. These services can help you access assistive technology, specialized equipment, and home modifications that allow you to live independently. They may even connect you with important caregiving services, help you find a job, give training, and provide support so you can have success at work.

In many countries, there are specialized transportation services, or 'assisted travel' for people with disabilities that run alongside standard transportation services. Reach out to your local council, municipality, or national disability agency to see what's available in your area.

Stay connected with transportation services

While public transport may be a great option for some, you 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. Talk to your doctor or local advocacy organization to learn how to register for these services.

Speak to caregivers for extra help

You may need extra assistance performing tasks that allow you to live independently. Care packages can provide you with help and the confidence to live on your own. Your doctor's office, local health authority, or social services/welfare department can often connect you with providers and advise on available funding or financial support.



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 adjustments you need.

Visit www.international.SMASHingMyLimits.com and check out the *How to Explain SMA to Others Guide* for tips and sample emails that can make asking for adjustments from your employer easier.

Build your 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 generative AI tools can help you stay organized as you become more independent. Use them to help write your CV, draft cover letters... and even create grocery lists!

Remember: Never share personal, health-related, or sensitive information when using these tools.



Managing your healthcare

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

Enquire about care coordinators

Care coordinators (also called case managers) act as a bridge between you and the various branches of the healthcare system to help get the care that you need. Contact your health provider or local health board to see if you can be assigned a care coordinator to help you manage medical appointments, referrals, and ensure you receive your prescriptions on time. Proactively send them the Care Standards for SMA, available at: www.sma-europe.eu/care-standards-for-sma. 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.

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 prescriptions can help you stay on top of your health.

Care standards for SMA

The Care Standards for SMA outline a multidisciplinary approach to care, helping individuals and caregivers understand the different types of support that may be involved across daily life. Use this resource to understand the standard of care for overall everyday management, as well as the roles of different healthcare professionals: www.sma-europe.eu/care-standards-for-sma

Building community

Having people to lean on can make a big difference

Make the most of university

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.

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.

University provides you direct access to many on-campus organizations and extracurricular activities 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. Making time for self care, getting good nutrition, and maintaining healthy sleep habits will help you SMASH your limits in the classroom, the office, and beyond.



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.international.SMAshingMyLimits.com
to learn more and see other
helpful resources