

Let's Talk SMA: A How-To Conversation Guide

Talking about your spinal muscular atrophy (SMA) with someone who isn't familiar with the disease can be challenging ... and even uncomfortable. In today's world, you may feel added pressure or hesitation to share your unique condition or experience. Opening up can be a powerful way to help others understand you better – and help you SMASH your limits!



Here are some suggestions to help you have these conversations.

How to Talk About SMA

SMA is a complex condition and can be hard to explain in simple terms. Here's a quick explanation you can use:

"I have a genetic disease that can worsen over time called spinal muscular atrophy, which prevents my neurons from communicating with my muscles. Basically, it makes it difficult to move my muscles easily. While I can still **[insert as applicable here]**, I may have trouble or need support with **[insert as applicable here]**."

Educate by Example

Focus the conversation on what you can do to help educate others about how to include you in activities. It may also be helpful to provide an analogy of how SMA actually feels like in your body.

For instance, if someone suggests an activity you can't do, offer a few alternatives instead:

Examples:

"It's hard for me to do **[insert physical action here]**. What if we tried doing **[insert activity here]** instead?"

"Sometimes SMA feels like **[insert analogy]**, so it is difficult for me to do **[insert physical action here]**."

Talking to Friends

Your friends care about you and want to help you SMASH your limits. But sometimes they may make assumptions about what you can and cannot do.

Here are some examples of what you can say to your friends to encourage open communication:

Examples:

"Thanks for stepping in to help me. This is something I can do myself! Could you give me a hand with **[insert task here]** instead?"

"Thank you for offering to help. I try to be as independent as possible so I would like to try this on my own. I am glad to know I can ask you for help if I need it."

"I am having a hard time doing this on my own, would you mind helping me out?"



"When you have a friend to share with when things are really hard and they have similar experiences, and can relate, it makes it easier to talk about."

– Bella B., SMA Patient Advocate, SMA Type 2



Talking to Teachers or Coworkers

Balancing school or work with SMA isn't always easy, but proactively talking to your teachers and coworkers can ensure you're supported. This section outlines key regulations under the [Individuals with Disabilities Education Act \(IDEA\)](#) and the [Americans with Disabilities Act \(ADA\)](#).

Whether you're in school or at work, there are important steps to take when discussing your needs with teachers or coworkers, often starting with a detailed 504 plan.^{1,2} For school, try to contact your teacher by the end of the first week to ensure accommodations are in place before your first exam or assignment. Talk to your school's disability services office or Human Resources department to learn more.



"The best relationships that I had were with my design professors and I think it's because they understood how taxing the outside world could be. If I told them I was out sick and couldn't do schoolwork, they were receptive about that, which is really nice, I just had to express that to them."

– Bella B., SMA Patient Advocate, SMA Type 2



Be Open About Your Situation

Schedule time with your teachers and coworkers to discuss any concerns you have. Bring ideas with you to ensure that you have a productive conversation.

Example:

"Sometimes I have a hard time with **[insert action here]** because of my SMA. I'm usually able to do it on my own with a little extra time, so please wait for a few minutes before offering to help me."



Ask for Official Accommodations

Many colleges and work environments have programs to support students and employees. Both may require appropriate documentation from a health care professional detailing your condition and how it may affect you. This will determine what appropriate accommodation you may need to succeed.

Ask your campus Disability Services office or Human Resources department about them.

Examples:

"Does the school have any programs for students who need extra accommodations?"

"I'm really good at **[insert task]**. I'd love to do more of that since I'm not always able to **[insert more challenging task]**."



What To Do if There Aren't Accommodations

Some colleges and companies may not have formal assistance programs, but all are required to evaluate your accommodation request. While they don't have to approve every request, there are official procedures you can follow if your needs are not met. These tips can help you access support.

- TIP 1:** Get a letter from your doctor to share with your school or company.³
- TIP 2:** Speak directly with your teacher or supervisor about the specific accommodations you need to be successful. You should come to this conversation with a note from your health care provider on why you require accommodations.³
- TIP 3:** If you still aren't getting anywhere, schedule a meeting with an authority figure, like your school's principal or dean, a Human Resources manager, or a senior leader.⁴
- TIP 4:** Consider completing the 'Voluntary Self-Identification of Disability' section of your initial employment application.⁵
- TIP 5:** The ADA offers a range of resources to help guide you through this process and any challenges that may arise. Check out their website [here](#).

Sample Email: Asking Your School for Accommodations

Dear [Insert name here],

My name is [insert name here] and I am a student in your [insert class name] reaching out to request accommodations. I have a disease called spinal muscular atrophy, which causes muscle weakness. This affects my ability to [insert tasks here]. To be at my best, it would be helpful if I could have [insert accommodation asks here].

I am happy to work with you to set accommodations that help me learn while not disrupting your class. Can we schedule a time to talk about what I need and any additional procedures I should follow to request accommodation?

Thank you,
[Insert your name here]

Having the confidence to speak up about living with SMA not only makes tough conversations easier but also reminds us that asking for help is a strength, not a weakness. Everyone relies on others, even if that support looks different for each of us.

By advocating for yourself and asking for the support you need, you can keep SMashing your 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. Frequently Asked Questions: Section 504 Free Appropriate Public Education (FAPE). Accessed April 22, 2025. <https://www.ed.gov/laws-and-policy/civil-rights-laws/disability-discrimination/frequently-asked-questions-section-504-fape>
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4. Job Accommodation Network. Your Accommodation Request Was Denied. What Now? Accessed May 29, 2025. https://askjan.org/publications/consultants-corner/Your-Accommodation-Request-Was-Denied-What-Now.cfm?csSearch=10022163_1
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