

Growing Up, Growing Independent

A guide to starting conversations about independence
with your parents or caregivers*

This guide is for you

SMASHing My Limits is about celebrating what you can do, including the big wins and the everyday moments that often go unnoticed. Part of that is growing into the life you want, on your own terms.

Growing up means a lot of things change: how you feel about yourself, what you want to do, and how you relate to the people around you. Living with SMA adds its own layer to all of that. Your parents or caregivers have been by your side through a lot, and they care deeply about you. But as you get older, it's natural to want more say in your own life, and it's okay to start those conversations!

This guide isn't about pulling away from your support system. It's about **growing into it in a way that works for you, at your own pace, in your own way.**

Some of these conversations might feel easy. Some might feel a bit uncomfortable or even a bit scary. That's completely normal, and this guide will help you take them one step at a time.

*This guide is intended for conversations with unpaid caregivers only (e.g., family, relatives, friends, etc.)

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Before you begin

Bringing up topics like independence, your social life, or your future can feel awkward, even with people you're close to. That's normal. Most people find these conversations hard at first, so it helps to have a structure to support you, like this guide!

Before you dive into the topics in this guide, here are a few things that can help you approach the conversation, and what to expect from it.

How to approach it	
Pick your moment	Start small
Choose a calm time, not when anyone is stressed, rushed, or distracted. A quiet evening or a long car journey can work well.	You don't have to cover everything at once. Pick one topic to begin with, you can always come back to the rest later.
Lead with how you feel	Acknowledge their perspective
Starting with "I feel..." or "I've been thinking about..." can feel more open and less pressured than diving straight into what you want to change.	Your parents or caregivers care about you deeply. Letting them know that you're not trying to push them away can help build trust in the conversation.

Pro tip



If talking out loud feels too difficult for now, don't pressure yourself. You could type your thoughts out in a note, send a text message or even share parts of this guide to help break the ice and start the conversation on your terms.

What to expect

Something really important: this is an ongoing conversation, not a one-off moment. You might bring something up once and feel like nothing changes immediately, but that doesn't mean you haven't succeeded. These conversations often take time, and that's completely normal.

If the first conversation doesn't go to plan...

Your parents or caregivers might find some of these conversations difficult too, not because they don't want the best for you, but because caring for someone deeply can make it hard to step back. They may need time to process things.



Give it some time and come back to it. It's okay to revisit a topic more than once



Try a different approach or a different moment



Ask a trusted person (like a healthcare professional or another family member) to help. You don't have to navigate this alone

Some conversation starters you could try:

"I've been thinking about something and I'd love to talk it through with you. Is now a good time?"

"I know you do so much for me, and I really appreciate it. I'm starting to feel like I'd like to be more involved in some of it."

"I'm not trying to change everything, I just want to talk about how things might work as I get older."

"There's something I've been wanting to bring up. Can we find a time to chat about it?"



Write your own starter:

Is there a way of kicking off the conversation that feels more like you? Try writing it out here.

Where are you starting from?

Everyone is in a different place when it comes to independence, and that's fine. Before jumping into specific topics, it helps to take stock of where you are right now and what you'd like things to look like going forward. Independence means something different to everyone.

Use this section to note down your honest thoughts. There are no right or wrong answers, it's just for you.

What I already manage on my own (or mostly on my own)

What I'd like to take more control of or be more involved in

What feels uncertain or difficult to bring up

For me, SMASHing my limits looks like



Taking small steps

Now that you've reflected on where you are, you can start thinking about different areas of your life. You don't need to tackle everything at once, but can start with what feels most relevant to you.

Daily life and independence



The behind-the-scenes stuff

There's a lot happening day-to-day, organizing transport, booking appointments. You might not always see it, but it's part of what keeps things running. As you get older, getting more involved in these things can feel empowering (even just understanding how they work).

It doesn't have to happen overnight. Learning what goes into one task can be a great first step.



Things you might want to explore together:

- Tasks my parent/caregiver currently manage that I'd like to understand more about
- One area I'd like to start taking more ownership of, even just step by step
- Asking for help when I need it, even after trying things more independently
- Bringing up future living plans (university, supported living, moving out) without it feeling like a big declaration
- Wanting more privacy. For example, how to incorporate more privacy into my personal care



My thoughts on daily independence:

The goals I want to communicate in this area are...

Social life and relationships



Your life is your own

Spending time with friends, going out, and travelling are normal parts of growing up. Talking about how to do this in a way that feels comfortable for both you and your caregiver is an important step.

It's also okay to talk about needing rest or flexibility. That's not letting anyone down, it's knowing yourself.



Things you might want to explore together:

- Independently socializing with friends or travelling in a way that feels comfortable for everyone
- Needing to rest or change plans without feeling guilty
- Dating and relationships in a way that feels honest and open



My thoughts on social life:

The goals I want to communicate in this area are...

Family relationships



Growing up changes family dynamics too

As you get older, your relationship with your parents and brothers and sisters (if you have them) naturally shifts. Some things, like wanting more privacy, or making your own choices (and yes, your own mistakes) can feel tricky to bring up. But they're worth talking about.

Future plans like university, moving out, or living more independently are big topics. Starting the conversation early, even just exploring ideas, can take a lot of pressure off later.



Things you might want to explore together:

- Wanting more privacy. For example, more independence in my own space at home
- Who gets to know about my health and what gets shared on social media
- Explaining that making mistakes is part of how I learn and grow
- Keeping my relationship with my siblings strong as things change



My thoughts on family relationships:

The goals I want to communicate in this area are...

Body confidence and identity



You're allowed to feel how you feel

Growing up involves a lot of changes, and when you're living with SMA, navigating puberty, and your changing body can bring up a lot of feelings. How you see yourself, how you feel about your body, and how you want to talk about it (or not) is completely personal.

These conversations can feel vulnerable. But you don't have to figure it all out alone, and you get to decide what support looks like for you.

Things you might want to explore together:

- How I feel about my body as I'm growing up
- Parts of puberty or physical changes I'd like more support or information about
- Talking about my identity (who I am, how I want to be seen) with the people around me



My thoughts on body confidence and identity:

The goals I want to communicate in this area are...

Healthcare and having your say



Your health, your voice

As you get older, you might want to take a more active role in your healthcare. That could mean speaking up more in appointments, understanding your treatment and support, or helping make decisions about what works best for you. Your doctors and healthcare team know about SMA, but you are the expert on your own life.

Getting more involved doesn't mean you have to do everything on your own straight away. You can start small, and your parent or caregiver can still support you while you build confidence.

"Make your voice heard. Visit the Smashing My Limits page to find our 'Your Appointment, Your Voice' guide: your go-to resource for navigating medical visits with confidence."



Things you might want to explore together:

- Being more involved in appointments, for example asking questions or sharing how you've been feeling
- Understanding more about your medication, treatments, equipment, or therapies
- Thinking about what you want your doctor or healthcare team to understand about your daily life and personal goals
- Starting to take more ownership of practical things like keeping track of appointments



My thoughts on having my say in healthcare:

The goals I want to communicate in this area are...

My SMashing goals worksheet

Every big change starts with a small step. Use this space to track the conversations you want to have and the limits you want to smash, however big or small. Come back and update it as things shift.



Goal 1

One limit I want to smash (something I'd like to try or take more ownership of):

A conversation I want to have (with who, and about what):

One small first step I can take:



Goal 2

One limit I want to smash (something I'd like to try or take more ownership of):

A conversation I want to have (with who, and about what):

One small first step I can take:



Goal 3

One limit I want to smash (something I'd like to try or take more ownership of):

A conversation I want to have (with who, and about what):

One small first step I can take:

SMASHING MY LIMITS

Keep SMAshing

Every appointment where you speak up, even just once, is a step towards leading your own care. You know your body, your goals, and your life better than anyone. That makes you a vital part of your medical team.

You're not doing this alone, and you don't have to figure everything out at once. Every conversation you have, every limit you push (even just a little), is worth celebrating. The big wins and the small ones.

You've got this!