

# Your Appointment, Your Voice

## Take a role in your healthcare, your voice matters

### Consider this your secret weapon

Your doctors understand SMA. But **you are the expert of your own body**, your daily life, and your goals, and that expertise is just as important.

As you get older and begin moving towards adult care, your appointments are an opportunity to take more of an active role in sharing how things feel day-to-day, asking about managing your condition, and **talking about what you want your life to look like beyond your condition.**

Sometimes, conversations in appointments can happen around you rather than with you, especially if a parent or caregiver has always led them, which is normal. But you can start to take part in a way that feels right for you. You don't have to do it all at once. Start with one question, one topic, one moment of speaking up and build from there!

You can also use the **Growing Up, Growing Independent** guide to think about how your care connects to your wider goals, including independence, family relationships, and your social life.

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# Getting ready for your appointment

A little preparation can go a long way. Noting a few things down beforehand can help you feel more confident and make the most of your time.

## 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](http://www.sma-europe.eu/care-standards-for-sma)

### Pro tip:

Keeping a symptom diary is a good way to keep a record of how you are feeling each day, making it easier to share updates during the appointment!



### Between appointments, keep a note of:

#### What's going well

*e.g., something feels easier than it used to, a new routine that's working, something new that you've achieved*

#### What's been difficult

*e.g., more fatigue than usual, something that's gotten harder, a symptom that's been bothering you, how you've been feeling mentally*

#### What I'd like to improve or change

*e.g., maintaining independence, having more energy for social plans, better support at school or college, maintaining mobility or motor function, getting more information about assistive technology, and new goals you want to reach*



### My questions for the appointment:

Write down anything you want to ask, no question is too small. Highlight the ones that feel most important, so you don't forget them even if you feel rushed.

## Topics worth raising

- Planning for independence i.e., socializing with friends independently, or travel or time away from home
- How my condition is affecting daily life and confidence not just physically
- Fatigue, anxiety, or feeling isolated (these are valid symptoms too)
- Assistive technology or equipment that could support my independence or mobility.
- Checking the settings on my existing equipment is up to date
- What to expect as I move to adult care. How to maintain a smooth transition between pediatric and adult care
- What services am I entitled to/are available to me
- Planning for the future, including goals and what I want to achieve

## Before you begin

I've noted what's going well, what's been difficult, and what I'd like to improve

I've written down my questions (and circled the most important ones)

I have a plan for remembering key points (notes, phone, or someone supporting me)

I've asked (or will ask) for information to be shared directly with me as well

## Tips for your appointment

Entering a medical appointment and speaking up, especially if a caregiver or parent is there too, can feel unfamiliar, which is completely normal. These tips can help you feel more confident.

- Set the tone of your appointment by presenting yourself confidently and assertively, such as maintaining eye contact.
- If you continue to feel unheard, you can invite a mediator to your appointments. Approach someone you feel safe speaking to. If you continue to feel unheard, you can invite a mediator to your appointments; approach someone you feel safe speaking to.

## Speaking up when a parent or caregiver is in the room

It can feel like the conversation naturally drifts towards your caregiver, particularly if they've always led appointments. These phrases can help you take a more active role in your appointment:

**TIP 1: When the doctor asks your caregiver or parent a question about you:**

*"Can I answer that? I'd like to describe it myself."*

**TIP 2: When you want to add something:**

*"Can I share my perspective on that?" or "I'd like to add something here, if that's okay."*

**TIP 3: To set the tone at the start of the appointment:**

*"I've been working on being more involved in my appointments. I'd love to try answering the questions myself today."*

## If your concerns feel ignored

Your perspective matters. If something feels brushed over, it's okay to push back respectfully and calmly.

**TIP 1: If you feel rushed:**

*"I want to make sure I've understood everything, can we go over that again?"*

**TIP 2: If a concern isn't picked up:**

*"I mentioned [x] I'm still worried about it. Can we make some time to talk about it today?"*

**TIP 3: If you don't understand something:**

*"Could you explain that in simpler terms? I want to make sure I've got it."*

**If you need more time in decision-making:**

**TIP 4:** *"I'd like to think this through. Is it okay if we come back to this?"*



**Remember:** You are allowed to ask for clarification. You are allowed to slow things down. You are allowed to say 'I'd like to answer that'. Every time you speak, you build confidence!

### Questions to ask your doctor

These are just prompts, pick the ones that feel relevant to you right now. Add your own at the bottom.

| Understanding your care team                                                                                                                                                                                                                                                                                                   | Care and support options                                                                                                                                                                                                                                                                                                                                                                                          |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"><li>• Who leads my care team, and who should I contact first if I have a question or need something?</li><li>• How do the different specialists on my team communicate with each other?</li><li>• Can you start sending appointment summaries and updates to my own email as well?</li></ul> | <ul style="list-style-type: none"><li>• What are the goals of my current care and how are we tracking against them?</li><li>• Are there any new assistive technologies or equipment that might support my independence or mobility?</li><li>• Are all the settings on my machines up to date?</li><li>• Can I have a referral to additional specialist (e.g., dietitians, mental health experts, etc.)?</li></ul> |

| Moving to adult care                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | My life goals (beyond my condition)                                                                                                                                                                                                                                         |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> <li>• What should I expect as I move from pediatric to adult care, and when will that transition happen?</li> <li>• Who will be taking over my care, and will I get a chance to meet them before the handover?</li> <li>• How do I make sure my medical records and history transfer over correctly?</li> <li>• Is there any support available to help me through the transition?</li> <li>• Can my medical information be emailed to me as well as my caregiver?</li> </ul> | <ul style="list-style-type: none"> <li>• I want to [go to university / travel / work / socialize more / live more independently] what do you think I should consider?</li> <li>• How can my care plan support my goals outside of my condition in everyday life?</li> </ul> |





### What I understood from today

*Anything else I want to ask or bring up...*

# After your appointment

Taking a few minutes after your appointment to reflect, can help you get more out of it and prepare better for next time.



## What I understood from today

*Key takeaway points, decisions made, next steps agreed*



## Something I want to follow up on

*A question I didn't get to ask, something I want to find out more about, or something I want to raise next time*



## Something I'd like to do differently next time

*e.g., speak up sooner, bring a specific question, ask for something in writing, try answering questions myself*

### Helpful to keep record of



- Appointments: dates, who you saw, anything agreed and set reminders
- Medications: what you take, when, and any changes
- Address book: note down all important contacts and who to contact for different things general practitioner vs specialist vs care coordinator

## My health and life goals worksheet

Your goals aren't just medical, they're about your whole life. Use this tracker to stay focused on what matters most to you, and to share your priorities with your care team.

What matters most to me right now

*e.g., school, friendships, having more energy, confidence, independence*

Something I want to improve

*e.g., managing fatigue better, being more involved in my own care, building confidence socially, understanding my treatment*

One step I can take

*e.g., asking one question at my next appointment, starting a symptom diary, talking to my care team about a goal I have*



## My next appointment

Date:

With:

One thing I want to make sure I raise:

# 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.

*This guide is part of the international SMAshing My Limits campaign. Bring it to your next appointment, it's yours to use and reuse!*