

Adults with SMA work with many doctors and health care providers. Here are some key questions to help guide patient-HCP conversations.



Staying Informed and Coordinating Care:

When I was younger, I saw my whole health care team at the same location. They all talked to each other and knew what was going on with me. Now, I am expected to coordinate everything between multiple specialists at multiple locations. It can get overwhelming.

- What can be done to make sure my care with you is communicated to the rest of my health care team and vice versa? Do you have a care coordinator? Do you share electronic records with other providers or incorporate medical passports?
- How have you worked with adult patients with SMA in the past? How have you helped them take ownership of their care? Do you have any examples of what has worked? What to avoid?
- Will you welcome any caregiver or friend who accompanies me to appointments for emotional and practical support?
- Will you explain things to me in terms I can understand and include my feedback and expertise when making decisions about my care?
- Do you use any digital tools, like telehealth or patient portals, to streamline communication and reduce the burden of commuting to appointments?

Discussing Symptoms and Treatments:

Sometimes it feels like nothing is actually happening with my medical care. It's just business as usual. Nothing is helping me function better from day-to-day.

- What can be done to help me move around and perform daily tasks more independently? Are there any medications, exercises, or assistive devices I can use?
- I want to set realistic goals and expectations. How much should I expect this treatment plan to improve my symptoms? When will I notice a difference?
- Is it possible this treatment could make things worse or cause adverse effects? If so, what should I watch out for? Is there a way to resolve smaller side effects on my own? What signs and symptoms should I report to you right away?
- How will you monitor the effectiveness of this treatment?
- Is there someone on staff who can help with insurance barriers and make sure I can access the care I need?
- Do you work with any therapists or social workers who understand what it's like for adults with SMA? What about community groups where I can talk to others like me?