

A STRONGER CONVERSATION ABOUT SMA

Make the most of your next appointment



Fill in the blanks or record your responses to assess how you're doing in between appointments with your healthcare team. Then read through the suggested questions, which can help you start conversations with your doctor about strength and SMA. Feel free to share this guide with a caregiver or loved one before your appointment—you might find additional points you'd like to cover. You can answer these questions regularly and keep your responses to monitor your progress over time. **Remember, sharing your experience helps improve SMA care.**

WHAT I'M NOTICING

Consider this list of daily activities and any others that are important to you. When are you feeling weaker, stronger, or the same? Are there any activities you're avoiding?

AVOIDING WEAKER SAME STRONGER

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Using the bathroom by yourself
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeding yourself
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Spending time alone
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Turning in bed
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Dressing yourself
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Transferring from wheelchair to bed
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Using a keyboard or an iPad/tablet
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Writing with a pen
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Brushing your teeth
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Brushing your hair
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Other _____

WHAT TO ASK

How are we evaluating muscle strength in my care plan?

What can we do to help preserve and strengthen the muscle I have now?

Is progressive muscle wasting something we should address more directly?

INDEPENDENCE GOALS

WHAT I'M NOTICING

I want to maintain...

TYPE OR WRITE ANSWERS BELOW 

I want to gain...

More strength would help me...

WHAT TO ASK

What's a realistic short-term goal before my next visit?

What's a longer-term goal we can work toward over the next 6-12 months?

What types of support would help me reach these goals?

ON THE HORIZON

WHAT TO ASK

What do you think about research looking into myostatin, the body's natural "brake" on muscle growth?

Can we talk about how muscle-targeted approaches might complement my care?

Are there clinical studies or research relating to muscle strength that I should know about?

TYPE OR WRITE YOUR QUESTION BELOW 