

A woman with long brown hair, wearing a pink long-sleeved shirt and light blue pants, is sitting in a black motorized wheelchair on a concrete sidewalk. She is smiling and looking towards the camera. A golden retriever dog is sitting next to her, looking to the right. The background shows a residential building with a porch and some greenery.

NEW

POSSIBILITIES

A STEP-BY-STEP GUIDE TO NEW POSSIBILITIES IN SMA

Discussing treatment options with adults living with SMA

INTENDED FOR HCPs ONLY

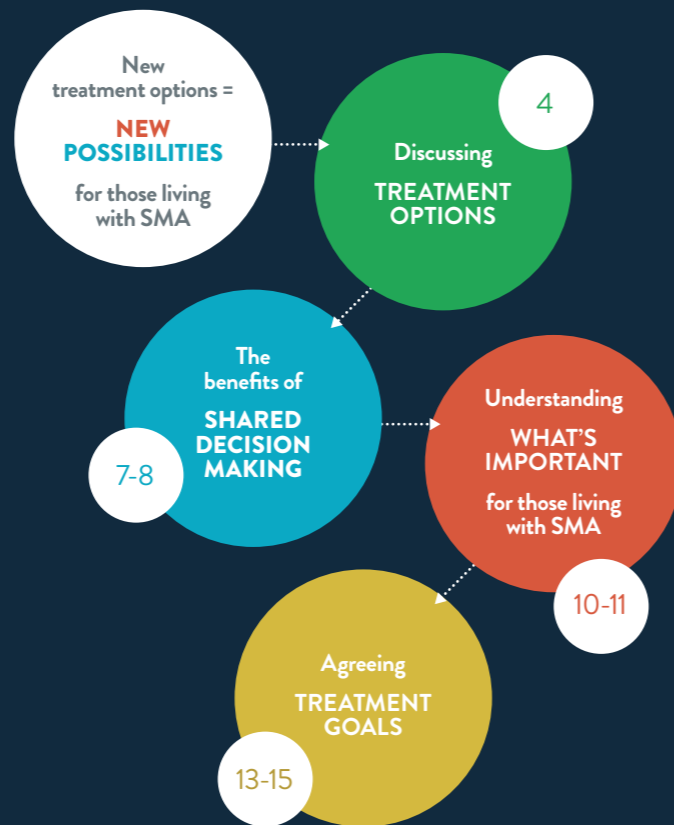
 **Biogen**

With more effective treatment options now available, the SMA story doesn't have to stop at childhood. Treatment can also provide substantial benefits for adults, including disease stabilisation, slowing disease progression and improving people's quality of life. In addition, clinically meaningful improvements in motor function are possible.¹

Previously, you might not have considered discussing options for adults living with SMA because there were no effective treatments. However, treatment expectations have changed over recent years. This guide is intended to provide you with some useful information and tips about discussing the potential treatment options that are now available for adults living with SMA.

IT MIGHT BE TIME TO LOOK AT SOME NEW POSSIBILITIES.

**NEW
POSSIBILITIES**



SMA CAN BE CONFUSING.

None more so than for adults living with SMA. No one knows their SMA better than those living with it. However, there can be confusion and a lack of understanding about the treatments available and the benefits they can provide.

Opening up the options for adults living with SMA and getting them to consider the benefits of treatment can enable them to achieve the life they want and you to achieve the results you expect.

**NEW
POSSIBILITIES**

DISCUSSING NEW TREATMENT OPTIONS CAN MAKE A DIFFERENCE TO THE LIVES OF THOSE LIVING WITH SMA.



A NUMBER OF CARE OPTIONS are now available with the potential to stabilise the disease²⁻⁴

WITHOUT INTERVENTION

People living with SMA will lose motoneurons and motor function continuously.⁵ Once motor function has been lost, it cannot be regained so early intervention is crucial for maintaining mobility.



of survey respondents felt that a treatment that could stabilise their disease would represent major therapeutic progress⁶



"I would like to treat as many patients as possible to give them a chance"⁷

NEUROLOGIST,
GERMANY, ACADEMIC
MEDICAL CENTRE*



The SMA standards of care have been updated and there are new care options available^{2,3}

YOU CAN MAKE A DIFFERENCE.

“We have had encouraging results for our adults that we had not expected⁷”

NEUROLOGIST, FRANCE,
ACADEMIC MEDICAL CENTRE*





THE BENEFITS OF SHARED DECISION MAKING WHEN DISCUSSING TREATMENT OPTIONS WITH THOSE LIVING WITH SMA



Discussing treatment options with those living with SMA involves a careful appraisal of their potential benefits and possible side effects. There can be a lot of information to impart so having visual aids and printed materials to give to them can help aid their understanding.



THE **TOGETHER IN SMA*** WEBSITE PROVIDES SOME USEFUL RESOURCES ABOUT SMA



Given the complex nature of SMA and its treatment, it is probable that those living with SMA will need time on their own to review all the available information before they can make an informed decision about the treatment that's best for them. It is therefore likely that several consultations will be needed before you can reach a mutually agreeable decision.

“It is important to adapt the message especially when talking to adult patients to make sure they have understood. If you give information that is too complex, sometimes gets more confusing. I want to be sure that they have understood the message.”

NEUROLOGIST, FRANCE,
ACADEMIC MEDICAL CENTRE*



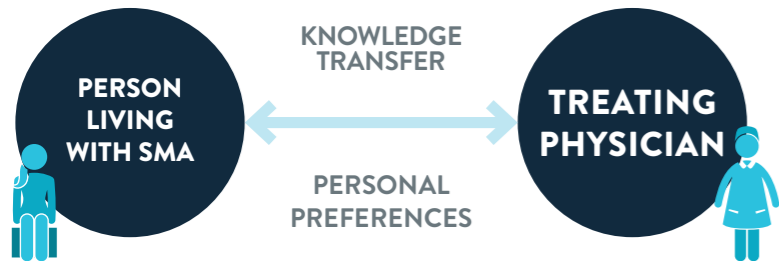
*<https://care.togetherinsma.eu/>

NEW
POSSIBILITIES

NO ONE KNOWS THEIR SMA BETTER THAN THOSE LIVING WITH IT

They are the best person to talk to in order to gain a good insight into their SMA, their quality of life and their hopes and aspirations. What are their concerns about their SMA? What would they like to achieve with any treatment options? What would they like to maintain or improve in their quality of life? For example, be able to continue studying or working, be able to travel, maintain their independence or look after their family.

Engaging with those living with SMA and involving them in the decision making process can lead to improved healthcare and better outcomes for both you and them.⁸⁻¹¹



In a study of how adults and adolescents with SMA perceive and experience healthcare, **10 of 25** participants described experiencing brief or superficial interactions with disinterested and unknowledgeable HCPs, generating a perception that adults with SMA were not valued by the health system.¹²

“It’s pretty important to me that I’ve got a good relationship with my doctor ... I have to build up a rapport before I open up to them.”¹²”

PERSON LIVING WITH SMA TYPE 2

“That kind of attitude is very, very reflective of what it’s like to be an adult especially with a condition that is degenerative and changes over time ... they just don’t really see the value in supporting you physically to help you with better health outcomes.”¹²

PERSON LIVING WITH SMA TYPE 3

THEN WE CAN UNDERSTAND WHAT IS IMPORTANT FOR ADULTS LIVING WITH SMA

In a US survey of adults living with SMA and caregivers of those living with SMA, the five most important treatment benefits, ranked in order of importance, were:¹³

- Using the toilet unassisted
- Spending time alone/being independent
- Engage in social activities/building relationships
- Attend to personal hygiene independently
- Chew and swallow food



“I was concerned I could deteriorate in the future even though at that moment I was rather stable.”

**PERSON LIVING WITH
SMA TYPE 2, GERMANY,
20 YEARS OLD***

“I think doctors should be up to date, and advise adults that there are available SMA treatments. I think that’s really important.”

**PERSON LIVING WITH SMA
TYPE 3, FRANCE,
32 YEARS OLD***



In the same survey, the five most important benefits in terms of activities of daily living, ranked in order of importance, were:¹³

- Increased mobility independence
- Using the toilet unassisted
- Self-feeding
- Spending time alone/being independent
- Turning in bed

In an international survey of adults living with SMA:

98.6%

limitations with mobility or walking



98.6%

the inability to do activities

were the most important issues and had the greatest effect on the lives of adults with SMA.¹⁴





AND AGREE THEIR TREATMENT GOALS



Once you have agreed which is the best treatment option, it is important that you agree what the treatment goals should be. These should be specific goals that can be realistically achieved with the chosen treatment. Ideally, these goals should have a defined time frame in which they should be attainable.

The space provided on page 16 can be used to lock down some specific, realistic and time-defined treatment goals with those living with SMA.

This can be a useful agreement to refer back to; it can help monitor and measure the success of the treatment.



“Taking into account the expectations of our patients, for which even slowing down a disease that inevitably degenerates and progresses, it represents a great victory for me.”

**IT NEUROLOGIST,
HOSPITAL NETWORK***

EXAMPLE QUESTIONS THOSE LIVING WITH SMA MAY WANT TO ASK YOU WHEN DISCUSSING TREATMENT OPTIONS

POTENTIAL TREATMENT BENEFITS



- How long has the treatment been available?

- How many people living with SMA have received it?
- How effective is it? What is the evidence?
- How does the treatment work? What does it do to the body?
- How will it help me reach my treatment goals?

POTENTIAL SIDE EFFECTS



- What are the potential side effects?
- How likely is it that I will experience these side effects?
- What can I do if I experience these side effects?

TREATMENT LOGISTICS



- How is the treatment administered and how often?
- Will I have to go to hospital to receive it?
- Who will administer the treatment?
- How will treatment be coordinated with my other multidisciplinary team (MDT) visits (for example Physiotherapy, Nutrition)?

TAKING THE TREATMENT



- What will the treatment experience be?
- Is special monitoring required?
- How will I know if the treatment is working?
- What happens if the treatment does not work?
- What if I'm thinking of starting a family?

GOAL SETTING

This space can be used to lock down some specific, realistic and time-defined treatment goals with those living with SMA.

DISCUSSION NOTES



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Think about what matters to you in your life and what you would like to continue being able to do in the future

TREATMENT GOALS

Agreeing therapy goals in the form of a contract can be helpful.



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IMMEDIATE NEXT STEPS

For example a next appointment date or important next steps related to each goal.



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Agree on a date to review this agreement to monitor the response to treatment

REMEMBER...

- ✔ There are new treatment options available for adults living with SMA
- ✔ Without intervention, those living with SMA will lose motor function continuously
- ✔ Even the smallest improvements can have a major impact on their quality of life
- ✔ People living with SMA are an important source of information about their SMA
- ✔ Shared decision making can lead to better outcomes for both you and those living with SMA
- ✔ Shared decision making can help achieve realistic treatment goals for those living with SMA

NOTES



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NOTES



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*Quotations from the market research represent the views or opinions of individual patients with SMA or healthcare professionals who treat patients with SMA. They do not represent the views or opinions of Biogen nor are they endorsed by the company.

Photographs are for illustrative purposes only. The subjects have given their required consent to use their image.

The information contained in this guide has been compiled from published peer-reviewed articles and market research conducted with adult SMA patients and HCPs experienced in the treatment of adult SMA patients.

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