



NEW

POSSIBILITIES

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

Discussing options with your doctor



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BEFORE AND DURING YOUR APPOINTMENT



All information contained therein is intended for educational purposes only and should not be used to replace a discussion with a healthcare professional or healthcare team. Please ask questions and discuss your concerns with your healthcare team.

1. EMPOWER YOURSELF

Empowering yourself to taking an active role in managing your SMA can have a number of benefits. Nobody knows your SMA better than you do so you are the best person to discuss your options.



“I am a member of the association. I go to many conventions even up North, so I am always up to date with new centres, new therapies and all sorts of new stuff.”¹

**PERSON LIVING WITH
SMA TYPE 2, ITALY,
43 YEARS OLD***



Embrace an active role in managing your SMA by:

- 1 Understanding your role as someone living with SMA and taking a co-operative approach in discussions with your physician. By thinking now about what you want to ask, what matters to you in your life and what you would like to continue being able to do in the future, you can have a better discussion later.
- 2 Having knowledge and understanding about your SMA and how the SMA space is evolving over time. There's always something new to learn!
- 3 Engaging with the SMA community. Is there a local patient support group you can join? Is there an online forum or Facebook group you can join? Learning about other peoples' experience with their SMA and their management could help you think about how you live your life with SMA and what you would like to achieve with any care option.
- 4 Being able to engage in discussions with your physician and participate in shared decision making. They are there to answer your questions and help.

2. REMEMBER, YOU REALLY CAN MAKE A DIFFERENCE

Taking an active role in managing your SMA by discussing your care options and your ongoing management with your physician can have a number of benefits for you:

- 1 Improve your health and wellbeing
- 2 Provide you with greater satisfaction with your care
- 3 Improve your quality of life
- 4 Increase your self-confidence to manage your SMA
- 5 Improve your ability to manage your SMA
- 6 Improve your coping skills to manage the impact SMA has on your daily life



3. KEY POINTS TO REMEMBER WHEN PREPARING FOR YOUR APPOINTMENT

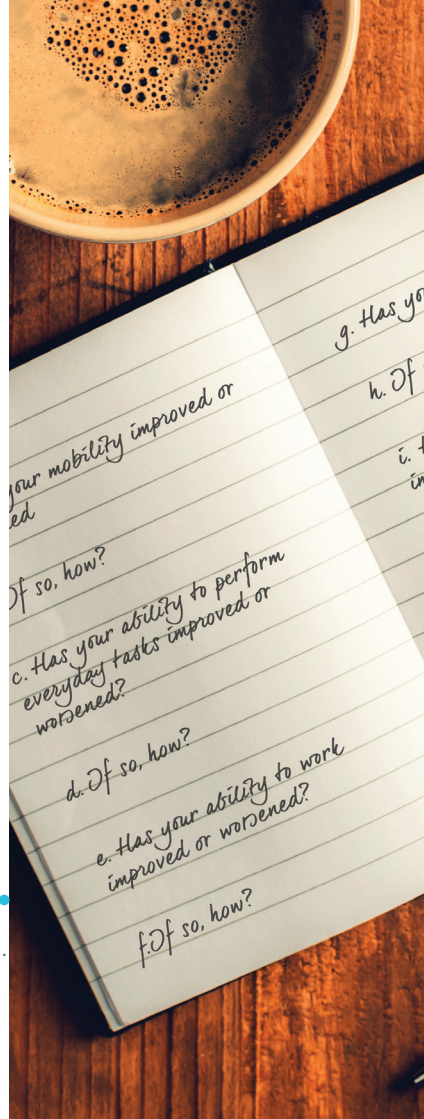
Clinic appointments can be shorter than we would like, and it may have been some time since you last spoke with your physician about your SMA management goals. There are a few things you can do in advance to prepare for your appointment that could help you to make the most of the time you have.



MAKE SOME NOTES about the things you want to discuss or that you want to tell your physician. Take those notes with you to your appointment so you know that you have discussed everything you want to.



MAKE A LIST of the questions you would like to ask your physician. If you have a number of questions, list these in order of importance so if your time with your physician is limited, you will have the opportunity to ask the questions that are most important to you. *Some example questions you might want to ask are provided in section 6.*



KEEP A SYMPTOM DIARY

so you have a record of how you are feeling each day. Make a note of when your condition improves or worsens and what might cause any changes in how you are feeling. For example, since your last appointment:

- a. Has your mobility improved or worsened? *If so, how?*
- b. Has your ability to perform everyday tasks improved or worsened?

c. Has your ability to work improved or worsened?

d. Has your mood changed?

e. Has your overall quality of life improved or worsened?



If you would like to **HAVE SOMEONE WITH YOU TO SUPPORT YOU**, ask a family member, carer or friend to go with you to your appointment. They can also help you to remember the details discussed.



4. OKAY, NOW LET'S TALK ABOUT THE ROLE OF YOUR PHYSICIAN

When discussing your SMA and the possible care options, your physician will provide you with all the relevant information, including explanations about your SMA, the different options available, the anticipated benefits and any potential risks that should be taken into account when deciding which care option is best for you. Your physician is just that. Yours. They are here for you and are aware of this disease and the impact it can have. By engaging with them, knowing they are here to get the best result for you, means a better outcome for everyone.

5. A FEW HANDY TOPICS YOU MAY WANT TO DISCUSS WITH YOUR PHYSICIAN



Make sure the details of your discussion are written down for you so you can remember everything and you have a written record.

WHAT ARE THE MOST IMPORTANT FACTORS FOR YOU?

Some examples could be, but not limited to the following:

To stabilise your SMA and slow its progression

To maintain your independence, e.g. your ability to work or take care of yourself etc.

?
..... Are there any other factors that you can think of?

Having a shared understanding of how you feel about these topics and clarifying what you expect from the management of your disease is important to help you and your physician define the best next steps



YOUR HOPES AND CONCERNS

WHAT ARE YOUR HOPES AND CONCERNS REGARDING YOUR SMA?

For example:

Maintaining independence

- The top 3 abilities people living with SMA chose to preserve:
Self-feeding, washing independently and using a keyboard²

Being able to manage your condition (e.g. be able to maintain or improve your breathing, be able to maintain or improve your ability to swallow food)

- 81% of people living with type II/III SMA felt a new care option to stabilise their disease would represent major progress²

Maintaining or improving your mobility (e.g. be able to climb upstairs, be able to walk, be able to get out of bed unaided)

Being more able to care for yourself (e.g. be able to wash yourself, be able to feed yourself, be able to dress yourself)

- 37% of those living with SMA want to stabilise self-feeding²

Another option is to record the conversation, if agreed with your physician, so you can remember all the details discussed.

6. EXAMPLE QUESTIONS YOU MAY WANT TO ASK YOUR PHYSICIAN WHEN DISCUSSING YOUR OPTIONS

POTENTIAL BENEFITS



- How will it help me reach my management goals?
- How does it work?
What does it do to my body?
- How effective is it? What is the evidence?

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?

LOGISTICS



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

MY EXPERIENCE



- What will the experience be for me?
- Is special monitoring required?
- How will I know if it is working?
- What happens if it does not work?
- Are there any special considerations e.g. thinking about starting a family?
- What would happen if I don't choose any of the available options?



7. OH, YES, AND SOME IMPORTANT POINTS BEFORE YOU LEAVE YOUR APPOINTMENT

Check the following before you leave:

- **Have you discussed all the points on your list?**
 - If not, ask your physician if they have any additional time to discuss these
 - If this is not possible, make a note so you know to discuss these first at your next appointment
 - Ask your physician if it would be possible to have a telephone appointment before your next face-to-face appointment
- **Have you understood everything that has been discussed?**
 - If not, ask for clarification. For example: Can I just check I understood what you said?
- **Do you know what should happen next and when?**
 - Clarify when your next appointment will be and if there is anything for you to do between now and then.



- Who to contact if you have any more concerns or questions
- About any support groups that could provide you with help and advice
- Where can you find reliable information about SMA



8. LET'S EVALUATE THE OPTIONS TO MANAGE YOUR SMA

SMA affects each person differently so your management has to be individualised to you. Choosing the best care option for you will be a very personal decision.

Your decision about the best care option may be influenced by a number of factors, such as your lifestyle, who you are as a person, your personal preferences and the severity of your SMA. For example, a change in your SMA may mean that you might benefit from a different approach.

When assessing the best care option for you, it's important to think about how important the benefits and the potential risks are to you. You should also consider how the approach may impact your lifestyle and your personal goals.

Using a decision aid may help you to consider your care options and decide what is best for you.



• List the benefits for each option

Points to consider could include:

- How much does each benefit mean to you?
- Would you be prepared to accept a potential greater risk to achieve the benefit you want?
-



• List the potential risks for each option

Points to consider could include:

- How much does each risk mean to you?
- What is the nature of the risk?
- What are the chances that you will be affected?
- Can the risk be minimised?
-



• Think about your lifestyle

Points to consider could include:

- What are the most important aspects of your lifestyle?
- What would you like to maintain or even improve?
- How could each option maintain or improve your lifestyle?
-



• Think about your personal goals

What are your most important goals?

Some examples could be, but not limited to the following:



- To be able to care for yourself
- To start a family
- To continue working
- To be more mobile
- To feel you're in control of your SMA
-

Points to consider could include:

How could each option help you to achieve your goals?

9. LET'S IDENTIFY THE BEST SMA CARE OPTION FOR YOU

The following steps may help you to consider the care options for your SMA and decide on the best approach for you. You might find it useful to work on completing this with a family member, your caregiver or your physician. If you have a voice notes app on your mobile or tablet this can be a good way to record your thoughts about these topics, if agreed with your physician.

- 1 List the possible options 
- 2 List the lifestyle factors that each option could help you to maintain or improve
- 3 List your personal goals that each option could help you to achieve
- 4 List the benefits for each of the options
- 5 List the possible risks for each of the options
- 6 



CONSIDER HOW IMPORTANT ALL THE ABOVE ARE



10. AGREEING ON YOUR MANAGEMENT GOALS







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



The space provided on the next page can be used to lock down some specific, realistic and time-defined goals with your physician.

This can be a useful agreement for you and your physician to refer back to; it can help monitor and measure the success of your approach.

REMEMBER...

-  You can benefit by taking an active role in managing your SMA
-  Preparing for your appointment can help you make the most of your time
-  Think about what's important to you and what you would like to achieve
-  Discussing your hopes and concerns with your physician can help you achieve the best results from your chosen approach
-  Identify the best care option for you
-  Shared decision making with your physician can help you achieve realistic management goals

GOAL SETTING

DISCUSSION NOTES



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

MANAGEMENT GOALS

Agreeing management goals in the form of a contract can be helpful for some people.



IMMEDIATE NEXT STEPS

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



Agree on a date to review this agreement to monitor your health status

REFERENCES

1. IQVIA 2019-2020 Qualitative Research with SMA Patients and Neurologists (CA, DE, FR, IT, ES; n=83).
2. Rouault F et al. Disease impact on general well-being and therapeutic expectations of European Type II and Type III spinal muscular atrophy patients. Neuromuscul Disord. 2017;27(5):428-438.

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

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

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Biogen-77307
Date of preparation: October 2020

