

Talk to be Heard

axSpA discussion guide

Why Talk to be Heard?

"A wave of relief swept over me after I talked openly about how axSpA really affected me and the impact it had on so many areas of my life."

Maranda van Dam, South Africa

Living with axial spondyloarthritis (axSpA) can be difficult and isolating. After years of living with the condition, it can be natural for those affected to stop talking about how it affects them – with their loved ones, or even their rheumatologist!

But it doesn't have to be this way. By making the time to talk about axSpA, you take an important step in prioritizing yourself and your personal health

This guide aims to help you so that when it comes to axSpA, you can Talk to be Heard! Whether at your upcoming rheumatologist appointment or when you're with your loved ones; use this guide to support them in supporting you.



How is axSpA affecting your life?

For a conversation about your health and wellbeing to be effective, it helps to be clear about how axSpA affects your life, and what you'd like to achieve with your care. Consider the following:

Which areas of your life are affected most by axSpA

For example, work, school, hobbies, family, social, intimate relationships, physical, emotional or financial.



Q1. How does axSpA affect these different areas of your life? For example:

- Fatigue, pain and poor sleep cause me to often be in a bad mood, affecting my relationships.
- My disability affects my confidence and self-esteem, negatively impacting my social life.
- The pain and stiffness make it difficult for me to take care of myself properly; I struggle to do things like wash my hair or dress myself.
- I worry about how the disease will progress and whether I will be able to take care of myself in the future, both physically and financially.
- The unpredictability of flares makes it difficult for me to attend university lectures regularly and keep up with work.



Instructions: These are just a few examples of how axSpA might affect people. Think about your own experiences and write down how your axSpA symptoms affect different areas of your life.

Q2. What would you like to achieve through your axSpA care? For example:

Care can include social support, meditation and mindfulness, mental health counselling or therapy, physiotherapy, aquatic therapy and medical treatment, among others.

- Being able to complete my university course.
- Being able to get through the workday and feeling that colleagues know I am doing a good job.
- Having the confidence to go out to meet friends more often.
- Achieving better sleep, where I feel rested.
- Being able to do the gardening or other hobbies again.
- Feeling motivated to take care of myself and feel less discouraged.

Q3. How satisfied are you that your current care allows you to achieve your goals?

If you were to give your current care a rating from **1 to 5**, where **1** is 'very unsatisfied' and **5** is 'very satisfied', what would your rating be?



Write down your responses, so you have them ready when discussing your axSpA.



How to Talk to be Heard with your Rheumatologist?

It can sometimes feel as though your rheumatologist focuses more on the "technical" elements of your axSpA. However, your rheumatologist should know that the effects of axSpA can be different for everyone and are much broader than pain and inflammation.

By telling your rheumatologist about how axSpA affects your life and what you'd like to achieve with your care, you can work together to improve it. Thinking about what you noted above, consider the following:

- Use clear language and examples to talk about the physical symptoms and non-physical impacts on your life that bother you most – for example "I cannot get out of bed most days" or "I am very worried about work."
- Discuss any major life decisions you are thinking of making, especially if it is related to your axSpA – for example, changing your job because of the disease or starting a family.
- Explain what is important to you when it comes to treatment and care.
- Express that you'd like to be involved in decisions regarding your treatment and care. Together, assess the benefits and risks of different options, agree on the plan and how you will monitor progress.
- Medical tests may not always give a complete picture. Even if a test result shows an improvement, it is important to give clear examples of how the symptoms may still be affecting you and talk about options to improve your care.
- Don't hesitate to talk about your future living with axSpA and discuss your longer-term care.
- If possible, take a family member or friend with you to support you.
- **Don't be worried to ask questions or raise doubts, even if they seem unimportant.**





Whenever axSpA affects you, write it down so you build a comprehensive picture of how your life is affected, and take the notes with you to your next appointment. Your rheumatologist may also be able to provide you with self-assessment tools to complete in between appointments.

Talking about axSpA with friends, family and those you trust

Living with axSpA can affect all aspects of everyday life including work, family, mental health and relationships²⁻⁵. Talking about your experiences with family, friends or those you trust can help to support you, making life a little easier.

Having a conversation about how axSpA affects you

Only you can decide if and when to talk with others about your axSpA. If you decide to do so, be honest and consider the things you have noted above. There are no right or wrong words, you have the right to express yourself however you choose.

Decide for yourself why you're having this conversation. Acknowledge how important it is to work together to best manage how axSpA impacts on your life and be clear about what you need. If you don't need anything but just want to be heard, you can be clear about that too.

With personal conversations, it can help to focus on how things affect you or how things make you feel, rather than focusing on the actions of the person you are talking to. For example:

"I feel worried because I cannot do all the things that need doing around the house" instead of "You don't help me around the house"

Some people feel embarrassed or ashamed of their condition – talking about it can help alleviate those feelings, and help others understand that it is hard to feel positive all the time.

We are all individuals, and what works for one person may not work for another. Think about what is important for you, take your time, and discuss it with others when you feel ready to do so.



For more information

For more information, please visit www.asif.info/talk-to-be-heard

To find out more about local patient organizations, please visit www.asif.info/members

References

1. Novartis data on file. axSpA Market Research. 2. Garrido-Cumbrera M, Bundy C, Navarro-Compán V, et al. Patient-reported Impact of Axial Spondyloarthritis on Working Life: Results from the EMAS survey. *Arthritis Care Res (Hoboken)*. 2021;73:1826-1833. 3. Garrido-Cumbrera M, Navarro-Compán V, Bundy C on behalf of EMAS Working Group, et al. SAT0374 ONSET OF AXIAL SPONDYLOARTHRITIS REPERCUSSIONS ON PATIENTS' SOCIAL AND FAMILY LIFE: RESULTS FROM THE EUROPEAN MAP OF AXIAL SPONDYLOARTHRITIS (EMAS). *Ann Rheum Dis*. 2020;79:1134-1135. 4. Garrido-Cumbrera M, Poddubnyy D, Gossec L, et al. The European Map of Axial Spondyloarthritis: Capturing the Patient Perspective-an Analysis of 2846 Patients Across 13 Countries. *Curr Rheumatol Rep*. 2019;21:19. 5. Garrido-Cumbrera M, Galvez-Ruiz D, Gossec L, et al. Psychological Distress in Patients with Axial Spondyloarthritis in Europe. Results from the European Map of Axial Spondyloarthritis Survey [abstract]. *Arthritis Rheumatol*. 2018;70 (suppl 10). <https://asif.info/wp-content/uploads/2018/04/ACR-Psych-Distress.pdf>.