

RACH YOURSELF

THE RACH FOUNDATION FOR ANKYLOSING SPONDYLITIS

CONVERSATION GUIDE

No matter how long it's been since you learned you have ankylosing spondylitis (AS), or how long you have been on treatment, taking stock of your progress regularly is a good idea. A range of effective treatments and therapies are available for AS and can each work differently depending on the person to ultimately help manage the daily challenges caused by AS.

Checking in with your healthcare team is critical to see whether you are achieving the level of control you would like. This simple discussion guide will help you reassess the impact AS may be having on your life and inform future conversations with your best ally, your rheumatologist.

EVALUATE YOUR CURRENT ACTIVITY

Thinking about the past month, on a 5-point scale (1 is easy to 5 impossible), please indicate your ability in relation to each of the following 'everyday' activities.*

Evaluating your current activity	1	2	3	4	5
Putting on socks or tights without help or aids (e.g., sock aid)	<input type="radio"/>				
Bending from the waist to pick up an item from the floor without aid	<input type="radio"/>				
Reaching a high shelf without help or aids (e.g., helping hand)	<input type="radio"/>				
Getting up from an armless chair without your hands or any other help	<input type="radio"/>				
Getting up off the floor (without help) from lying on your back	<input type="radio"/>				
Standing unsupported for 10 minutes without discomfort	<input type="radio"/>				
Getting out of bed (without help) from any position	<input type="radio"/>				
Climbing 12-15 steps without using a handrail or walking aid	<input type="radio"/>				
Looking over your shoulder without turning your body	<input type="radio"/>				
Doing physically demanding activities (e.g., physiotherapy exercises, gardening or sports)	<input type="radio"/>				
Doing a full day's activities at home or at work	<input type="radio"/>				

In addition to impacting everyday activities, tell your rheumatologist if you are experiencing any of the following challenges. Select any and all that apply:

- Fatigue
- Poor quality sleep
- Bowel problems e.g., constipation
- Eye pain or discomfort
- Blurred vision or light sensitivity
- Pain during sex
- Joint pain
- Reduced ability to work or study
- Reduced independence
- Relationship problems
- Avoiding socialising
- Avoiding activities I want to enjoy
- Poor mental health e.g., anxiety or depression

Take a note of your healthcare team if you are experiencing any of the above symptoms, as well as any other symptoms you are experiencing for your health.

HOW ARE YOUR AS SYMPTOMS AFFECTING YOU?*

Thinking about the past 12 months, how would you describe the:

Overall level of fatigue/tiredness you have experienced? None 1 2 3 4 5 None at all

Overall level of AS neck, back or hip pain you have had? None 1 2 3 4 5 None at all

Overall level of pain/swelling in joints other than neck, back, hips you have had? None 1 2 3 4 5 None at all

Overall level of discomfort you have had from any procedures to touch or pressure? None 1 2 3 4 5 None at all

Overall level of morning stiffness you have had from the time you wake up? None 1 2 3 4 5 None at all

Longer duration of morning stiffness from the time you wake up? None 1 2 3 4 5 None at all

MANAGING YOUR AS

How do you feel that your current management plan is controlling your AS to the best you would like?

Yes No

Reflect to speak to your rheumatologist about whether your current treatment is managing symptoms well and ensure they factor in your preferred administration route (e.g., oral vs. IV and daily vs. monthly), work and other life commitments, and personal goals such as long-term and other activities. A healthcare professional should decide on the appropriate AS in consultation with the patient.

What treatment administration method (with prescription and over the counter) do you use?

- None Topical cream Other
- Oral Injection

Do you consider other forms of therapy outside of prescription and over the counter to help manage your AS (e.g., physiotherapy, swimming, acupuncture, exercise, and chiropractor)? If you are using other treatments (e.g., alcohol):

PLEASE SPEAK TO YOUR RHEUMATOLOGIST AND DISCOVER HOW TO BETTER MANAGE YOUR ANKYLOSING SPONDYLITIS.

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