

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

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 used to enjoy
- Poor mental health e.g., anxiety or depression

Let your healthcare team if you are experiencing any of the above symptoms, as they may be able to help you find ways to manage your health.

## HOW ARE YOUR AS SYMPTOMS AFFECTING YOU?\*

Thinking about the past 1-3 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 mouth 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
- Usual duration of morning stiffness from the time you wake up?  0-15  15-30  30-45  45-60  60-75  75-90  90-105  105-120  120-135  135-150  150-165  165-180  180-195  195-210  210-225  225-240  240-255  255-270  270-285  285-300  300-315  315-330  330-345  345-360  360-375  375-390  390-405  405-420  420-435  435-450  450-465  465-480  480-495  495-510  510-525  525-540  540-555  555-570  570-585  585-600  600-615  615-630  630-645  645-660  660-675  675-690  690-705  705-720  720-735  735-750  750-765  765-780  780-795  795-810  810-825  825-840  840-855  855-870  870-885  885-900  900-915  915-930  930-945  945-960  960-975  975-990  990-1005  1005-1020  1020-1035  1035-1050  1050-1065  1065-1080  1080-1095  1095-1110  1110-1125  1125-1140  1140-1155  1155-1170  1170-1185  1185-1200  1200-1215  1215-1230  1230-1245  1245-1260  1260-1275  1275-1290  1290-1305  1305-1320  1320-1335  1335-1350  1350-1365  1365-1380  1380-1395  1395-1410  1410-1425  1425-1440  1440-1455  1455-1470  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# Guide To Conversation

**Mark Steyvers**



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